



# National Indigenous Palliative Care Needs Study

Final Report | April 2003



THE NATIONAL  
**PALLIATIVE CARE**  
PROGRAM

Prepared for the Australian Government  
Department of Health and Ageing  
by Kate Sullivan and Associates Pty Ltd

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Report by  
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# Glossary

ACAT	Aged care assessment team
ACCHS	Aboriginal Community Controlled Health Service. This term is used when referring to general policy issues or sometimes when referring to this group of services globally. In other places we use the term AMS because it is the term which health consumers and service providers commonly use in speaking about their local ACCHS.
AH&MRC (NSW)	The Aboriginal Health and Medical Research Council (NSW)
AHLO	Aboriginal Hospital Liaison Officer (see also ALO)
AHREC	The Aboriginal Health Research Ethics Committee of South Australia
AHW	Aboriginal Health Worker
AIDA	Australian Indigenous Doctors' Association
AIN	Aid In Nursing
ALO	Aboriginal liaison officer (usually based in hospital), usually called KLO (Koori liaison officer) in Victoria (see also AHLO)
AMS	Aboriginal Medical Service (This refers to the local ACCHS. We generally used this term because it is the term that most participants and interviewees used.)
Anangu	Aboriginal people, central Australia
AMSANT	Aboriginal Medical Services Alliance Northern Territory
AP lands	Anangu Pitjatjantjara Lands
Bama	Aboriginal people (North Queensland)
Blue Care	Blue Care Nursing Service (Queensland)
CAAC	Central Australian Aboriginal Congress
CACP	Community Aged Care Packages
CALD	Culturally and Linguistically Diverse
CAPD	Continuous Ambulatory Peritoneal Dialysis
CATSIN	Congress of Aboriginal and Torres Strait Islander Nurses
COPS	Community Options Program
CME	Continuing Medical Education
CNC	Clinical Nurse Consultant
CNS	Clinical Nurse Specialist
DCS	Domiciliary Care Service
EPC	Enhanced Primary Care
EN	Enrolled Nurse

GP	General practitioner, doctor
GPAC	General Practice Advisory Council
Green Nurses	Domiciliary nursing service (North Queensland)
HACC	Health and Community Care worker
HOP	Hospital to home Pathways (Adelaide)
HOPS	Homemakers and Old Peoples Services (Alice Springs)
ICAN	Indigenous Clinical Advisory Nurse
Koori	Aboriginal person (in general use in NSW and Victoria)
maparn	Traditional healer (northern Western Australia)
Murri	Aboriginal person (Queensland)
NACCHO	National Aboriginal Community Controlled Health Organisation
<i>ngangkari</i>	Traditional healer (Central Australia)
NHMRC	National Health and Medical Research Council
Noongar	Group name for Aboriginal people of south-west Western Australia including the traditional inhabitants of Perth; also spelt Nyoongar and Nyoongah
NPCS	National Palliative Care Strategy
NPYWC	Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council
OATSHI	Office of Aboriginal and Torres Strait Islander Health
PATS	Patient Assisted Travel Scheme
PCA	Palliative Care Australia
PHCAP	Primary Health Care Access Program
QAIHF	Queensland Aboriginal and Islander Health Forum
RCIADIC	Royal Commission into Aboriginal Deaths in Custody
RDNS	Royal District Nursing Service (South Australia and Victoria)
RFDS	Royal Flying Doctor Service
RN	Registered nurse
Silver Chain	Silver Chain Nursing Service (domiciliary nursing service Western Australia)
St Luke's	Domiciliary nursing service (Queensland)
TAFE	Technical and Further Education
VACCHO	Victorian Aboriginal Community Controlled Health Organisation
VET	Vocational Education Training
WAAHIEC	Western Australian Aboriginal Health Information and Ethics Committee
Wongi	Aboriginal people of central desert region, Western Australia.

# Executive summary

## a) Background

The Australian Government's National Palliative Care Strategy, adopted in October 2000, recognises the need for services which cater sensitively and flexibly for the needs of Aboriginal and Torres Strait Islander peoples. The strategy has the potential to improve the delivery of services to Aboriginal and Torres Strait Islander communities (urban, rural and remote) by concentrating on three broad areas:

- the development of awareness and understanding in the community and the professions;
- the development of appropriate standards and tying resource allocation to best practice; and
- the building of partnerships between those delivering services and communities, and facilitating coordination of and access to services

The purpose of this study was to provide an understanding of:

- what palliative care services are currently being delivered to Aboriginal and Torres Strait Islander people;
- what the real needs of Aboriginal and Torres Strait Islander clients are (whether they are in urban or remote areas);
- how well current services meet the needs (especially in relation to culturally appropriate service delivery and ability to access appropriate services); and
- how the National Strategy can be focussed to ensure that its aims are achieved in relation to Aboriginal and Torres Strait Islander people.

## b) Initial scoping and field methodology (Chapters 1 and 2)

The project commenced with an initial scoping period during which the relevant branches of all State and Australian Government health departments and other key stakeholder groups (including the community controlled health sector) were contacted for information regarding Indigenous palliative care. Telephone interviews were conducted with service providers that had been identified as providers of palliative care services to Aboriginal and Torres Strait Islander clients. The outcome of the initial scoping was the discovery that there were very few Indigenous specific services or initiatives in palliative care. It was decided to canvass mainstream service providers to discover the rate of Indigenous access to their services.

After the initial scoping, the study turned toward the task of identifying the needs (including unmet needs) of Aboriginal and Torres Strait Islander palliative care patients and their families.

Field locations were selected that were representative of either those areas in which we had had reports of 'good practice' (which in this case usually meant 'any practice reported as having Indigenous clients') or areas of high Aboriginal and/or Torres Strait Islander population where it appeared there were few palliative care services. One location was also selected for the development of draft regional guidelines on the basis that this had been requested by the Aboriginal medical service (AMS) in the area.



Field methodology was developed and proposed to relevant ethics committees. In New South Wales, a delay in receiving a response from the ethics committee necessitated a change in field methodology (see further Chapter 1, Sections 1.6.3 and 1.6.4).

In each location to be visited, palliative care service providers and the community controlled health organisation and/or local State funded Aboriginal or Torres Strait Islander health service were contacted by letter and followed up by telephone. Aboriginal and Torres Strait Islander organisations were asked if they were willing to participate and if so to nominate the form in which they wished to receive feedback. (The project already had a newsletter component.) All responded favourably to our request to participate in the field work, though none were specific about the nature of the feedback they wanted. In some areas we responded to informal requests for advice or for assistance with funding applications. After completion of the fieldwork it was decided that uniform and general feedback for all the participants was needed and so a special, more detailed edition of the Newsletter (number 3) was produced for this purpose. Multiple copies were supplied to all the areas we had visited.

This report lists the geographic locations where fieldwork took place but the reporting protects the identity of communities and individuals as was required in our methodology.

Chapter 2 documents what the study discovered about how and where palliative care services are delivered around Australia.

### **c) Socio-economic contexts (Chapter 3)**

Chapter 3 outlines key issues of importance (socio economic and traditional contexts) for policy makers and palliative care service providers and Chapter 5 examines how some of these issues affect service delivery in the various settings of care.

Service providers and policy makers in palliative care need to understand the socio-economic realities of many Aboriginal and Torres Strait Islander clients, and the impact of historical factors in Aboriginal and Torres Strait Islander peoples' views about health services. The importance of self-determination and the existence of culturally appropriate services, in particular those provided by Aboriginal community controlled health services (ACCHS), should be recognised. Mainstream service providers should be sensitive to the needs of clients, modifying their service provision in consultation with local people, and try to engage with existing Aboriginal and Torres Strait Islander health providers to provide an integrated service.

### **d) Communication (Chapter 3)**

Good communication is central to understanding the palliative care client's wishes and needs:

*Palliative care respects the dignity of the person who is dying, and is based on the person's needs and wishes, with attention to the specific needs of different cultural and religious groups.* [extract from the definition of palliative care in the National Palliative Care Strategy (2000)]

The barriers to good communication with Aboriginal and Torres Strait Islander clients identified in the study included both language and non-language barriers. Differing values and beliefs create hidden difficulties. Understanding that complex cultural relationships exist and impact upon who should or

should not be involved, for instance in care or decision making, is critical. Both cultural brokers and language interpreters are needed to deliver good palliative care. In many places in Australia there are Aboriginal and Torres Strait Islander people who do not speak English but there are few, if any, interpreter services available to service providers. This need applies equally in capital cities as in remote areas or remote regional centres. City hospitals in Adelaide and Perth, for example, often treat Aboriginal patients from remote areas who do not speak English. Interpreters working in palliative care require some orientation in palliative care philosophy and practice.

Cultural awareness training specifically designed for palliative care workers is needed but should not be regarded as a substitute for employing (or 'buying in' the services of) Aboriginal and/or Torres Strait Islander staff.

### **e) Traditional issues (Chapter 3)**

Many Aboriginal and Torres Strait Islander people use traditional medicine to varying degrees. Facilitation of access to traditional medicine and traditional healers where requested, and ensuring that protocols are in place to discover and accommodate end of life cultural practices should be usual palliative care practice.

Service providers must be sure that actions taken or permissions sought will not have cultural repercussions, either for family or community members or for themselves. They should work with local cultural interpreters to find solutions. Examples are given of traditional practices such as avoidance practices and ascribing 'blame' which, whilst not relevant to all Aboriginal and/or Torres Strait Islander communities, are very serious issues which underline the need for effective cultural awareness training and access to knowledgeable Aboriginal or Torres Strait Islander staff. It is critical that practices and protocols be checked for cultural safety and that they allow for case by case variation and advice.

It is clear that many doctors make assumptions based on a limited understanding of cultural issues. Without the advice of a cultural advocate they may make assumptions which reduce the choices of care available to their clients. We discovered misconceptions about pain, about ready acceptance of death, and about speaking about death. These all have serious consequences for Aboriginal and Torres Strait Islanders peoples' ability to access palliative care and to receive a high standard of palliative care service.

### **f) Access to Palliative Care Services (Chapter 4)**

A key finding of the research is that comprehensive data on the rates of Indigenous access to palliative care services does not exist. Most palliative care service providers do not have access to data on the Indigenous status of their clients as this is usually recorded 'upstream' of their admittance to a palliative care program. Anecdotal evidence also suggests that the recording of clients' Indigenous status may not be accurate because data recorders make assumptions, rather than ask the question.

These issues aside, there is enough information to be sure that people of Aboriginal and Torres Strait Islander descent are not accessing palliative care services at a rate commensurate with their representation in the population, and especially given their high mortality rate. The reasons for this are explored in Chapter 4 and include the following:

- lack of availability of services in some areas where Aboriginal and Torres Strait Islander people live;
- lack of referral by specialists, GPs and doctors in ACCHS;

- lack of knowledge about palliative care services on the part of Aboriginal and Torres Strait Islander health service providers and community members;
- a number of perceived barriers including:
  - past experiences of the health system,
  - dislike of hospitals and hospices,
  - lack of Aboriginal and Torres Strait Islander staff in mainstream services,
  - lack of support at the time of referral, including the lack of involvement of cultural advocates in discharge planning,
  - the cost, and perceived cost, of palliative care,
  - attitudes (of some Aboriginal and Torres Strait Islander peoples and some doctors) to speaking about death,
  - attitudes and perceived attitudes of mainstream service providers that provide services to clients at home.

Probably the most significant factor influencing access (or lack of access) to palliative care services is the question of referral.

In general, Aboriginal and Torres Strait Islander clients are either not referred to palliative care at all or are referred at a very late stage of their illness.

In part this is due to the underlying health status of Indigenous people, however lack of referral and late referral and are also due to assumptions of doctors (GPs, AMS doctors and specialists) about whether Aboriginal and Torres Strait Islander clients will want to be referred to palliative care services. Many GPs have a poor understanding of what palliative care is and how it may benefit clients, and/or how they can be involved in providing an integrated service. It appears that many doctors make assumptions that patients will not want to be referred to mainstream services, yet most AMSs have neither the resources nor staff with the skills needed to provide palliative care.

If referrals are made, but are not supported by cultural advocacy and/or the participation of Aboriginal and Torres Strait Islander staff, then they may not be taken up.

As a result of late referrals, service providers and families do not have the time needed to establish good relationships, which are essential to good service delivery and to 'good word of mouth' about palliative care.

If clients are not referred, or are referred late, they do not receive the information they need to be able to make informed choices about how or where they wish to care or be cared for. As a result Aboriginal and/or Torres Strait Islander patients are more likely to die in hospital, which may not be their wish.

These issues point to three main areas for attention: staffing, attitude change and information. Increased Aboriginal and Torres Strait Islander staffing in palliative care services, the provision of cultural brokerage services at key points such as discharge and referral, and effective cultural awareness training should improve access rates.

Effective information strategies are needed, both to increase the understanding and awareness of community members about palliative care and to educate GPs, AMS doctors and specialists. Information strategies need to be targeted:

- among Aboriginal and Torres Strait Islander peoples there is a need to change the image of palliative care from being about 'being put in a hospice' or being only for cancer patients, to developing an awareness that palliative care can support families to look after their own at home;

- for GPs and AMS staff, there is a need to re-position palliative care so that they appreciate that rather than handing over the care of their patient to strangers, they can continue to be involved as a member of the palliative care team;
- for mainstream palliative care service providers there is a significant need for effective cultural awareness training (including information about Aboriginal and Torres Strait Islander service providers) which can deliver competence in cross cultural practice. This would equip service providers with the skills to build relationships with these groups so that they can work together to provide the best support to Aboriginal and Torres Strait Islander clients.

‘Word of mouth’ was widely acknowledged as the most effective way of providing information about palliative care to Aboriginal and Torres Strait Islander communities and should be backed up by clear written materials which are specifically targeted to an Aboriginal and Torres Strait Islander audience.

Another issue that is critical for Aboriginal and Torres Strait Islander clients’ ability to access palliative care is the recognition that diseases other than cancer, such as chronic obstructive pulmonary disease, heart failure and renal failure, may require referral for palliative care. Whilst these diseases do not always present symptoms that require the kind of management usually associated with palliative care (i.e. they may not be painful until very late in the disease), clients and their families may well need timely psychosocial support which is part and parcel of palliative care. These conditions are very frequent amongst Aboriginal and Torres Strait Islander populations.

## **g) Planning and delivery of care (Chapter 5)**

Chapter 5 documents findings in relation to care planning and delivery of care and presents suggestions for how the problems that were reported might be addressed. This chapter focuses on the setting of care and examines the significance of the place of death to Aboriginal and Torres Strait Islander peoples. Discharge planning and assessment, bereavement counselling, medication and pain management, equipment and palliative care providers’ access to specialist advice are also examined in this chapter.

### **i) Attitudes and expectations**

An issue that is fundamental to access to services and to the quality of care is the underlying experience of and attitude of Aboriginal and Torres Strait Islander people towards the health system and towards non-Indigenous bureaucrats and service providers. Past experience has a powerful impact on whether Aboriginal and Torres Strait Islander people will be willing to accept referrals to palliative care.

In general, Aboriginal and Torres Strait Islander people strongly dislike, distrust and fear hospitals and non-Indigenous strangers coming to their homes. Informants said that in their past experience, such strangers were usually police or ‘the welfare’.

Mainstream service providers should acknowledge these attitudes and the historical reasons for them. ACCHSs exist in order to overcome some of these difficulties and to allow community control of health service delivery. ACCHSs should be invited to become a central part of the specialist palliative care network and/or palliative care service providers should put their specialist skills at the disposal of these units, especially where they have mutual clients.

Service providers, in turn, hold attitudes which affect their behaviour towards Aboriginal and Torres Strait Islander clients. Many have never met or spoken with an Aboriginal person or Torres Strait

Islander and know little, or nothing, about Aboriginal and Torres Strait Islander health services. Unfortunately, many are perceived as highly judgemental by Aboriginal and Torres Strait Islander people. Most, for example, are unaware of complex family relationships or the group nature of many Aboriginal households and do not understand the implications of these when home visiting. Many would not feel comfortable in the often over-crowded conditions of many Aboriginal and Torres Strait Islander households. Concerns about hygiene and personal safety (both perceived and real) were reported. For their part, we were told that many Aboriginal and Torres Strait Islander people feel 'shame' when non-Indigenous strangers visit their home.

## ii) Relationships

The attitudes and expectations of clients and service providers have very real significance for discharge planning and assessment and care planning. The importance of the referral process and the need for cultural advocacy at this time have been mentioned above.

In parallel with the need for supported referrals is the need for the development of trust between clients and service providers. Development of trust requires the development of a relationship. In many cases there is not enough time for this relationship to develop because of late referral.

Service providers working with Aboriginal and Torres Strait Islander clients should start to develop relationships with the community by beginning a dialogue with Aboriginal and community organisations (including health and home care providers). They need to establish their 'credentials' in the community first to pave the way for meeting clients and families. Being introduced or recommended by a community member is an essential first step to forming a relationship and is particularly critical where time is short.

## iii) Discharge planning and assessment

There is a need to develop care pathways for palliative care clients which ensure consistent involvement of the palliative care team, a cultural advocate<sup>1</sup> (Aboriginal Hospital Liaison Officer [AHLO], Aboriginal Health Worker [AHW] from AMS, or Indigenous staff of the service provider) and appropriate family members in discharge planning.

A question about Indigenous status should be asked on admission as a palliative care client (with an explanation of why it is being asked). Assessment should not take place without the participation of appropriate Indigenous staff. Assessment processes should try to avoid a stream of individual service providers and may need to be done over several visits as relationships develop. The location of the assessment (including the place it is done in the home) and the language and listening skills used are crucial. Understanding the relationships of family members and realising that roles within the family may be culturally determined are also critical. The main carer may not be the decision maker. Service providers should work with Indigenous staff and/or community advisers to develop effective assessment processes for their particular situation.

## iv) Access to cultural specialists

Service providers should ensure that they have ready access to and funding for a cultural specialist and should develop ongoing relationships with local Aboriginal and Torres Strait Islander health and community organisations.

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<sup>1</sup> Unless this is expressly rejected.

## v) Place of death

Issues about where people would prefer to die are vitally important to Aboriginal and Torres Strait Islander people and to the delivery of good palliative care. (See Chapter 5, Section 5.3)

During the fieldwork, community members and AHWs were interviewed about whether there was a 'right' place for someone to pass away, and if so whether there were problems in achieving this. Two major issues were explored. Firstly, there is the issue of the desire of Aboriginal people and Torres Strait Islanders to return to their country or home community to die and whether (and how) this can be accommodated. There is also the question of where the person should pass away within that country, town or community, and whether it should be at home or in the clinic, hospital or hospice.

For many people the importance of 'getting home to country' is the highest priority. This issue has been well documented and most service providers are aware of it, though there are still many reported instances of people being sent from remote areas to city hospitals for unnecessary treatment or treatment that will reduce their chance of passing away in their own country. This occurs because of inadequate information and a lack of informed choice on the part of the patient. In some instances patients may have preferred to stay in their own country with a reduced level of care or without treatment.

The key issue, is that rather than taking a decision about what they believe is in the best interest of the patient, health care professionals should assist the patient and family to decide what is best for them and should try to find ways to support that decision.

In many places it was reported that patients and their families would prefer the person to die at home, but few actually achieve that. Even in cases where a person has been cared for at home throughout their illness, they are likely to go to the hospital suddenly, at the final stage. Several reasons why this occurs were explored, including the capacity of the family to care for the patient, fear of the unknown, concerns about pain, not being ready to let go of a loved one, fear about spirits of the deceased, the desire to avoid the cultural requirement to vacate the home after a death and not wanting to be in proximity to the dying person for fear of 'blame' or payback.

Socio-economic contexts, traditional obligations and a mistrust of the health system combine to create significant dilemmas for families of palliative care clients. A key issue for both urban and remote peoples is that these matters, especially place of death, should be discussed early enough and with better information, so that clients can be clear about what they want and know that it can be made to happen. There was general and strong agreement that the place of death should be decided by the individual and their family.

Other implications for policy makers and service providers include: finding solutions to cultural dilemmas by provision of appropriate 'neutral' places where people can pass away with their family around them (several are suggested, see *1) Good practice* below); advocating on behalf of clients to get them home and getting the best service for them once they are there; improvement of hospital and nursing home facilities; and putting in place tracing systems in hospitals so that if the client is admitted to the emergency ward at the final stage, the staff will know that they are a palliative care client and will not give inappropriate treatment (see Chapter 5, Section 5.9.3).

## h) Settings of care (Chapter 5)

Specific suggestions are made to address the shortcomings of delivery of care to Indigenous clients at home (see Chapter 5, Sections 5.4.1 and 5.4.2), in hospitals (Section 5.4.3) and in hospices (Section 5.4.4), and in nursing home and aged care facilities (Section 5.4.5). The importance of the continuity of care between the various settings as circumstances change is raised.

### i) Care at home

Care at home was the preferred option of most people we spoke with. Issues identified to improve this included:

- service provider visits should be made in the company of Aboriginal and Torres Strait Islander staff;
- taking the time (and having the skills) to establish a relationship;
- competence in cross cultural communication and practice;
- being sure to establish who are the decision makers in the household;
- coordinating and reorganising services to reduce the number of strangers coming to the house;
- providing appropriate information on a range of issues and delivering these both verbally and in written form; and
- maintaining confidentiality and being discrete.

Having enough respite care services available to give carers a break is critical to most families' capacity to care at home.

The most appropriate role for the palliative care worker will be determined by the context in which they are working. For home based care, the model that best accorded with what Aboriginal and Torres Strait Islander informants said they wanted was to act as a coach to support and train the family so that they could undertake the care.

### ii) Hospital and hospice

Hospitals are often seen as places of death rather than of healing by many Aboriginal and Torres Strait Islander people, and many communities are acutely aware of relatively recent racist practices, such as segregated wards, and labelling of cutlery and linen for Aboriginal patients (see Chapter 5, Section 5.4.4).

Few hospitals employ any Aboriginal or Torres Strait Islander staff except for an Aboriginal Liaison Officer (ALO) and these staff often described their experience as one of overwork and isolation. ALOs are rarely members of the palliative care team and generally do not participate in discharge planning of palliative care clients.

Few hospital staff receive adequate cultural awareness training and in regional hospitals the high staff turnover is particularly problematic, especially as there is a high use of agency staff and foreign nurses on temporary work visas who have no experience or understanding of Aboriginal clients and cultures.

We were told that attitudes and practices in hospitals were changing so as to be more accommodating to Aboriginal visitors and customs; for example some hospitals now permit smoking ceremonies to cleanse a room after a death. There remain many problems, however. The sterile and alienating environment, air conditioning, unfamiliar food and lack of accommodation, access to the outside and even enough space



for visitors who wish to be with the person who is dying or after death, are all barriers to the delivery of high quality, appropriate palliative care. Most hospitals do not have protocols to ensure that cultural practices and needs can be accommodated.

In contrast, interviewees who had had experience of a hospice for pain management or terminal care of a family member were very satisfied with the facilities and with staff attitudes. Many people interviewed thought that palliative care was synonymous with placing someone in a hospice and said they would not want to do that, however in two regions where familiarisation visits had been conducted, community attitudes had changed considerably and community members had begun to make greater use of the hospice as a result.

### iii) Aged care and nursing homes

Indigenous specific aged care facilities and nursing homes play an important role in providing residential facilities for Aboriginal and Torres Strait Islander people who cannot be cared for at home by their families (see Chapter 5, Section 5.4.5). In some places, they employ a high percentage of Aboriginal and/or Torres Strait Islander staff (in some cases more than 50%). They offer a level of cultural comfort for residents that makes such facilities a valuable alternative to home care.

The quality and availability of palliative care in these facilities varies considerably, due in some cases to a lack of trained staff or lack of access to palliative care specialists. In some instances there is little or no relationship between these facilities and local palliative care service providers.

There are also some structural barriers to the provision of palliative care in these facilities. For example, regulations about administration of medication (and funding issues) may prevent a patient from staying in an aged care facility and receiving appropriate medication. Similarly, funding restrictions and the high cost of treatment at the terminal stage of illness may result in patients being transferred to a hospital at this stage.

Although most try to comply with cultural preferences associated with the end of life, in some regions the concern that others will be unable to occupy a room or use the facility after a death there is often managed by the transfer of patients to hospital at the final stage of their illness. As a result, patients may not be able to pass away in the place that has become their home. It is unclear whether the patient's wishes are consulted or respected where this occurs.

There are some regions, including major population centres such as Perth, where there are no Indigenous specific aged care facilities or nursing homes. This study did not investigate the delivery of palliative care to Aboriginal and Torres Strait Islander people in mainstream aged care facilities and nursing homes, but it would be expected that similar concerns would exist in relation to the delivery of culturally appropriate care.

### iv) Need for medically supported hostels and palliative care for itinerant people

In cities such as Perth and Adelaide and in Alice Springs, a need was identified for medically supported hostels for short term accommodation of Aboriginal and Torres Strait Islander palliative care clients visiting for medical treatment (see Chapter 5, Section 5.4.6).

There is a need to develop strategies and funding arrangements to allow delivery of palliative care services to all people in the setting of their choice. This should include itinerant or homeless people who need palliative care and symptom management.



#### v) Counselling and bereavement care

Chapter 5, Section 5.5 discusses the availability and use of bereavement care services. There are very few appropriate services available for Aboriginal and Torres Strait Islander clients. It examines the special needs of Aboriginal and Torres Strait Islander people because of the burden of unresolved grief that most carry as a result of losses through dispossession of land, culture and identity, as well as the high mortality rate within their families.

The section examines how people grieve, and reports what people said they wanted. The need for early counselling, trained Indigenous counsellors and support for cultural protocols is most critical. Barriers to delivering bereavement services are examined and some areas of innovation and good practice are reported (Section 5.5.6).

A number of areas of need were identified, including needs for: more trained Aboriginal and Torres Strait Islander psychologists and counsellors; post graduate AHW training in grief and loss counselling; support groups; Aboriginal and Torres Strait Islander palliative care workers to be included as part of the palliative care team to ensure that early counselling takes place; greater emphasis on early referral; and recognition of the practical role in bereavement care played by Aboriginal and Torres Strait Islander staff assisting in funeral preparations. It is suggested that some mental health or counselling training for AHWs who assist with funeral preparations would augment their capacity in this vital role.

This section also identifies the need for more research into the best approaches to grief and loss for Aboriginal and Torres Strait Islander communities and for appropriate counselling and debriefing for Aboriginal and Torres Strait Islander health professionals who carry a particular burden with respect to grief and loss.

#### vi) Pain management, medication and equipment

The major issues here relate to how Indigenous people experience pain, the need for information about pain management, and the cost and perceived cost of medication (see Chapter 5, Section 5.7). Many Aboriginal people and Torres Strait Islanders cannot afford the dispensing fees, let alone the cost of medication which is not available on the Pharmaceutical Benefits Scheme. People often go without medication to pay for other family needs.

There were many reported cases of doctors prescribing inappropriate medication, that was either not the most suitable for symptom management, or that would not be available or be able to be administered when the patient returned home. There were numerous stories of clients arriving home in remote communities with prescriptions for medication that was unavailable in the community.

There are many issues of concern about the use of morphine. Many Aboriginal and Torres Strait Islander people are fearful of morphine and there are apparently many misunderstandings about its use. There are also safety and security issues about access to this drug by palliative care clients. Issues concerning equipment shortages are reported in *n) Funding and resources* below.

#### vii) Access to palliative care specialists

Access to symptom management specialist advice can be critical. Many services are now set up so that specialist doctors or nurses provide consulting services. In many places, palliative care advice lines exist for doctors and/or nurses, however these are not always well known and are often not used by GPs and

AMS doctors. Advice lines and personal networks are especially valuable to nurses working in relative isolation in remote communities or small towns. Palliative care providers state however that it is not the lack of advice opportunities that presents a problem, but rather GPs who do not *recognise* that they need advice.

Clients' access to after hours and weekend advice varies enormously but where it is available it is greatly appreciated. After hours emergency numbers are only useful to Aboriginal and Torres Strait Islander clients if they have a telephone or can access one.

Some implications are:

- the existence of palliative care service and advice lines should be marketed to GPs and AMS doctors;
- service providers should keep in mind that Aboriginal and Torres Strait Islander clients may not have telephone access and should either advocate for phone access on their behalf or set up emergency procedures that do not rely on phones;
- funding structures should be examined to allow for the funding of telephones for palliative care clients who otherwise would not have them;
- service providers should budget for the employment or brokering in of Aboriginal and/or Torres Strait Islander cultural specialists who could be on call to provide advice.

## **i) Workforce issues (Chapter 6)**

Traditional healers should be seen as an important adjunct to palliative care services where families want this care. Funds should be available to facilitate access to healers if required.

Aboriginal Hospital Liaison Officers should participate in palliative care teams and in discharge planning. Currently, they are usually not involved.

- If ALOs were to be more involved in palliative care support and liaison roles, more would need to be employed or they would need to work more hours; they should also receive some medical training (AHW, Enrolled Nurse [EN] or Registered Nurse [RN]), because of the need for medical advocacy, as well as palliative care training.
- All ALOs should receive basic training in the nature of palliative care and the services available in that field.
- Roles, job descriptions, workloads, staffing levels, working conditions and qualifications should be examined to prevent exploitation of these workers and to ensure that Aboriginal and Torres Strait Islander clients receive the best service possible.
- ALOs should be better supported through formal supervision and emotional or counselling support.

Aboriginal and Torres Strait Islander Health and Community Care (HACC) workers play a large role in delivering palliative care to Indigenous clients, although this is often informal. The skill and knowledge of HACC workers in delivering care to palliative care clients should be acknowledged and they should receive appropriate training and counselling.

- Funding barriers to the involvement of these workers in palliative care should be removed.
- The task of developing a trained work force of Aboriginal and Torres Strait Islander workers in palliative care may be more complex than attracting Aboriginal and Torres Strait Islander workers into HACC programs, however the HACC model may offer some valuable lessons.

Aboriginal Health Workers (AHWs) work for AMSs, community clinics, community health centres, and in some cases in hospitals as ALOs. Their roles vary from State to State.

In remote areas AHWs, together with clinic doctors and nurses, provide the only palliative care services available, and in some towns AHWs from the local AMS provide an informal (and untrained) palliative care role, often in their own time. Many AHWs spoke of the huge personal cost of this work as, especially in remote communities, the role is often akin to nursing their extended family and there is insufficient time to deal emotionally with the high number of deaths while other clients need to be cared for. Coordinators spoke of the need for additional resources to backfill positions so that AHWs could take the leave they needed.

AHW training should include a palliative care component, and funding is needed to employ and broker out trained workers as needed. In some regions it was suggested that an AHW with palliative care training could serve an entire sub-district or health region by being brokered out to various services as needed. In some regions it would be necessary to employ both male and female AHWs.

Where there is a significant Aboriginal and/or Torres Strait Islander population, trained Aboriginal and/or Torres Strait Islander palliative care workers are needed either as full-time palliative care workers or to undertake additional duties. How these positions are funded should not necessarily affect where they are based, which would depend on the local situation. It may be more appropriate to locate them in, or share them, with an Aboriginal and Torres Strait Islander service. A number of alternatives are suggested.

They could be regional workers, working throughout a health district with a number of service providers (mainstream and Indigenous), or they may be community based, or service provider based.

Two sorts of roles are needed: development and promotion roles to improve existing services; and hands-on or face to face roles dealing with cultural medical advocacy. Sample duty statements for these roles are given in Appendix 14.

In-patient facilities and domiciliary nursing services (both generalist and palliative care specialist units) should develop strategies to increase the numbers of Indigenous staff. Special programs to attract Aboriginal and Torres Strait Islander RNs should be developed, and cadetships or scholarships offered. Home-based services should employ ALOs to assist in development of their service and to liaise between mainstream nurses and Aboriginal and Torres Strait Islander clients.

There are very few Aboriginal and Torres Strait Islander nurses, doctors, psychologists and social workers involved in palliative care. Strategies to raise the awareness of these groups and to solicit their input into the development of culturally appropriate practice should be pursued through their professional associations eg CATSIN and AIDA.

## **j) Information (Chapter 7)**

Most Aboriginal and Torres Strait Islander people and Aboriginal and Torres Strait Islander service providers (AMSs, HACCs, Community Aged Care [CACAP] and AHLOs) are not aware of what palliative care is or what services might be available. Information strategies are needed which address these issues.

‘Word of mouth’ strategies are the most effective in providing information and raising awareness in Aboriginal and Torres Strait Islander communities, and AHWs, ALOs and HACC workers will be the

key to the success of such strategies. Introduction of information about palliative care into undergraduate training programs for these workers will assist in the long term, and in the short term, other information strategies should be developed. Finding ways to encourage people to tell stories of good service, arranging information days and 'yarning' sessions were some of the strategies suggested to reach the community (see Chapter 7, Section 7.1).

Aboriginal and Torres Strait Islander community members who had experienced palliative care clearly identified the kinds of issues about which they wished they had received more information, and indicated that the earlier the information was available the better. As well as information about the range of services available (including Indigenous specific services), the clearest need was for the kind of information that has been provided in the *Palliative Caring at Home* booklets produced by the Palliative Care Associations of South Australian and Western Australia. These booklets could readily be revised to meet this need.

## **k) Training and education (Chapter 7)**

There is an urgent need for the development and provision of palliative care training for Aboriginal health workers, for example, including a component in graduate courses and creation of post graduate certificate courses in palliative care, mental health and bereavement. There is also an urgent need for trained Indigenous psychologists and mental health workers to provide support or counselling in grief and loss.

Many GPs and specialist doctors are not aware of palliative care services and their benefits. Education and awareness programs for GPs encourage earlier referral to palliative care.

Community Controlled Health Organisations (AMSs) need education about palliative care and its benefits, and how they can get help from palliative care specialists for their clients. AMS doctors need to be reassured that palliative care does not have to mean that they must stop caring for the patient, and local arrangements for integrated delivery of service should be encouraged.

A specific module on Indigenous issues in palliative and bereavement care should be included in undergraduate training for all doctors and nurses, and professional development curricula for GPs, nurse practitioners and registered nurses should include palliative and bereavement care (for example, through continuing medical education programs for GPs, and the development of post-graduate courses for nursing graduates).

Cultural awareness programs may reduce the incidence of doctors making assumptions about clients' wishes which deny their clients choices and may encourage doctors to seek appropriate cultural guidance.

Cultural awareness training is not uniformly available for palliative care service providers. Such training should be provided to all groups including generalist domiciliary nurses, hospital and hospice staff, and doctors.

It should be noted that generalist cultural awareness training of the kind that many health professionals receive is not adequate for the sort of cross cultural practice required of palliative care workers. Cultural training needs to deliver competence, not only 'awareness'. Such training needs to provide opportunities for practitioners to review their own beliefs and values, develop skills and competence in cross cultural communication, and should encompass issues surrounding death and dying for Indigenous people – without implying that being sensitised to these issues confers cultural expertise. Cultural awareness

training or training to deliver competence in cross cultural practice, should equip practitioners to know when they should seek advice from cultural advocates and how to access such services. Local orientation will usually be required.

Cultural awareness training course design and delivery standards should be reviewed and standards developed so that courses deliver competency in cross cultural communications and practice.

Cultural awareness training must not be considered a substitute for the engagement of Aboriginal and Torres Strait Islander staff.

A great deal of informal counselling and bereavement support is provided by volunteers who are usually trained and coordinated by palliative care units. To date, volunteer programs have not attempted to recruit members from Indigenous communities. Some community members expressed interest in setting up similar groups, and some volunteer coordinators are keen to recruit Indigenous members. Both volunteers and their coordinators require cultural awareness training. Training currently provided to volunteers about palliative care could be immediately adapted for delivery to ALOs and AHWs as part of an information strategy (see above).

## **1) Good practice (Chapter 8)**

Key elements in delivery of quality care include:

- early referral;
- cultural advocacy and brokerage;
- good communication and relationship development;
- clear coordination (i.e. everyone's role is clear);
- regular case management meetings, including cultural advocates;
- continuity of care; and
- flexibility and responsiveness which recognises individual needs.

A number of models are reported because they are said to work well in the communities where they operate. It is probable that none could be directly 'transported' elsewhere, however they may contain elements that would be appropriate in other places.

In the course of our investigation we discovered aspects of practice which we considered to be innovative and/or effective. Some highlights are listed below.

- Employment of Aboriginal and Torres Strait Islander staff.
- The staff of one palliative care service viewed themselves as coaches for the family, providing training and support so that they could look after a family member at home. They also provided specialist advice and coordinated other needed services (including access to residential facilities if required). This approach enabled family members to feel in control of care (see Chapter 8, Section 8.2.1).
- The provision of a comfortable and 'neutral' place that is readily accessible to family members and will not result in cultural avoidance problems after the death where the patient could pass away.

Some suggestions to achieve this (some of which have been put in place) included:

- development of care centres separate from hospitals where families could come for the terminal phase;
  - in remote communities, a room and family accommodation near the clinic that could be used during the terminal phase;
  - in regional urban areas, a public (or Aboriginal) housing authority could make a house available where families could stay for the duration of the palliation so they would not have to vacate their own home after the death.
- In-patient and residential palliative care facilities need to be better designed and managed to accommodate cultural practices. An extensive list of issues (see Chapter 5, Sections 5.4.3 and 5.4.4) and two best practice examples are provided (see Appendix 8 and Appendix 9).
  - In some other areas of health service provision, service providers are working to develop pathways of care (see Chapter 8, Section 8.4.2) which include checkpoints for cultural advocacy and cultural safety. Service providers argue that such pathways are needed in palliative care.
  - In a rural area in Victoria, mainstream and Indigenous service providers held a workshop and developed a set of regional network guidelines to assist them to communicate with each other and deliver more integrated services (see Appendix 12).
  - There are few examples of good practice in bereavement care. Some AMSs provide valuable practical assistance to families by assisting in the funeral arrangements and preparation of the 'order of service' and eulogies at the funeral service. These are highly appropriate bereavement care responses which could be enhanced by funding and equipping the health workers who undertake it with appropriate counselling skills. Other innovations and good practice in bereavement care are provided in Chapter 5, Section 5.5.6.

## **m) Standards (Chapter 8)**

An objective of the National Palliative Care Strategy (2000) suggests that resources should be tied to good practice, however there is a danger that tying resource allocation to good practice will further disadvantage consumers who are not well served by existing services. Action needs to be taken to ensure that those services are improved rather than withdrawn because they do not meet standards.

The setting of standards in relation to these matters is not simple and needs to be approached with caution. Practice standards developed must give due weight to emotional, social, cultural and spiritual issues and must be carefully checked for their applicability to all Indigenous situations. In some cases the best palliative care for a person may involve their return to an environment which would not be regarded as meeting usual medical or personal care standards.

It may not in fact be practicable to set prescriptive standards for the delivery of culturally appropriate palliative care, however it should be possible to set standards for appropriate cross cultural communication and practice, such as: ensuring effective Indigenous input into policy; employment or participation of Aboriginal and/or Torres Strait Islander staff where possible; and effective communication between Indigenous and non-Indigenous service providers. Observance of these standards would need to be monitored by (culturally knowledgeable) third party interviews of consumers (see Section 8.5).

## **n) Funding and resources (Chapter 9)**

Some significant structural issues were identified in our review of funding of palliative care for Aboriginal and Torres Strait Islander clients.

New initiatives in Indigenous funding focus on providing funding to fill gaps in the delivery of primary health care. Palliative care does not fit the definition of primary health care (being neither curative nor rehabilitative) even though it is often (and increasingly) delivered by primary health care providers. This, together with a general lack of awareness of palliative care, has probably resulted in palliative care not being identified as a priority issue in the first round of the regional planning upon which the Primary Health Care Access Program (PHCAP) formulas are based.

HACC funding guidelines now identify palliative care as a 'no growth' area. This is particularly significant to Aboriginal and Torres Strait Islander clients because HACC programs are amongst the few that successfully deliver services to Indigenous people at home, largely because of the employment of Indigenous HACC workers.

Most funding formulae for palliative care use cancer as a proxy. This means that the needs of HIV/AIDS, renal disease, cardio and respiratory disease palliative care clients may be overlooked. Aboriginal and Torres Strait Islander people are highly represented in these client groups which have been under-represented in palliative care numbers because traditionally these clients have not been referred to palliative care services.

Funding for Indigenous-specific initiatives appears to have been piecemeal to date. The New South Wales approach of adopting regional strategic plans which identify Aboriginal and Torres Strait Islander people as key target groups is commended, although these plans are framed in broad general terms and have not yet resulted in comprehensive or targeted funded initiatives. Further development and implementation of plans such as these will need to engage local Indigenous service providers and consumers in developing local priorities and solutions.

The multipurpose funding model used by one central Australian health service appears to be an effective way of ensuring that funds flow to identified local palliative care needs.

A number of service providers have suggested that funding packages similar to Community Aged Care Packages may allow them to purchase cultural advocacy services when required for Indigenous clients.

Enhanced Primary Care Items, (whereby Medicare payments may be claimed for multidisciplinary team care planning) should be marketed to palliative care and Indigenous health providers as a strategy to encourage the participation of Indigenous health providers into a more integrated (and better coordinated) service delivery for Indigenous clients.

In some circumstances, the funding arrangements for aged care facilities and nursing homes appeared to present barriers to clients receiving the best palliative care service in these facilities. Funding arrangements are needed that will allow aged care facilities and nursing homes to broker in palliative care services for symptom management advice, cultural support and additional nursing care when needed (see Chapter 9, Section 9.2.5).



Some key resource issues (see Section 9.3) were repeatedly raised with us by service providers. These included the following.

- The need for funding for Aboriginal and Torres Strait Islander staff. Such staff are needed in all regions where there is a substantial Aboriginal and/or Torres Strait Islander population. In all of Australia we identified only two Aboriginal staff employed directly by palliative care service providers. Even in areas where 50% of the clients are Aboriginal there are no Aboriginal staff.
- ACCHSs report that they are not funded for palliative care and have no specialist staff to undertake palliative care roles. Most ACCHSs operate only 9.00 – 5.00, five days per week, and if any palliative care services are provided, they are often undertaken by staff outside of normal working hours who are not paid for the additional work. Many would like to be able to provide staff to coordinate the care of clients with mainstream service providers and/or to provide Indigenous workers to accompany mainstream palliative care workers on home visits.
- There is a serious and widespread shortage of respite services, especially in places where Aboriginal and Torres Strait Islander people live. This makes it doubly difficult to care for family members at home effectively.
- Similarly, in many places where Indigenous people live access to allied health and ancillary services is a major issue. This ranges from access to speech pathologists and occupational therapists, to arranging home modifications. We repeatedly heard of waiting list periods which were longer than the life expectancy of the clients who needed the service.
- There were serious shortages of equipment in many areas and/or there was no funding for transport of equipment.
- In some areas, service providers acknowledged that funding restrictions prevented them admitting end stage renal cases as clients because if they were admitted while still on dialysis, they might live longer than the funding guidelines allowed.
- Lack of funds to allow for weekend visits by palliative care specialists was repeatedly raised as an issue.

In some areas there are no Indigenous specific aged care nursing home facilities; where there are aged care facilities, there are no (or too few) high care beds available.

In most States no fees are charged for palliative care services, however there is a widespread belief amongst Aboriginal and Torres Strait Islander people that these services do attract fees. Hidden costs of caring for family members at home, medication, home modification, equipment and power for heating and equipment, are significant however, and are costs that most can ill afford to pay.

## **o) Conclusions and recommendations (Chapter 10)**

The goals and objectives of the National Indigenous Palliative Care Strategy were reviewed in the light of our findings. Suggested changes and additions are provided in Chapter 10, Section 10.2 and it is recommended that the Strategy be reviewed in line with these suggested changes.



## i) Conducting demonstration projects and identifying resource shortfalls

It is clear that an infusion of funds is required in the short term to:

- develop the capacity of Aboriginal and Torres Strait Islanders to access and take part in delivery of palliative care services. Immediately, training for Aboriginal and Torres Strait Islander health workers, nurses, psychologists, social workers, doctors and allied health professionals is needed.
- develop services to provide culturally sensitive delivery of palliative care by improving the design and coordination of services, employing Aboriginal and Torres Strait Islander staff and improving the cultural competence of mainstream staff. Coordination must involve ACCHS and/or Area Health Boards.

It is estimated that five years' funding is required to develop pilot and demonstration projects which will set up the infrastructure, develop models of coordination and identify resource shortfalls so that the States and Territories could deliver needed services in a prioritised way.

This approach might be managed by the establishment of a committee of each of the State Partnership Forums (including the community controlled health sector) to develop State palliative care strategies for Aboriginal and Torres Strait Islander peoples. The intergovernmental forum on palliative care and the non-government sector should be engaged in this process.

## ii) Some key targets

A number of key targets were identified, many of which are relevant to other culturally and linguistically diverse groups as well as to Indigenous peoples.

- Employment and training of Aboriginal and Torres Strait Islander staff to work in palliative care (see Chapters 6 and 7).
- Information strategies for Aboriginal and Torres Strait Islander communities and for decision makers working in Aboriginal and Torres Strait Islander health (discussed in Chapter 7).
- Education for GPs and AMS doctors to improve their understanding of palliative care and cultural issues surrounding death and dying. It is important that AMS doctors come to see palliative care as a special service which they can access for their clients and in which they can take a central role if desired. A targeted Continuing Medical Education (CME) package is suggested.
- Cultural and linguistic advocacy should be available to all clients who need it. All palliative care teams should have the capacity (service delivery design and resources) to engage cultural and linguistic advocates for their clients (both Indigenous and Culturally and Linguistically Diverse (CALD) clients). Such advocates need orientation in the objectives and methods of palliative care (especially respect for the individual's wishes) as well as cultural awareness training (in respect of the mainstream medical culture in which they will be working). Cultural advocates should also receive supported debriefing as part of their engagement.
- Improvement in the effectiveness, content and incidence of cultural awareness training (see Chapter 7).
- Improvement in hospital and hospice design and management for in-patient palliative care is needed in order to accommodate cultural requirements (see Chapter 5). These issues have wide applicability in the Australian context. Many of the needs identified are applicable to other culturally and linguistically diverse groups in situations relating to death in hospital.

### iii) Research targets

- The way in which ‘bad news’ is delivered is critical to whether Indigenous people will access palliative care services. There is a need for State or regionally based research on how ‘bad news’ is usually delivered, how it should be done, the roles of family and cultural supporters, and links between the initial or subsequent advice of diagnosis and follow up actions such as referral to palliative care. Indigenous people need to be told about their condition in a way that is appropriate to their culture and that will support them in making informed choices about their future options. What is appropriate will vary from place to place.
- Contemporary Aboriginal and Torres Strait Islander modes of dealing with grief and loss, and the development of effective and accessible methodologies and programs in this area.
- Review of the incidence and effectiveness of cultural awareness training and developing competencies in cross cultural communication and service delivery.
- Development of models of palliative care pathways which include checkpoints for cultural advocacy and cultural safety.

### p) Immediate actions that would help increase Indigenous people’s access to palliative care (Chapter 10)

Two key issues identified during the research were: the need for mainstream services to employ more Indigenous staff; and the lack of communication between the Aboriginal and Torres Strait Islander health sector and mainstream palliative care service providers. Each lacks awareness of the way the other operates and the services provided. Closing the communication gap so that the two sectors can work together to provide an integrated service would have a significant positive effect in increasing Indigenous people’s access to palliative care services.

The following actions could be undertaken immediately:

- Initiate a dialogue between mainstream and Indigenous service providers in your region or local area to find out what each does, what each has to offer and to work out how the gaps can be filled. The solutions should be developed in response to local circumstances and cultural needs. This action can be taken by individual service providers and/or Indigenous health services. It should be encouraged and supported by State governments and non-government associations.
- Development of an Indigenous palliative care network and ongoing Indigenous palliative care newsletter.
- Employ Indigenous people in local palliative care services (see model duty statement, Appendix 14).
- Schedule a planning workshop for the region for all relevant parties.

### q) Conclusion

One of the immediate outcomes of this project has been that it has raised awareness of the issues involved in palliative care for Aboriginal and Torres Strait Islander clients, especially among both mainstream palliative care providers and Aboriginal and Torres Strait Islander health providers.

The need for Aboriginal and Torres Strait Islander people to be able to access culturally appropriate health services is a fundamental issue which service providers and policy makers must act upon. Mainstream service providers cannot assume that Aboriginal people will, or will not, be able to access palliative care services through an Indigenous health service and must make sure that their own services are appropriate and accessible, and/or that they are working in partnership with Indigenous organisations to deliver the best possible care.

## References

(2000). *National Palliative Care Strategy: A National Framework for Palliative Care Service Development*, Commonwealth Department of Health and Aged Care.

Table of Key Findings appears on the following pages.

# Table of key findings

	Finding	Ref	Page
<b>Chapter 2 National survey of palliative care provision</b>			
<b>Availability of services</b>	<p>Availability and structure of service delivery varies from region to region and State to State.</p> <p>Nationwide, only two palliative care services employ Aboriginal or Torres Strait Islander staff.</p> <p>ACCCHS/AMSs do not consider that they are palliative care service providers and are not linked to palliative care services.</p> <p>Some ACCCHS/AMSs do provide some palliative care services but lack training, expertise or support and do not offer after hours care.</p>	2.2	50
<b>Chapter 3 Socio-economic and cultural contexts</b>			
<b>Socio-economic contexts</b>	<p>Service providers and policy makers need awareness of socio-economic realities for Aboriginal and Torres Strait Islander peoples including poor housing, poverty, and poor underlying health (3.2) as well as the historical relationship between Indigenous peoples with health and welfare systems (3.2.7).</p> <p>The importance of self-determination and the role of community controlled health services must be acknowledged and recognised.</p> <p>Mainstream services need to engage with Aboriginal and Torres Strait Islander health service providers to provide an integrated service.</p> <p>Mainstream services need to modify service provision in consultation with local Indigenous communities to make services accessible and appropriate.</p>	3.4.1	82
<b>Communication</b>	<p>Barriers to communication include language and non-language barriers (see 3.2, especially 3.3.2).</p> <p>Cultural brokers and language interpreters are needed to provide quality palliative care to Aboriginal people and Torres Strait Islanders.</p>	3.4.2	82

Finding	Ref	Page
<b>Chapter 3 Socio-economic and cultural contexts</b> <i>continued</i>		
<b>Traditional issues</b>	3.4.3	82
<p>In some regions, traditional issues are an important consideration for palliative care service providers (3.3).</p> <p>Traditional medicine is widely used in a many regions and access to traditional healers should be facilitated where it is requested (3.3.6).</p> <p>Protocols to ensure that end of life cultural practices are discovered and accommodated should be an integral part of palliative care service delivery (3.3.7).</p> <p>Service providers need to be aware of the complexity of traditional cultures and that some actions may have serious cultural repercussions (3.3.3 and 3.3.8).</p> <p>Whilst awareness and respect for Indigenous cultures is critical to providing a high quality of care, service providers should not expect to be able to 'learn Indigenous culture'. Cultural awareness training should aim to develop awareness, sensitivity and skills in cross cultural practice, without creating the impression that Indigenous culture can be 'taught'.</p> <p>Cultural interpreters should be engaged in some regions.</p> <p>Practices and protocols should be checked for cultural safety.</p>		
<b>Chapter 4 Access to palliative care services</b>		
<b>Referral issues</b>	4.6	103
<p>The failure of GPs (both mainstream and employed by ACCHSs) to refer patients to palliative care services is a significant reason why few Aboriginal and/or Torres Strait Islander people do not access palliative care services (4.3).</p> <p>Aboriginal and Torres Strait Islander patients are often diagnosed very late in their illness and so if they are referred to palliative care, they are referred very late (4.3.5)</p>		
<b>Information and awareness</b>	4.6.1	103
<p>There is a need for information strategies:</p> <ul style="list-style-type: none"> <li>• to create awareness in Aboriginal and Torres Strait Islander communities about the nature and benefits of palliative care (4.4)</li> <li>• for ACCHS health professionals, including GPs</li> <li>• for mainstream service providers in cultural awareness and information about ACCHSs to build relationships and improve integration of services</li> <li>• 'word of mouth' strategies to enable Indigenous health and HACC workers to inform communities about palliative care, supported by appropriate printed information.</li> </ul>		
<b>Discharge planning</b> (see also Chapter 5)	4.6.2	104
<p>Better discharge planning (supported by cultural advocates) and the development of palliative care pathways which pinpoint key points requiring participation of cultural advocates is needed.</p>		

Finding		Ref	Page
<b>Chapter 4 Access to palliative care services</b> <i>continued</i>			
<b>Indigenous staff</b>	Employment of trained Indigenous staff, or the brokering in of Aboriginal and Torres Strait Islander services is essential (see Chapters 6 and 7)	4.6.3	104
<b>Supported referrals</b>	Aboriginal and Torres Strait Islander people need culturally appropriate support at the time of referral to palliative care services (4.4) to ensure that they receive adequate information about the illness and the potential benefits of palliative care.	4.6.4	104
<b>Relationship building</b>	Relationships need to be developed between mainstream and Indigenous service providers  Palliative care service providers need to develop relationships with Aboriginal and Torres Strait Islander communities and clients.	4.6.5	104
<b>Breaking ‘bad news’</b>	The way in which the patient and family are told about the illness is critical to Indigenous peoples’ access to palliative care services (4.6.6).  GPs and specialists need training in cultural awareness and how to break ‘bad news’.  Research is needed in this area – bodies representing Indigenous health professionals should be consulted on the design of the research.	4.6.6	104
<b>Attitudes and assumptions</b> (see also Chapter 5)	The attitudes and assumptions of service providers and health professionals play a critical role in whether Aboriginal and Torres Strait Islander people have access to or are offered palliative care services (4.3.1, 4.3.2 and 4.4.10; 5.1.1 and 5.9.1).  Attitudes of Aboriginal and Torres Strait Islander peoples towards the mainstream health system, the presence of non-Indigenous strangers in their homes and a perceived lack of entitlement impact upon their ability and willingness to access palliative care services (4.4.9, 5.1.1 and 5.9.1)  Attitudes and assumptions need to be challenged and changed through effective information and awareness strategies.	4.6.7	104
<b>Eligibility</b>	The range of serious and life-limiting conditions for which palliative care would be appropriate is much broader for Indigenous people than for the mainstream population (4.5).  Though the incidence of cancer is similar to that of mainstream populations, there are much higher incidences of diabetes, respiratory and circulatory illnesses and renal disease amongst Aboriginal people and Torres Strait Islanders and they are more likely to present with a range of co-morbid conditions because of underlying poor health (4.5 and 9.2).  Eligibility and funding rules need to be amended to include this broader range of conditions, in particular end stage renal disease (see 4.5.1).	4.6.8	104

	Finding	Ref	Page
<b>Chapter 5 Planning and delivery of care</b>			
<b>Expectations, attitudes and relationships</b>	In general, Aboriginal and Torres Strait Islander people strongly dislike, distrust and fear hospitals and non-Indigenous strangers coming to their homes, in part due to historical factors. ACCHSs allow community control of health service delivery and need to become part of the palliative care network, or be able to access specialist palliative care services (5.1.1).	5.9.1	150
	<p>Service providers and their staff hold attitudes that affect their behaviour towards Indigenous clients and which are perceived as judgmental, yet appear to be unaware of a cultural divide (5.1.1).</p> <p>Service providers need to establish relationships with Aboriginal and Torres Strait Islander Health service providers, and 'establish credentials' and develop relationships with Aboriginal and Torres Strait Islander communities. Introduction by an Indigenous community member is essential, especially when time to develop a relationship is short (in palliative care context) and trust is critical.</p> <p>An immediate action that could (and needs to be) taken by Aboriginal and Torres Strait Islander and/or mainstream service providers is to establish a dialogue to find out what services each provides, what each has to offer and how gaps can be filled (see also this project's Newsletter no.3 which outlines an approach to opening a dialogue and opportunities for cooperation).</p>	5.9.1	150
<b>Discharge planning and assessment</b>	There is a need for development of care pathways for palliative care clients which ensure continuing involvement of the palliative care team, a cultural advocate (such as AHLO, AHW or Indigenous staff of the service provider) and family members (5.2.1).	5.9.2	151
	<p>A question on Indigenous status should be asked on admission as a palliative care client.</p> <p>Appropriate Indigenous staff and/or cultural advocates need to be involved in assessment of palliative care clients (5.2.2).</p> <p>Assessment processes need to be sensitive to the circumstances of Indigenous clients – if possible, they should try to avoid a stream of different service providers, allow relationships to develop over several visits and deal sensitively with the dynamics of the household (eg in choosing the location for assessment, identifying decision-makers, etc)</p> <p>Service providers should ensure they have access to and funding for cultural specialists.</p>		

Finding		Ref	Page
Chapter 5 Planning and delivery of care <i>continued</i>			
Place of death issues	It is well documented that, in general, Aboriginal people and Torres Strait Islanders wish to die in their own country or community (5.3.1).	5.9.3	151
Early information, being prepared, choices	<p>Clients and their families need information as early as possible about the nature of the illness and their options, so as to make informed choices (5.3.1-5.3.2).</p> <p>Late referrals reduce the client's capacity to make choices about end of life decisions.</p> <p>In remote areas sending patients to distant cities for treatment may result in them being unable to return to their own country or community to die (5.3.1). This should be considered carefully with the family as well as the client and options such as use of tele-medicine should be considered.</p>		
Solutions for cultural dilemmas	Cultural dilemmas (5.3.2) may arise in relation to the place of death, especially in regions where homes may need to be vacated after a death. (see 5.3.2 and 5.9.3 for possible solutions)		
Advocacy	Palliative care service providers and ACCHSs should advocate on behalf of clients to enable them to return to their home country or community whenever possible.		
Setting of care	Most Aboriginal and Torres Strait Islander clients and their families want the client to be cared for at home (5.4.1).	5.9.4	152
Caring at home	<p>There are barriers to provision of palliative care services at home (5.4.2) but service providers could make improvements in a number of ways, including: visits accompanied by Indigenous staff; taking time to establish relationships; competence in cross cultural communication and practice; providing good information; confidentiality (5.9.4).</p> <p>Availability of respite services is critical to enabling families to care for palliative care clients at home.</p> <p>Hospitals are seen as places of death rather than healing and many members of Indigenous communities remember relatively recent racist practices in local hospitals (5.4.3).</p>		
Hospitals	<p>Current design, visitor facilities and perceived attitudes of staff continue to present barriers (5.4.3).</p> <p>Staffing and care practices at hospitals should be reviewed and action taken (based on consultation with local Aboriginal and Torres Strait Islander communities), for example to increase the number of Aboriginal and Torres Strait Islander staff at all levels and ensure that staff receive cultural awareness training (5.4.3).</p>		
Hospices	In general, Aboriginal and Torres Strait Islander people whose family had used a hospice were very satisfied with the facilities and staff attitudes (5.4.4).		



	Finding	Ref	Page
<b>Chapter 5 Planning and delivery of care</b> <i>continued</i>			
<b>Setting of care</b>			
<i>Hospices</i>	Anecdotal evidence from two regions indicated that orientation visits for key community members and clients were very effective in informing and changing community attitudes (7.1.5).	5.9.4	153
<i>Nursing homes and aged care facilities</i>	<p>Aboriginal and Torres Strait Islander people are generally reluctant to place family members in such institutions, but Aboriginal and Torres Strait Islander people do reside in nursing home and aged care facilities, including mainstream facilities (5.4.5).</p> <p>The higher percentage of Aboriginal and Torres Strait Islander staff in Indigenous specific facilities provides a level of 'cultural comfort' for residents (5.4.5).</p> <p>More funding and more flexible funding is needed to ensure that aged care facilities and nursing homes can access palliative care services for their clients (5.9.4).</p> <p>In areas of high Aboriginal and/or Torres Strait Islander populations, designated Indigenous staff positions commensurate with the population the facility serves are needed (5.9.4).</p> <p>The capacity to backfill positions when staff are on bereavement leave is needed (5.9.4).</p> <p>Nursing homes and aged care facilities should ensure that all staff have undertaken cultural awareness training (5.9.4).</p> <p>Aboriginal and Torres Strait Islander residents of nursing homes / aged care facilities may wish to return to their home country to pass away. They should be supported to make this choice (even if there will be insufficient care facilities for them) (5.9.4).</p>		
<i>Medically supported hostels and palliative care for itinerant people</i>	<p>A need was identified for medically supported hostels for short term accommodation of Aboriginal and Torres Strait Islander palliative care clients visiting for remedial treatment (5.4.6).</p> <p>There is a need for strategies and funding arrangements for delivery of palliative care services to all people, including itinerant or 'homeless' people (5.4.7 and 5.9.4)</p>		
<b>Counselling and bereavement care</b>	<p>Aboriginal and Torres Strait Islander people have limited access to counselling and bereavement care services (5.5.1 and 5.5.2).</p> <p>Aboriginal and Torres Strait Islander communities carry an enormous burden of grief which goes largely unrecognised.</p> <p>The limited bereavement care and support available from service providers (such as HACC worker and AMS health workers) is often informal and unpaid, although it may be a very important (and practical) part of bereavement care (such as assisting with funeral arrangements).</p>	5.9.5	154

	Finding	Ref	Page
Continuity of care	<p>Most Aboriginal and Torres Strait Islander people would prefer to die at home, but in practice this may not happen or may not be possible.</p> <p>Flexible and responsive services are needed to ensure that continuity of care is maintained if the circumstances require a change of plan.</p> <p>Client tracking systems (especially in hospitals) that include cultural advocacy at key points and ensure that client's wishes are respected are needed.</p>	5.9.6	155
Pain management, medication and equipment	<p>There are many cultural misperceptions about how Aboriginal and Torres Strait Islander people experience and manage pain, which may lead to false assumptions by non-Indigenous health professionals. Apparent differences are due to cultural expression rather than physiological differences, as explained in recent publications (5.7.1).</p> <p>The cost of medication is a significant burden to many Aboriginal and Torres Strait Islander families. Many cannot afford the cost of medication and dispensing fees and may go without medication in order to pay for other family needs (5.7.2).</p> <p>Suitability of medication, and availability of medication on return to the home community of the client are important considerations (5.7.3).</p> <p>Many Aboriginal and Torres Strait Islander people are fearful about the use of morphine and there are apparently many misunderstandings about its use. There are safety and security issues associated with the use of morphine (5.7.5).</p>	5.9.7	155
Access to palliative care specialists <i>For health professionals</i>	<p>Access to specialist advice is especially important (and sometimes critical) in effective symptom management (5.8.1).</p> <p>Palliative care advice lines for GPs and nurses have been set up in many areas, but are not always well known and are not often used by GPs and AMS doctors (5.8.1).</p> <p>Palliative care service advice lines should be 'marketed' to GPs and AMS doctors.</p>	5.9.8	156
<i>Symptom management advice</i>	<p>Many palliative care nursing staff contact city hospitals for advice if no local advice line is available, and develop their own advice networks (5.8.1).</p> <p>Service providers should advocate on behalf of Aboriginal and Torres Strait Islander clients who do not have a telephone, either for telephone access or for alternative emergency procedures.</p> <p>Funding structures should allow for funding of telephones in these circumstances.</p>	5.9.8	156

	Finding	Ref	Page
<b>Chapter 6 Workforce issues</b>			
<b>Aboriginal and Torres Strait Islander staff</b>	More trained Aboriginal and Torres Strait Islander staff are needed and should be employed in palliative care and support services, or their services bought in.	<b>6.8.1</b>	<b>164</b>
	More Indigenous staff would assist to develop relationships between mainstream service providers and Indigenous communities, and in development of culturally appropriate services.		
<b>Aboriginal and Torres Strait Islander staff</b>	Training of Indigenous health workers in counselling, domiciliary and palliative care should be promoted, especially in remote areas.		
	Additional Indigenous workers are needed in development and promotion roles and in hands on roles (see Appendix 14).		
	There is a need to employ or broker in services of medically trained Indigenous cultural advocates (such AHWs, EN or RN) in hospitals, health services and palliative care services.		
<b>HACC workers</b>	HACC workers play an important role in delivering palliative care and should receive appropriate training and counselling.	<b>6.8.2</b>	<b>165</b>
	Funding barriers limiting or preventing involvement of HACC workers in palliative care should be removed.		
	The HACC model may offer lessons for increasing the number of trained Indigenous workers in palliative care.		
<b>Aboriginal Liaison Officers</b>	ALOs should be more actively involved in discharge planning and delivery of palliative care.	<b>6.8.3</b>	<b>165</b>
	ALO job descriptions, workloads, staff levels, qualifications and working conditions need to be reviewed.		
	More ALO positions or increased working hours will be needed to increase their participation in palliative care support and liaison.		
	ALOs should receive some medical training (because of the need for medical advocacy), and basic training in palliative care and about local palliative care services.		
<b>Traditional healers</b>	Traditional healers play an important role in palliative care in some regions and funding should be available to facilitate access to them where necessary (such as fares, purchase of services).	<b>6.8.4</b>	<b>165</b>

	Finding	Ref	Page
<b>Chapter 6 Workforce issues <i>continued</i></b>			
<b>Language and cultural interpreters</b>	<p>All palliative care services should have the capacity to engage interpreters where the family involved does not speak English.</p> <p>Funding is needed to broker in interpreter services or in some places to establish such services (eg there is a need in Perth to offer interpreters for several Aboriginal languages).</p> <p>Palliative care teams should have resources and capacity in to engage cultural advocates for clients.</p> <p>Cultural advocates need palliative care training, training in respect of the mainstream medical culture and supported debriefing as part of the engagement.</p>	<b>6.8.5</b>	166
<b>Other Indigenous health professionals</b>	<p>Strategies are needed to raise awareness of Aboriginal and Torres Strait Islander nurses, doctors, psychologists and social worker of palliative care.</p> <p>Indigenous health professionals should have input into the development and delivery of culturally appropriate practice, through participation of professional associations (such as CATSIN, AIDA).</p>	<b>6.8.6</b>	166
<b>Chapter 7 Information, Education and Training</b>			
<b>General issues</b>	<p>Trained Aboriginal and Torres Strait Islander staff are needed at State level (government and palliative care associations) and in services.</p> <p>Policy makers need greater awareness of palliative care issues and should ensure that Indigenous communities are engaged in advising on their particular needs.</p>	<b>7.10</b>	184
<b>Information for communities</b>	<p>‘Word of mouth’ strategies, involving participation of staff from AMSs, HACCS, CACP and AHLOs will be most effective.</p> <p>Communication strategies for communities and for decision makers working Aboriginal and Torres Strait Islander health are needed.</p>	<b>7.10.1</b>	184
<b>Information for Indigenous clients</b>	<p>More information about the nature of the illnesses and care options available, provided earlier, is needed by most clients.</p> <p>There may be barriers to communication for Indigenous clients and they have particular information needs (7.2).</p> <p>Meeting information needs requires different solutions in different settings, such as language interpreters, cultural and medical interpreters and support, printed information. (7.2)</p>	<b>7.10.2</b>	185

Finding	Ref	Page
<b>Chapter 7 Information, Education and Training</b> <i>continued</i>		
<b>Information for Indigenous clients</b>	7.10.2 There is a clear need for a booklet such as <i>Palliative Caring at Home</i> (produced by PCAs in SA and WA), revised for Indigenous audiences.	185
<b>Information exchange between mainstream and Indigenous health providers</b>	7.10.3 There is little communication between mainstream and Indigenous health providers (4.3 and 7.3).  Local planning workshops (including all Indigenous and mainstream service providers) are needed to initiate communication about what each service provides, establish relationships and working partnerships (5.4.2 and 7.3).  Protocols are needed at local and regional levels.	185
<b>Education and training for Indigenous staff</b>	7.10.4 There is an urgent need for development and provision of formal training in palliative care, mental health and bereavement for Indigenous health workers (in undergraduate and post graduate courses).	185
	7.10.5 Indigenous health workers need training and awareness programs about palliative care and palliative care services in their State and region (Chapter 6 and 7.4)	185
	Indigenous health services and their staff need education about palliative care and its benefits and how to access palliative care specialists for their clients (4.3.2 and 7.6.2)	
	There is a need for a post graduate certificate in palliative care for AHWs and for a component on grief and loss associated with palliative care in the Mental Health Certificate qualification (7.6.1-7.6.2)	
<b>Education and training for other health professionals</b>	7.10.6 CME programs and post graduate certificate courses for nursing graduates in palliative care and bereavement are needed.  Mainstream palliative care workers need cultural awareness training, tailored for the palliative care context, that will result in effective cross cultural practice and competence (7.7)  Cross cultural education aimed at developing cross cultural partnerships between mainstream and Indigenous service providers are needed at local regional level.  GPs and specialists need education and awareness about the potential benefits of palliative care for their clients and their role in delivery of palliative care (4.3.2 and 7.6.1).  Organisations such as NACCHO, CATSIN, AIDA, together with OATSIH, should have an advisory role in development of appropriate education and training courses, and information and education programs.	186

Finding	Ref	Page
<b>Chapter 7 Information, Education and Training</b> <i>continued</i>		
<b>Cultural awareness training</b>	All palliative care workers and community nurses should have regular cultural awareness training and work experience opportunities to enable them to develop competence in cross cultural communication.  Competencies in cross cultural communication and service delivery need to be developed and applied. Cultural awareness training needs to deliver more than 'awareness'.	7.10.7 187
<b>Volunteer programs and support groups</b>	Volunteer programs have not previously attempted to recruit volunteers within Aboriginal and Torres Strait Islander communities (7.9).  There is interest in Aboriginal and Torres Strait Islander communities in participating in volunteer programs. Coordinators would need cultural awareness training and guidance from community advisers on recruitment and training approaches (7.9).	7.10.8 187
<b>Chapter 8 Some aspects of good practice</b>		
<b>Elements of good practice</b>	Key elements of good practice include: early referral, cultural advocacy, good communication, relationship development, clear coordination, regular case management meetings, continuity of care, flexibility and responsiveness (8.2.2)	8.7.1 202
<b>Good practice in Indigenous palliative care</b>	Employment of Aboriginal and Torres Strait Islander staff.  Palliative care providers act as coaches, providing training and support to family (8.2.1).  A comfortable and 'neutral' place for the person to pass away, which the family can readily access and which will not result in cultural avoidance problems after death.  Good design and management of residential palliative care facilities that accommodate cultural practices (5.4.3 - 5.4.4., Appendices 8 and 9).  Pathways of care that include checkpoints for cultural advocacy and cultural safety (8.4.2).  Practical assistance to families is a valuable form of bereavement care (5.5).  Workshops and planning sessions are needed to develop regional network guidelines that will assist in communication and delivery of integrated services (Appendix 12).	8.7.1 202

	Finding	Ref	Page
<b>Chapter 8</b> Some aspects of good practice <i>continued</i>			
<b>Standards and monitoring</b>	<p>The issue of palliative care standards should be approached with caution and practice standards must be checked for applicability to all Indigenous situations (8.5.1).</p> <p>Practice standards must give weight to emotional, social, cultural and spiritual issues (8.5.1).</p> <p>Rather than prescriptive standards for delivery of culturally appropriate care, standards should be established for effective cross cultural communication and practice, such as ensuring Indigenous input into policy development, ensuring employment and participation of Indigenous staff and cultural advocates.</p> <p>There is a need for systems for monitoring and review of effectiveness and quality of delivery of care to Aboriginal and Torres Strait Islander clients (8.5.2).</p> <p>Where standards are not met, services should be improved rather than withdrawn because they do not meet standards.</p>	8.7.2	203
<b>Chapter 9</b> Resources, fees and funding			
<b>Structural funding issues</b>	<p>Palliative care does not fit into the definition of primary health care but is increasingly delivered by primary health care providers (9.2.2).</p> <p>HACC services often provide palliative care services, but HACC funding guidelines now identify palliative care as a 'no growth' area (9.2.3).</p> <p>The use of 'cancer as proxy' funding formulae appears inappropriate to the needs of Aboriginal and Torres Strait Islander palliative care clients (4.5 and 9.2).</p> <p>Multipurpose funding for rural and remote communities may be effective in ensuring funding for palliative care services, but the scheme is currently used by only community (9.2.6).</p> <p>Packages similar to CACP may enable service providers to purchase cultural advocacy services for palliative care clients.</p> <p>Enhanced Primary Care items (Care Planning and Case Conferencing) could support more integrated and better coordinated service delivery for Indigenous clients and should be 'marketed' to palliative care and Indigenous health providers.</p> <p>Funding arrangements may present barriers to clients receiving quality palliative care in aged care facilities and nursing homes. These facilities require funding arrangements that enable them to broker in palliative care services, additional nursing care and cultural support for Indigenous clients (9.2.5).</p>	9.5.1	215

	Finding	Ref	Page
<b>Chapter 9 Resources, fees and funding</b> <i>continued</i>			
<b>Resource issues</b>	<p>Funding is needed for employment of more Aboriginal and Torres Strait Islander staff (9.3).</p> <p>ACCHSs are not funded to provide palliative care, do not employ specialist staff and usually do not provide after hours service.</p> <p>There is a widespread, serious shortage of respite care services, especially in regions of high Aboriginal and Torres Strait Islander population.</p> <p>Funds available for personal care and home help services are inadequate. These services are not funded to provide palliative care and sometimes ‘close the books’ to palliative care clients.</p> <p>Funds are needed to address serious equipment shortages and cover costs of transporting equipment.</p> <p>There is no funding for Indigenous liaison positions.</p> <p>Funding is not available to cover after hours visits by palliative care specialists.</p>	<b>9.5.2</b>	<b>215</b>
<i>Costs related to cultural needs</i>	The cost of temporary housing, transport to return clients to home communities, traditional healers, transport of deceased to home country, language and cultural interpreters, and support to families in preparing funerals should be recognised as legitimate costs of provision of palliative care.		
<i>Indigenous specific aged care facilities</i>	In some regions there are no Indigenous-specific nursing homes or aged care facilities; where they exist there are too few high care beds (9.3.8).		
<b>Flexible funding</b>	Funding needs to be flexible so that palliative care ‘packages’ can be purchased when needed – for example, additional resources that allow a palliative care patient to remain in an aged care facility, or in a remote community in their home country (9.2.7).	<b>9.5.3</b>	<b>216</b>
<b>Fees</b>	<p>A widespread belief amongst Aboriginal and Torres Strait Islander peoples that fees will be charged for palliative care services discourages them from accessing the services. (9.4).</p> <p>In general, fees are not charged or are waived for clients who cannot afford them, however Aboriginal and Torres Strait Islander clients may be reluctant or unable to seek a waiver. Most Indigenous families do not have the financial resources to pay contributions for home care services, equipment or cost of medication. Few have private health cover.</p> <p>The absence of fees (and fee waiver schemes) needs to be better publicised, and funding support schemes should be developed to assist people in hardship who cannot afford the ‘hidden costs’ of caring for someone at home.</p> <p>Fees charged by home nursing services should be reimbursable through Medicare.</p>	<b>9.5.4</b>	<b>216</b>



	Finding	Ref	Page
<b>Chapter 10 Summary of findings and conclusions</b>			
<b>Issues for palliative care policy makers and service providers</b>	<p>Policy makers and/or palliative care service providers could undertake an advocacy role for Aboriginal and Torres Strait Islander clients on issues such as:</p> <ul style="list-style-type: none"> <li>• Housing (to enable relocation during palliation, and for family after the death) in regions where there are powerful cultural traditions surrounding the place of death (5.3 and 5.9.3).</li> <li>• Ensuring that palliative care and Indigenous health providers and Indigenous liaison staff are involved in hospital discharge planning (4.3.6 and 5.2.1).</li> <li>• Development of ‘tagging’ systems in hospital that palliative care clients are identified on admission to emergency wards (5.6 and 5.9.3).</li> <li>• Changes in hospital practices in areas such as attitudes and expectations, appropriate spaces for visitors, allowing time for families to be with deceased and design of facilities to meet cultural needs of Indigenous clients (5.3.3 - 5.3.4).</li> <li>• Development of culturally appropriate grief and loss counselling strategies and services (5.5).</li> </ul>	10.1.5	218
<b>Lack of resources</b>	There are insufficient resources for the provision of palliative care services and there are some major gaps in the services that are provided (Chapter 9)	10.1.7	219
<b>Lack of palliative care training</b>	<p>There exists an urgent need for development and provision of appropriate training, inclusion of palliative care in undergraduate courses and development of post-graduate courses (6.6).</p> <p>There is a need for medically trained Indigenous advocates (6.6).</p> <p>Indigenous staff working in palliative care need adequate supervision and debriefing (5.5.7).</p>	10.1.8	219
<b>What community members want</b>	<p>Early information and support (5.5.7).</p> <p>More information about the course of the illness and what to expect, including at final stage (7.2).</p> <p>More information about services (7.10).</p> <p>Respite care (5.4.2).</p>	10.1.9	220
<b>Implications for the National Strategy</b>	The research findings indicate several areas where the NPCSC could be strengthened to take into account the special needs of Aboriginal and Torres Strait Islander peoples. The following summarises recommendations detailed in Chapter 10, Section 10.2.	10.2.1	220

Finding	Ref	Page
Chapter 10 Summary of findings and conclusions <i>continued</i>		
Implications for the National Strategy	Goal 1: Awareness and understanding	10.2.1 220
	<p>The research revealed a great need to increase awareness of palliative care and what it can offer, for professional training and for strategies to ensure that Aboriginal and Torres Strait Islander people can access the services they need.</p> <ul style="list-style-type: none"> <li>• Good word of mouth strategies are needed to inform Indigenous communities.</li> <li>• Training and education is needed for health workers and health professionals working in the Aboriginal and Torres Strait Islander medical sector.</li> <li>• For mainstream services, strategies aimed at increased awareness of the Indigenous peoples cultural needs and recruitment of Indigenous staff and volunteers, are needed.</li> <li>• Increased awareness at State and Australian Government level to ensure that Indigenous peoples' needs are taken into account and that Aboriginal and Torres Strait Islander health organisations are actively engaged in developing policy.</li> </ul>	
	Goal 2: Quality and effectiveness	10.2.2 222
<p>While it is important to set high quality standards in delivery of care, it is also important to ensure that they are suitable for all situations, particularly in delivering care to Aboriginal and Torres Strait Islander clients.</p> <ul style="list-style-type: none"> <li>• Setting of care standards should be approached with caution.</li> <li>• Standards should be established for appropriate cross cultural communication and good cultural practice.</li> <li>• Palliative care services should be encouraged to develop good practice locally, in partnership with local Aboriginal and Torres Strait Islander health services.</li> <li>• Aboriginal and Torres Strait Islander patients may have special resource needs which should be recognised as part of the cost of providing good palliative care</li> <li>• Care pathways should aim to ensure that Indigenous clients are referred early and have good cultural support throughout their care; palliative care services need to develop systems to check the quality of their services to Indigenous clients.</li> </ul>		

	Finding	Ref	Page
Chapter 10 Summary of findings and conclusions <i>continued</i>			
Implications for the National Strategy	<p><b>Goal 3: Partnerships in care</b></p> <p>Strong relationships between Indigenous communities and mainstream service providers in palliative care need to be developed and fostered through:</p> <ul style="list-style-type: none"> <li>• Local planning workshops,</li> <li>• Strong local and regional protocols,</li> <li>• Training and employment of Aboriginal and Torres Strait Islander staff in mainstream palliative care services.</li> <li>• Employment of trained Indigenous staff in policy development</li> </ul>	10.2.3	224
10.3 Conclusions: immediate and medium term actions and targets			
Demonstration projects and resource shortfalls	<p>An infusion of funds is required in the short term for:</p> <ul style="list-style-type: none"> <li>• Training for Aboriginal and Torres Strait Islander health workers, nurses, psychologists, social workers, doctors and allied health professionals to develop the capacity of Aboriginal and Torres Strait islander communities to access and take part in delivery of services.</li> <li>• Improving design and coordination of services, employment of Aboriginal and Torres Strait Islander staff and improving cultural competence of mainstream staff.</li> <li>• Pilot and demonstration projects, some at State or regional level and some at local level, giving high priority to training, planning and coordination.</li> </ul> <p>Five years' funding is required to develop pilot and demonstration projects to establish infrastructure to enable States and Territories to prioritise and deliver needed services.</p> <p>Projects could be managed by a committee of each of the State or Territory Partnership Forums which would develop palliative care strategies in consultation with the community controlled health sector and non-government bodies such as State Palliative Care Associations and Cancer Councils.</p>	10.3.1	225
Key targets	<p>Employment and training of Aboriginal and Torres Strait Islander staff to work in palliative care (Chapters 6 and 7).</p> <p>Information strategies (Chapter 7).</p> <p>GP and AMS (ACCHS) doctor education (Chapter 7).</p> <p>Cultural and linguistic advocacy (3.2.8 and 3.3.2).</p> <p>Cultural awareness training (Chapter 7).</p> <p>Hospital and hospice design and management</p>	10.3.2	226

Finding	Ref	Page
<b>10.3 Conclusions: immediate and medium term actions and targets</b> <i>continued</i>		
<b>Research targets</b>	<p>Four key areas for research are identified:</p> <ul style="list-style-type: none"> <li>• The way in which ‘bad news’ is delivered and the roles of family and cultural supporters, as this stage and subsequent follow up are critical to Indigenous access to palliative care services (Chapter 4).</li> <li>• Contemporary Aboriginal and Torres Strait Islander modes of dealing with grief and loss and development of effective, accessible methodologies and programs (5.5).</li> <li>• Review of the effectiveness of cultural awareness training and development of competencies in cross cultural communication and service delivery (Chapter 7).</li> <li>• Development of model palliative care pathways which include checkpoints for cultural advocacy and cultural safety (5.6 and 5.9.2).</li> </ul>	<b>10.3.2</b> 226
<b>Immediate actions to increase Indigenous access to palliative care</b>	<p>Dialogue should be initiated between mainstream and Indigenous service providers at local/regional level to establish what each does, what each offers and how gaps can be filled. Solutions should be developed in response to local circumstances and cultural needs. The process should be encouraged and supported by State governments and non-government associations.</p> <p>Development of an Indigenous Palliative Care Network and ongoing Indigenous palliative care newsletter.</p> <p>Employ Indigenous people in local palliative care services (model duty statements are provided in Appendix 14).</p> <p>Schedule a planning workshop at regional level for all relevant parties.</p>	<b>10.3.3</b> 227

# Chapter 1

## Background and methodology



### 1.1 The brief

The Study was commissioned by the Australian Government Department of Health and Ageing, Mental Health Branch. The main objectives of the project as set out in the tender project description were to identify:

- (a) Existing activities in palliative care for Aboriginal and Torres Strait Islander peoples at the Australian Government, State/Territory and community levels. This should include mainstream activities which incorporate Indigenous components as well as Indigenous specific activities;
- (b) Areas that could be enhanced or developed under the National Palliative Care Strategy (2000) at the Australian Government, State/Territory and community levels;
- (c) The needs of Aboriginal and Torres Strait Islander peoples for palliative care, taking into account the diversity of Aboriginal and Torres Strait Islander communities and the different needs for rural, remote and metropolitan settings; and
- (d) Spiritual and cultural practices that relate to death and examine the extent to which these are being implemented in a culturally sensitive way, taking into account the diversity of settings and cultural beliefs.

The study was conducted in four main parts:

- In **Stages 1-3** (March-April 2002) a literature review (looking at previous research and other documented activities) and scoping study were conducted. State and regional agencies, service providers and community organisations were contacted by telephone to identify palliative care services in their regions.
- **Stages 4-5** (May-July 2002) focused on developing field methodology (the steps to be followed when visiting and talking with communities and organisations) and building partnerships with communities which consultants were to visit later.
- During **Stages 6-7** (August-November 2002) field work was conducted in rural and remote areas and some towns and cities. A question sheet was posted to community organisations in selected communities that could not be visited.
- **Stages 8-9** are the reporting phases. The final report consists of a detailed report for the Australian Government Department of Health and Ageing (this report) and a short report (newsletters 3 and 4) which will be circulated to all communities and organisations that have participated in the study.

## 1.2 The steering committee

The steering committee for this project included representatives from:

- the Congress of Aboriginal and Torres Strait Islander Nurses;
- the Aboriginal and Torres Strait Islander Research Agenda Working Group of the National Health and Medical Research Council;
- the Intergovernmental Forum on Palliative Care (State/Territory representatives); and
- the National Aboriginal Community Controlled Health Organisation (NACCHO).

The steering committee reviewed interim reports, methodology proposals and newsletter texts and provided invaluable support, advice and guidance.

## 1.3 The scoping study

Letters outlining the project and inviting input were written to:

- all the State and Territory Associations of Aboriginal Community Controlled Health Services (ACCHS);
- all State Health Departments;
- all ATSIC Regional Councillors;
- regional Aboriginal organisations (eg Northern Land Council, NPY Women's Council, Apunipima in Far North Queensland, and some regional Indigenous health providers like Nganampa Health Council and Ngaanyatjarra Health Service Aboriginal Corporation); and
- a range of stakeholders including Nurses Associations, Carers Associations, major Church organisations, Royal Flying Doctor Service, Division of General Practice, Rural Doctors' Association etc.

The scoping study methodology followed that set out in the tender and took place by telephone. Sets of scoping questions were developed for telephone interviews, including separate sets of questions for State or national level informants, regional level informants, and service providers. These questions were also posted on the project web site at <http://member.telpacific.com.au/ksa>.

The intention was to develop a tiered information framework, first to understand the structure of palliative care for each State and Territory, then to discover what Indigenous-specific services exist and, finally, to undertake interviews with some of these services providers.

In each State and Territory telephone calls were made to officers of:

- Office of Aboriginal and Torres Strait Islander Health (OATSIH)
- State Health palliative care representatives
- State Health Aboriginal and/or Torres State Islander Units
- State Government Aged Care Sections or Departments
- Palliative Care Australia (PCA) State divisions
- major regional Aboriginal and Torres Strait Islander organisations
- some Aboriginal and Torres Strait Islander service providers
- some non-Indigenous Service Providers

Representatives of the Aboriginal and Torres Strait Islander HACC Reference Group and various Australian Government Health and Ageing funding program representatives were also contacted by phone.

In addition to the methodology agreed to in the brief, we developed a questionnaire which was sent to all mainstream palliative care service providers listed in the Palliative Care Australia mailing list. The main purpose of this questionnaire was to find out about the levels of access by Indigenous clients to mainstream palliative care services and to gain information about perceived needs and issues from those with Indigenous clients. A copy of this questionnaire is at Appendix 1.

## 1.4 Scoping study responses

Many of the people we spoke with at this stage of the project were public servants, however the information about service models and the comments on issues and needs has come primarily from service providers working on the ground. About half of these informants were Aboriginal and/or Torres Strait Islander people.

Most State agencies were very helpful in providing information and advice. Few provided (or were able to provide) the lists of palliative care providers we sought. NSW Health preferred to circulate a copy of our questions to their regional officers, rather than put us in contact with them.

Some agencies were better than others at responding to telephone calls. At least 98% of our calls were answered or returned positively. We did not receive a response from any State or Territory Associations of ACCHS during this phase of the study. From the 76 letters we sent to stakeholders, ATSIC Regional Councils and regional community organisations, we had eight responses, six of which provided information and two of which indicated no involvement in palliative care. The letters we sent proved a useful introduction to the project for telephone respondents. When we telephoned many of the organisations we had written to, having been referred to them from State level enquiries, phone responses were generally positive and helpful.

Responses to the mainstream service questionnaire were as follows.

NUMBER OF RESPONSES BY NUMBER OF INDIGENOUS CLIENTS:							
Numbers of Indigenous clients	0	1	2-5	5-10	10-20	20+	Total Responses
Number of responses	46	12	19	3	2	1	83 i.e. 29.3 %

A response rate of approximately 30% is very high for this sort of survey.

While the methodology is dependant upon the knowledge of the people we spoke with, we are confident that this initial scoping identified the major activities in Indigenous palliative care. A level of confidence is gained from the fact that we were repeatedly told the same things and referred to the same organisations as providers of palliative care to Aboriginal and Torres Strait Islander clients. Data from the mainstream questionnaire is summarised in Appendix 2 and discussed in Chapter 4.

NEWSLETTERS - RESPONSES BY STATE:								
Newsletter	NSW	ACT	VIC	TAS	SA	WA	NT	QLD
No.1	9	1	4	1	1	4	6	9
No.2	3	-	1	-	1	6	1	8

The findings of the preliminary scoping study were reported in an interim report at the end of Stage 2 and have been incorporated into this report.

## 1.5 Previous research and relevant literature

The literature search involved searches of available databases and review of bibliographies of studies that had already been located. Further references were also gathered during the scoping study and fieldwork.

The database lists of major universities were reviewed and databases to be searched were selected. Those selected fell into three broad categories:

- collections centred on Aboriginal and Torres Strait Islander and multicultural issues;
- collections of medical, allied health and sociological issues; and
- collections of anthropological or ethnological research.

The following databases were searched:

- ATSIROM
- ATSIC Library catalogue
- ATSIhealth
- IndigiNet
- HealthInfonet
- Menzies School of Health Research
- AMI (Australian Medical Index)
- AMED (Allied and contemporary medicine)
- AUSTHealth
- CINAHL (Cumulative Index to Nursing and Allied Health Literature)
- APAIS (Australian Public Affairs Information Service)
- APAIS-Health
- Health and Society Database
- RURAL (Rural and remote health database)
- AUSTROM:FAMILY
- AIATSIS catalogue
- RCIADIC (Royal Commission into Aboriginal Deaths in Custody)
- The Cochrane Library



The search results were reviewed, an annotated bibliography developed, and specific items were selected for further consideration according to their relevance for this study. The 'Indigenous Palliative Care Bibliography' is attached at Appendix 4 together with a list of international references collated from data bases and a 'Training Resource Bibliography'.

An 'Anthropological Bibliography' containing items from a range of data bases (primarily the AIATSIS database) was assembled. Many of the references deal with traditional mortuary practices and do not inform the current study. While some of the ethnographic data is relevant to current beliefs and practices, it is unlikely to be of use to palliative care service providers or policy makers. Selected items that may be of interest are listed as Anthropological Library in Appendix 4.

Summaries of the most significant reports of field research to date (Collis-McAnespie, Dunn et al. 1997) (Mobbs 1995) (Wagstaff 1997) (Williamson 1996), several significant articles; (Prior 1999), (Prior 2001) (Fried 1999) and (Fried 2000), and a recent theses (Fried 2000) highlighting the key points raised, are provided in Appendix 5.

## 1.6 The field work

### 1.6.1 Methodology development

The three types of field work planned involved:

- regional needs analysis;
- good practice studies; and
- facilitation of protocol development (one location only, in Victoria)

The methodology was developed during May and June and was circulated to the steering committee for comment. The methodology paper which was submitted to the Aboriginal Health and Medical Research Council (AH&MRC) NSW is attached at Appendix 6.

### 1.6.2 Field work locations

The field locations were selected in locations and regions where:

- there is a relatively high Aboriginal and/or Torres Strait Islander population, but little is known about palliative care service delivery to Aboriginal and Torres Strait Islander clients (regional needs analysis);
- we had received reports of good practice.

Consideration was given to where previous studies had been conducted and to where other research projects were underway, so as not to duplicate work unnecessarily. It was seen as important to build upon, rather than replicate, previous research, done in specific regions.

The election of location was endorsed by the steering committee after discussion. The field work was conducted in the following locations:

<b>Northern Territory</b> Darwin Alice Springs Tennant Creek Tiwi Islands <sup>1</sup>	<b>Victoria</b> Shepparton-Mooroopna  <b>New South Wales</b> Nowra Kempsey Western Sydney
<b>Central Australia</b> One community/ health service district	<b>Queensland</b> Mt Isa Cairns and District Rockhampton Torres Strait Brisbane
<b>Western Australia</b> Kimberley Kalgoorlie Perth	
<b>South Australia</b> Adelaide and a rural/regional area	

In the case of organisations or locations which we would have liked to include in our field work but which we could not visit (due to logistics or budget), question sheets which mirrored the information being collected (and headed by an informed consent form) were forwarded for completion. (see below Needs Survey questionnaires). The information from these responses has been incorporated into this report.

### 1.6.3 Ethical approvals

We wrote to each State ACCHS umbrella body about ethics procedures. The response in each State was as follows.

#### Western Australia

In Western Australia we were referred to the Western Australian Aboriginal Health Information and Ethics Committee (WAAHIEC). Our paper was received the day before the next scheduled meeting and was not considered. WAAHIEC advised that a submission for ethics approval needed to be provided in their own format and that the next meeting was scheduled for mid-late September. This meeting was delayed due to a bereavement but approval was granted at the re-scheduled meeting on 4 October. As a result, our field work in Western Australia was delayed by several weeks and resulted in some changes to field locations.

<sup>1</sup> At the request of the Tiwi Health Board we developed a special set of questions for Tiwi health workers which was administered in the Islands by Mr Jeremy Smith of the Board.

## **South Australia**

The Aboriginal Health Research Ethics Committee (AHREC) of South Australia meeting on 11 July gave conditional endorsement, pending information about sample size and timing. This was supplied and approval was granted.

## **Queensland**

Mr Mick Adams, CEO of the Queensland Aboriginal and Islander Health Forum (QAIHF) advised us that they were satisfied with our approach to the proposed fieldwork and invited us to address their annual general meeting in Mackay in August. Luana Johnston addressed the meeting and field work proceeded.

## **Northern Territory**

The Aboriginal Medical Service Alliance of the Northern Territory (AMSANT) considered the matter at their annual general meeting and advised that since we had ethics approval from another state (South Australia) they did not require any additional submissions and were happy for us to proceed.

## **Victoria**

We were advised that the Victorian Aboriginal Community Controlled Health Organisation (VACCHO) ethics committee was not currently operational and in any case the nature of the work in Victoria was similar to that in the other states. We therefore wrote to VACCHO to inform them about the project but not to ask for approval.

## **New South Wales**

The methodology proposal was submitted to the AH&MRC (NSW) on 12 June for their meeting on 19 June. On 6 August we received advice to say that they had referred the matter to NACCHO. No response was received from them until 8 January 2003, by which time the field work had concluded. The field approach in New South Wales was therefore modified (see below). The committee raised a number of issues which have been responded to.

### **1.6.4 Methodological issues encountered in the field**

The interview guidelines set out in Appendix 6 were used throughout as a guide to interview, with the language being modified where necessary. The questions were usually read as printed and then restated in a way more appropriate to the local situation and language. Group discussions took between 1.5 - 2 hours. One on one interviews usually lasted about one hour.

The information sheets and informed consent forms used were the same for each State and Territory and varied only in the provision of contacts for local (State) ethical approval bodies and in recording the status of the relevant request for ethical approval. In New South Wales the information was changed to indicate that the AH&MRC was still considering our proposal.

The delay in obtaining ethical approval in New South Wales meant that the field work could not be undertaken by Jennifer Beale and Jack Gibson. It was instead undertaken by Kate Sullivan and Jennifer Beale in one location and by Kate Sullivan and Kerry Welsh in two other locations.

The time required to arrange meetings and liaise by phone, fax and email prior to field work far exceeded that allowed for. In most cases it took far longer to arrange visits and meetings than it did to carry them out, however the careful planning meant that the field visits went smoothly and that solid relationships were developed prior to visits.

A significant aspect of the field work was the importance of the local contact person who undertook the recruiting of community members. This person was usually a representative of a local AMS<sup>2</sup> or HACC program. The role of this person was extremely important.<sup>3</sup> Details of the recruitment process they were asked to use is provided in Appendix 6. Considerable time was spent in telephone communications with the local contact prior to visits and in face to face meetings before the group discussion. The role of these people varied but they usually (especially on the occasions where an Indigenous team member was not present) sat in on the interview, provided introductions and assisted in translation of questions to suit local circumstances or generally assisted with communication issues. Their contribution to the project was substantial.

### Participation issues

- It is noted that the mainstream palliative care responses contained only a very few from major hospitals, many of which provide palliative care services.
- In many centres it was difficult to identify many Aboriginal and/or Torres Strait Islander community members who had had experience of palliative care because of the low numbers of Aboriginal and/or Torres Strait Islander people accessing these services. These people were usually identified for us by the local AMS or other Aboriginal Health service provider. We are confident that in any given centre we spoke with most of the people who fitted our criteria, however, as we were consistently referred to the same people by both mainstream and Aboriginal and Torres Strait Islander service providers.
- We found that speaking with Aboriginal (and Torres Strait Islander) Health Workers (who are also community members) was very fruitful as they were able to speak about how community members managed when a family member had a life-limiting illness (even though they may not have accessed palliative care services) and they were also able to make informed comment about access to services.
- The number of people interviewed during the field work is set out in the table below. Every effort was made to engage with Aboriginal and Torres Strait Islander community members and health workers.
- The majority of people we spoke with were women. This is to be expected as the main carer role in many communities falls to women. Views expressed by the men we spoke with were not substantially different from those expressed by women.
- While we specifically asked *not* to speak with people who were more recently bereaved than six months, we did speak with some (about five people) who were more recently bereaved because these people specifically wanted to speak with us. In each case these peoples' willingness to take part was double and triple checked and they were reassured that they could change their minds at any time. These people signed a modified consent form. Where it seemed appropriate, the local community contact who had recruited participants (see above) was asked to (or themselves initiated a) check on the person the next day to see that they were all right. Feedback from these and indeed all interviews was that the participants were very pleased to have had the opportunity to speak with us and with others in the small groups about their experiences.
- As we had not received a response from the Ethics Committee in New South Wales by the end of our planned field season and given the time constraints of the project, we modified our field strategy in New South Wales after consultation with the funding body. We were not able to recruit community members to interview through the AMS (i.e. patient records) so we concentrated on service provider

<sup>2</sup> We use the term AMS to refer to the local Aboriginal Community Controlled Health Service (ACCHS) because it is generally the term which our informants use to describe the local ACCHS.

<sup>3</sup> Some times the work was done in their own time and was reimbursed and sometimes in the time of their employer. All organisations were made written offers of reimbursement for time and venue use.

interviews. We spoke with mainstream service providers and AMS doctors and health workers in all three areas visited. In all cases the New South Wales AMSs were informed that we did not have ethical approval. We spoke with community members recruited in two of the three locations using other contacts. Informed consent, including disclosure that we had not received a response from the ethics committee, was gained in all cases.

In (NSW Rural area 1) we met with a group of nine elders and the AMS arranged for us to speak with a group of five health workers who had a community perspective. In western Sydney, we used local contacts to locate people with experience of palliative care. In (NSW Rural area 2) we did not interview any community members but spoke with health workers and AMS doctors and health workers.

FIELD WORK INTERVIEWS BY LOCATION											
State	Indigenous							Non Indigenous			
	Nurse/ Doctor	HW	ALO	Comm. Member	Manager	Worker HACC	Other	Nurse	Doctor	Manager	Other
ACT											
NSW		7	6	14	6	5	0	8	5	2	2
NT	1	14	2	9	3	3	0	2	5	8	3
Cent A	0	0	0	18	0	2	0	5	2	2	1
SA	0	6	0	28	3	3	1	5	5	3	1
QLD	8	5	8	36	10	1	0	10	15	14	7
TAS	0	0	0	0	0	0	0	0	0	0	0
VIC	1	1	1	5	1	1	0	5	1	4	0
WA	4	7	5	18	4	7	3	9	6	10	5
Totals	14	40	22	128	27	22	4	44	39	43	19
							257				145

## 1.7 Needs Survey Questionnaires

The intent of the stage 6 questionnaire was to make contact with organisations or communities that we could not include in our field work but which we thought would have a view on future needs and issues related to our study.

Originally we had intended to send 600 questionnaires at this stage, however during the scoping stage of the study (Stages 2 and 3), we sent a detailed questionnaire (which also canvassed needs and issues) to all mainstream palliative care service providers as identified to us by Palliative Care Australia and State government agencies (N=283). 30 % of these service providers responded. Most had no Indigenous clients and of those that did most had only one or two clients. It is highly likely that the 70% who did not respond had no Indigenous clients. The results of the mainstream questionnaire were used to plan the fieldwork locations and methodology.

The 'Needs' questionnaire (covering some of the same ground as the Stage 3 'Mainstream' questionnaire) was directed to organisations which we felt would have an Aboriginal and/or Torres Strait Islander or a practical perspective on future issues and needs.

<b>Stage 3</b> questionnaires were sent to	<b>283</b>
<hr/>	
<b>Stage 6</b> questionnaires were sent out to:	
• Community Controlled Health Organisations	132
• Flexi-funded or residential Aboriginal Aged Care hostels or nursing homes	55
• Newsletter respondents (people who had responded to the previous newsletters wishing to contribute)	43
	<b>230</b>
<hr/>	
<b>Total</b>	<b>513</b>

A summary of the results of the Stage 6 'Needs' questionnaire is provided at Appendix 7. The results strongly mirror the same issues and concerns identified in the field work. The information elicited by these questions has been incorporated into this report.

## 1.8 Data analysis

Most of the data gathered was of a qualitative nature. Data from questionnaire responses was reviewed and summarised under the question headings. After analysis of field notes from eight locations in Victoria, South Australia and Queensland and bearing in mind the questionnaire responses, a common reporting format was devised using headings grouped under the following main themes.

1. Models of service delivery
2. Discharge planning
3. Information
4. Education
5. Communication
6. Traditional Issues
7. Counselling and bereavement issues
8. Place of death, funerals, 'sorry business' and repatriation of deceased
9. Resources – and funding issues
10. Medication
11. Marginal social conditions
12. Equipment
13. Role of AHWs, ALOs, Aboriginal HACC workers
14. Confidentiality
15. Access of Indigenous people to palliative care services

16. Administration of the Indigenous status question
17. Referrals of Indigenous people to palliative care
18. Care planning and delivery
19. Importance of service provider networks and the need for a team approach
20. Access to and value of palliative care specialist consultants
21. Cultural awareness training
22. Volunteers and volunteer training
23. Palliative care in aged care facilities
24. Palliative care in nursing homes
25. Eligibility for palliative care
26. Aspects of good and bad practice

Field notes were reviewed and reported under these broad headings with some variation in sub-headings which reflects variations from place to place. These notes and the questionnaire response summaries were reviewed to produce this report. Issues relating to the analysis of data about rates of access are discussed in Chapter 4.

## 1.9 Reporting

Three interim reports were prepared and delivered at the end of stage 2, stage 5 and at stage 8. Steering committee meetings were held by phone hook-up (2 meetings) for reporting and discussion of field destinations. The steering committee's input was solicited by email on issues such as methodology, newsletter text, and other issues as they arose.

At the end of stage 8 the contract was varied to allow for the production of an additional newsletter, primarily to provide more rapid and substantial feedback to people who had taken part in the fieldwork.

As requested by the funding agency, the field notes were transcribed and typed and a de-identified version of the notes was supplied for use by the Wodonga Project/Mungabareena National Guidelines project.

Because of the nature of our agreements with participants not to disclose information about communities and individuals, the field notes will not be published. Voices of community participants have been quoted at length in this report in ways which do not identify specific communities or individuals.

A fourth and final newsletter will be produced on acceptance of this report. Each newsletters was posted to approximately 1500 people and placed on the project web site at <http://member.telpacific.com.au/ksa>.

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## Chapter 2

# National survey of palliative care provision



Many people know little about palliative care and how and where it is delivered. We have therefore documented what we discovered about the services that exist around Australia.

### 2.1 Introduction – variation of models

Mainstream palliative care services in most States and Territories include palliative care beds in a small number of metropolitan hospitals and a network of palliative care coordinators and community-based services, which usually operates as part of the State Government's regional health delivery structure. In some metropolitan centres there are separate palliative care units or hospices, often run by private service providers.

The community-based services either include, or coordinate access to, services to deliver palliative care in the home: services such as palliative care nurses, social workers, grief counsellors and home help. Some regional hospitals also have limited palliative care beds, usually in surgical or acute wards. The structure of palliative care service delivery in Western Australia, South Australia and Queensland is outlined in recent comprehensive reports or strategies<sup>1</sup>.

A snapshot of several States illustrates the variation that exists not only from State to State but within States.

### 2.2 Palliative care in Queensland

The services available in Queensland, as in other States, are comprised of the following major components (Adams and Schweizer 2001):

- tertiary hospitals, palliative care consultative services and designated palliative care in-patient facilities
- community based services
- general practitioners

The level and range of palliative service available throughout the State vary considerably, with notable differences between urban, rural and remote areas.

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<sup>1</sup> (1995). Palliative Care in Western Australia to the Year 2001, Part One, 'Metropolitan Area', Health Department of Western Australia. and (1996). Palliative Care in Western Australia to the Year 2001, Part Two, 'Country Services', Health Department of Western Australia.

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### 2.2.1 Tertiary hospitals, palliative care consultative services and designated palliative care in-patient facilities

Most of these palliative care specific services are concentrated in the south-eastern and coastal areas of the State, though most of the districts within the areas defined as Regional, Coastal and Urban provide either tertiary hospitals, palliative care consultative services and/or designated palliative care in-patient facilities. the availability of palliative care specific services in the rural and remote areas of the State especially in central and northern Queensland is limited (Adams and Schweizer (2001) (p19).

### 2.2.2 Community based services

There is great variation amongst the providers of community-based services and in the distribution of these services within the State (Adams and Schweizer 2001) (p21). In most areas, community-based services include one or more of the following main domiciliary providers: Blue Care, St Luke's Nursing Service and St Vincent's Community Services; as well as some independent or private domiciliary providers such as The Green Nurses in Townsville. Community and District Health Services also provide some palliative care in rural and remote areas, including clinics, Community Aged Care Packages (CACPS) and Community Options (COPS) in isolated areas.

In Gordonvale, south of Cairns, a decommissioned hospital is now the base for a palliative care service providing 14 in-patient beds and community nursing services. This service has close links with the local Aboriginal community. The service also has provided training for Torres Strait Islander health workers, based on Thursday Island.

An analysis of the distribution of community-based palliative care services using data from Adams and Schweizer (2001) (p21 and p39) indicates that:

- in metropolitan Queensland there are 12 community based palliative care services in three health districts;
- in Regional, Coastal and Urban regions there is one service in each of seven districts out of a total of 15 districts);
- in rural and remote regions there is one service in each of four health districts out of a total 16 districts.

### 2.2.3 General practitioners

Adams and Schweizer (2001) paint the GP as the key primary provider of palliative care in the home. They point out that most GPs have very few palliative care patients in any one year and that this creates difficulties in care provision by GPs and in the coordination of seamless care.

Other key aspects of the system include the use of:

- other (non tertiary) hospital facilities, especially in rural areas;
- residential care facilities;
- respite services allied health;
- bereavement support (usually built into most palliative care services) and pharmaceuticals and equipment;
- volunteers; and
- community education and awareness programs.

#### 2.2.4 Indigenous palliative care in Queensland

There are no Indigenous-specific palliative care services in Queensland. As far as could be established, only one palliative care service provider employs an Indigenous staff member (an Aboriginal Liaison Officer).

There are two partnership agreements between States and the Australian Government concerning Aboriginal and Torres Strait Islander health in Queensland: one covering the Torres Strait region; and one for the mainland. These are broad, general agreements covering issues relating to access to mainstream services, maintenance of Indigenous-specific services and coordination issues. They have given rise to Partnership Forums which have developed Frameworks for Action documents which identify particular areas of need for Indigenous health. Palliative care is not mentioned in these framework documents<sup>2</sup>.

Aboriginal and Torres Strait Islander health services in Queensland are delivered either by Aboriginal and Islander Health Services as part of the Community Health system, or by Community Controlled Health Organisations (usually referred to as AMSs or AHSs), some of which affiliate under the banner of the Queensland Aboriginal and Islander Health Forum (QAIHF).

Some AMSs have some palliative care clients. In Brisbane, the Aboriginal and Islander Community Health Service at Woolloongabba provides no specific palliative care service but works closely with the Mt Olivet Palliative Care Service. In Cairns, the Wuchopperan Medical Service provides clinical, cultural and carer support to palliative care clients, as well as bereavement and grief counselling through its Social Health Team. Wuchopperan doctors consult with the palliative care unit based at Cairns hospital, but have no formal after hours service.

Some AMSs have nurses who provide home visits, but most are 9.00 – 5.00, five days per week services and offer no after hours service. Other AMSs report that they *‘have no resources to pick up palliative care but would like to work with other service providers’*.

Some mainstream palliative care services in Brisbane contact the AMS at Inala or the Aboriginal and Islander Community Health Service at Woolloongabba if they have an Aboriginal or Torres Strait Islander client. The Princess Alexandra Hospital palliative care unit will contact the Inala Community Health service to ensure services are put into place for the client on their return home.

State-run Aboriginal and Islander Community Health services provide no specific palliative care services but some services will make home visits to palliative care clients if requested. This may occur if one of the palliative care hospitals in Brisbane contacts them about a palliative care client.

Whilst some hospitals employ ALOs, they may not be directly involved with palliative care clients or with discharge planning. As far as we are aware, none of the domiciliary nursing services (important partners in palliative care provision in the home) have Indigenous staff as yet, though we have been advised that Blue Care has engaged an Aboriginal Employment Officer.

The Aboriginal and Islander Women’s Cancer Prevention and Support Service is an important resource in Indigenous palliative care. This service is disease-specific and provides important support to clients, many of whom are palliative care clients and who are older women who have presented late via the Oncology Unit.

Established and collaborative relationships between palliative care service providers and Aboriginal health service providers would be the exception rather than the rule.

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<sup>2</sup> Queensland Department of Health.

## 2.3 Palliative care in New South Wales

In each of the 17 health service regions of the State there is a Palliative Care Service headed by a Palliative Care Director, CNC or CNS Palliative Care. These units typically coordinate palliative care services in their regions, providing consultative services, liaising with in-patient facilities and coordinating community nurses, volunteers, allied health and home help services. Some of the regions have several sectors or sub-districts which may each have a palliative care coordinator. In-patient facilities vary, from beds in public hospitals to dedicated hospice facilities, both public and private.

Each of the 17 health service districts also has a director of Aboriginal Health who contributes to policy and planning in relation to Aboriginal Health and coordinates the work of health workers, much of which is focused on health promotion and education.

Each health region has begun the development of a Palliative Care Strategic Plan. Of the four strategic plans reviewed, all included Indigenous peoples as special client groups and had identified actions aimed to improve access. The Regional Director of Aboriginal Health had been actively involved in the planning process for one of the strategic plans, but it appears that the Regional Directors of Aboriginal Health and the relevant AMSs had not always been actively involved in the planning process for the strategic plans.

Our scoping study and field interviews indicate that at the local level there is little contact between palliative care units and AMSs or Community Health based AHWs. There are no Indigenous-specific palliative care services. Rather, AMS doctors tend to manage those of their clients who require palliative care and are unlikely to refer them to specialist palliative care services. AMS services are usually 9.00 – 5.00, five days per week services.

The New South Wales Aboriginal Health Strategic Plan (1999)<sup>3</sup>, produced as a result of the New South Wales Health Partnership Agreement, does not specifically mention palliative care. Most palliative care services have little knowledge of the needs of Indigenous people, nor do they have relationships with Aboriginal and Torres Strait Islander health service providers.

## 2.4 Palliative care in the Northern Territory

The Northern Territory Health web page states that palliative care is '*shared by family/partners, health services and community organisations*'. Education, support and consultation is provided to clients, service providers and the community by members of palliative care teams.

Palliative care teams based in Darwin and Alice Springs provide:

- client assessment;
- facilitation of care coordination (case management);
- advice, counselling and support for clients;
- direct specialist care and consultancies;
- access to services of medical officer, nurse, allied health professionals, pastoral care and volunteers;
- telephone support and advice to clients and health care providers 24 hours per day, seven days per week bereavement services;

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<sup>3</sup> (1999). New South Wales Aboriginal Health Strategic Plan 1999, State Health Publication No: (AH) 990151, NSW Health Department.

- community education;
- education for service providers;
- access to equipment; and
- access to dedicated palliative care hospital beds.

An interdisciplinary palliative care team may include people from public, private and non-government community organisations. Services may include:

- medical care;
- nursing care;
- culturally relevant care;
- allied health professional care;
- respite care;
- hospital care;
- hospice care;
- care in nursing homes and hostels;
- personal care;
- spiritual care;
- home support; and
- transport.

#### 2.4.1 Eligibility

Any person of any age in the advanced stages of a life threatening disease where cure is no longer possible is eligible to access palliative care along with their family, partner and carers.

#### 2.4.2 Referral

Referral to palliative care can be made by:

- self referral;
- family members and friends;
- general practitioners;
- specialists;
- community health nurses; or
- other health professionals.

#### 2.4.3 Indigenous palliative care in the Northern Territory

There are no Indigenous-specific palliative care services in the Northern Territory. The Territory is essentially covered by two palliative care services, the Top End Palliative Care Service (40% Aboriginal

and/or Torres Strait clients) which operates out of Darwin, and the Territory Palliative Care Service which operates from Alice Springs (50% Aboriginal clients). One Aboriginal staff member is attached to the Top End service.

The Top End Palliative Care Service is a consultative service providing education and support to health practitioners in the community and in hospital settings, as well as clients, carers and families in urban Darwin, rural and remote areas, East Arnhem and the Katherine region. Outreach services are limited because of the cost of getting staff into remote communities and the lack of accommodation. It employs an AHW as well as doctors (2), nurses (3), part-time occupational therapist, part time pastoral care worker, administration staff (2) and a full time social worker.

Danila Dilba Aboriginal Health Service in Darwin also provides some palliative care services in the Darwin area and works in conjunction with the Top End Service to provide a coordinated approach to care. Although the Aboriginal health service receives no palliative care funding, they recorded a total of 20-25 palliative care clients during 2000/2001. The Aboriginal health service and Top End Palliative Care Service meet at least every four weeks to discuss mutual clients.

#### 2.4.4 Regional and remote areas

Remote regions such as East Arnhem can be cut off for six months at a time due to seasonal weather conditions and Aboriginal health services there report that regionally based respite and palliative care services are badly needed.

In the Tiwi Islands the population of approximately 2,400 people form a distinct language group. Palliative care is provided here by the extended family (mothers, fathers, children, husband, wife, aunties, uncles) with support from health service staff including doctors, nurses and AHW's. There is a large health clinic with a staff of 50 in the main population centre on Bathurst Island and two clinics on Melville Island. The clinics are directed by the Tiwi Health Board and are managed by senior Aboriginal health workers who oversee the work of nurses, GP's, program managers and visiting specialists. The registered nurse and AHW from the Top End Palliative Care Service in Darwin are available as required and a physiotherapist visits regularly.

The Territory Health Palliative Care Service based in Alice Springs provides case management of clients in Alice Springs and an outreach consultative service to outlying remote Aboriginal communities in its region in the Northern Territory, South Australia and Western Australia. It offers support, advice and education and works on an empowerment model by assisting local health staff to work out solutions. The service employs a male RN Coordinator, a female RN and a part-time female medical officer who has extensive experience working with Indigenous palliative care clients. This service has no Indigenous staff. Despite the large number of Aboriginal clients (50%) it has been unsuccessful in attracting funds for Aboriginal positions.

Some services are also provided to palliative care clients in central Australia by the following Aboriginal organisations:

- Central Australian Aboriginal Congress (CAAC) (an AMS);
- Arrente Council;
- Tangentyere Council;
- Old Timers Nursing Home;

- Home Help Alice Springs;
- Hetti Perkins Nursing Home.

The Territory Health Palliative Care Service works closely with the Central Australian Aboriginal Congress, Frail Aged and Disability Service team and the Tangentyere Council Homemakers and Old Peoples Services (HOPS) team. The Congress Health Worker accompanies the Territory Health Palliative Care Service staff on all initial visits to Aboriginal palliative care clients in Alice Springs.

The Tangentyere HOPS program has two HACC workers. A full time CACP carer is responsible for providing services to clients in 22 town camps and a 'share house' of 6 clients. They also work closely with the Palliative Care Service and CAAC. Their specific role in providing palliative care services is to arrange and deliver special food to the client (cooked by the Alice Springs Hospital), monitoring medication dosette boxes and ensuring their wardens keep an eye on clients during their day and night patrols.

In another town in the region the hospital employs a part time nurse to provide palliative care and receives support from the Territory Health Palliative Care Service based in Alice Springs. The Aboriginal Medical Service in the town cares for palliative clients as needed.

Representatives of Aboriginal organisations in Alice Spring recommended that a male and female AHW be employed to work with the palliative care team, but suggested they be physically located in an Aboriginal organisation (possibly AMS) so they would not be working in isolation. They suggested that at least two full time Aboriginal employees (male and female) were needed, but ideally three should be employed to carry the responsibility, and that these should be trained in palliative care and rotated throughout the year to avoid 'burn out'.

The majority of Aboriginal people living in remote communities are unable to access government supported palliative care services.

## 2.5 Palliative care in Tasmania

'The Tasmanian Palliative Care Service is a specialist State-wide service that each year provides direct care, assessment and ongoing involvement and advice to approximately 1000 individuals, and their families.

'Funded through the Tasmanian Department of Health and Human Services and part of the Division of Community, Population and Rural Health... the Tasmanian Palliative Care Service provides specialist medical, nursing and social work expertise and trained volunteer support to people with a life-limiting illness, as well as to their families.

'Palliative care is offered directly to people in need or indirectly through the provision of education, consultancy and information to health professionals who are essential to the delivery of palliative care.

'The Tasmanian Palliative Care Service has three specialist community teams based in Hobart, Launceston and Burnie, with outreach to rural and urban areas.

'The service funds a 10-bed in-patient facility (J W Whittle Palliative Care Unit) in Hobart, and three State-funded beds at Phillip Oakden House (the Manor hospice) in Launceston, with a commitment to extend in-patient facilities in the North West. The Whittle Unit provides care to public, private and Department of Veterans Affairs clients. People are admitted to Whittle via referral from a medical practitioner to one of the palliative care medical specialists.



‘The medical director of the Tasmanian Palliative Care Service and two palliative medicine specialists hold conjoint positions with the University of Tasmania, recognising the importance of research and undergraduate and post-graduate palliative care education.

‘Palliative care teams work collaboratively with the Hospice Care Associations (South and North West). The Hospice Care Associations provide trained volunteer support to families and people in need of palliative care.’<sup>4</sup>

### 2.5.1 Indigenous palliative care in Tasmania

Aboriginal health services are provided by The Tasmanian Aboriginal Corporation and the South East Tasmanian Aboriginal Corporation (SETAC). SETAC informed us that Aboriginal people in Tasmania access mainstream services without difficulty. Palliative care service providers in Hobart report that The Tasmanian Aboriginal Corporation medical service is involved if desired by clients. For Cape Barron Islanders, however, remoteness means that people usually have to travel to the Tasmanian mainland for treatment and care and usually pass away there.

The Tasmanian Aboriginal Health Framework agreement does not include any reference to palliative care.

## 2.6 Palliative care in Victoria

Delivery of palliative care in Victoria is divided between five regional palliative care units in the country and four palliative care units in metropolitan Melbourne. A typical region might coordinate four or five sites within it. These sites are coordinated by Clinical Nurse Specialists (CNS) who take referrals, assess patients and coordinate care plans. Care will be delivered wherever is appropriate – at home, in a hospital or in a nursing home or hostel. There will usually be a general after hours telephone information and advice service and sometimes patients are put ‘on-call’ giving them direct phone access to nurses after hours. Services available include:

- advice or assistance to manage distressing symptoms (eg. pain, nausea, vomiting);
- a central information point for advice;
- coordination for support services in the community and between hospital and home;
- access to respite care;
- emotional support to patients’ families and carers;
- specialised equipment loans;
- grief and bereavement support.

CNS services are free and funding is available for a range of other services where these are deemed necessary, for example:

- residential care;
- short term respite care;
- nursing care;
- personal care attendants;

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<sup>4</sup> Drawn from Tasmanian Government website [www.dhhs.tas.gov.au/palliativecare](http://www.dhhs.tas.gov.au/palliativecare).



- allied health care;
- pastoral care and counselling;
- home help;
- travel costs;
- complementary therapies;
- equipment hire and dressings and pharmacy.

Eligibility criteria include:

- person has been diagnosed as having a life limiting illness;
- a progressively deteriorating disease;
- a life expectancy of six months or less, or requires earlier support in facing a significantly foreshortened life expectancy.

Variations from this model exist, for example some palliative care services are brokered out to private suppliers.

### 2.6.1 Indigenous palliative care in Victoria

There are Aboriginal community controlled health organisations throughout Victoria, 27 of which are affiliated with the Victorian Community Controlled Health Organisation (VACCHO) umbrella body. Some of these have developed relationships with local palliative care service providers but this is the exception rather than the rule. There are 18 Koori Liaison Officers (ALOs) in hospitals throughout Victoria.

A draft report prepared in 1997 (Wagstaff 1997) assessed the situation regarding Indigenous palliative care in Victoria at that time. This report is summarised in Appendix 5. Little appears to have changed in the intervening period.

The Victorian Koori Health Framework Agreement does not include any reference to palliative care.<sup>5</sup>

## 2.7 Palliative care in South Australia

In South Australia, palliative care can be provided in a person's home, community-based residential settings, in-patient units or acute care units.

### 2.7.1 Acute care

Patients in acute care facilities (hospitals) are managed by their treating specialist, with palliative care specialists providing consultancy. In rural health units, there has been a trend toward developing family suites that provide greater opportunity for family members to actively participate in the care of a person who is dying.

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<sup>5</sup> Victorian Department of Human Services (Pers Com).

### 2.7.2 Community care

Community palliative care is provided by all public palliative care services in South Australia, offering a range of supports for people remaining in their place of residence.

### 2.7.3 Hospice care

Hospices provide intensive in-patient care, day care and support, including respite care and short-term admission to stabilise symptoms or provide in-patient care when death approaches and community care is not viable. Care may be provided in a freestanding building or a separate special purpose area within a hospital.

### 2.7.4 Public hospitals

Most major metropolitan hospitals have palliative care beds. This may be a converted area within a ward or unit, or patients may be managed in a general ward.

### 2.7.5 Palliative care services

There are five metropolitan specialist palliative care services providing in-patient and community based care. The following provides a summary of these services.

Each of the five palliative care services (PCS) is focused around a hospital which has in-patient facilities. The palliative care teams based at these five hospitals coordinate the services of the in-patient units, the community nursing service and the domiciliary care providers, liaising with hospices and ancillary services as needed. For example:

#### **Lyell McEwin PCS:**

- forms the northern arm of North Western Adelaide Health Service (NWAHS) PCS;
- provides a team management approach to the care of palliative patients;
- consults with community-based clients and Central Districts Private Hospital;
- provides outpatient services and psychosocial support, counselling, respite care, and bereavement program with close liaison and availability of shared-care with a consultant psychiatrist;
- medical consultants share an after hours telephone service for clients with the western arm of the NWAHS;
- provides an on-call palliative care doctor;
- provides a community outreach program, maintaining close working relationships with general practitioners Royal District Nursing Service (RDNS), Domiciliary Care Service (DCS) and other community services.

Two organisations which are central to the service provision of the palliative care services are the RDNS and the Domiciliary Care Service.

### **Royal District Nursing Service (RDNS):**

- has three palliative care nursing groups – central, southern and northern – that care for 550 patients per month;
- has specialist and generic nursing service that supports patients dying at home;
- has specialist palliative care clinical nurse consultants (CNCs) who provide palliative care and liaise with other palliative care services;
- has field nurses who provide daily general palliative care nursing care in consultation with specialists and palliative care CNCs;
- provides pain and symptom management, general nursing care, carer support and bereavement care;
- has public and private liaison nurses to facilitate discharge planning for clients;
- provides a 24 hour call centre which streamlines referrals to ensure clients, carers and referral agencies receive a timely response from specialist nurses.

### **Metropolitan DCSs:**

- underpins and supports the work of other agencies;
- the three metropolitan DCSs – Southern DCS; Eastern DCS; Northern DCS – provide case management from allied health and nursing clinicians;
- has case coordinators which work with palliative services and RDNS;
- has clients who require palliative care services from clinicians best able to meet the care needs;
- provides clinical assessment (occupational therapy, physiotherapy and some social work), nursing care, equipment provision, environment modification, some respite care and home help;
- provides a consultancy service to other clinicians within DCS.

In addition to these services, the Women's and Children's Hospital (WCH) has a paediatric palliative care liaison nurse supporting PCS providers who deliver home-based palliative services to paediatric patients and their families. It offers home-based palliative care for dying children, including 24 hour on call support, and provides bereavement support for parents and siblings where no other appropriate services are available.

### **Rural services**

There are no nominated palliative care beds in rural regions, but local hospitals have developed small suites or comfortably furnished rooms which greatly increase the capacity for family members to participate more actively in the care of the dying person.

In the country, palliative care services are sited within regional government health services and there are several palliative care services within some regions.

A rural palliative care service typically:

- provides some direct care for palliative care patients;
- coordinates care needs with local community providers;
- provides consultancy to local health units and community outreach services that do not have dedicated palliative care workers.

For example, one region has:

- a palliative care consultant who provides some direct care, education, and visits the hospital as a consultant;
- a clinical nurse who provides counselling, symptom management and case management and staff who provide nursing to palliative care clients;
- a bereavement coordinator who provides a counselling service for patients and families; and
- provides allied health services (social worker, physiotherapist, dietician, occupational therapy, equipment etc) that are coordinated through the health centres

In contrast another has only:

- a palliative care nursing service which provides a consultancy role to generalist providers and works with complex cases;
- a bereavement support worker to coordinate bereavement services and develop the role of volunteers; and
- has out of hours support managed by GPs.

REGION	PALLIATIVE CARE SERVICES
Eyre	Pt Lincoln & Lower Eyre Palliative Service
Hills, Mallee, Southern	Hills Mallee Southern Region District Nursing Service South Coast Palliative Care Service Murray-Mallee Palliative Service
South East	Mount Gambier & District Palliative Care Service Naracoorte & Lucindale Palliative Care Service
Mid North	Port Pirie Palliative Care Service Laura & Districts Hospital
Northern & Far Western	Whyalla Palliative Care Service Port Augusta Palliative Care Service
Riverland	Riverland Palliative Care Service
Wakefield	Barossa & Districts Palliative Care Service Northern Yorke Peninsula Health Service Gawler Palliative Care Service

## 2.7.6 Aboriginal health services

Aboriginal health services in South Australia include community controlled health organisations<sup>6</sup> and South Australian Department of Human Services Regional Community Health Services Aboriginal Health Teams (for example Muna Paiendi based at Lyall McEwin Hospital, The West Nunga Health Team at Angle Park in Adelaide, and others set in rural areas). Some hospitals have ALOs but these are not necessarily (or usually) involved in palliative care planning or service delivery.

<sup>6</sup> There are 26 affiliated members of NACCHO (for example Nunkuwarin Yunti in Adelaide and Pika Wiya in Port Augusta).

The South Australia Aboriginal Health Partnership Agreement<sup>7</sup> does not mention palliative care, however it does include improvement of Aboriginal access to all mainstream services as a major strand.

In metropolitan Adelaide, the palliative care service providers do not have much knowledge of Aboriginal health services, whilst Aboriginal health service providers appear to have very limited knowledge of palliative care services. Few established relationships exist, though there have been cases where the AMS has operated as a case coordinator, bringing in palliative care services as required. AMSs and Aboriginal Community Health Services are 9.00 – 5.00, five days per week services.

In remote areas, community clinics are the main service providers. For example, Nganampa Health Council is an Aboriginal (Anangu) community controlled health organisation providing primary health care services to people living on the Anangu Pitjantjatjara (AP) Lands, in the far north-west of South Australia. There are six main clinics and three health worker stations in smaller communities across the AP Lands.

The administrative centre of the Nganampa Health Council is based at Umuwa, 470 kms south-west of Alice Springs while an office in Alice Springs handles finance, supply and purchasing, personnel and payroll, mail services, data entry and program coordination.

As well as providing 24 hour primary clinical care, Nganampa Health delivers a range of public health programs including aged and disability care. The *Tjilpi Pampa Ngura* was opened at Pukatja in October 2000 and is part of the Multi Purpose Service funded by the Australian Government Department of Health and Ageing. It provides short-term care (up to 2 months) for respite and convalescence for older Anangu, and stores and distributes palliative care equipment (purchased some years ago with a one off grant) to communities as required.

Nganampa Health also has Home and Community Care (HACC) funded services in six communities. In Pukatja the HACC program is run from the *Tjilpi Pampa Ngura*. The program delivers meals and laundry services to older Anangu from Pukatja and surrounding homelands, who also visit the facility for the day on a regular basis, where they are assisted with showering and provided with a cooked meal. In other communities basic HACC services are provided, including a cooked meal five days a week, laundering of bedding and clothes, provision of firewood and transport from camp to store, clinic and office.

For specialist treatment, people from the AP Lands are required to travel to Alice Springs or Adelaide. Nganampa Health Council coordinates assistance to people requiring specialist treatment, by providing airfares, bus fares, transport and accommodation, interpreters and hospital liaison services.

Palliative care has been identified as an important need on the AP Lands. A strategy for developing palliative care for Aboriginal Australians was prepared for Nganampa Health by Robyn Mobbs (1996) as part of a national palliative care project funded by the Australian Government Department of Health and Family Services in 1996.

A report by Bourke, *et al* (1998) is the final report of a Australian Government funded investigation into the feasibility of an Aboriginal Palliative Care Strategy for South Australia.

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<sup>7</sup> SA Aboriginal Health Council.

## 2.8 Western Australia

The system and structure of palliative care in Western Australia is different from other States. Initiatives in palliative care in Western Australia have come almost exclusively from the private sector and 75% of palliative care services are provided by the private sector. However this seems to have resulted in an uneven distribution of services, which are strong and integrated in some areas, but have gaps in other areas.

The main palliative care services in Perth consist of:

- palliative care units in hospitals such as Royal Perth and Sir Charles Gardener (Monday-Friday) using a 'roving model' within the hospital (ie not 'bed based')<sup>8</sup>;
- several hospices such as The Cottage Hospice, Hollywood Private Hospital Palliative Care Unit and the Murdoch Community Hospice. The Cottage Hospice and Murdoch provide admission for symptom control, respite care and terminal care. The average length of stay at the Cottage Hospice is 12-14 days and the mode<sup>9</sup> is 1 day. People generally come to these facilities because they cannot die at home – either because the family cannot cope or because of the complexity of their symptom management;
- Silver Chain Hospice Care Service provides domiciliary palliative care for metropolitan Perth, including consultative and direct support in the patient's own home or in hostels. They provide a 24 hour service with CNCs on call. There are eight Silver Chain teams in the metropolitan area. Each team consists of nurses, care aids, doctors (Silver Chain employs 30 GPs), volunteers, a counsellor, a chaplain and a specialist palliative care consultant. All Silver Chain nurses have palliative care training.

The Aboriginal Medical Service, Derbal Yerrigan, does not have specialised palliative care services or staff. It employs 150 staff over seven sites, including four community nurses, six care aids, nine Aboriginal health workers, three senior health workers and 8.4 (effective full time) doctors. It also provides physiotherapy, podiatry and dental services, and employs a mental health nurse and social worker. Derbal Yerrigan has a transport service and provides access to a range of other specialists. They see themselves as playing a coordination role with Silver Chain which provides services outside normal working hours. Derbal Yerrigan sometimes receives referrals from Royal Perth if one of their doctors has been involved with the client.

The AMS does not keep data on palliative care client numbers but believes there are currently 11 cases at its Maddington site (two are renal clients and some of the nine others may be elderly<sup>10</sup>). There are also 13 HIV positive clients.

One hostel (36 beds) caters for long term renal clients from remote areas who are in Perth for dialysis.

Currently, there are virtually no Indigenous-specific mental health services in Perth and none which specialise in grief and loss care. Aboriginal people do not access mainstream bereavement services. The Aboriginal Medical Service hopes to employ psychologists on its staff in the near future.

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<sup>8</sup> For example the palliative care team at Royal Perth do not have any in-patient beds. They provide a consultative service to in-patients and their role varies depending upon the medical team with whom they are working. As a rule they do not have patients under their own care. Patients are referred to the unit by doctors (doctor to doctor) or by nurses (nurse to nurse). A large part of the role of the palliative care team is to advocate for what the patient needs and for the involvement of the palliative care team.

Sir Charles Gardener Hospital has a similar system though they have access to two palliative care beds for emergencies. These are rarely used, however. The Charles Gardener Palliative Care Team also runs an outpatient clinic three times per week for symptom management.

<sup>9</sup> Most common length of stay.

<sup>10</sup> Many people working in Indigenous health do not distinguish between palliative care and care of the frail aged.

One small unfunded service has put together what the staff believe to be culturally sensitive processes. Most staff at this centre do not have formal tertiary qualifications.

### 2.8.1 Eligibility

Sir Charles Gardener Hospital eligibility criteria include complex physical or emotional symptoms related to a life-limiting illness. 90% of clients use the facility for three months. Sir Charles Gardener Hospital also undertakes symptom management while patients are undergoing curative treatment.

### 2.8.2 Contact with Aboriginal health and community organisations

The Western Australian Commonwealth–State Health Partnership Agreements on Aboriginal Health do not specifically mention palliative care, though they address the issue of improving access to mainstream services and coordination issues.<sup>11</sup>

One Perth hospital employs no Aboriginal liaison staff, while the other employs a number of Aboriginal liaison officers and an Indigenous clinical advisory nurse (ICAN). This position is an innovation. The ICAN acts as a medical advocate, checking patients' understanding of their situation and assisting with communication. She works closely with the palliative care team.

A mainstream service provider reported that there are limited or non-existent relationships with Aboriginal service providers and there are no regular contacts with Aboriginal health organisations. There are no formal or regular meetings between the palliative care team and the hospital ALOs or the ICAN. Contact is on an as-needs basis and is made with the community organisations or the AMS when someone is going to go home to the community or it is necessary to talk to the wider family.

The Aboriginal Hospital Liaison Unit (funded by the State government) provides a vital service to remote area clients, especially where the hospital has no Aboriginal staff.

### 2.8.3 Metropolitan/remote areas relationship

#### **Aboriginal Hospital Liaison Unit**

All Aboriginal patients from remote areas are referred to this service. A remote area is anywhere outside of a regional town. This unit provides discharge planning for all remote area Aboriginal clients for all Perth public hospitals. Clients are not referred to local palliative care services but to their local or regional hospital.

The service visits patients in Perth hospitals and twice weekly provides a brief report back to their referring hospital in the region. This usually contains some information for family as well as medical information. When a patient is ready to be discharged the Aboriginal Hospital Liaison Service arranges their discharge and travel back to the local hospital, or regional hospital if there are no beds at the local hospital. They ensure that patients are met from the bus or plane. Patients are repatriated using QANTAS flights, not the Royal Flying Doctor Service (RFDS).

If patients require palliative care then every effort is made to get them back to their 'country'. If someone is *non compos mentis* or cannot go home for any reason then, in consultation with the patient's family,

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<sup>11</sup> WA Department of Health (Pers Com).

they may be referred to a C-Class nursing home in Perth. This must be a family decision. This situation generally rises once or twice a year.

Repatriation of deceased people is now paid for by the Department of Health.

The clients who most need the services of this unit are from the Kimberley and the Pilbara.

About 1000 remote area Aboriginal patients a year come to Perth, and about 800 of these go to Royal Perth. Of these possibly five per year would be considered palliative care patients. These clients would be referred to the local hospital (eg Halls Creek or Fitzroy Crossing) and if there were no beds there, then to the regional hospital – such as Derby. If they go to Derby and can't go home then they may go to Numbla Nunga, an Aboriginal nursing home in Derby.

At any one time there are about 40 Indigenous patients from remote areas on renal dialysis in Perth. These patients either die in Perth or are discharged to a location where there are dialysis machines and travel to Perth as needed. If dialysis patients decide to discontinue treatment they will be sent home, however when these patients become ill in the community the nurses, usually under instruction from family members, will call the RFDS and they will be flown back to the local or regional hospital. This is an ethical issue for the nurses who feel they have an obligation to do what the family asks – especially when the patient is unconscious.

There are many stories of patients being brought to Perth for treatment when such treatment was pointless and then being unable to return home to die. There were also stories of renal patients coming to Perth for treatment without fully understanding that the treatment would require them to stay in Perth for the rest of their lives. Lack of facilities in remote areas sometimes means that the medical profession takes the view that *'they can't go home – there is no one there to look after them'*. It would be preferable to ask either: *'what would have to be done or put in place to allow these people to go home and how could that be achieved?'*; or: *'knowing what you will face, would you prefer to go home even though there are no facilities?'*

There are no Indigenous-specific nursing or aged care facilities in Perth.

The Palliative Care WA (Inc) *Palliative Caring at Home* booklet indicates that there are 18 country locations which have palliative care services. Five of these are regional services which have three or four sites or service providers within them (ie there are an additional 12 services providers). The models of delivery in these areas vary greatly. For example:

- In Geraldton there is a tripartite arrangement between the St John of God Hospice, Silver Chain, and the hospital under the auspices of an incorporated body called the Geraldton Palliative Care Service. This arrangement receives funding from the State Government, but not enough to cover equipment or capital costs.
- In Kalgoorlie there are palliative care beds and trained palliative CNCs at the hospital who are funded to provide a consulting service, but there is no hands on home-based palliative care nursing. A volunteer organisation is funded to provide some home visiting. An education and consulting position is funded (by the Cancer Foundation) for cancer patients.
- In the Kimberley, palliative care has been delivered across the region by the Kimberley Palliative Care Service, which is a network of community-based palliative care teams located in several population centres across the region. These teams (some with Aboriginal members) generally consist of volunteers and palliative care nurses (community nurses) whose after hours work is funded through the State by the Australian Government's Palliative Care Program and administered by the Kimberley Health



Service through the Division of General Practice. Networks such as this are readily affected by staff changes, particularly of key coordinators. A new palliative care service which will be administered by the Kimberley Health Service (as part of its Population Health Program) is being set up, broadening the scope of the existing model to provide consistent clinical support, care coordination, education and a more comprehensive coverage. It has been suggested that there is a need to fund palliative care positions in the Aboriginal Medical Services in some population centres in this region to become part of this palliative care network.

## **2.9 Palliative care in the ACT**

In the ACT there is a home-based palliative care program and a hospice at Clare Holland House. The home-based service works closely with the hospice and offers nursing and allied health services to patients at home, and a consultative service to residents of aged care facilities. A non-government volunteer program is also run from Clare Holland house. There are no Indigenous volunteers.

## **2.10 Findings and implications**

We set out to discover what sort of services are available to and are being accessed by Aboriginal and Torres Strait Islander people. This chapter records what we discovered about palliative care services around Australia. It is not a comprehensive study of all palliative care services and there are gaps in the information that we gathered.

What is clear however is that the structure and operation of palliative care services varies markedly for State to State and from region to region and that there are very few if any Indigenous-specific palliative care services.

Nationwide, only two services employ Indigenous palliative care staff to work specifically with Indigenous clients. Most of the palliative care services do not have any working relationships with Aboriginal and Torres Strait Islander health services (where these exist).

Most Aboriginal and Torres Strait Islander health services (community-controlled or government-run) do not consider themselves to be palliative care service providers and though most attempt to manage their clients' illness through the terminal stage, they do this without expertise, training or support. These services are 9.00 – 5.00, five day a week services and are not linked to any palliative care service.

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## Chapter 3

# Socio-economic and cultural contexts

*Some families are prepared to look after [the] sick person. General nursing can be heavy going. Some families want to do the caring but find it is a different story in reality – its too much hard work. Sometimes if there is no family to look after an old sick person, the community will nominate someone and top up their CDEP. On odd occasions family are willing and have the community nurse if they get ‘unstuck’ – maybe if the catheter falls out. Have seen situations where the family will take someone home and a week later ring up and say they can’t do it anymore. [Aboriginal RN – remote community, Western Australia]*

### 3.1 Introduction

A feature of Indigenous history and culture is the variation in cultural traditions across different regions. At the time of invasion there were some 600 Indigenous languages, reflecting the level of cultural variation at that time. Aboriginal and Torres Strait Islander cultures are alive, and like other cultures are subject to change and development.

The purpose of this chapter is to try to provide some background information for service providers and policy makers about the context of planning and delivering palliative care services to Indigenous communities, as well as the underlying constraints or opportunities for service delivery. Whilst there are many common themes, there are still enormous variations between Indigenous cultures in Australia today. We aim to provide enough background to show that service providers will encounter significant social and cultural issues. We hope that it will demonstrate to policy makers and practitioners that this knowledge can’t be simply acquired and that they will need to work in close partnership with local community mentors.

*Non-aboriginal workers are often keen to have some sort of simple checklist or guide to ritual practices important to Aboriginal clients, but these will differ according to the individual circumstance. Assumptions made on the basis of any rigid set of rules can lead to mistakes. The most useful advice for a novice to any new community is to seek local guidance... Nevertheless, the preparation practitioners have for dealing with and learning from a given death can be improved. Recognition of the complex and dynamic nature of Aboriginal societies, a critical examination of ones own beliefs and values, consideration of the practical work involved and advice about the cultural mentoring process can all be valuable tools in constructing an appropriate cross cultural response...[(Fried 2000) (p236)]*

### 3.2 Socio-economic circumstances

Many Aboriginal and Torres Strait Islander people live in very marginal social and economic conditions, with high levels of unemployment, low levels of education and literacy, poor underlying health and high death rates. The median age at death for Aboriginal and Torres Strait Islander people is 51, some 26 years

less than for non-Indigenous people, and the life expectancy gap between Indigenous and non-Indigenous people is 20 years (Ring and Brown 2002). School retention rates at Year 12 are 36% for Indigenous people compared with 73% for the total population<sup>1</sup> and in some regions literacy rates are extremely low<sup>2</sup>.

On the other hand, many Aboriginal and Torres Strait Islander people live ordinary middle class lives. It is important not to create or apply stereotypes or make assumptions about the socio-economic conditions of clients, but there are some circumstances which will be true for many Aboriginal and Torres Strait Islander people and which will impact upon the ability of service providers to deliver appropriate services. Some of these include:

- literacy and education levels;
- high mobility;
- poor housing and overcrowding;
- high levels of domestic violence and substance misuse;
- low income levels;
- poor underlying health;
- fear and dislike of hospitals, of the health system and officials generally;
- fear and distrust of non-Indigenous people coming to their home.

It is important that the reality of the socio-economic factors affecting delivery of palliative care are acknowledged. Service providers must find ways to provide services in the contexts in which people feel comfortable, and if it is the wish of the client, to advocate to change those conditions to allow appropriate levels of care. Some of these issues are directly relevant to the capacity of Indigenous people to care for family members at home and to their willingness to access health services.

### 3.2.1 Housing

Many Indigenous people live in public housing. Rooms are often very small and unsuitable for hospital beds and other equipment. Dealing with public housing authorities to arrange modifications (eg. for bathrooms) can take long periods of time. Sometimes patients don't live long enough to see the modifications that have been ordered.

*Aboriginal peoples' houses are not set up for palliative care. There is too much overcrowding. Many people in this town live in caravan parks – there is a severe housing shortage. There is embarrassment about inviting strangers to homes such as these and yet there is a great need for respite services for people looking after people at home. [AHW, NSW]*

Extended families often live together in a house, which may be too crowded to easily provide an appropriate setting for care; yet being with family is likely to be an important issue for the client and family.

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<sup>1</sup> Ring, I. and N. Brown (2002). 'Indigenous health: chronically inadequate responses to damning statistics'. *Medical Journal of Australia* 177((11)): 629-631.

<sup>2</sup> Learning Lessons, the independent review of Indigenous education in the Northern Territory by former Senator, Bob Collins, reported that only 4% of Year 5 Indigenous students in non-urban NT schools, and only 36% in urban schools met national reading benchmarks in 1998, and that standards were in fact deteriorating.

In the words of an AMS doctor:

*Service providers do not understand that the home they are visiting is likely to be the home of an extended family and that the client or their carer may not be the dominant person in the household. Visitors need to understand that all of the lives of the people who live in the household are affected by the visit.*

In many remote communities there is a serious shortage of housing stock. In many areas the fact that families must vacate a house (for substantial periods of time) when someone dies there, adds to the housing shortage and overcrowding.

Often housing is substandard and in some remote areas there is no power. There may be no refrigerator for medication and no ability to secure dangerous drugs. There may be no washing machine.

*Dealing with bed sores, getting toileting and pain under control in the dirt is a difficult thing; having a bunk – commode chair and rails on the bed. There are also the practical things like running out of sheets and pillowcases and blankets and no one to wash the dirty ones.* [Remote area clinic staff]

It is often a major problem for families to travel from remote places to support sick people in city hospitals, or visit family in nursing homes or aged care accommodation.

### 3.2.2 Capacity

Many families do not have the capacity to care for sick family members. Some people reported that the breakdown of family and cultural values mean that younger people don't take the responsibility they should, and therefore the burden of care may often fall on just one person. Access to respite care is very difficult, especially in remote locations and people find it difficult to find out how to access the carer pension. Families have commitments to work to earn money which sometimes makes caring for a sick person difficult. In Queensland we were told of one case where the palliative care client was looked after by her grandchildren outside school hours and was heavily sedated much of the time to assist with the caring.

Many families are only too well aware of their shortcomings in western eyes.

*We won't ask because it is a shame job.* [Queensland metropolitan community member]

Low income levels makes any extra cost a severe burden and we were often told of people going without medication to pay for other family necessities.

We were also told that some family members take advantage of sick family members and take their pension money.

### 3.2.3 Poor underlying health

Late diagnosis was reported as a major issue by service providers everywhere – both in cities and in remote areas. Aboriginal and Torres Strait Islander people tend not to live long after diagnosis. This has important implications for palliative care service providers who have little or no time to develop a relationship with the family before the patient passes away.

The poor health status of Indigenous people means that many people die before they develop the sorts of diseases, such as cancer, which account for 80% of non-Indigenous palliative care cases. A study of cancer (Thompson and Irvine 2001) amongst Aboriginal people in Western Australia revealed that the incidence of cancer among Aboriginal males was significantly lower than for non-Aboriginal males, while the female rate was about the same as for non-Aboriginal females. However the study showed that if Aboriginal people develop cancer they are much more likely to die of it than non-Aboriginal people, and that for every 100 cases of cancer among Aboriginal males there were 73 deaths, compared with only 47 for every 100 cases diagnosed among non-Aboriginal males. For every 100 cases of cancer diagnosed among Aboriginal females there were 52 deaths, compared with 43 deaths for every 100 cases diagnosed among non-Aboriginal females.

A recent article in the Medical Journal of Australia pointed out: *'Death rates overall for Indigenous people are three times as high as the rest of the population; diabetes death rates are eight times as high, respiratory deaths four times as high and circulatory conditions almost three times as high.'* [Ring and Brown 2002]

### 3.2.4 Poor community resources

Many households do not have telephones; public phones are unreliable or don't work at all. Many Aboriginal and Torres Strait Islander people do not have vehicles and live in areas where there is either no public transport or public transport is inadequate. Access to health services in many areas is poor.<sup>3</sup>

### 3.2.5 Literacy and education levels

Low levels of literacy and education have the potential to reduce the effectiveness of symptom management in the home. Awareness of these issues by policy makers and service providers is critical to development of communication systems that will guarantee adequate information and access to services. Low levels of education and illiteracy do not reduce families' need and right to know what is going on and what is likely to happen. Rather, it increases the need for better systems of communication. If service providers are supported by AHWs or Aboriginal liaison staff these problems may be reduced.

### 3.2.6 High levels of mobility

There are high levels of mobility within Aboriginal families, which may result from traditional practice, the need to attend to family business and/or from socio-economic factors. As a result, service deliverers find it difficult to provide consistent care. This can be a particular problem for bereavement care if the family has to relocate for cultural reasons and loses contact with support workers. These problems may be reduced if service providers are supported by AHWs or Aboriginal liaison staff.

Some service providers are reluctant to provide equipment under these circumstances because of a fear that they will not be able to retrieve it.

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<sup>3</sup> Bailie *et al.*

### 3.2.7 History of relationship between Aboriginal and Torres Strait Islander peoples and health systems

The history of dispossession of Aboriginal and Torres Strait Islander peoples and the link between the control of Aboriginal and Torres Strait Islander lives by white bureaucracies, their experience of a welfare system which removed children, and their experience of and attitude to hospitals is well documented in the literature. (Franklin and White 1991; Mobbs 1991; Reid and Lupton 1991) It is this history which led the Royal Commission into Aboriginal Deaths in Custody (RCIADIC) (Johnston 1991) to recommend:

- That Aboriginal people should be involved in the design and operation of health care facilities that are located in communities where Aboriginal people live. (Recommendation 530)
- That mainstream health care organisations involve Aboriginal people in meaningful ways in the process of assessing needs and providing health care. (Recommendation 254)
- That Aboriginal health services be sufficiently resourced to provide a broad range of services that include promotion and disease prevention, environmental improvements and better social welfare service. (Recommendation 259)

The National Aboriginal Health Strategy (NAHS 1989)<sup>4</sup> was centred around self-determination and the later Commonwealth-State Health Framework Agreements maintain this underlying platform. These framework agreements seek to collaboratively support and develop health service delivery through community controlled health services and at the same time improve Aboriginal and Torres Strait Islander access to mainstream services.

The need for Aboriginal and Torres Strait Islander people to be able to access culturally appropriate health services is a fundamental issue which service providers and policy makers must act on. Mainstream service providers cannot assume that Aboriginal people will, or will be able to access palliative care services through an Indigenous health service and must make sure that their own services are appropriate and accessible, and/or that they are working in partnership with Indigenous organisations to deliver the best possible care.

### 3.2.8 Language

In many parts of Australia, Aboriginal and Torres Strait Islander people do not speak English or their English is not adequate for meaningful (and safe) discussions of medical or end-of-life issues. Medical and palliative care staff do not usually speak any of the relevant regional Indigenous languages at all. In areas where English is the first language of Aboriginal and Torres Strait Islander peoples, the form of English spoken and the context of the conversation may be difficult to understand for people who are not members of the community (see Eades 1988:97) and many language words may remain in use, especially for private parts of the body or intimate subjects.

Understanding medical language is difficult for well educated fluent English speakers; it is considerably more difficult if you do not speak English, if English is your second language or if your English varies in dialect from that of the speaker. Similarly English speakers should not expect to understand complex spiritual and cultural issues if they do not speak the language of the holders of those traditions. (Language barriers are discussed in more detail in Section 3.3.2 below.)

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<sup>4</sup> (1989). *National Aboriginal Health Strategy*. Canberra, Australian Government Publishing Service.



### 3.3 Some traditional issues impacting on palliative care provision

*What is important about traditional practices is that hospital staff and palliative care staff ask about them. They need to ask if there is anything that people want done.” [AHW]*

Policy makers and service providers should not think that they can ‘learn Aboriginal culture’. It is also important that they are not seen to be interfering or ‘sticky beaking’. They should be sensitive to needs, creating an atmosphere where people can ask for what they need and facilitating where necessary. Notwithstanding that most Indigenous people in an area may *usually* do one thing, every person is an individual and some people may want to do things differently. What is true for one person may not be true for another. Assumptions should not be made about cultural issues, which may change through time. What was true five years ago may not be true now.

Service providers need to be keenly aware that they come from a dominant social group and that their clients are members of a marginalised minority (which, especially for older people, has had a painful history and often painful experiences with the dominant group). Aboriginal and Torres Strait Islander people may be reluctant or unable to speak up. The cultural context of the service provider may blind them to cultural expressions of Aboriginal and Torres Strait Islander peoples. Good cultural awareness training programs (see Chapter 7) should assist in raising awareness of these issues.

#### 3.3.1 Talking about death

Death is a highly sensitive issue for many Aboriginal and Torres Strait Islander people. In some places merely using the words ‘death’, ‘dying’ or ‘dead’ is highly offensive – *‘like a very bad swear word’*. End-of-life issues are often spoken of indirectly. Using the name of a deceased person should also be avoided in some communities and regions.

It is important to check with local Indigenous health workers about the appropriate ways to speak of these issues in the local area. Sometimes it will not be possible to speak about them. In one community in northern Western Australia, local indigenous people did not wish to speak with us about these issues at all and local clinic staff explained that people there would not look after people who were dying but would employ non-indigenous staff to do it. On the other hand, we found many other places where clinic staff and community representatives expected a similar response and were surprised by peoples’ willingness to discuss the issues we raised.<sup>5</sup>

In some areas of Western Australia it is important that the death of a person not be spoken of directly, however some community members in Perth (Noongars) expressed the view that talking about death at the time of diagnosis was quite different from talking about death after a person had passed away.

*The medical profession should be more up front about the likelihood of someone dying so that people can get ready for it.*

The Aboriginal Hospital Liaison Unit reinforced this view, even for people from remote areas. They say that knowing about a likely death beforehand is different to speaking about it afterwards and that knowing what is likely to happen is very important to people (see further below, *Doctors speaking about death*).

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<sup>5</sup> Sometimes their willingness indicated just how important (and problematical) people thought the issues were and sometimes it may have been an indication of how things are changing. Many people had personal experiences that they wanted to share.



There are no language or cultural interpretation services in Perth.

Whilst there is not the same sort of taboo about speaking about death in other areas, including NSW, Victoria and Tasmania, some parts of Queensland and in the south of South Australia and Western Australia, it is nevertheless a highly sensitive issue and many Aboriginal people use euphemisms when speaking about death. 'Passed away' is very commonly used. Other common terms used included:

- ready to go to sleep;
- finish up;
- pass on;
- ready to go.

Instead of saying 'terminal illness', many prefer to use the phrase 'not going to get better'. Prior (1997) (p140) states that the term 'terminally ill' is incongruent with the Aboriginal world view of '*life-death-life*' as a continuum.

These issues have relevance for both service providers and policy makers and impact on the preparation of written materials about palliative care.

Some families do not want the patient to be told that they have a life limiting illness in case the patient 'gives up'. In some parts of Queensland it was reported that patients often will not tell other family members of their condition: '*They are ashamed of it – they think that somehow it is their fault or the fault of their lifestyle. Sometimes they only tell their wife or husband and don't tell children till right at the end*'.

In the Torres Strait Islands approaching death is not commonly talked about. Suggesting to someone that they make a will is said to be like trying to put a curse on them. We were told of one case where a man accused his daughter of cursing him to die because she raised the question of a will and his wishes.

Reluctance to speak about an impending death makes it difficult to discuss 'living wills' covering issues of resuscitation or place of burial (see also Chapter 5, Section 5.5.8.)

### **Doctors speaking about death**

The seriousness, the cultural variations and the complexity of these issues mean that health providers need training and the support of skilled and knowledgeable Indigenous people when speaking about death.

Doctors need to give families straight answers.

A doctor who has had many years' experience with an (Northern Territory) Aboriginal medical service believes clients need to be told the facts about their condition in the simplest terms possible. He has suggested that if one doctor uses an analogy to describe a medical condition to the client and another doctor tells it in another way there is a risk that the clients may believe they are being told different stories, which just adds to the confusion.

An Aboriginal woman in a regional population centre told how she had contacted staff at the Darwin hospital to request they notify her if there were any changes to her mother-in-law's condition. The staff rang after her mother-in-law had died and when she contacted the family in Darwin they had not yet been told. This caused serious problems between the woman and her in-laws.

An Indigenous doctor spoke about giving bad news to clients.

*The hardest thing I find to do as a doctor is giving bad news. It's not a good thing giving bad news. I say you've got cancer – we've got to make sure that you are pain free and try and make you as comfy as possible and visit you regularly etc. Sometimes when you say it first up, when they first come back from the hospital they are still in denial and haven't come to grips that it is cancer. It is difficult giving that type of news – to tell it. Need to display empathy. Sometimes family comes in too – depending on the family dynamics. Helps to know the family – who is talking to whom. Sometimes the family will come in and talk to you. Empathy is the secret. Put yourself in that position and just think how you would feel.*

As a general rule (and remembering that every situation is different), for most Aboriginal people it is very important that the family be informed that someone is close to passing away in enough time to ensure that final visits can be paid and the family can be prepared. If the right family members know then they can make the decision about who to inform, when (see below Section 3.3.3 Communication with the right people).

### 3.3.2 Language and communication

As mentioned above, in many parts of Australia, Aboriginal or Torres Strait Islander peoples do not speak English as a first language and some do not speak English at all. Similarly, health service providers rarely speak any of the local Aboriginal language(s). To attempt to deliver appropriate and sensitive health services, and palliative care services in particular, without being able to speak the language is extremely difficult. This is especially so in dealing with grief and loss.

Even when people do speak English, misunderstandings can occur. The following examples illustrate:

#### Story 1 (Northern Territory)

A palliative care coordinator gave an example of gross mis-communication between medical staff at the (major regional centre) hospital and the parents of a young boy from a remote community. Young boy was scheduled for leg surgery – parents were told ‘*don't worry we will fix it*’. When he returned from surgery his leg had been amputated.

#### Story 2 (Northern Territory)

Another example was an elderly palliative care client who was in hospital awaiting surgery. The day before surgery the client was sent to have an x-ray. After the x-rays were taken, he was told ‘*okay you can go now*’. The client thought this meant it was okay to leave the hospital. The hospital assumed client was being non-compliant and had absconded. Palliative Care AHW eventually found the client at home with family unaware of any problem.

Palliative care team suggested high turnover of staff at the (Regional) Hospital can mean Indigenous patients can see different people each day – each with a slightly different slant to the situation and this can cause serious misunderstanding.

### Story 3 ( South Australia)

An insulin dependent diabetic and her carer were at home. A visiting RDNS nurse asked the carer a question about feeding the client her breakfast. (The question was something about time and nature of the food). The question was interpreted as an insult; the reason for the question (in relation to sugar levels etc) was not explained and the carer took offence. The carer did not understand about the importance of diet and the time of eating to the management of diabetes. She thought that the nurse was accusing her of not feeding the client. There is a need for Aboriginal liaison to bridge the gaps. The RDNS staff member did not understand what the carer and client knew or didn't know and made wrong assumptions. Good communication did not happen.

### Story 5 (Western Australia)

*'Often the medical people won't listen.'* A community member told a story of her son who had a tumour on the brain. The hospital sent him home. The family took him back to the hospital and told them he wasn't right – but the hospital ignored them *'then he collapsed and he never came to'*.

Even in New South Wales, the use of traditional language words is important, especially when speaking of intimate issues and parts of the body.

*Having Aboriginal staff who can use local language words for sensitive issues (eg private body functions) is extremely important in putting people at their ease.* [Manager of aged care facility with majority of Indigenous clients]

The need for people who can translate medical information clearly to Indigenous clients is critical. Sometimes this can be achieved by a medically trained Indigenous person, sometimes it will also require a language speaker. Having indigenous staff and/or budgeting for language speakers to work with staff is important.

Even in communities where everyone speaks English there is a need for medical and cultural advocacy. (Fried 2000) p113 citing (Harkins 1994) p180-1 describes

*...the 'pseudo-intelligibility trap' which results when speakers of standard English and Aboriginal English communicate, and either or both parties incorrectly assume they have understood. This results in the rather common experience many of us have of talking with an Aboriginal person and subsequently realising that we have little idea what has transpired.*

### 3.3.3 Communication with the right people

Service providers often assume that the main carer is also the main decision-maker. Aboriginal family relationships are often complex and individuals' roles and responsibilities should not be assumed. This is as true in urbanised communities as in more remote areas.

In some traditional communities there are strict rules about who can talk to whom about certain issues. Some people are in 'avoidance relationships' with other people in relation to certain matters. This point is very well illustrated in examples given by (Trugden 2000) and in the following examples given during field discussions:

*An Aboriginal man was told of his terminal illness while in a major city for treatment. Culturally it was not his place then to tell the family so the local hospital arranged for someone from the Aboriginal medical service to tell the right people who could then pass on the information to the rest of the family.*

and:

*A service provider told of how a woman was always being asked to case management meetings to talk about the palliative care needs of her son and it was only when she eventually broke down and said 'Its not up to me and my husband to make decisions' staff realised they were talking to the 'wrong' person. It is not culturally appropriate for mother and father to make decisions.*

An Aboriginal Health Worker said:

*Service providers must get informed consent from appropriate family members. It is important for the right person to give consent otherwise there can be serious implications [eg payback – see below] for the person who gave consent.*

Roles and relationships are different again in the Torres Strait:

*When someone passes away here the news has to go to the in-laws. They are the ones to break the news to the family. The son-in-law tells the news to the other in-laws. In the past when you saw the in-law standing there you knew it was bad news. We call that murrigeth 'spirit hands'. At the tombstone ceremony all gifts are distributed to the in-laws – it is the family's way of saying thank you for carrying out all the arrangements.*

Pressure is often placed on 'escorts' to give consent. A palliative care team member spoke of one escort who didn't have any authority to speak on behalf of the patient but authorised a procedure and the patient died. This had serious implications for the escort.

When patients have to go to the city only one escort will be funded and this is not usually enough to allow cultural safety. The single escort may not be able to fulfil the various roles required.

### **Need to have the right people present**

As well as being sure to speak with family who are in an appropriate relationship to the client, medical staff should ensure that there is someone present who can speak the language of the person and can explain the medical issues. This may mean having someone like an Aboriginal or Torres Strait Islander nurse or health worker as well as an interpreter.

*Doctors will tell patients to come back in a week – even if they have been discharged home several thousand kilometres away. Doctors don't think about what they are saying and don't understand the geography, and the patients think that they have to do what the doctor says.*

Patients don't realise that they have a choice. In one case a patient was told to come to Perth for six months of chemotherapy treatment and then two months radiotherapy. With the advice and support of an Indigenous health professional, the patient decided that she would rather spend the next eight months at home with her young child with no treatment, than be in Perth receiving treatment with no guarantee of success and missing her young child.

Community members said ‘*it is important to involve the family in telling a patient what is in store for them and explaining about how it is now, how it is likely to be and about what sort of palliative care services would be appropriate.*’

As noted above, it is critical that service providers do not make assumptions about the roles and relationships of family members (eg carer, decision maker, advocate, ability to speak about a matter). There may be complex cultural issues involved in who takes what role when.

### 3.3.4 Male and female issues

In many places it is not appropriate for people of the opposite sex to deal with certain matters. Even in urban areas it may be culturally quite inappropriate for a young woman to bathe a senior man. It is not surprising that home-based services are rejected if these sorts of issues are not discovered or addressed.

### 3.3.5 Family and community

The importance of family, extended family and community members in interactions between Aboriginal and Torres Strait Islander people is important in understanding the nature of many Aboriginal and Torres Strait Islander households and the need for suitable visiting hours and spaces in hospitals (Prior 1997) (p141). The nature of Aboriginal families is discussed by Gray, Tromp and Houston (Gray, Trompf *et al.* 1991).

*It is in the obligation of Aboriginal men and women to supply food outside the nuclear family unit that the term ‘family’ acquires a wider meaning in Aboriginal societies than would be allowed by direct application of the functions of Western nuclear families to an Aboriginal social context... it becomes increasingly clear that this wider sense of family is pervasive in Aboriginal societies. The most outstanding aspect of Aboriginal kinship systems was and in many ways still is, the existence of whole classes of people identified by an Aboriginal person as his or her ‘brothers’, ‘fathers’, ‘sisters’, ‘mother’, ‘husbands’, ‘wives’ or the various other classes of affines. These classificatory systems governed almost all social situations, including marriage. [p82]*

Gray, Tromp and Houston go on to outline the practical implications for Aboriginal families of the attempted control of Aboriginal societies by the regulation of families and State.

*Today Aboriginal families are in a constant state of flux as the result of these deprivations and their appallingly high mortality rate... Yet by any standards, and certainly from an Aboriginal perspective, the Aboriginal family has endured and retained a commonality across all regions of Australia.*

They note the way members of extended families assume functions, duties and rights which in non-Aboriginal communities would be assumed either by biological parents or by the State or the Church. The role of family in palliative care is likely to be central.

### 3.3.6 Traditional medicine

In many parts of the Northern Territory, South Australia, Western Australia and Queensland, traditional healers are often called in by family. In some places (eg Perth, Darwin, Adelaide and Alice Springs) hospitals will facilitate access to traditional healers if requested. Sometimes the ALO will do it discreetly.

More often than not, however, it is a family matter and the hospital does not even know that a traditional healer has visited.

*...if every thing else has failed sometimes the presence of the ngangkari pacifies them. It gives the sufferer peace of mind. The family feels that they have done everything that can be done and they feel culturally whole. Sometimes the intervention of the ngangkari brings remission.*  
[Senior AHW/AHLO, Adelaide]

*The health service employs them because they believe they help them. They are an important part of maintaining Aboriginal people's health. Dying people use them. They are part of the daily lives of people and the management of the health of these people. I find if the ngangkari are worried about someone then I should be. I often consult after them, find out what the problem is – watch them when they consult.* [Remote community doctor, Northern Territory]

For palliative care clients, people say that it is comforting to the patient and the family to have the traditional healer visit, because people know that they have tried everything. It is apparently becoming increasingly difficult to access traditional healers and if they have to be flown long distances it can become expensive. Some health services and community organisations now employ traditional healers or run traditional medicine clinics when a healer is in town.<sup>6</sup>

It is important that, if requested, palliative care service providers facilitate access to such healers without interference.

*However we were also told that in some parts of the east coast of Australia some 'charlatans' were operating as traditional healers who had no basis for the knowledge that they claimed.*  
[Senior ALO]

Traditional medicine and traditional foods are used often throughout Australia. For example in New South Wales an Aboriginal health worker said:

*Access to traditional remedies is important for people's peace of mind. A range of traditional medicines is used in the area, usually gathered by family members. This includes dy-berry leaf, cobra, nettles, red river gum sap, spores of tree ferns and tea tree smoke. The most important issue here is facilitation of access to these materials. Transport for family members to gather them is probably the area of greatest need.*

In a town in Western Australia we also heard that people use a mixture of modern alternative medicine, with traditional medicines from several different cultural groups.

*When Mum was first diagnosed I really wanted to know what it was, because sometimes they don't explain it to you properly. And some of them have got different languages – like Chinese or whatever. I had a friend who helped me look up on the internet about cancer and that and I looked up different medicines and went to a naturopath and got her, minerals and that. And that helped her a little, but we all fall back on the Wongi medicine.*

*And we also requested for some Northern (Kimberley mob) medicine and that was sent down. Believe it or not she did last a long time. We didn't think that she would last. She was supposed to pass on in January when she was diagnosed and she had the radiation.*

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<sup>6</sup> See further recently completed film made by Erica Glynn called *Ngangkari*. The film was funded by the National Indigenous Documentary Fund (Series Five) and produced by P.Y. Media.

*It was hard looking after her – the doctor said that I had to look after myself to look after her – physically, emotionally and spiritually. We really want to know what that disease is and if we can help them survive for a couple of months – we really want to know what is out there that we can use. Doctors say to you that they don't really want you using home remedies and that – we want to treat them our way. We use the Wongi medicine – use creams and drinks and teas and various things made from plants. [Woman who nursed her mother who had cancer]*

### 3.3.7 Post death practices

Post death practices vary markedly from place to place and family to family. It is very important that palliative care providers and hospitals inquire beforehand if there are preparations that might need to be made.

In many areas of the east coast of Australia and in the south of South Australia and Western Australia, we were told that Aboriginal people like to spend a lot of time with the deceased person. Family and friends come long distances to visit, and generally expect to be able to visit the person where they passed away. In Queensland it is common for families to dress the deceased person and stay with them for 24-48 hours. One AMS suggested that rules should be changed so that if someone passed away in hospital the family should be able to take the person home to allow people to visit. Generally people do not want to visit people in the morgue, which would not usually have a suitable space for Aboriginal families (see Chapter 5, Section 5.4.3 for issues relating to hospital facilities). In fact, most people are very unclear about what the law says about how the bodies of deceased family members must be dealt with. This is an issue that should be researched (on a State by State basis) and written into the review of information booklets (eg *Palliative Caring at Home*) suggested in Chapter 7.

Some Torres Strait Islanders are Muslim and bury the person before sunset.

In some regions in the Northern Territory, the body will be flown from island to island so that people can pay respects. In central Australia and the north of Western Australia the place of death is stringently avoided and houses will be vacated until after Christian or traditional ceremonies take place 6-12 months later or sometimes after the first rains if this happens sooner. The house will then be smoked and repainted. In traditional communities the smoking ceremony must be conducted by a qualified 'law' man of the right group and it is a very different sort of ceremony to those conducted on the east coast. In some places practices are changing.

An Aboriginal person suggested that:

*People need to start thinking about some of these things. People are dying one after another. There will be no rooms [houses] at all. Maybe after 2 or 3 days smoke it and then move back.*

and:

*People are emotionally full up and overflowing with so many deaths. In some areas if there is a death there is a shorter waiting period before moving back into a house than in the past; the house is done up and someone else moves back in.*

Most aged care facilities and nursing homes in the Northern Territory with whom we spoke or who responded to our questionnaire support cultural practices. One reported waiting six weeks for a smoking ceremony before the room was re-used (despite a 20 person waiting list). The timing of the ceremonies



cannot be scheduled and are dependent on a range of issues and the availability of the right person to undertake the ceremony (see further discussion of these issues in Chapter 5, Section 5.4.5).

It was reported that some hospitals sometimes make it difficult for traditional practices to take place. This is sometimes due to staff turnover and new staff not knowing the 'right thing'; sometimes it is just bad attitude.

In many places on the east coast, smoking ceremonies are incorporated into funeral services and people sometimes want the place of death 'smoked'.

When the sick person is close to death or when they die, some people may begin traditional wailing, self flagellation, striking their heads and so on. Hospital staff in metropolitan hospitals often do not deal well with this situation (see further Section 5.5.3 *Upon Death*).

Even Aboriginal staff from different cultural groups are sometimes intolerant of this behaviour. In Perth we were told that traditional wailing by Aboriginal people from remote areas visiting relatives who are very ill or who have died is discouraged by the hospital and sometimes by Noongar staff.

*Everyone needs cultural awareness training, even Noongars – because the Wongi way and the Kimberley mob way is different.* [Community member]

When people die in hospital away from their family, people back at home may have difficulties following their cultural traditions. In South Australia we were told that currently no system or protocol has been established with the hospitals or the coroner that will allow for cultural needs. There is a need to establish a protocol regarding clothes and the body before the police or coroner become involved. One Aboriginal health unit has had great difficulty in the past accessing the clothes or body of the deceased when asked to do so by traditional people who urgently needed certain things to be done for 'sorry business' back in the community (eg the clothes or a lock of hair may need to be taken back to the community for 'sorry business').

*Hospitals and hospices also need to know what it is a family wants to do, and what needs to be done. Are there special things for remote people? These things should be clear.* [AHW, South Australia]

### 3.3.8 Blame and payback

In some communities in South Australia, the Northern Territory and Western Australia, blame for a death is often attributed to another person (rather than to the illness or event that led to their death). The person blamed will often be the last person who was with the person who died, or the last person to feed, bathe or give them a tablet. Being blamed for a death can have very serious consequences including abuse in the street, physical beating and ostracism.

Whilst it is not necessary for service providers to understand the complex religious and cultural issues involved, it is important that they are aware of these cultural issues and how they may affect delivery of service and the approach taken by the service provider.

'Blaming' has important implications for the delivery of palliative care

*One old man is having a battle because of the fear of blame. No one in the family wants to feel responsible for him because of blame issues. If someone looks like being close to passing away the ambulance will be called. People won't bring that person to the clinic in their car because if they die they will get blamed but they don't want them to die in the house.* [Clinic nurse]



It often means that it is difficult for local Aboriginal people to work in palliative care and in health care generally. It is also a reason for families 'pushing' family members into the hospital to 'finish up' in some regions.

Blame can be a problem especially when the death of a child occurs, and in Adelaide the Children's Hospital makes a regular practice of arranging tele-conferences with remote communities to make clear the medical causes of an illness and death, to try to explain that no one is to blame.

Palliative care workers can sometimes help families at this time. For example, in one instance a wife was afraid to stay with her dying husband because of her concerns about payback, so the palliative care team arranged for a carer to stay during this time.

### 3.4 Findings and implications

The diversity of Indigenous peoples and families and their social and cultural circumstances, vary from region to region and between States and Territories. This means that service delivery solutions will need to have local cultural input.

#### 3.4.1 Socio economic contexts

Service providers and policy makers in palliative care need to understand the socio-economic realities of many Aboriginal and Torres Strait Islander consumers, and the impact of historical factors in Aboriginal and Torres Strait Islander peoples' views about health services. The importance of self-determination and the existence of culturally appropriate services, in particular those provided by ACCHS, should be acknowledged. Mainstream service providers should be sensitive to the needs of clients, modifying their service provision in consultation with local people, and try to engage with existing Aboriginal and Torres Strait Islander health providers to provide an integrated service.

#### 3.4.2 Communication

*Palliative care respects the dignity of the person who is dying, and is based on the person's needs and wishes, with attention to the specific needs of different cultural and religious groups.* [extract from the definition of palliative care in the National Palliative Care Strategy (2000)].

Good communication is central to learning the person's wishes and needs. Barriers to communication include language and non-language barriers. Differing values and beliefs can create hidden difficulties. Being aware that complex relationships exist and impact on who should or should not be involved, for instance in care or decision making, are critical. Both cultural brokers and language interpreters are needed to deliver good palliative care.

#### 3.4.3 Traditional issues

Facilitation of access to traditional medicine where requested and ensuring that protocols are in place to discover and accommodate end-of-life cultural practices should be an integral part of palliative care service delivery.

Service providers must be sure that actions taken or permissions sought will not have cultural repercussions, either for family members or for themselves. They should work with local cultural interpreters to find solutions. Whilst the issue of blame is not relevant to many people in metropolitan areas or on the east coast of Australia, in certain regions it is a serious issue which underlines the need for cultural awareness training and access to knowledgeable Aboriginal staff. It is important that practices and protocols are checked for cultural safety.

Some community members we spoke with in Perth (Noongars) believe that one reason why some medical staff are reluctant to tell the truth about life limiting illness is because they have heard stories about how some cultural groups look for someone to blame for deaths which would otherwise be ascribed to natural causes. Failure to inform people in a timely and appropriate manner about their long term prognosis creates serious problems for patients, especially where diagnosis may have been late. There is a need for research (and training) into appropriate ways to pass on bad news to Aboriginal and Torres Strait Islander clients. This is discussed further in Chapter 4.

To conclude, we reiterate a valuable point made by Ofra Freid (Fried 2000):

*Recognition of the complex and dynamic nature of Aboriginal societies, a critical examination of one's own beliefs and values, consideration of the practical work involved and advice about the cultural mentoring process can all be valuable tools in constructing an appropriate cross cultural response...* [p236]

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# Chapter 4

## Access to palliative care services



### 4.1 Information about rates of Indigenous access

#### 4.1.1 Data sources

Systematic information about Aboriginal and Torres Strait Islander peoples' access to palliative care does not currently exist.

In response to the mainstream service provider questionnaire circulated, most responded that they ask a question about Indigenous status and most claimed that the question was actually asked, rather than the answer being assumed.

The interviews with palliative care service providers and Aboriginal and Torres Strait Islander health care providers, however, painted a different picture.

During interviews, we learned that while an Indigenous status question was asked somewhere in the admission or referral system, this was often 'upstream' of the actual palliative care admission and this data could not be readily accessed. Palliative care assessment forms usually do not explicitly ask the Indigenous status question. Most service providers could not access the information about how many of their clients were Indigenous because their systems did not allow it. For example, the Indigenous status question was often asked at the point of hospital admission, but the information about Indigenous status was not necessarily linked to the patient's records if they subsequently became a palliative care client.

Similarly, the Indigenous medical services interviewed did not keep records of the numbers of palliative care clients.

Many mainstream service providers interviewed indicated that although the Indigenous Status question was supposed to be asked, they believed that in many cases the answer was assumed, rather than asked by the person completing the form (where this was not the patient). This was confirmed by many Aboriginal and Torres Strait Islander people interviewed, who cited situations where they had not been asked the question.

When asked if their assessment forms ask about Indigenous status, most service providers initially answered 'yes', but when this matter was probed the reality almost invariably was that the form asks about social or cultural issues and does not explicitly ask about Indigenous status. This has significant implications for the delivery of appropriate care. As will be shown later, Aboriginal and Torres Strait Islander people are unlikely to volunteer social and cultural information to non-Indigenous strangers, yet it is critical that appropriate cultural advocates are enlisted to support the client at the earliest opportunity. This cannot happen if the clients' Indigenous status is not recognised.

#### 4.1.2 Data about access to mainstream services

##### General information from the mainstream survey

As would be expected, the data from the mainstream survey shows that services in areas which have larger Aboriginal and Torres Strait Islander populations have more Indigenous clients. Most commonly, palliative care service providers which had had Indigenous clients stated there had only been one or two. Most respondents did not complete the question about the numbers of clients who were Aboriginal or Torres Strait Islander. Very few major base or regional hospitals responded to the survey. The service provider which had had more than 20 palliative care clients in the previous financial year was a hospital serving a very large Aboriginal and Torres Strait Islander population (7.6% of the total regional population)<sup>1</sup>. The 23 Indigenous clients they had had in fact represented 8.8% of the total number of clients.

##### Percentage of Indigenous clients: information from survey and field interviews

The data show that in 75% of responses Aboriginal and Torres Strait Islander people are under-represented as clients in palliative care services.

Although many respondents could not access information about the number of Aboriginal and Torres Strait Islander clients they had, it was possible to extract some interesting information about access rates from:

- those that indicated they did know how many Indigenous clients they had and said it was nil, and
- those that were able to provide a percentage.

These responses (n=78) were recorded and compared with the 1996 ABS figures<sup>2</sup> on Aboriginal population. The results are graphed and shown in Appendix 3. Using the Australia Post map<sup>3</sup> of post codes and the ABS population information, rough estimates were made of the Aboriginal population of the areas concerned.<sup>4</sup> These figures are general approximations as there was no information about the catchment boundaries of the various services which responded. The ABS catchment boundaries do not coincide with postcode areas (the best data we had for the location of services).

Theoretically and in general, one should expect that the percentage of Aboriginal and Torres Strait Islander palliative care clients of a service should reflect the percentage of Aboriginal and Torres Strait Islander people in the overall population. The data show that in fact in 75% of responses Aboriginal and Torres Strait Islander people are under-represented as clients in palliative care services.

Given the burden of illness and high mortality rate in Aboriginal and Torres Strait Islander communities, one would expect an over-representation of Aboriginal people not an under-representation. Even though Aboriginal people are more likely to die of acute illnesses (or alternatively chronic illnesses that are not normally the province of palliative care, such as cardio-vascular disease), and therefore one might expect less need for palliative care, in fact Aboriginal people are more likely than others to die of all causes, including neoplasms.

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<sup>1</sup> (1997). Population Distributions, Indigenous Australians – ABS 1996 Census Data. Canberra, Australian Bureau of Statistics.

<sup>2</sup> Ibid.

<sup>3</sup> Official Australian Postcode Map, produced by AUSLIG 1993.

<sup>4</sup> Most Aboriginal medical services believed that the Aboriginal population statistics underestimate the Indigenous population because for a number of reasons many Indigenous people do not complete the census.

In (McLennan and Maddon 1999), the standardised mortality rates for Indigenous cancer are calculated as 1.5 times for males and 1.4 times for females compared to the general population. Therefore, among those diseases where palliative care is traditionally seen as appropriate, Aboriginal people should be represented more strongly than their percentage in the population (in the case of cancers, up to one and a half times their proportion in the general population).<sup>5</sup> In fact, instead of being over-represented by a factor of 1.5 they are under-represented.

## 4.2 Availability of services and resources

This study aimed to discover what sorts of palliative care services were available to Aboriginal and Torres Strait Islander clients. The types of services available in each state are outlined in Chapter 2, however the key issue in access to palliative care service is the availability of such services within each region.

There are many parts of Australia which have Aboriginal and Torres Strait Islander populations where there are few medical services (Bailie, Siciliano *et al.* 2002) and no palliative care services at all. Even where there are some medical services, there may be no services to assist people to stay at home. For example there are no palliative care services as such in the Torres Strait region:

*People who are dying and come into hospital are placed in a 2-bed ward and families can come in and stay with them. There are no services to assist them to stay at home.* [Field notes]

In other parts of Queensland:

*There are no specific palliative care services provided to more remote Aboriginal communities in the region but some of the clinics and HACC services including [location name] Isolated Care are providing some support services.* [Field notes Queensland Regional Area 1]

There is no specific funding for palliative care in the Anangu Pitjantjatjara Lands in central Australia. The community controlled health organisation provides services with the support of the Family and Aged Care Team and expert consultation advice, however caring for a palliative care client can be an enormous drain on resources.

*Resource issues will decide whether palliative care clients can stay in the community or not. Not enough manpower. Finding extra nursing staff is one of the practical issues.*  
[Community nurse]

Even in areas where some palliative care services exist, there are often major gaps in the services available and the services which do exist are not integrated or coordinated. For instance, in one major remote population centre there was no home based palliative care service at all during 2002.

In Western Australia, Aboriginal peoples' access to medical services is an ongoing issue of concern. A media release issued by Warren Smith, Chairperson ATSIC Malarabah Regional Council, on 13 September 2002<sup>6</sup> stated:

*The WA government's plan to move specialist medical and administrative staff from Derby Regional Hospital to Broome contradicts both its commitment to improving regional services and the urgent need to improve the access to health services for Indigenous communities.*

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<sup>5</sup> Given the age profile of Aboriginal disease, we would expect this greater proportion of Aboriginal patients to be generally younger than their non-Aboriginal counterparts. This of course does not take into account our argument in section 4.5 that more disease states should be considered as requiring palliative care for Aboriginal people than for others, on the basis that Aboriginal people are more likely than others to die as a result of their illnesses.

<sup>6</sup> *Health Service Move Raises Access Barrier.*

The press release continues:

*Derby is predominantly an Aboriginal town – Aboriginal people feel comfortable coming to town because they can find places to stay when visiting family and friends in hospital. Aboriginal people are more likely to make use of health services when they feel confident and comfortable in doing so.*

*Derby is also much better placed to service communities such as Fitzroy Crossing, Halls Creek and those along the Gibb River Road. Emergency travel to Broome will require extra time – perhaps the difference between life and death.*

*In the longer term, Derby needs to move towards a community-controlled health service such as those that operate in other communities with training and employment for local Indigenous people. The result would be more consistent health services, decisions made locally, an end to cultural differences and new regional employment opportunities.*

This situation described in the press release is also relevant to palliative care provision because of the traditional values widely held by people in the Fitzroy Valley. It is crucial that health professionals know how to approach sensitive issues with tact, timing and appropriate use of language when explaining sickness.

Resource issues also affect people in metropolitan areas. A western Sydney palliative care coordinator said:

*A major problem in access to palliative care services and to being supported in dying at home is that is what is wanted is that there is a three week wait for community nurses. To be admitted as a palliative patient you have to first see a generalist community nurse to be assessed. Once you are on the list you can access the 24 hour nursing and the 24 hour phone number is the thing that most people find most useful. [Palliative care team at (H2)]*

Not having access to 24 hour nursing is a particular problem for people who have been referred to palliative care late in their illness. They may have left it too late and so will end up at the hospice or hospital.

*Kooris don't have the phone on and so the 24 hour service is not much help. Kooris will wait till Monday and go to the medical service. [ALO]*

### 4.3 Referral issues

A major issue affecting the access of Aboriginal and Torres Strait Islander people to palliative care services is the failure of medical practitioners, both in the mainstream and Aboriginal health care systems, to refer Indigenous clients to palliative care. It appears that many Aboriginal and Torres Strait Islander people are not being referred to palliative care services or, if referrals occur they occur very late.

Most mainstream palliative care service providers we spoke with said that many GPs and specialists did not refer clients (both Indigenous and non-Indigenous) to palliative care services because of ignorance of the sort of services provided and disapproval of the palliative care approach.

Failure to refer to palliative care is also influenced by a number of other factors, including late diagnosis, the underlying health status of Indigenous Australians and eligibility issues.



### 4.3.1 Aboriginal medical services

Most of the Aboriginal medical services (ACCHS) we spoke with do not regard themselves as palliative care service providers. They usually see clients 9.00 – 5.00, five days per week and do not provide after hours services. Most do not employ community nurses.

AMS GPs will manage clients who have a terminal illness (usually without the advice of a palliative care specialist and often without the most appropriate drugs and equipment) and most do not provide home visiting services. (Some AMS doctors and many health workers do conduct visits in their own time where needed.)

In some areas there are no suitable palliative care services, however AMS GPs rarely refer clients to palliative care services even where they do exist. In this they are no different to other GPs. Generally GPs' knowledge of palliative care services is poor. We were told most AMS GPs would probably make an assumption that their clients will not want to access these services. Many believe that referral to a palliative care service means passing responsibility for the client to that service (rather than remaining a central part of an integrated service).

If referrals are made to palliative care, this is generally done very late in the client's illness because of:

- late diagnosis;
- lack of understanding about what palliative care can offer and the benefits of early referral; and
- a belief on the part of the GP that clients will not want to access palliative care services.

Referrals are often made only when the situation becomes desperate.

There are some examples where the AMS (often the health worker/s) has taken a coordinating and advocacy role, actively seeking out palliative care services and providing liaison between the AMS and the palliative care service provider.

When referrals are not made the patient often ends up in hospital and passes away there, which may not have been their preferred option had they been given a choice and received adequate support and advice.

*An Aboriginal health service in a regional city in Queensland said they haven't had time or resources to pick up palliative care but would like to work in with other service providers – complement other services. It would be too exhausting on current staffing resources and service is open only Monday to Friday 8.30am-5pm, but suggested they could provide services during work hours if the hospital could pick up after hours. [Field notes Queensland Regional Area 1]*

A metropolitan AMS doctor expressed the view that not only have AMSs made assumptions about whether clients would want to access palliative care services (and have assumed that they would not want referral to a mainstream service) but that many mainstream services believe that the AMS will provide services for Aboriginal clients.<sup>7</sup>

We received a report about one AMS doctor in Queensland who, when asked why he did not refer clients to the local palliative care service, said that because of Aboriginal peoples' feelings about death ('they accepted it readily as a part of life') they would not want 'life prolonging treatment' such as

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<sup>7</sup> This assumption is apparently fuelled in some cases by a belief on the part of mainstream nurses that there should not be separate health services for Kooris, but since there is, then Aboriginal people should go to the AMS and should not use mainstream services (*non-Indigenous nurse working for an AMS*).



palliative care and therefore he did not refer them. This example demonstrates the doctor's lack of understanding of the nature of palliative care and also the gross assumptions he made on behalf of Aboriginal people and Torres Strait Islanders in his care.

In short, mainstream services assume that Aboriginal clients will be looked after by the AMS, whilst the AMS assumes that clients will not want mainstream palliative care services. Fewer assumptions and more communication are clearly needed to ensure that AMSs and mainstream services work in partnership to provide continuity of care and the best service for clients.

A Queensland palliative care service suggested that some Aboriginal (and ethnic) organisations 'gate keep' on behalf of their clients and do not refer them to mainstream services, even when no equivalent service is provided by that cultural group.

#### 4.3.2 Attitudes of GPs and specialists in the mainstream health system

Some Aboriginal and Torres Strait Islander people prefer to visit local GPs, rather than an AMS, or, in areas where there is no AMS, prefer to visit a GP rather than the hospital. A recent survey of local GPs in western Sydney conducted by an AMS found that most GPs did not know whether they had Indigenous clients or not.

*Some people will not access the AMS because of local politics and because of confidentiality. Some don't like to wait – we don't have an appointment system. Recent interviews with local GPs revealed that most GPs didn't know if they had any Koori clients. [AMS]*

Little is known about the behaviour of GPs and specialists in passing on bad news to Indigenous clients, however it is known that the GP or specialist who breaks bad news is a critical link in the referral process. The anecdotal evidence we collected suggests that:

- GPs and specialists lack knowledge of palliative care services and the benefits of palliative care;
- GPs and specialists may be reluctant to refer clients to palliative care services;
- GPs and specialists often assume that Aboriginal and Torres Strait Islander peoples will not want to access palliative care services;
- Referrals are made in a way that does not give the client sufficient support, such as:
  - bad news may be given in a way that cannot be 'heard' or properly understood by the client; and
  - referrals may be made without adequate explanation and with inadequate cultural support.

There is an assumption among non-Indigenous and medical people that Aboriginal families like to look after their own and they therefore leave it up to the family. They don't provide information to the clients or the family about how the family might be supported.

Many of the community members we spoke with believed that GPs would make an assumption that Aboriginal people would turn to their family for help, and that therefore they would not refer them to palliative care services. This was confirmed by mainstream service providers who assumed that one reason why they did not get many referrals was that *'Aboriginal families like to look after their own and medical practitioners leave it up to the family. They (doctors) don't provide information to the clients or the family'*.

In some remote and rural areas the role of the GP is critical in providing ongoing support to clients who require palliative care.

According to a Queensland hospital medical officer, an important issue for palliative care medical officers is how to manage patients in outlying centres. When patients return to their community, the local GP takes over and provides day-to-day management for these patients but there is still confusion about who is responsible for the patient. There are clear advantages in involving the family GP, and coordination mechanisms need to be worked out.

*An advantage of people having their own GP is that they have taken care of that person all their life – know them and their family.* [Queensland Regional Area 1]

In a rural centre in New South Wales we were told that GPs were reluctant to refer clients to the palliative care service and to palliative care specialists because this would mean that they had ‘failed’. Some refer, but refer *very late*, whilst some know about the services but still don’t refer clients.

In many places we were told that oncology departments were often late in referring clients to palliative care. ‘*They treat and treat and treat – when it is too late they refer.*’ [Palliative care CNC]

On the other hand, hospital-based palliative care workers in Brisbane believed that patients with an incurable disease who were treated in the general medical or surgical system rather than in oncology (which is often the case with Indigenous clients) were less likely to encounter health professionals who would refer them to palliative care services, apparently because of lack of awareness of those services and what they can offer.

*Many patients are referred to Blue Care Palliative Care Service when they are in their last days of life. Up until this time the GP and family have been ‘managing’ to get by. It is an inappropriate use of the service.* [Blue Care Nursing Service, Brisbane]

A major Queensland palliative care service provider stated:

*... there is a great lack of knowledge of palliative care services on the part of GPs or hospitals unless they are dealing with a cancer patient. There is also a reluctance amongst GPs and families to access palliative care services because of what it means – or is thought to mean – and if GPs do mention it to families it is often not well explained.*

In western Sydney a palliative care team reported that they were receiving an overall increase in the number of referrals from local GPs as a result of education initiatives, (however the AMS had not been included in these initiatives because it is not physically located within the boundary of that health district, even though its Indigenous clients generally do live within the health district concerned).

#### 4.3.3 Contributory health status of Indigenous populations

Poor underlying health and late diagnosis of disease, especially of cancer, mean that Aboriginal people often die very soon after diagnosis and are not referred to palliative care services (or are not in a position to act on referral).

#### 4.3.4 Dying of illnesses where palliative care is not appropriate

An Indigenous doctor in a Queensland AMS stated:

*Palliative care numbers are low – we had 1200 Indigenous patients on data base and only two palliative care in past year. Heart disease is the biggest killer. They are probably dying from other things rather than cancer. Cancer is considered an old person's disease – Indigenous clients die from other things – very few Indigenous men die of prostate cancer. Most common is lung and GIT [Gastrointestinal Tract] cancer because of smoking.*

A health professional at a major hospital in Brisbane suggested that Indigenous people are under-represented in palliative care because most illnesses that require palliative care are diseases of old age and Indigenous people do not live long enough to develop them.

#### 4.3.5 Late diagnosis

Palliative care service providers and a number of AMS doctors believe that late diagnosis of terminal illness is one of the major factors in the lack of access to home-based palliative care.

*Many Aboriginal people don't go anywhere for help until it is really necessary – when they are desperate and then they will turn up at a local GP. [AMS]*

Screening programs that result in early detection of terminal illness (such as breast cancer) will result in more Aboriginal and Torres Strait Islander people accessing appropriate palliative care.

The Aboriginal and Islander Women's Cancer Prevention and Support service in Townsville, offers support to palliative care clients. This service believes they are now seeing more Aboriginal and Torres Strait Islander women with breast cancer because of the success of their screening program. More women are being diagnosed through the screening process whereas in the past they would have presented with 'secondaries' and breast cancer would not have been recorded.

#### 4.3.6 Discharge planning and co-ordination

Inadequate or non-existent discharge planning results in poor referral to palliative care units or poor take up rates. In many places we visited, discharge planning to link patients to palliative care services was not done systematically and if it was done, it did not include the hospital Aboriginal liaison officer or other cultural advocate. This problem is usually worse where patients are discharged from city hospitals to return to a rural or remote area.

In a New South Wales rural area we were told:

*If Aboriginal patients have received medical attention in hospital in Canberra or Sydney they may not have a regular GP in the home town and may not be referred to local services. City hospitals need better knowledge of palliative care services in the country and should make more referrals.*

Even in metropolitan areas in some states there are problems; unless the palliative care team at the hospital has been involved with the client they may not be referred to appropriate home based services.

Discharge planning needs to take account of the context of the Indigenous clients, the social and cultural situation they will be going or returning to, and what pharmacy support and equipment will be available in their home or future care environment.

For clients in remote communities, discharge letters to local clinics or GPs are essential. We were told of many situations where patients had been discharged and returned to the community without the local community clinic, the AMS or the patient's GP knowing about it and as a result the clients are left to themselves without local support. Discharge letters may also be essential for clients to access funding for equipment.

*Clients from remote communities needing specialist treatment have to travel to [the major regional population centre]. Clinic staff report the client is often back in the community for ages before they know the outcome of the visit to the specialist because discharge letters can take such a long time to be sent back to the community clinic. [Queensland Regional Area 2]*

If a link to a palliative care service together with appropriate cultural liaison or support is not made at the time of discharge, then Aboriginal and Torres Strait Islander clients are unlikely to access palliative care services.

A number of service providers spoke of the need for the development of 'palliative care pathways' which could identify critical points where cultural advocacy should be included. In Chapter 8 some examples are given of 'hospital to home pathways' which, while not being palliative care examples, could be adapted for a palliative care situation. Both involve appropriate cultural support as a component of the planning.

#### 4.3.7 Medical referrals

Some home based palliative care services providers take only medical referrals. This is potentially a barrier to Aboriginal people accessing these services as many avoid the health system. It is often the case that the need for palliative care is identified by an Aboriginal HACC worker or AHW rather than a medical practitioner. The various service providers should develop protocols that allow acceptance of these referrals and arrangement of appropriate assessments of such clients.

### 4.4 'Shame, fear and lack of knowledge': barriers to Aboriginal and Torres Strait Islander access to palliative care services

This section outlines the major barriers to Indigenous access to palliative care services (other than barriers to referral or failure to refer which are discussed above).

#### 4.4.1 Indigenous knowledge of and understanding of palliative care

Most Aboriginal and Torres Strait Islander people do not know what palliative care is, and are not aware of the kinds of palliative care services available in their area or the medical conditions which might benefit from palliative care (a lack of understanding which is also evident in the mainstream community).

Many believe that palliative care services are always delivered in a hospital or hospice, and are unaware that palliative care services can be delivered at home and indeed that they may aim to assist people to stay at home if that is what they want. The problem here is that Aboriginal and Torres Strait Islander people feel isolated in a mainstream residential model and the family feel they will have limited access in a residential facility. They are unaware of the potential for home based care.

Most people were not aware of the kind of services provided or the environment that is offered by local hospices. In one centre on the south coast of New South Wales, the ALO from the district hospital organised a familiarisation tour for an elders' group to the newly opened hospice on another (former hospital) campus. This seemed to have been extremely successful in breaking down barriers relating to the past history of the hospital, as well as explaining what the hospice offered. It created positive 'word of mouth' in the community and since the visit the hospice has been well used by the Aboriginal community.

There are many misperceptions about palliative care. Many of those who had heard of palliative care thought that palliative care was only for cancer patients at the final stage of life. Many associate palliative care with aged care, and do not make a distinction between these kinds of services.

Lack of knowledge about palliative care and palliative care services is also an issue for Aboriginal and Torres Strait Islander health services, community controlled and otherwise. Most AMSs and other Aboriginal health services we spoke with (including doctors, managers and Aboriginal health workers) had little knowledge of palliative care services in their area and how they worked.

#### 4.4.2 Indigenous experience of the health system

Aboriginal people have not always had good experiences of the health system and have themselves had, or have heard about, bad experiences of having strangers in the home. One regional service provider stated that some of the Aboriginal community members in the area do not access medical services at all. In order to work around this, the local Aboriginal Health Unit had begun running mobile clinics to the township twice a week – taking the medicine to the people.

Fear and avoidance of the health system mean it is unlikely that these patients would access palliative care. These fears are compounded by the failure of GPs to refer clients to palliative care services.

A senior Aboriginal health worker emphasised that many Aboriginal people don't visit doctors at all because they don't feel comfortable at the surgery (*'they don't feel it is a place for them'*) and feel disempowered when visiting a doctor.

#### 4.4.3 Lack of Aboriginal and Torres Strait Islander staff

Few mainstream palliative care services employ Indigenous people. When asked about barriers to accessing palliative care services, most Aboriginal people's first response was the lack of Aboriginal and Torres Strait Islander staff.

*Aboriginal staff need to be employed in these services and especially at the front desk for first point of contact. At the [aged care facility] there are no Aboriginal staff. People need to be made welcome – it is cold walking in there. Need caring person/caring attitude/common courtesy and respect.*

*Families are keeping to themselves. They don't want to be a burden. Don't want anyone to go into their house. Don't want strangers coming in – white face. Don't want to have visitors – people calling in who never used to call in just because you are sick. [Queensland Regional Area 1]*

This critical issue is discussed further in Chapters 5 and 6.

#### 4.4.4 Lack of support at time of referral

Many Aboriginal and Torres Strait Islander people are unlikely to take up a referral to palliative care unless they receive culturally appropriate support at the time of referral.

Effective support would include the presence of a community or family member, or an Aboriginal health worker to check that the client/s had heard and understood the news about the sick family member, understood the implications and the likely course of the disease and knew what sort of services were available. Service providers tell us that it often takes families some time to come to terms with their situation and that the support offered at time of referral needs to be followed up. Having a 'cultural bridge' between the medical profession and the family, and between the service providers and the family is very important.

A South Australian community member commented:

*There is a lot of grief and sorrow. People try to cope within their own family structure but they can't really address the needs of the person. This is partly because they are not given the information and counselling that they need. They need counselling so that they can handle the situation and go out and get the services that they need.*

*When the family looks after the person who is sick they feel that they are doing the right thing by the person.*

*They could make an informed choice if they had the right information and counselling to begin with.*

*It is imperative that the information and advice is given by an Aboriginal person. Palliative care service providers need to train and employ Aboriginal people to provide advice and support.*

Aboriginal community members in Perth said that they and their family would rather be told as soon as possible and as clearly as possible – especially as the diagnosis is often late – and preferably with the aid of an Aboriginal health worker or Aboriginal nurse so that they have as much time as possible to get home or get in touch with family and get things organised.

#### 4.4.5 Late diagnosis and referral

Late diagnosis and late referral has a serious impact on whether Indigenous people will access or successfully use palliative care services. A significant issue is that there is inadequate time for a palliative care team to develop a relationship with the client and the family. This generally takes longer with Aboriginal families than with other cultural groups, because of past negative experiences, and the history of suspicion of non-Indigenous services and fear of (non-Indigenous) authority. Many Aboriginal people believe that mainstream service providers will not take the time that will be needed.

Often, because of late referral, there is in fact no time and the problem is compounded in the stressful period of the terminal phase of the illness. The lack of time to develop relationships between mainstream staff and families can result in bad experiences. This is likely to have an ongoing impact on the take up of palliative care services, as people will communicate negative experiences by word of mouth.

#### 4.4.6 The cost, or perceived cost, of palliative care

*In Brisbane, Mrs [ ] suggested Aboriginal people won't access services if they have to pay fees and gave an example of Aboriginal people refusing Aged Care Packages because they would have to pay fees. [Field notes]*

There was a strong belief among people we spoke with that palliative care services would cost money (which is often not the case). For many Aboriginal and/or Torres Strait Islander people, a 'normal' visit to the doctor is avoided because of the expense, so there is concern that home visits or nursing would involve costs that families cannot afford (see further discussion on this issue in Chapter 9).

#### 4.4.7 Not knowing, not being told, not wanting to know, not wanting others to know

Many people we interviewed spoke of communication problems with doctors and felt doctors had not being 'straight' with them or their families. There were reports that people had not being told the true nature or their condition, or were not told in a way that enabled them to understand the implications and what it would mean.

As a result many people did not access palliative care services as early as they should have, and in some cases did not access them at all.

We also heard from some Aboriginal people who had not wanted the sick person to know they had a life limiting illness in case it made them 'give up'. These people were reluctant to access palliative care services, though some did so and their wishes regarding informing the patient were respected. This seems to be a very individual issue.

In regional South Australia, service providers believe that many clients, including Aboriginal clients, are not receiving palliative care. One reason given for this is that until recently palliative care was seen as care for a patient in the last seven days of life. This was changed to the last 30 days of life, then the last 90 days of life. The time period associated with palliative care had created a stigma as people felt that they were imposing that time-limit on their life or the life of a family member. Now these time frames have been removed in South Australia, palliative care services are receiving earlier referrals and as a result, families and patients are receiving support and counselling much earlier. In some other states, such as Queensland, time limits still apply.

*Aboriginal people think differently – some people might not want to think about palliative care – because it usually means the end. They associate it with terminal care. [Senior health worker]*

For some families, privacy is an important issue. Shame is often associated with illness, and having strangers come to the house would signal that something was 'going on' and privacy would be breached.

#### 4.4.8 The physical setting of care

Many palliative care units are based within hospitals or hospices and are linked to palliative care beds located within them. This is a significant barrier to Indigenous access to palliative care due to the fear and dislike of hospitals and similar institutions amongst Aboriginal and Torres Strait Islander peoples. There are also practical problems of access (including transport and numbers of visitors) and concerns that the person who is ill will be isolated from family and community. Concerns about loss of control and the inability of family to be involved are also central.



### Location of palliative care units in hospitals

*People hate the hospital – there's a lack of respect from hospital staff – no courtesy. Queensland health workers are not community-based people; local people don't have faith in them.* [Community member, Queensland]

The history of Aboriginal and Torres Strait Islander attitudes to hospitals is discussed in Chapter 5, Section 5.1.1.

South Australian community members said:

*The services need to be provided in or from premises which Aboriginal people will feel comfortable approaching. Some of the hospices, hospitals and nursing homes are unsuitable – they are too polished up for Aboriginal people; they won't want to go in. If Aboriginal people are to approach a service they need to be able to see and feel sure that they will be welcome. Need to see an Aboriginal person, or flag or poster at least.*

Travel to a hospice, nursing home or aged care facility can also be a significant practical problem for families, and families may feel a loss of control if their family member is in a nursing home or aged care facility. People in nursing homes and similar places often feel isolated from their family and culture.

### Hospices seen as inappropriate places

Some Aboriginal and Torres Strait Islander peoples find some hospices very alien and unfriendly environments and would not consider going there. Building design or decor, air-conditioning, or lack of Indigenous staff may all be factors in their discomfort. Suitable spaces for large groups of people and access to outdoor spaces are very important to Aboriginal and Torres Strait Islander patients and their families, but are often not possible because of the physical design.

In some places people will not want to go to a place where other family or community members have died (though in some cases this can be managed by providing for cultural cleansing of the room or building).

### Non-Indigenous services in the home

Whilst Aboriginal and Torres Strait Islander people are not aware that palliative care services can be delivered at home, in discussions about home-based services it was clear there was a general dislike of non-Indigenous people ('white strangers') coming to the home. The difficulties in delivering culturally appropriate support to Aboriginal and Torres Strait Islander families at home are discussed in Chapter 5 Section 5.4.

It is likely that a combination of fear of 'white strangers' coming to the house and a lack of positive ('good') 'word of mouth' within communities impact upon the take up rate of referral to palliative care.

#### 4.4.9 Aboriginal and Torres Strait Islander attitudes and concerns

Community members and Aboriginal health workers repeatedly stated that 'people won't ask'. They don't like to ask for help. In relation to palliative care, even if people were aware of what services were available they would be unlikely to ask. It was suggested that if people were absolutely convinced it was their right and they would not be refused then they might ask for these services.



Many reasons were given to explain why people would be reluctant to take up a referral to palliative care services. For example, in Perth several comments were made:

*There is often conflict between what the patient and or the wife or children want and what the culture dictates, and there is need for support in talking through these issues.*

*Many people don't like strangers coming in and if the person who is sick is male, there are issues with female nurses and care aids looking after him.*

*Aboriginal people don't know what services are available and they don't know the rules – often the eligibility criteria don't make sense – and people are shamed to ask – especially if they will be refused.*

*There is still a fear of 'authority'.*

One Indigenous service provider said that some people don't mind accepting Meals on Wheels and having their yards cleaned, but they would not want housekeeping.

In one Western Australian community some members said that:

*Many Aboriginal people would not be happy about mainstream service providers coming to the home because the nurses would see how messy the house was. [Western Australia, community member]*

Similar views were echoed in Sydney:

*Aboriginal people feel that the Community Health nurse is making judgements about the home and the family. [ALO]*

*Aboriginal people who see a white person knocking at the door are frightened – they think you are the police [Non-indigenous AMS community health nurse]*

One AMS staff member suggested:

*It is likely that some clients fear that if they go to the palliative care team then they might lose their link with the AMS – with the people they are used to. [AMS senior health worker]*

#### 4.4.10 Attitudes and beliefs of some mainstream service providers

##### **Beliefs about the Aboriginal home environment**

Service providers expect that Aboriginal houses will be overcrowded and that appointments will not be kept. It is also likely that some service providers believe that they and other mainstream service providers will not be welcome.

Staff on the palliative care team of a major Brisbane Hospital thought that Aboriginal and Torres Strait Islander people may be too embarrassed by their poverty to have strangers involved.

Some service providers are afraid to visit Aboriginal homes. The following example, while it does not deal with a palliative care case, is illustrative of the problem:

*...a man with 'diabetic foot' who should have been offered home treatment for his feet because he could not walk and had no private transport. He had to struggle on public transport to the clinic. Apparently he did not receive home treatment when he should have because the nursing service did not want to visit the home of this person. Eventually, after advocacy intervention, the appropriate service was offered at the man's home. Community members felt that the nursing service should have Aboriginal liaison staff to check that they are providing appropriate services and assist with communication.<sup>8</sup>*

The experience of a nurse who has done home visits in a remote town in Western Australia is that visiting Aboriginal clients in the home is difficult because:

*Aboriginal people often might not want non-Aboriginal people in their home and Aboriginal people move around such a lot and live such an itinerant life that the right people are often not at home when nurses call as arranged. It is often necessary to come back several times before they will be admitted – or the whole family might have moved somewhere else either locally or gone back to another community.*

Some mainstream service providers say that it would be better if the Aboriginal medical service had its own community nurses.

*There are many Aboriginal families who provide care for their families at home and they don't have any support [hospital social worker – who knew this through her friends]*

We received some reports of non-Indigenous service providers refusing to make home visits because of occupational health and safety issues.

#### **Attitudes to Aboriginal families and culture**

One community member told of a situation where there were many people visiting a person who was dying. They were there to honour the dying person. The Silver Chain nurse came in and said that there were too many people in the room. She was 'speaking down' to them. She did not understand the cultural importance of the visitors or why they were there.

## **4.5 Eligibility – non cancer clients**

It was clear from our discussions with Aboriginal and Torres Strait Islander Health Services and community members that the range of conditions for which palliative care might be considered was greater than for other Australians. This is partly because Indigenous Australians frequently present with advanced and serious illness, and consequently reduced opportunities for treatment and cure. Partly it is also because Indigenous Australians often present with a number of co-morbid conditions or complications because of concurrent ill health which mean that their capacity to recover from serious illness is reduced. Illnesses which for non-Indigenous Australians may be serious but treatable, may be much more complicated for Aboriginal and Torres Strait Islander people, and lead to deteriorating health

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<sup>8</sup> This anecdote was related to the researchers from several different sources and on several occasions during field work in a major metropolitan centre. The fact that it was told again and again illustrates the importance of 'word of mouth' communication and that negative experiences will quickly become common knowledge in Aboriginal and Torres Strait Islander communities.

and eventual death. This situation is exacerbated in areas where there is reduced access to tertiary care including specialist medical treatment, and where the capacity and resources of primary care services are limited.

People that we spoke with during this project suggested that there are a number of diseases where Aboriginal and Torres Strait Islander patients were presented with few options for treatment and recovery, and yet which are not typically thought of as terminal illnesses. Despite the fact that the terminal nature of these condition was often recognised by health service providers, there has typically been no acknowledgement of the end of life issues faced by Aboriginal and Torres Strait Islander people suffering these conditions. One remote town GP in Western Australia said:

*Aboriginal people suffer from a broader range of illness (other than just cancer) which could be classed as situations where palliation is appropriate, for example renal dialysis and chronic obstructive airways disease. Some renal units tend to hang onto renal patients until the end who possibly should be referred to palliative care specialists and of course there are a group of patients who choose not to begin dialysis – because they don't want to move to Perth when there is no space in the local renal unit. They usually end up in Perth anyway when they get sick. But some people make the decision not to move. Those on dialysis who are very sick could probably benefit from the skills of the palliative care team.*

Part of the problem with some of these conditions is that they do not necessarily present with symptoms that require management as it is usually thought of in standard models of palliative care: they are not necessarily painful, and so technical aspects of palliation may not be called for. Patients may require ongoing medical management of their condition – for example, renal dialysis – but such management is not thought of as palliative even where there is a recognition that the patient will die in the short to medium term. Even when patients had finished with dialysis, either by choice or because the therapy was no longer effective for them, the kind of problems that they experience in the final weeks of their life are not classic palliative care issues such as pain, but, as one AMS doctor reported, ‘*an overloading of fluid, debility because of the inability to walk around, and an intractable itch which is hard to treat*’. Renal patients and their families are rarely referred for psycho-social support though they may well need to come to terms with end-of-life issues. Indeed, in the very common case where an Indigenous patient has a terminal but non-malignant illness, our informants talked about the difficulty of accessing palliative care funding for them because they were unlikely to die within six months of diagnosis. Even where funding is obtained, if patients live longer than six months then the funding may be withdrawn.

#### 4.5.1 The particular problem of end-stage renal disease

Aboriginal and Torres Strait Islander peoples suffer from disproportionately high rates of renal failure, yet renal clients are generally not seen as palliative care clients. For example, in one remote part of Western Australia, the Palliative Care Service showed that palliative care numbers are relatively low in the region, yet an AMS doctor reported that end stage renal failure was reaching ‘mammoth proportions’ in the region and was expected to be a much bigger issue in the next five years. A new ten-machine dialysis unit was due to be set up there in a major regional town in October 2002 but it was suggested that it may not be able to cope with the increasing numbers of people from other parts of the region requiring dialysis, or meet the needs of Aboriginal people who have no connection the town.

For most non-Indigenous renal patients, renal dialysis is seen as a supportive therapy that maintains the patient until a suitable transplant can be arranged. For Indigenous patients, co-morbidities including non-insulin dependant diabetes mellitus, cardio-vascular disease, and hypertension mean that they are

often viewed as poor candidates for transplantation, and so renal dialysis is the final stage of therapy. There is a strong argument that unless a renal patient is scheduled for transplantation, they should be considered for palliative care, but with Aboriginal and Torres Strait Islander patients, even when active treatment ceases, they may not be referred to palliative care units.

Aboriginal health staff of one Northern Territory service suggested that clients on renal dialysis should be considered routinely for palliative care. They said that because of late diagnosis, someone can be in hospital, diagnosed and placed on dialysis within a single week, with no time to go home to talk to family and make decisions. They pointed out that dialysis patients were spending up to three days a week for five hours on dialysis. They often have other medical problems, and spend long periods – up to four hours – in hospital waiting rooms between appointments. Despite this, end stage renal patients were not usually being referred to palliative care services. The renal unit is now holding multi-disciplinary meetings and involving the social work department (where the ALO is situated) in these meetings. The workers pointed out that if renal clients were counted as palliative care clients there would be enough clients to support the employment of a palliative care Aboriginal Health Advocate.

Although many renal units with significant Aboriginal and Torres Strait Islander case loads look after their clients right up to the end, these units do not have the capacity to engage with the family in the same way that a palliative care unit would do. Families are often not sufficiently involved in management and treatment decisions, and are not involved early enough. A senior AHW expressed the view that

*Aboriginal people need to be given an informed choice about whether to remain on dialysis or not. Patients generally do not have dialysis and the available choices explained to them. This needs to be done in time so that people can choose to go back home and die if that is what they want.*

Domiciliary care workers, nursing staff and palliative care nurses and doctors often expressed the view that renal failure patients were not being referred to palliative care services early enough. The relationship between the renal unit and the palliative care team ‘needs to be built up especially in the areas of pain control and withdrawal from treatment and ethical and end of life issues’.

Renal patients are usually not regarded as palliative until the end and consequently families do not receive advice and counselling. Many people we spoke to said that patients and families are not adequately informed of the long term choices open to them early enough. It is often harder for Aboriginal families to make the decision to stop active treatment because they do not have good family support in the location in which renal dialysis is being administered – for example, in large regional centres, or in capital cities like Perth. It is often not appropriate for the family members escorting or accompanying the patient to make the decision or counsel the patient about withdrawal from treatment (see further Chapter 3, Section 3.3.3 Communicating with the right people). We heard stories from many of our remote informants, but particularly those in the Kimberley region of Western Australia, of people sent long distances from home for dialysis treatment who chose to come off dialysis treatment to return home to their families.

Although it was raised a number of times in our field work, access issues in relation to renal dialysis are not the subject of this study, and have been adequately canvassed in the work of other researchers, (Bennett, Manderson *et al.* 1995; Willis 1995; Preece 1997; Devitt and McMasters 1998a; Devitt and McMasters 1998b) This study is, however, concerned with the obvious palliative care needs of renal patients who decide to cease dialysis or for whom dialysis can no longer work. After cessation of dialysis, an end-stage patient usually has about two weeks to live. Trying to put palliative care into place in such a short timeframe is inappropriate, especially if some of that time will be taken up with travelling home.

Palliative care services and advice for the family and the patient need to anticipate the cessation of dialysis, and be introduced in plenty of time.

There was some indication that services are becoming more flexible about viewing renal patients as palliative care candidates, despite the fact that they are actively receiving dialysis and so categorised as having a chronic condition as opposed to a progressive terminal illness. For example, the eligibility criteria of one palliative care service in Western Australia included that patients must be medically referred with a progressive terminal illness with associated symptoms – physical, psycho-social, or spiritual. Despite this, the service has recently taken on several renal clients who are still receiving dialysis including continuous ambulatory peritoneal dialysis (CAPD). This means that these clients and their families have been able to avail themselves of the full range of palliative care services as needed.

#### 4.5.2 Other chronic conditions where palliative care may be indicated

The same sorts of issues arise for clients with HIV/AIDS clients, patients with advanced cardio-vascular disease and some respiratory diseases. In South Australia and Western Australia, HIV/AIDS was raised as an issue. One informant said:

*There is a major problem with follow-up treatment for HIV/AIDS patients who return to the regions. They cannot get confidential treatment and won't want people to know in their own community. They often won't tell people and end up with inappropriate care, sometimes in communities other than their own. [Health Worker SA]*

In Adelaide, we were told that Huntington's Disease (Huntington's Chorea) is genetically present in a number of Aboriginal families, but sufferers were not connecting with palliative care services. Service providers raised the problem of eligibility criteria in relation to this disease.

In Perth a counselling service reported that many young Aboriginal people are being diagnosed with Hepatitis C and are being told that they will die. It appeared that they are not receiving adequate support at this time and are likely to present in the future as palliative care clients. Issues were also raised concerning long term illnesses that require nursing home care, and the problems that arise when there are no Indigenous specific facilities.

In the view of one service provider there was a need to raise the awareness of the medical profession about palliative care for non-cancer conditions. This informant felt that it was a matter of improving the medical profession's capacity to raise questions about palliative care, provide adequate information and to be able to assist the family to make a plan for the end stage of the disease.

#### 4.5.3 Non compliance and eligibility for various services.

One final issue that was raised by informants was the relation between a history of compliance with medical directions (for example, compliance with medication) and eligibility for palliative care services. Some informants said that service deliverers were too concerned about making judgements about whether patients with complex needs 'deserved' the service they provided, and that service providers needed to be less judgemental and to be seen to be non-judgemental. A number of informants mentioned the case of renal patients who are often treated as 'non-compliant' when compliance is beyond the capacity of the client and family (Humphry, Weeramanthri *et al.* 2001) (see also (Preece 1997) and (Fisher 1998)).

Another example was given of a woman who was suffering from liver failure. She was very seriously ill and dying. She had been a drinker years before but had not been drinking recently and was not drinking at the time of diagnosis. Staff from the AMS acted as advocates for the woman. They were shunted backwards and forwards because the service providers believed that the woman was 'a boozier'. Her notes recorded the fact that she had been a drinker and she was treated as 'a boozier' rather than as someone who was dying and needed palliative care. The hospital palliative care unit wouldn't accept her. She was eventually found a private bed at a hospice and had a good death with her family around her, but there was much painful and costly to-ing and fro-ing and a great deal of ill-founded judgement.

## 4.6 Findings and implications

There is little information about or knowledge of palliative care in Aboriginal and Torres Strait Islander communities. It is likely that the most effective information strategy would be a 'word of mouth' strategy.

As a result of late referrals service providers and families don't have the time or opportunity needed to establish good relationships, which are essential to good service delivery and to 'good word of mouth' about palliative care.

When referred late, clients do not get the information they need to be able to make informed choices about how or where they wish to care or be cared for. As a result Aboriginal and/or Torres Strait Islander patients are more likely to die in hospital, which may not be their wish.

Late referrals are due not only to the underlying health conditions of Indigenous people but also to assumptions of doctors (GPs, AMS doctors and specialists) about whether Aboriginal and Torres Strait Islander clients will want to be referred to palliative care services.

If referrals are made, but are not supported by cultural advocacy, and/or the participation of Aboriginal and Torres Strait Islander staff, then they may not be taken up.

This points to the need for the following.

### 4.6.1 Effective information strategies (see also Chapter 7)

The following sorts of information strategies are needed:

- Among Aboriginal and Torres Strait Islander peoples there is a need to change the image of palliative care from being about 'being put in a hospice' to being about supporting families to look after their own at home;
- For doctors and AMSs there is a need to re-position palliative care so that they appreciate and understand that rather than handing over care of the patient to strangers, they could continue to be involved as a member of the palliative care team;
- For mainstream palliative care service providers there is a need to ensure that cultural awareness training takes place (including information about Aboriginal and Torres Strait Islander service providers), to equip service providers with the skills to build relationships with these groups so that they can work together to provide the best support to Aboriginal and Torres Strait Islander clients; and
- For Indigenous health and HACC workers, develop word of mouth strategies to spread information about palliative care services to those who need it. The strategy should include information, training and education for ALOs, AHWs and Aboriginal HACC workers, and should be supported by appropriate printed information for the community.



#### 4.6.2 Discharge planning

Better discharge planning supported by cultural advocates and/or the development of palliative care pathways which can highlight key points for participation of cultural advocates is needed

#### 4.6.3 Indigenous staff

Employment of trained Indigenous staff or the brokering in of Aboriginal and Torres Strait Islander services (see further Chapter 6 and 7) is essential.

#### 4.6.4 Supported referrals

It is important that families be given adequate information about illness and the course of a disease, and about what palliative care can offer to support them. This information should be given by someone they know and trust rather than a stranger.

#### 4.6.5 Relationship building

Relationships need to be developed between mainstream and Indigenous service providers, and relationships between service providers and with clients and community.

#### 4.6.6 Better practice in 'breaking bad news'

The way in which 'bad news' is delivered is critical to Indigenous peoples' access to palliative care services. People need to be told in a way that is appropriate to their culture and in a way that will support them in making informed choices about their future options. What is appropriate will vary from place to place.

Better training for GPs and specialists in cultural awareness and in breaking 'bad news' is needed. Before this can be undertaken there is a need for State or regionally-based research into how 'bad news' is usually delivered, how it should be done, the roles of family and cultural supporters, and links between the initial or subsequent advice of diagnosis and follow up actions such as referral to palliative care. Bodies representing Indigenous health professionals such as nurses (CATSIN), doctors (AIDA), psychologists and social workers should be consulted in the development of this research.

#### 4.6.7 Attitudes to be changed

Assumptions need to be challenged and attitudes changed. For example, an Aged Care coordinator said it used to be assumed that Aboriginal people would not wear continence pads because they would be 'too shamed', but as a result of sensitive discussion and education they now distribute large quantities of continence aids in the region. Attitudes of mainstream service providers, GPs and Aboriginal and Torres Strait Islander people can be influenced (see further Chapter 5).

#### 4.6.8 Eligibility for palliative care services

Understanding of and rules about the kinds of diseases and conditions palliative care might apply to should be broadened and National Palliative Care Strategy objective 2.4, strategy 2.4.4 should be amended to include diseases such as end stage renal failure and others (see Section 4.5 above).

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# Chapter 5

## Planning and delivery of care



### 5.1 Expectations and attitudes

#### 5.1.1 Aboriginal and Torres Strait Islander peoples' expectations and service provider attitudes

The socio-economic and cultural contexts of most Aboriginal and Torres Strait Islanders peoples was touched on in Chapter 3, which outlines a number of issues that impact specifically upon service delivery at home, including:

- literacy, and education levels;
- high mobility;
- poor housing and overcrowding;
- low income levels;
- poor underlying health; and
- fear and dislike of hospitals, the health system and officials generally.

Aboriginal and Torres Strait Islander communities are marginal communities within the dominant 'majority' community.

These issues have implications for the way service providers are perceived and for their ability to deliver services to that marginal community.

#### Aboriginal and Torres Strait Islander expectations

Aboriginal peoples' experience of the health system must be seen against a background of dispossession and control by white society (Franklin and White 1991; Mobbs 1991; Reid and Lupton 1991). The health system has often not been distinguished from the 'welfare' system which was responsible for the forced separation of children from their families in the past. For example, in central Australia up until 1970, the health of Aboriginal people was within the jurisdiction of the Native Affairs Branch which had wide control over Aboriginal lives (see further (Fried 2000) (p10).

Hospitals are considered to be places of death, not of healing, and have always been feared. '*We have learned from our grandmothers not to trust hospitals.*'<sup>1</sup>

General fear and distrust of white officials also impacts upon service delivery options.

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<sup>1</sup> Aboriginal community member in Perth. This sentiment has been expressed to members of our research team numerous times and in many locations.

Aboriginal and Torres Strait Islander peoples' fear and distrust of non-Indigenous people coming to their home was touched on in Chapter 3 and is explored further here. Aboriginal people are generally not used to having non-Aboriginal visitors. For many the only non-Aboriginal or non-family members visiting their homes in the past have been people like 'the welfare' or 'the police', and many Aboriginal people still have strong fears of outside visitors because of the long history of 'stolen children'.

*Aboriginal people who see a white person knocking at the door are frightened. They think you are the police.* [non-Indigenous AMS community nurse]

Aboriginal and Torres Strait Islander people expect white visitors to be bossy and judgmental. They are aware that their houses may not be 'up to standard' and are 'shamed' to allow people in.

*Families are keeping to themselves. They don't want to be a burden. Don't want anyone to go into their house. Don't want strangers coming in – white face. Don't want to have visitors – people calling in who never used to call in just because you are sick.* [community member, Queensland]

South Australian community members spoke of the fear of the judgmental attitudes they expected palliative care workers would have.

*People are often too shamed to get help. They have too many kids or too many relatives in the house and can't keep the house clean. When non-Aboriginal people come Aboriginal people pick up the judgment straight away. Some people are just scared of white people.* [community member, South Australia]

*A lot of shame goes with it. Aboriginal people worry that non-Aboriginal people will look at what the house is like and will make judgments about the house and family. Aboriginal people are scarred from the history of previous interactions at home – having children stolen etc. There is a very large lack of trust.* [community member, South Australia]

An Indigenous carer in Queensland said:

*Some people feel shame about having white people coming in to their homes when they are ill and yet never having them to visit at any other time. People would feel they would have to rush around and clean up.*

She added that over time and through familiarity with a mainstream nursing service there is a level of acceptance.

An Aboriginal and Torres Strait Islander service provider in Queensland observed that:

*There are not too many Indigenous people employed in nursing services and this has a major influence.*

*Many Aboriginal and Torres Strait Islander people don't feel comfortable with others coming into their home – may only agree for shopping, transport and lawn mowing.*

In the view of an AMS doctor:

*Aboriginal people would not want strangers coming into the home. Aboriginal people will perceive non-Aboriginal service providers as being judgmental and taking an 'inspecting' attitude. They are also perceived as being bossy. It is not acceptable to be bossy in someone else's home. Service providers are also known for 'visiting at the wrong time.' If people turn up at the wrong time they may not be admitted. The house is likely to be a group house and*

*it may not be the prerogative of the client to have the visitor at that time if there is other family business going on. Experience from the midwife program has shown that having an AHW accompany the visit makes an enormous difference.* [AMS doctor, New South Wales]

### Service provider attitudes

Many mainstream service providers have never met or spoken with an Aboriginal person or a Torres Strait Islander, though they often hold preconceived ideas. Some are afraid to make approaches to Aboriginal and/or Torres Strait Islander organisations. Some have made one approach and, not being welcomed with open arms the first time, give up.

We heard stories of service providers whose attitudes and practices were supportive and non-intrusive, and who took time to build relationships with the families for whom they were caring. We also heard of service providers:

- being judgmental about the number of people present in the house;
- being concerned at the levels of hygiene possible in the house given the conditions;
- not being willing to enter Aboriginal households out of concern for personal safety.

The story of the man with ‘diabetic foot’ who did not receive appropriate treatment quoted in (Chapter 4, Section 4.4.10) illustrates the problem.

Attitudes and expectations need to be consciously considered in the planning and delivery of care to Aboriginal and Torres Strait Islander people. The need for cultural awareness training is discussed in Chapter 7.

### Lack of perception of the cultural divide

Service providers need to be aware of their own prejudices and expectations. Aboriginal people claim to be able to see the judgments in the faces of the service providers, even though the service providers are not aware that they are making judgments. Fried (2000) explores in detail the barriers to cross cultural communication, including the notion of ‘cultural boundedness’ – the idea that people (especially members of a dominant culture) are so bound by their own reality that they have no awareness of the reality of others. ‘*A communication event occurs between individuals contextualised within their personal and community histories and bearing different status value and world views from one another.*’ (p116). She also argues (referencing (Reynolds 1999)) that as a result of colonial history, racism is an integral part of the fabric of Australian society, though it is rarely acknowledged (p257).

*Racism... needs to be addressed with individual practitioners in a safe training and support environment, and confronted at an institutional level where it impacts on policy and practice. A culturally safe palliative practice cannot be developed and sustained unless this work is done.* [Fried 2000) (p257)]

## 5.2 Planning and assessment

### 5.2.1 Discharge planning and referral

The fact that Aboriginal and Torres Strait Islander clients are not being referred to palliative care services, or are not being referred in such a way that they can act upon referrals (i.e. with adequate cultural

support and advocacy) has been discussed in Chapter 4. The referral process is critical to everything that follows.

The lack of involvement of hospital ALOs and/or the local AMS Aboriginal health workers or doctors in discharge planning for Aboriginal and Torres Strait Islander patients has also been discussed in Chapter 4.

*Discharge planning has been very inadequate. One Aboriginal client with long term post-operative special dietary needs was discharged without the hospital checking the availability of the dietary supplement or the patient's ability to afford it. It is quite likely that (other) Aboriginal clients are not receiving the referrals that they should have. [AMS doctor, New South Wales]*

It was suggested to us on more than one occasion that the family should be involved in discharge planning, and indeed that not only should the family be involved in decisions about the setting and nature of the care of the patient, but if the patient wishes to be cared for at home then there should be a deliberate effort to teach the family some of the key caring and nursing components while the patient is still in hospital. Inviting the family to be part of the care team prior to discharge will assist the family to understand the role that they will be taking on.

Involving the health professionals with whom the patient is comfortable, whether it is an Aboriginal health worker, their GP or a doctor from the AMS, will also be important and will assist in developing a relationship of trust with the palliative care service provider. It was suggested that discharge planning for palliative care clients should have a pathway or prescribed protocols which could include the participation points for appropriate cultural support.

### 5.2.2 Assessment

*There was a situation where there were three ill family members (not all of them were Aboriginal) and one had Parkinson's disease. There was a context of child abuse and it was not a happy home. However there was a need for palliative care at home.*

*The Aboriginal liaison officer asked the domiciliary care worker and the RDNS nurse to meet her there (for the assessment) and she would do the introductions. When the nurse and domiciliary care worker turned up together they took one look at the house and family and both left together saying that they couldn't handle it. They did not even wait outside to speak with the ALO about it. They just got in their cars and took off. This was a few years ago – but there are still dysfunctional families out there. It is the reality. The ALO was in a position to assess if the environment was safe. The service providers took one look and made an assumption that it was not. The matter was eventually resolved when the ALO got a non-Aboriginal advocate to approach the service providers and they came back and an appropriate assessment was done. [South Australian care worker]*

Assessment processes vary but the following describes what usually occurs.

On admission to a service or unit, service providers use the information provided by hospitals if it exists. They usually then undertake an assessment which includes establishing what the client's understanding of palliative care is and an explanation of the services available. A physical and emotional needs assessment is done and carer issues are assessed. A genealogy is drawn up. This does not specifically ask about Aboriginality, however most service providers think that the issue would come up at this time.

There is generally no involvement of Aboriginal or Torres Strait Islander liaison staff in care planning for Aboriginal and/or Torres Strait Islander palliative care clients. Sometimes each service provider will have its own assessment process and as a result questions are repeated.

There is a need for better coordination between the hospital and the palliative care service (home-based, hospital-based or hospice-based) to try to develop continuity from referral, through discharge to assessment and service delivery. Involving family and cultural advocates together with palliative care specialists as early as possible should allow better continuity than is usually experienced.

Given that Aboriginal and Torres Strait Islander people are usually not asked about their Indigenous status (see Chapter 4) and are likely to be reluctant to speak about cultural and spiritual issues with a non-Indigenous stranger, it is unlikely that the assessment process used by most service providers will come anywhere near discovering peoples' needs and wishes.

Prior (Prior 1997) claims that the way multidisciplinary assessment is handled may '*place the integrity of holistic care at risk*' if '*each member of the multidisciplinary team is focused on only one aspect of the sick person's problem*'. Further, the mix of the team may skew the emphasis. She seems to argue that a holistic approach of a palliative care team systematically examining physical, psychological, emotional and spiritual components, may be incompatible with a culturally holistic approach (involving family, community and personal issues). She advocates the inclusion of someone from the Aboriginal or Torres Strait Islander community who can address specific cultural issues.

### **The way people ask questions**

Prior (Prior 1997) (p136) comments that systematic questioning can be perceived as authoritative and threatening.

Her study confirmed that the Aboriginal people in her study had a reluctance to share personal information with strangers. She found that people willingly disclose only details which concerned the immediate problem of the sick and were unlikely to go beyond issues of immediate needs.

Eckermann (Eckermann, Dowd *et al.* 1992) discusses good communication skills in an Indigenous health setting. In particular:

- avoiding direct questions;
- avoiding questions which invite agreement;
- using open ended questions; and
- seeking clarification.

are important communication techniques. Setting up a conversation so that it flows 'two ways' is important. The interviewer must be prepared to share information about who they are. '*We want to know who we are talking to*' we were told by community members. This didn't mean knowing from which organisation a person came, but knowing enough about the person to allow a level of trust. This level of trust may not be established on one visit alone and is likely to be hastened if an introduction is made by a trusted, mutually-known party.

### **Location of assessment**

Where the assessment takes place may be as important as how it is undertaken. Consideration should be given to ensuring that the environment is one in which the participants feel comfortable and not

alienated or strange. If discussions take place in the home, and especially if it is a group home with more than one family present, then it may be appropriate that the discussion not take place in the sitting room or kitchen but on the verandah or outside under a tree. Service providers should be sensitive to these issues and ask the family where they want to do these things.

### Aboriginal perceptions of wellbeing

Prior's study (1997) (p133) found that Aboriginal people '*placed a relatively low priority on physical illness in contrast to the importance of their community and family business. A diagnosis of life-threatening disease such as cancer, is not necessarily the person's first concern nor is it perceived as preventing them from caring [sic] out their family duties*'. The importance of other issues, such as getting home to country, as opposed to symptom control is discussed in Section 5.3 below.

Prior (1997) (p140) emphasises the need to include the social and cultural basis of illness. She recommends that practitioners use an 'explanatory' model of illness in forming assessment. Such a model guides practitioners to seek out not only the social basis of illness but also what the illness means to the person and their community.

As was suggested to us numerous times, the services of Aboriginal and Torres Strait Islander workers trained in palliative care and who bring cultural skills to the situation should be purchased in the same way as other members of the allied health team, except that their involvement should begin even earlier. Indeed, in many cases Aboriginal and Torres Strait Islander workers should be the coordinators and/or Aboriginal and Torres Strait Islander health organisations the purchasers of the palliative care and other services where their clients are involved.<sup>2</sup>

The involvement of appropriate Aboriginal and Torres Strait Islander staff as members of multidisciplinary teams and their presence and active involvement in the assessment process is critical. Conducting assessments in a culturally appropriate way (without multiple service providers asking their particular sets of questions) seems to be critical in building a relationship and in finding out what people actually need.

Involving family in the development of care plans is critical. One of the objectives of the assessment and planning meetings should be to establish what the family needs in order to be able to provide care. This should not focus only on equipment but should also consider information and coaching needs of family members (note however Section 5.4.2 below, *Identification of the right person*).

Service providers should work with local Aboriginal and Torres Strait Islander health professionals to develop appropriate assessment tools and protocols. It is not only the questions that are asked, but the manner and context in which they are asked that is important. Given the great variation in Aboriginal and Torres Strait Islander cultures, local input is essential.

### 5.2.3 Palliative care service provider access to cultural specialists

Most palliative care service providers have ready access to a range of specialist advisors and ancillary services. Large gaps include service provider access to Aboriginal and/or Torres Strait Islander cultural

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<sup>2</sup> The education and training needs of Aboriginal and Torres Strait Islander health organisations about palliative care are addressed in Chapter 7.

advisors, liaison staff, language interpreters and Aboriginal health professionals. Palliative care service providers should make every effort to:

- identify what Aboriginal and/or Torres Strait Islander services are available in their areas (eg: AMS, State Government Indigenous Health Unit, community organisation, language and culture centres);
- develop relationships with these organisations; and
- budget for funds to broker in services where needed.

Alternatively, service providers could employ their own Aboriginal and/or Torres Strait Islander specialists. None of the major nursing services we spoke with (Blue Care, Silver Chain, RDNS, etc.) had any Aboriginal or Torres Strait Islander liaison staff working in palliative care and most had no Aboriginal or Torres Strait Islander staff at all. We understand that Blue Care in Queensland has recently employed an Indigenous Employment Officer to develop Aboriginal and Torres Strait Islander employment within the organisation.

Aboriginal and/or Torres Strait Islander service providers who are delivering some palliative care services or services to palliative care clients should make contact with mainstream palliative care service providers to help ensure that mutual clients are receiving all the services they need and are entitled to, and to establish ways of working together.

#### 5.2.4 Appropriate roles of palliative care workers

The role taken by the palliative care service provider will depend upon what is appropriate to the local area (whether the care setting is in a remote location, whether the palliative client is also a client of the AMS, whether the GP is involved, who it has been agreed will be the co-ordinator, etc<sup>3</sup>), but it will also depend upon the attitude of the service provider. In our discussions with service providers and their clients around the country, we were struck by the range of roles that service providers took or were perceived as having.

In the area of symptom control, the different roles we heard about ranged from ‘bossy know-it-all’ to ‘humble coach’, or from ‘nurse in shining uniform bearing syringe’ to ‘willing supporter of family needs’.

*An Aboriginal woman described how much her family appreciated having a palliative care person coming in to show the family how to do things for her son who had a brain tumour. She said the palliative care nurse became part of the family and they could ring her in the middle of the night to check to see whether they were doing the right thing or she would pop around and check that things were okay and share a cup of tea. [Western Australia Regional Area 1]*

One palliative care service we spoke with saw their role as providing education and supporting the family so that the family could undertake the care themselves. This is the sort of approach which most of the Aboriginal and Torres Strait Islander people we spoke with would appreciate.

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<sup>3</sup> ‘A major example of breaking down barriers and building relationships between Indigenous organisations is in [2pop3] where the 2ABCultural Health Service, 2AF Health Service and the community have recently formed a partnership to provide an integrated, culturally appropriate health care model for the communities of the (major river) Valley in order to avoid duplication of services and to foster continuity of care.’ (Field notes Western Australia, remote area). See also Appendix 12 for an example of a draft regional network plan from Victoria.



## 5.3 Place of death

*Death should not be an isolated issue – there should be community involvement – you should be surrounded by the people you love. [community member, Perth]*

The desire of Aboriginal people to die in their country has been well documented (Willis 1999), (Williamson 1996). The need for people to return from a hospital to their community in time is documented further in Section 5.3.1 below.

There are two other issues about the actual place of death which will affect palliative care service delivery. In many places families, although willing to look after a dying person throughout their illness (especially if they are supported in this), do not want the person to actually die at home. This is one reason why a person will often be transferred just before death to a clinic or hospital if there is one close by. There are likely to be several cultural reasons for this. People are reluctant to be 'blamed' or held responsible for a death as traditionally they may have been if a person died in their care. A death in a house may also mean significant disruption as the family may have to vacate the house for some time.

These traditions, together with a mistrust of the health system, often create significant dilemmas for the families of palliative care clients.

During the fieldwork, community members and AHWs were interviewed about whether there was a 'right' place for someone to pass away, and if so whether there were problems in achieving this. Essentially two major issues were explored. Firstly, there is the issue of an Aboriginal or Torres Strait Islander person's desire to return to their country or their home community to die and whether (and if so, how) this can be accommodated. There is also the question of where they will pass away within that country, town or community and whether it should be at home, in the clinic, in the hospital or the hospice.

There is general and strong agreement that the place of death should be the choice of the individual and their family. Views on these issues were canvassed with those we spoke with and, not surprisingly, there was variation from place to place and individual to individual. A key issue for both urban and remote peoples is that these matters (place of death) should be discussed early enough so that people can be clear about what they want and know that it can be made to happen.

### 5.3.1 Issues about getting home to country

In many areas the people we interviewed expressed the view that people wanted to go home to their own country or community to die. The following anecdotal evidence was provided during this study.

- A high proportion of Aboriginal and Torres Strait Islander clients are at a terminal stage of illness when diagnosed. Medical staff in remote communities may believe they are acting in the 'best interests' of the client and evacuate them to a town hospital, when often the main concern of Aboriginal patients who have reached the terminal stage may not be the physical pain but their need to return or remain at 'home'. Sometimes remote medical staff do not feel that they can take that responsibility.
- We were told of cases where patients records had not been properly checked and people with incurable illnesses were sent to Perth for treatment. We were also told of cases where people chose to return home rather than receive treatment. For example a young woman with a young family decided to go home rather than stay in Perth for six months of radiotherapy treatment.



- Staff in one remote clinic said that [Aboriginal people] should be able to die wherever they want to die and clinic staff will support them to stay in the community if that is what they want but,
 

*There needs to be informed consent and this is very difficult when nursing staff have no ability to speak the language. Nurses need to feel confident that the family understands that the person may be cutting off their options to living.*
- People would prefer to pass away in their own country with their own family, and for Walpiri people, 'It is important that we see the passing with our own eyes'.
- People are often admitted to hospital to die and are not given any information about alternative ways of coping with this stage of life.
- People often die in Perth, away from home.
 

*Hospitals wait too long and leave it until people are too sick to travel. It is difficult ensuring that there is informed choice at the right time. The longer they stay in Perth and the sicker they are, the more expensive it is for them to get home. If they are on a stretcher then they need a nurse escort. People prefer to go home to country die – even to a regional hospital – not to die in Perth.* [hospital-based Aboriginal health professional]
- A palliative care service in the Northern Territory reported that nearly all of their clients would prefer to go home but that only 50% manage to do so. The rest die in hospital, nursing home or aged care facility in the regional centre.
- Many Aboriginal people who live in Adelaide were born at (Aboriginal community), and apparently many of them would prefer to return there to die. The general view is that there are no facilities or support services in (the community) to allow this. However upon questioning informants (service providers) further, no one actually knew what sort of services might be available at (the community). Transport to get home and to get to services when they got there would also be an issue. A story was told of a child who was dying who went home to (the community) and she died in the nearest hospital at ( ) because no one would arrange for her to have pain relief administered at home due to fears that the drugs would be stolen. The point here is that service providers too easily assume that there is no way people can go home without exploring all the options and finding a way to make it work.

### 5.3.2 People wanting to die at home but ending up in hospital

In many places people reported that they and their families would prefer to die at home, but apparently few achieve that. Even where people are looked after at home throughout their illness they are likely to go to the hospital suddenly at the final stage. There may be several reasons why this occurs.

#### Capacity

Sometimes people do not have the capacity to care for people at home. They may not have appropriate housing, or may not have the skills or time to care for someone, especially if they have young children and/or other people (eg parents to care for). Houses are overcrowded and not well equipped to allow people to be looked after at home.

### **Fear of the unknown**

Sometimes, because most people have never been faced with this choice and have little knowledge about it, people will choose to take the person to the hospital close to the end. Sometimes this is what the dying person wants. This is likely to be the case where people have not been referred to a palliative care service or received appropriate advice and support.

### **Concern for pain or not being ready to let go**

Sometimes (even with good preparation) people panic and call an ambulance close to the end. They are afraid that they're not doing enough for pain management or think that the hospital could look after the person better.

### **Fear of spirits of the dead and/or the need to vacate the house for cleansing**

In many parts of South Australia, the Northern Territory and Western Australia there are strong cultural requirements regarding ritual cleansing and/or vacating places where people have passed away and this can cause people to have to leave home. Sometimes houses are abandoned for months or years; sometimes they can be cleansed and re-occupied; sometimes they are cleansed and the family will swap with another family. Sometimes people have beliefs about spirits which may not be traditional but which will still require them to leave home.

Most State and/or Aboriginal housing authorities are sensitive to these issues and accommodate a change of property, though in more remote communities there may be very limited housing stock and this is a major problem.

Aged care facilities and nursing homes in the Northern Territory and Western Australia often rush a person to hospital if they think that they are going to die so they will not have to have rooms empty or cleansed. The death of a person in a clinic in a remote community also causes difficulties for ongoing use.

### **Not wanting to be in proximity – blame and payback**

In some traditional communities it is common for family members to look for someone to blame for a death and to take 'payback' actions which may include physical violence toward the person blamed for the death. Often the person blamed is the person who has been caring for the sick person. Fear of payback means that family may be reluctant to keep the person with them when they are near death.

In one remote town where many people wanted to look after family members but could not have them die at home because of the need to vacate the house, and where the hospital is strongly associated with death (which makes it uncomfortable for people to use it for births or healing), the community had proposed the building of a 'care centre':

*We should have a separate care centre here in town. A place put aside for people who have illnesses who know that their time is up. Not at the hospital which should be for treatment of things – separate from the hospital, a different place altogether. And a place where family can come and go. It would be a big room – really two units with some shared facilities so that the family can stay.*

*This centre could be used by renal clients well as cancer patients.*

*The care centre should have a unit for people from out of town.*

Community members said they would prefer it if such a centre was just for Aboriginal people. The AMS doctor in this town supported this notion, believing that one reason for late diagnosis was that people feared the health system and the hospital so much that they avoided seeking help until the very end.

At a meeting in the Pitjantjatjara Lands on the border between South Australia and the Northern Territory, senior men and women discussed the problem of caring for people who were dying and the cultural dilemmas that arose. What they suggested was that each community should have a building – detached from but close to the main health clinic building – specifically for palliative care clients. It was also suggested that it have a similar design to the guest quarters on the Lands, which have bedrooms, a detached kitchen and ablution block and have a phone connected to the clinic for emergencies at night. The building should have room for the family to stay and to cook. People suggested that after the person had passed away the building could be ‘cleaned up’ after ‘sorry camp’ and be ready for the next person to move in.

In a relatively remote but large town in South Australia an example was given of how the cultural dilemma (and overcrowding) could be overcome. The Aboriginal housing authority provided a house for a man who needed palliative care. This meant that his family could come and care for him there, but not everyone had to live there. There was enough room for him to have a hospital bed and lock up his medication etc. After he died the house was cleansed and the family members who had been staying went home to their normal house.

There are several aged care facilities in remote communities which are being designed to take account of cultural issues (eg Oak Valley). At Wanarn community in the central desert region of Western Australia, an aged care facility was built and opened in 2002.

*Our main aim in the beginning of the palliative care program was that the elderly had/have a choice to die in their own Lands, rather than being sent to Kalgoorlie nursing homes... The facility is currently only a low care facility, (due to staffing)... at first it was thought that maybe in the Aged Care Centre there could be a respite bed for palliative patients, but that could be difficult if the person was under 50 years of age, as due to the way funding works there are strict rules that only people over 50 or 55 can stay at the Aged Care Centre... there have been discussions and decisions made re the old people dying in the aged care centre, as this is very much a cultural issue. [email from palliative care coordinator]*

### 5.3.3 Inadequacy of hospital facilities

There are three major problems with people dying in hospital:

- hospitals often do not cater well for the cultural and social needs of Aboriginal and Torres Strait Islander people and their families, both because of the physical layout and staff attitude;
- hospitals are alien places, with few if any Aboriginal or Torres Strait Islander staff and where Aboriginal and Torres Strait Islander people feel they have no control. Hospitals are associated with the government and the welfare system and are feared; and
- hospitals are generally viewed as places of death, not of healing or caring.

These issues are discussed further in Section 5.4.3, Setting of care – care in hospital.

Another issue which arose in relation to hospitals was that when palliative care patients presented at hospitals for additional pain management or because family panicked and called the ambulance,

they sometimes ended up in the emergency ward receiving inappropriate treatment rather than being referred to the palliative care unit. Most Aboriginal and Torres Strait Islander people are not good at speaking up about their needs, especially in what they perceive to be a hostile environment such as a hospital. This means that it is especially important that palliative clients are tagged in some way. One palliative care unit in western Sydney provides a registration card or booklet to people which they can take with them if they are going to hospital. This clearly identifies them as palliative care clients and indicates which service provider or doctor should be contacted. Such registration information could include directions about resuscitation preferences. Some other places are experimenting with a 'tag' or 'alert' on the hospital file in the same place that allergies are recorded.

#### 5.3.4 Suitability of hospice facilities

Most Aboriginal and/or Torres Strait Islander people we spoke with whose family members had used hospices were generally very pleased with them. They found them and the staff a great contrast to the hospitals. Where the patient and family had visited the hospice early on in the illness for pain management or for familiarisation, this had made a big difference. Hospices that are well designed, with large enough spaces and rooms with outdoor access, and that are willing to accommodate large families and smoking ceremonies, are very much appreciated by Aboriginal and Torres Strait Islander communities. Arrangements for visiting ALOs at hospices is also very important.

Darwin hospital has been planning a new hospice and the AHW from the Northern Territory (Top End) Palliative Care Service has canvassed what should be there with the community (see Appendix 8).

The implications of place of death issues for service providers and policy makers are discussed in Section 5.9.4.

### 5.4 Setting of Care

#### 5.4.1 Care in the home

*'Take the time to talk – we like to know who you are.'* [community member, South Australia]

Most Aboriginal and Torres Strait Islander people we spoke with told us that when someone is diagnosed with an illness from which they will not get better the family will look after that person. This is seen as the 'Aboriginal way': *'it is what we have always done, for generations'*. It is likely to be true that many Aboriginal and Torres Strait Islander families do look after their own at home without any assistance. It is also the case, however, that many Aboriginal and Torres Strait Islander people pass away in hospital when that may not be their preferred choice.

In discussions about whether palliative care was thought to be a good thing or not, most people thought that if it helped families to look after family members themselves then it was a good thing and could support what people saw as a 'traditional' way of doing things. Some serious issues were identified regarding whether that care could be appropriately delivered. The key issue was whether it was possible to receive services in the home that would not be so alien and intrusive as to make people feel they were not in control of looking after their own.

### 5.4.2 Planning and care issues at home

The major barriers to delivery of appropriate palliative care services in the home were identified as:

- lack of relationship;
- lack of flexibility;
- need for Aboriginal and Torres Strait Islander staff;
- lack of acceptance of social and cultural differences;
- too many strangers; and
- that the right people to discuss issues with would not be identified.

These issues and some suggestions for overcoming barriers are discussed below.

#### **Relationships and consistency of care**

One of the most commonly reported problems is that service providers are seen as strangers. Usually, no relationship exists between the service provider and the client family at the outset. There is also usually no relationship between the mainstream service provider and the Aboriginal and/or Torres Strait Islander community. This lack of relationship is exacerbated by late referrals, lack of understanding of what services can be offered, the way nursing staff are rostered, the multidisciplinary approach (multiple service providers) and cultural barriers, including lack of understanding (on the part of service providers) of what is needed and wanted.

When Aboriginal and Torres Strait Islander people who had experience of palliative care were asked what could be done to improve upon the service they had received, the most common responses were:

- have Aboriginal and Torres Strait Islander staff;
- take time – time to have a cup of tea, time to talk, time to understand;
- fewer strangers; and
- more and better information, earlier.

It takes time for people to understand what to expect, what can be offered and how they can be supported. It also takes time for palliative care providers to find out what their service can do best for the client. There is often a tendency for providers to offer services without first establishing what will be most useful to the family.

Nurses reported that an important part of developing a relationship with any palliative care client is taking the time that is needed, recognising the need to repeat information and being able to pass on information at the right time.

*With Aboriginal clients who are referred very late (either because of late diagnosis or for other reasons) there is never time to pass on the information in an appropriate way or at an appropriate time. This is complicated by the living conditions where people often live in a group house, and access may be difficult. [Western Australian nurse]*

Some nursing staff report having difficulty with the number of people in the household and have difficulty trying to work out who is who, especially in the short time frame.

### Strategies to involve Aboriginal and Torres Strait Islander staff

The need for Aboriginal and Torres Strait Islander workers in palliative care was raised again and again. Chapter 4 discusses the need for Aboriginal and Torres Strait Islander workers to be involved in the referral process, the discharge process and in, at least, the early visits of service providers. The current role of AHWs and ALOs and other Indigenous health professionals is discussed further in Chapter 6.

Mainstream service providers that have Aboriginal and Torres Strait Islander clients need to find ways of involving Aboriginal and/or Torres Strait Islander workers, especially in home based services.

*Aboriginal clients are reluctant to use the palliative care service because there is no Aboriginal face in the palliative care service. Someone [an Aboriginal person] needs to walk them through the service and they need to meet the community nurse first – before they will say yes. I often get the Aboriginal Homecare service instead of the palliative care. [ALO, New South Wales]*

Some of the ways they can do this are:

- build relationships with the AHLO, Aboriginal and Torres Strait Islander HACC and CACP staff, and AMS staff;
- broker in the services of staff from these agencies to be part of the team;
- employ qualified Aboriginal and Torres Strait Islander staff in the palliative care service;
- in some places palliative care teams work closely with the AMS (if the patient is an AMS client) and this might mean that the AMS AHW acts as liaison and co-coordinator with the palliative care service, providing pain management and other advice;
- involve Aboriginal and Torres Strait Islander service providers and family members in discharge planning, care planning meetings and case management meetings; and
- work with local Aboriginal and Torres Strait Islander organisations to explore setting up and training some Aboriginal and/or Torres Strait Islander volunteers, or at least see that recruitment programs reach Aboriginal and Torres Strait Islander people and that training programs are appropriate (see further Chapter 7, Section 7.8).

### Ways to build relationships with clients

*‘Respect the family home – don’t look around.’*

Advice for mainstream service providers from community members and Aboriginal and Torres Strait Islander service providers about how to build relationships with Aboriginal and Torres Strait Islander clients included:

- ensure that there is an Aboriginal or Torres Strait Islander staff member or liaison person present at the early interviews and for as long as necessary;
- be prepared to revisit and to spend time in order to find out what you can do to assist; and
- develop your credentials with the community.

Several experienced non-Indigenous service providers’ staff (eg non-Indigenous doctors and nurses working for AMSs) explained the importance of establishing credentials in the community. The importance of ‘word of mouth’ about the service and about the individual staff members is very important. This means establishing lasting relationships with Aboriginal and Torres Strait Islander staff

and service providers, showing good faith and demonstrating sensitivity, listening skills and responsiveness.

Two ways of beginning the development of these relationships with the Aboriginal and/or Torres Strait Islander community include:

- offering in-service training; and
- taking up (or offering) work placements.

It takes considerable commitment to develop such relationships. For example, an Aboriginal Homecare coordinator in New South Wales reported that it had taken several years before the AMS and other service providers started making referrals to her service.

*We [the service] had to build up our profile and had to do door-knocking to get clients for the first couple of years – despite the fact that we have Koori workers. It takes time and energy to build up trust.*

An ALO from Queensland said that building up credibility with clients helps to break down barriers to access:

*If people have had a positive experience with a non-Indigenous service provider they will come back to that service and look for that person even if they are there to see someone else – they feel comfortable knowing someone they know is there.*

#### **Identification of the right person within the family that the service provider can liaise with (not necessarily the carer or escort)**

The complexity of Aboriginal and Torres Strait Islander family relationships was discussed in Chapter 3, Section 3.2.5. Palliative care workers providing services in the home need to be careful not to make assumptions about who the decision makers are. The primary care givers may not be the decision makers. A family spokesperson may be just that – a spokesperson only, but not a decision maker. Roles and relationships may be doubly confusing to a non-Indigenous person if the family is living in a group house. The critical thing is that assumptions about roles should not be made, though these issues should be discussed with family. Service providers should seek assistance where appropriate from trained Aboriginal and/or Torres Strait Islander colleagues.

It is quite possible that some Aboriginal and Torres Strait Islander clients will not want the local ALO or AHW involved because these people may not be in an appropriate relationship with the family. This issue also needs to be carefully checked. In the course of our study a palliative care doctor, inspired by our visit to try to do the right thing, took a new Aboriginal client along to meet with the hospital ALO (whom he himself had not met previously). It turned out that the ALO was cousin or niece of the client and was not an appropriate person to be involved.

#### **Reducing the numbers of strangers**

Another issue which people found difficult was the number of strangers involved in palliative care delivery, with each one having to make their own assessments and repeat questions. Minimising intrusion is important in all palliative care service delivery, but is doubly important for Aboriginal and Torres Strait Islander clients.

Where possible, local strategies should be developed to reduce the number of different service providers visiting a house and to make the roles of various organisations and individuals clear. This could include



preparing a list of the various service providers, providing photos of 'who is who' and drawing diagrams of the relationships between them. The most efficient way of running a service (for example, rostering staff so that clients see a different staff member each day) may present enormous difficulties for clients.

Many service providers use case management meetings as a way of coordinating care, and these can be very useful in clarifying roles and reducing the number of visitors to a house. Currently, however, case management meetings do not usually involve the AMS, the hospital ALO or another cultural representative. When palliative care services have Aboriginal and Torres Strait Islander clients they should ensure the participation of an appropriate Aboriginal and/or Torres Strait Islander service provider or community representative in the care team and case management meetings, unless that is against the wishes of the client. This person can act as a 'cultural quality reviewer'.

### **Provision of information**

Sensitivity to the client's information needs is an important part of developing the relationship. The kinds of information which Aboriginal and Torres Strait Islander people said that they would like is summarised in Chapter 7, Section 7.2.

The need for information was one of the most common themes.

*No one really knows what is involved in looking after someone with a terminal illness until they have to do it. Need information and guidance to allow the client to make a choice about their treatment, about guardianship, about where they want to die. We had a family conference, and that was good. People said they would do things but that didn't happen. We needed more information and explanation from someone. Training for family members is needed.* [woman who nursed sister with HIV/AIDS]

In providing information about the condition, symptom management or what is likely to happen, it is important to recognise and to keep in mind that family members may have little education. It is possible that no one in the household may be able to read, or that English may not be the first language. Information should *always* be provided verbally, and service providers should check that it has been understood by sensitively seeking feedback. It is often necessary to repeat information on successive visits. It is also important to leave written versions of the advice and information. This enables the family to show it to others and independently check their understanding.

### **Being able to listen, hear and respond: communication and flexibility**

*The quality of the palliative care will be as good as the person is at asking and listening.*  
[nurse from a town in Western Australia]

Chapter 3 provided some examples of the sorts of misunderstandings that can occur in cross cultural communication.

*The biggest challenge for us is to understand what they need and to make our services acceptable to them. Often the people we are dealing with are very far ahead in their illness but are still in denial because it has been left too long, and then it is too late to be able to develop what people would like.* [Silver Chain nurse]

The way a service is 'normally' provided may not be appropriate. Service providers need to be prepared to modify the service to respond to cultural and socio-economic needs.



Sometimes good listening is not enough in cross cultural situations. It is very important to have assistance from someone of the same cultural group as the client, to double check that good communication is taking place. In many places it will be necessary to have an interpreter. One of the few Aboriginal health workers working in palliative care (in a region where she does not speak the local language) has reported how, having recently used the services of an interpreter, could see how essential this was to being able to explain what palliative care can offer.

### Confidentiality

Many people spoke of not wanting it known that nurses were calling and said that it was very important that service providers use unmarked cars and not wear uniforms. Most service providers already aim to provide this kind of confidentiality. One nursing service had developed a system of removable deckles on their cars so that they could be anonymous when visiting clients but at other times could advertise their service.

### Capacity to care and respite care

Issues dealing with capacity have been covered in Chapter 3 and in Section 5.3. The need for access to respite services was raised time and again. This is especially an issue for clients who do not fit the HACC criteria and for people in remote areas where no respite services are available.

#### 5.4.3 Care in hospital

*How can the Palliative Care Unit be culturally appropriate when it is in the thick of the hospital environment – not in a friendly environment? If a family member is ill we stay right there with them.* [Queensland AHW]

The context of Aboriginal and Torres Strait Islander peoples' interactions with and fears about the health system are discussed above and in Chapter 3. As noted above, hospitals are often seen as places of death rather than healing. There may also be cultural issues (avoidance) associated with the place of death (see Section 5.3).

The strength of people's feelings about hospitals should not be underestimated.

Ofra Fried (Fried 2000) (p11) refers to the relatively recent practice of having segregated hospitals in the Northern Territory. In several of the centres we visited in New South Wales there were strong recent memories of racism at hospitals. For example, an AHW now in her 50s told us that she had given up her nursing training because of racism; in another case, people still remember a separate Aboriginal-only ward in the hospital, where the cutlery and laundry were labelled 'ABO'; another hospital, where people remember mothers going to have their babies, is 'full of bad memories'. In Queensland, interviewees generally (and frequently) spoke of hospitals as hated places, staffed by people with bad attitudes.

The issues raised about hospitals were remarkably common, whether or not they were located in communities with large Aboriginal populations, or whether in cities or country areas.

The issues raised included:

- not enough (often no) Aboriginal staff except perhaps an ALO, even in areas with a relatively high Aboriginal population (for example a town where the Aboriginal population is 13% of the total has only one ALO and she is the only Aboriginal employee in the hospital). *'Just having some black faces makes a great difference'* [community member];

- ALOs are overworked, or do not work full time, or are too busy with day-to-day patient issues to get involved in palliative care issues;
- high staff turnover, especially in regional hospitals so that the number of fewer nurses have had cultural awareness training. In remote areas, the use of agency staff and foreign nurses on temporary work visas adds to the problem.

*One example was a young Irish nurse who was confronted with 20 or 30 grieving Aboriginal people during her first week and did not understand about protocol and who she should speak to about the situation. This had serious repercussions for the hospital and was raised by community members on several occasions during our visit to the area.*

- staff attitudes – they ‘always tell us to be quiet’:

*Nursing staff need cultural understanding... Aboriginal people in [a Queensland regional centre] would rather use private GP's than go to the hospital. There are some staff with bad attitudes at the hospital. Some good ones. Local white staff have bad attitudes and bully patients. They need an Aboriginal liaison person at the front desk. Need bama<sup>4</sup> in there.*

*Hospital staff need to have someone in there who understands language and to know:*

- *about looking old people in the eye – they don't like it.*
- *never turn your back to people*
- *women need to work with women, men with men*
- *who it is appropriate to talk to [community member, Queensland]*
- inadequate communication and relationship development. (Many of the issues raised above in relation to assessment and home visiting are relevant here – see also sections on communication in Chapter 3, Section 3.3.2 and 3.4.2);
- patients' rooms are too small for visiting family and community members. Aboriginal and Torres Strait Islander community members' experience is of always having to stand in corridors;
- air conditioning (this was reported as a problem right across northern Australia, from Western Australia to Queensland – most Aboriginal and/or Torres Strait Islander people in these regions find air conditioning uncomfortable);
- palliative care units are either not located on the ground floor or there is no easy access to them, nor easy access to the outside – we were told that people desire access to open spaces from the palliative care area;
- there are no suitable places where the family the whole family can come together to be with the deceased and are able to stay long enough;
- there is no accommodation nearby for family visiting from 'country'. At one Perth hospital, visiting family members from remote areas frequently camp in the car park;
- people need to be able to eat food they are used to and hospitals should facilitate families bringing in appropriate food;
- sterile and alienating environment;
- hospitals and nursing staff are reluctant to relinquish responsibility for personal care of the patient – family members would often like to be involved;

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<sup>4</sup> Bama means Aboriginal people.

- association of hospitals with death (see Section 5.3); many suggested that palliative care beds be located in a separate building or with a separate entrance;
- some hospitals do not permit smoking ceremonies:

*There is one problem. 'Smoking' a room to get rid of the dead person's spirit is not allowed at the hospital and so this means that the room where the person died is not really safe for other Aboriginal or Tiwi people. This may be one reason why Aboriginal people are often not keen to go to the hospital, because it is unsafe from spirits. Perhaps something could be done about this to accommodate the needs of Aboriginal people. [Northern Territory]*

- most hospitals do not have protocols to follow to check that cultural needs can be accommodated (eg immediate access to clothing and a lock of hair for 'sorry business') especially if the person who has died is from a remote community.

We were told that things had improved in many hospitals, that attitudes were changing and staff would try to accommodate the large family groups if they could. This was especially the case with staff managing palliative care beds, however many were only too aware of how inadequate the hospitals were in accommodating the needs of Aboriginal people and of other cultural groups with extended families. In some places ALOs had organised orientation days to familiarise people in their community with the hospital and the changes that had taken place. These seemed to be effective.

One hospital has developed a special room for family groups, designed to meet the needs of the Aboriginal community, but also available for other groups (see Appendix 9). In other places we heard that requests for suitable accommodation for families had been ignored.

The trend in some States towards non-smoking (of cigarettes) on health campuses creates problems for Aboriginal families at a sensitive time, given the high proportion of Aboriginal people who smoke. Some feel that this is another way to make people feel alienated in hospitals.

The display of Aboriginal and/or Torres Strait Islander art and artefacts would be a very positive change. Community members commented favourably on hospices and nursing homes where Aboriginal art and artefacts were displayed, saying that it made them feel welcome. Prior (1997) (p131) also comments that this is an important way to demonstrate acceptance of Aboriginal and Torres Strait Islander cultures, and recommends consultation with local communities about the selection of the art works.

A list of the features Aboriginal and Torres Strait Islander people have said they would like to see incorporated into the proposed hospice in Darwin, so that it will be culturally appropriate and user friendly for Aboriginal and/or Torres Strait Islander clients, is provided at Appendix 8. The list was developed by the Aboriginal health worker of the Top End Palliative Care Service and circulated to various Aboriginal organisations, health professionals and community members throughout the Northern Territory for feedback and comment.

#### 5.4.4 Care in a hospice

Hospices are usually separately-run facilities for symptom management, respite and terminal care which are usually physically separated from the hospital to which they are attached.

Most of the people with whom we spoke whose family had used a hospice either for pain management or for terminal care were very satisfied with the facilities and with the attitudes of staff. In general, interviewees reported that hospices did not have the same physical or attitudinal problems as hospitals. In some instances, spaces for families were not large enough or there was no private room at the time

of death, but most had rooms with suitable access to outdoor spaces and the attitudes of staff were accommodating. The biggest identified need was for a large space with its own entrance for family to remain with the deceased. In one hospice in western Sydney an Aboriginal mural and didgeridoo in the foyer made people feel at home.

Many people we spoke with thought that palliative care was synonymous with placing someone in a hospice and said that they would not want to do that, although most of these people had not been to a hospice. In two places we visited in New South Wales, the ALO from the local hospital had arranged familiarisation visits (one being a general visit for community elders and decision-makers, and another for palliative care clients) and these had made a big difference to people's attitudes towards the hospices.

We were told of a young HIV/AIDS patient who was offered a place in a hospice specifically for AIDS patients. He went and looked at it but found it too alien. He said he would not have felt comfortable there and his family would not have been comfortable visiting him there.

#### 5.4.5 Palliative care in nursing homes and/or aged care facilities

This study has not concentrated upon palliative care of Aboriginal and Torres Strait Islander people in aged care facilities or nursing homes. Little is known about Aboriginal and Torres Strait Islander occupancy rates of these mainstream facilities.

A number of facilities are funded for Aboriginal and/or Torres Strait Islander places by the Australian Government under the Residential Care or Indigenous Flexible Funding programs, including the nursing homes and aged care facilities listed in Appendix 10.

Aboriginal and Torres Strait Islander people are generally reluctant to place family members in institutions and especially not in mainstream institutions, nor in locations remote from the person's country. However it is known that Aboriginal and Torres Strait Islander people do reside in mainstream facilities.

*Some people in Indigenous-specific facilities are a long way from home, but families opt for these places because they are not mainstream...* [Facility directors and family members]

While aged care and nursing homes were not the focus of this study, our initial scoping indicated that some of the Indigenous-specific facilities should be surveyed or interviewed<sup>5</sup>.

One of the major differences between Indigenous-specific aged care facilities and mainstream facilities is that although many of the Indigenous facilities also take non-Indigenous clients, they have very high Aboriginal and Torres Strait Islander staff numbers – usually more than 50% of staff.

In one nursing home we visited, nearly all staff, except for the nursing staff and some administrative staff, were Aboriginal. Aboriginal and Torres Strait Islander residents feel at home and comfortable where there is a high percentage of Aboriginal and/or Torres Strait Islander staff. This is in stark contrast to hospitals where there are usually no Aboriginal and/or Torres Strait Islander staff, except perhaps for an ALO.

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<sup>5</sup> Initial referrals to these places occurred partly because of a perception amongst some Aboriginal people that palliative care and aged care are synonymous.

## Aged care facilities

The following issues were identified in relation to delivery of palliative care in aged care facilities. It is not possible to say whether these issues can be generalised to all such facilities or not. They had significance for Aboriginal and Torres Strait Islander residents.

- Aged care facilities need both male and female staff.
- In one aged care facility clients were not able to access their own doctor (informant was director of facility).
- In one instance we were told of a case in which a resident had been unable to access appropriate pain management in the aged care facility. It did not have two registered nurses and so could not administer the required drugs. We were told that the local domiciliary nurses could not attend because both they and the aged care facility were HACC funded. This very frustrating situation resulted in the resident having to leave the aged care hostel to receive the drugs she required. She went to live with relatives who were able to administer the medication. If people have chosen to live in an aged care facility they should be able to have palliative care services in what is then their home.
- In one aged care facility, residents who required palliative care generally had to be relocated to a mainstream nursing home. This was because the aged care facility did not have the staff or nursing staff to provide 24 hour care. Three palliative care clients had managed to stay 'at home' in the facility until they passed away, by a combination of assistance from family who provided 24 hour care and visits from the palliative care CNC and community health nurses. Generally this is not possible because the reason people are in such a facility is that they do not have family who can care for them.
- Lack of accommodation is a problem for Aboriginal and Torres Strait Islander people visiting family in aged care facilities. Many residents have travel a long way to get a place in an Indigenous-specific facility, which makes it difficult for visitors.
- Some aged care facilities in remote communities have apparently been designed to accommodate palliative care clients. Some are still under construction. One which is completed and occupied is viewed by community members as a place of respite – *'like a holiday home'* – and residents do not want anyone to die there, as this would mean having to vacate the centre. There would also be problems with younger palliative care clients (including end stage renal patients) being accommodated in these facilities as the funding is for people over 50 years. One new centre recently occupied by aged care clients, which was originally intended to have a section for palliative care clients, has been the focus of community discussion about the difficulties for continued occupancy should someone pass away there. This and other matters, including staffing levels, has meant that palliative care clients have not taken up occupancy.
- The layout or configuration of aged care facilities seems to be an important consideration. One family was most unhappy about the fact that their relative was in a room by herself with the door closed when she needed companionship and close monitoring. This may have resulted from the fact that she should have been in a high care facility, however some other places (hostels and nursing homes) were designed especially so that people would not be alone. Ensuring that people do not have to share with people with whom they may be in an avoidance relationship is also an important design and management issue.

## Nursing homes

- In some nursing homes with Aboriginal and/or Torres Strait Islander clients, the local AMS and the local palliative care nurses work closely together to provide an integrated palliative care service.
- In one home we were told the cost of additional nursing at the time of terminal care was so great that, although the director would have preferred to buy in additional nursing and allow the person to stay until the end, she could not do so and usually sent the person to hospital to pass away.
- In several nursing homes in the Northern Territory and parts of Western Australia, Aboriginal clients judged to be at the terminal stage are removed to the local hospital as death approaches (last 3-4 days) so as to avoid the need to keep rooms vacant because of cultural requirements.
- In one nursing home, specially designed for Aboriginal clients and built from mud bricks from the major surrounding communities, a special larger room was built to accommodate a dying person and their visiting family. The room has its own access to the car park and an attached bedroom for family members. We were told this room has not been used for the purpose for which it was designed because people prefer to remain in their own room (their 'home') at this time. Use of the room would probably require additional nursing staff, and this may also have influenced whether or not it was used. This nursing home is not in a region where death necessitates vacating premises.
- One nursing home which had some palliative care clients there specifically for palliation (as well as its own clients) had no links with the local palliative care CNC and no nurses with specialised palliative care training.
- Another nursing home had a good relationship with the local palliative care team which provided symptom management advice and coordinated ancillary services as required. It also had a relationship with the local AMS whose doctors visited residents.
- In some places there did not seem to be good or regular liaison between the local AMS and Indigenous-specific care facilities.
- One AMS doctor stated that she would rather send palliative care clients to the hospital for terminal care than to the local Aboriginal nursing home because she believed that the medical care at the hospital would be better. This was despite that fact that many Aboriginal people in this town had a fear and hatred of the hospital, while in contrast, the nursing home was considered to be culturally 'comfortable'. This doctor's judgment about the level of care at the nursing home did not seem to be based on experience but on her belief in the medical system.
- A number of nursing homes and aged care facilities with Aboriginal clients provide bush tucker on the menu, facilities for outdoor cooking and living, and facilitate clients meeting their cultural obligations.
- One nursing home identified improved and more frequent access to traditional/ spiritual healers as an issue.
- Most of the nursing homes we surveyed endeavoured to comply with cultural protocols around death (see Section 5.3 Place of Death and also Chapter 3, Section 3.3.7). Some had detailed written policies (see for example Appendix 11), though many tried to avoid these situations by transferring dying people to hospital.
- There is a potential for 'western standards' to conflict with cultural desires. The importance of shared rooms is discussed above in the section on aged care hostels. The policy of one nursing home we visited (part of an international group of nursing homes) was that each patient would have a room



of their own. When asked if this was what the patients wanted, the Director replied that it was not a matter of what they wanted, the nursing home's standard was that each resident would have a room of their own and that was how it would be.

- A major issue identified by directors of nursing homes (and palliative care units at hospitals) was the lack of accommodation for families visiting from out of town. This is exacerbated by the fact that nursing homes are not usually centrally located and many visitors do not have private transport. In some places people are far from their families because there is no suitable (or Indigenous-specific) facility any closer. Some suggested that some special travel assistance to enable relatives to visit was needed.
- One nursing home identified the need for a staff position (or funding to broker in the services) of a family/cultural liaison person especially to help communicate with distant families.
- Lack of palliative care support in nursing homes means that not only may the palliative care client not be receiving the best medication, but they and their family may not be receiving the support and counselling that palliative care can offer. One nursing home director specifically identified the need for a counselling service or family liaison staff to explain what is happening to clients.
- In some places respite beds held by nursing homes are extremely important to community based palliative care services, allowing a break for families.
- A written response to our questionnaire stated:

*We do and have provided care of the dying without labelling it as palliative care and within our existing minimal resources. We will continue with these practices but look forward to the result of this study to hopefully highlight to relevant bodies that our needs are different and broader than just administering medical care.*

*It is the extra resource of medical care that we at [name or organisation]<sup>6</sup> need and of course for us to access additional resources to deliver services and support to families of the dying (i.e. accommodating immediate family members through the time of passing, advocating, coordinating and arranging travel, financial assistance, contact and whereabouts of family members, funerals, transporting back to country etc). We are able to do all these things in a sensitive and culturally relevant way, ensuring no added stress to an already stressful situation. At [name or organisation] we know the make up, factions and frictions on families and communities which is extremely important in death and dying situations... I would suggest that our organisation would look at a joint program with an appropriate mainstream unit providing medical requirements and [name or organisation] providing the social and cultural support.*

Another Indigenous-specific nursing home and aged care hostel described what they thought made a good practice service:

1. *adherence to residents' and family's personal choice of care provision; includes culturally appropriate care and traditional care methods where possible;*
2. *adequate pain management – maintain comfort;*

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<sup>6</sup> This nursing home received 'flexible cashed out model' funding (15 high level and 10 low beds), mid-range subsidy cashed out on a monthly basis. This nursing home found it very difficult to cover the costs of additional nursing for terminal care and had had to send patients to hospital because they would not have been able to provide the level of care needed despite their high care beds. They wanted to be able to buy in palliative care services as needed.



3. *liaison with palliative care nurses, MO and allied health professions;*
4. *access to spiritual/ traditional guidance; and*
5. *training for staff specific to palliative care, where required.*

In many places (eg western Sydney and Perth) there appear to be no Indigenous-specific aged care or nursing homes.

We do not have any information about how mainstream nursing homes or aged care facilities accommodate the needs of Aboriginal and/or Torres Strait Islander clients except in some remote areas where these facilities have a high number of Aboriginal clients. In one area visited in Queensland there were no Aboriginal staff in the local aged care facility despite the fact that it had a large number of Aboriginal residents. The aged care worker from the local Aboriginal and Torres Strait Islander corporation visits this facility and takes people out to the family for the day. We were told *'it is obvious how isolated the Aboriginal and Torres Strait Islander residents feel because whenever an Indigenous person visits, residents would show immediate interest and wave and call out.'* [aged care worker]

A hostel in Perth accommodates remote area renal dialysis patients who must reside in Perth to visit the hospital for regular dialysis. It does not have the capacity to accommodate all renal patients (see Section 5.4.6, Medically supported hostels below).

The implications of the findings about aged care and nursing homes are discussed below at section 5.9.4.

#### 5.4.6 Medically supported hostels

In centres such as Alice Springs and Perth there is a need for hostels that are designed to cater for the needs of palliative care clients and others who are very ill and in town for medical appointments.

In central Australia people talked about the need for a hostel located close to the Alice Springs Hospital, specifically for palliative care clients from remote communities who are in town for follow up appointments or travelling to or from Adelaide for treatment. The existing hostel is considered inappropriate for 'really sick people' and very restrictive, allowing only one hour for breakfast, lunch at 11.00 am and dinner between 4.00 and 5.00 pm, when people are often still at appointments.

The same issue was identified in Perth and Cairns, and such a hostel is probably needed in Adelaide as well. There are several such hostels in existence, though not specifically for palliative care clients. One hostel in Perth<sup>7</sup> specialises in housing remote renal patients who are in town for ongoing dialysis. This hostel is always full and cannot handle the number of dialysis clients who come to Perth. In Cairns a hostel caters for pregnant women who have come to town to await the birth of their babies<sup>8</sup> and has taken in very sick women if needed. These hostels provide health worker support, some health education and assist with transport to medical appointments. Similar hostels which specialise in short term stays for palliative clients who are in town for symptom management may be needed in a number of locations.

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<sup>7</sup> Elizabeth Hansen Autumn Centre.

<sup>8</sup> Mookai Rosie-Bi-Bayan.

#### 5.4.7 Palliative care for itinerant people

There are many Aboriginal and Torres Strait Islander people who do not have a house or home who may be termed ‘itinerant’ or ‘homeless’<sup>9</sup>. These people often live in city parks and include people who need palliative care and symptom management.

AHWs told us of their frustrations in trying to obtain any services for these people. In one regional centre in Queensland the palliative care unit and local Diversional Centre have begun discussions about ways of taking palliative care to the homeless population.

Local palliative care service providers should work with AMSs and other Aboriginal and/or Torres Strait Islander service providers and appropriate funding agencies to develop strategies to allow delivery of services to these people in the setting of their choice.

#### 5.4.8 Palliative care in gaol

It was beyond the scope of this study to investigate palliative care in gaol, however, given the high number of Aboriginal and Torres Strait Islander people in Australian correctional institutions, and the sensitivities surrounding place of death, the question of the kinds and availability of palliative care services in prisons is clearly an important area for inmates and their families. Our data base search did not reveal this as an issue addressed by the Royal Commission Into Aboriginal Deaths In Custody (RCIADIC). Advice from Western Australia (AMS) was that if Aboriginal prisoners are diagnosed with a life limiting illness their sentence is usually commuted and they are released. This had not been confirmed.

### 5.5 Counselling and bereavement care

#### 5.5.1 Counselling and bereavement care as part of palliative care services

##### **Mainstream services**

Nearly every palliative care service includes some component of counselling and bereavement care. Counselling (for the patient or family members) may occur at any time from referral onwards and varies from informal counselling by nursing staff or trained volunteers, to formal referrals to counsellors and psychologists who may be part of the palliative care team or may be an ancillary service.

Bereavement services range from those which conduct formal risk analysis followed by tailored referrals to counsellors where necessary, to fairly uniform systems of follow-up including phone calls and cards. A typical bereavement process will include a phone call a week after the funeral (usually by the team member who has had most to do with the family) and then another phone call at about six weeks. These phone calls usually offer the option for additional counselling if requested. Some programs also follow up at three and six months with phone calls, and many palliative care services hold six monthly or annual memorial services to which families are invited. Some palliative care services send a card at the first anniversary of the death.

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<sup>9</sup> They do not necessarily regard themselves as homeless but do not live in a conventional house and may choose to reside in a city park.

Much informal counselling is provided by trained volunteers or nurses who offer 'a listening ear'. These workers may do no more than chat with patients or family members or provide a break for them. None of the volunteer programs had attempted to recruit Aboriginal or Torres Strait Islander members. Aboriginal health workers and Aboriginal or Torres Strait Islander HACC workers provide a similar service to Aboriginal and Torres Strait Islander clients but this is usually informal and not coordinated with palliative care services.

Most palliative care services do not ask about the Indigenous status of the family of patients although some services are now formally admitting family members as clients and would then ask the question of them.

Many palliative care services are moving away from a standard bereavement counselling model (for example, programmed phone calls and cards) to conducting individual risk assessment followed by more tailored approaches where needed. The following example, drafted by the Mid North Coast Palliative Care Service in New South Wales (apparently based on the work of Mal McKissock<sup>10</sup>) identifies the following risk categories:

- death of a child;
- sudden death;
- trauma;
- ambivalence in the relationship;
- pre-existing psychopathology (including unresolved losses, alcohol and drug dependence, history of depression, personality disorder);
- concurrent crisis;
- centrality;
- perceived preventability;
- decreased (or lack of) role diversity;
- decreased (or absence of) social support;
- lack of reality; and
- overly prolonged dying.

#### **Aboriginal and Torres Strait Islander bereavement services**

Most AMSs do not have any formal process for managing bereavement, though some provide assistance with funerals or provide advocacy roles in dealing with issues surrounding death (such as making claims from Centrelink). Aboriginal health workers often provide informal and unpaid counselling which involves being available to talk with a family.

*Mainstream counsellors tend to avoid Aboriginal clients and put it on untrained Aboriginal workers. There is a need to recognise the role of Aboriginal health workers in providing counselling. Training for health workers needs to be hands on – on the job. Aboriginal health workers and Aboriginal liaison staff carry a large burden – providing informal counselling and support with no training, support, or debriefing. [AMS health worker, South Australia]*

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<sup>10</sup> see for example Mc Kissock, D. and M. Mc Kissock (1998). *Bereavement Counseling, Guidelines for Practitioners*, Bereavement C.A.R.E. Centre, Terrigal NSW.

There are few Indigenous-specific counselling services in existence, although there are some emotional and social well-being services associated with AMSs. Where these exist, community members we interviewed identified problems in using these services for bereavement counselling:

- The emphasis of these services tends to be on family (violence) counselling or substance misuse;
- Many of the staff in these centres are not qualified counsellors or are not qualified in grief and loss counselling; and
- There are perceived issues of confidentiality, especially where these services are housed in a general health clinic where *'everyone knows your business'*.

Most people we spoke with, including AMS staff, did not associate these services with bereavement counselling.

This study did not focus on emotional and social well-being services, although we spoke with some staff from these centres. Several of the AMSs we visited indicated problems with recruiting and retaining qualified staff. It was clear that the issues that are the focus of emotional and social well-being services are very difficult areas, and AMSs face difficulties in keeping up with the demand for trained counsellors and other appropriate services. Although grief and loss is acknowledged as a common underlying issue, most people who use emotional and social well being services present with drug and alcohol or family violence issues as the more immediate problems.

There are some exceptions to this. Wuchopperan Aboriginal Medical Centre in Cairns is said to provide clinical, cultural and carer support to palliative care clients as well as bereavement and grief counselling through their Social Health team.

Two projects have been funded recently to look specifically at Aboriginal grief and loss issues: one in Victoria, managed by VACCHO; and one in New South Wales, managed by New England Community Health. Both projects are in their early stages and have not yet generated publicly available information.

### 5.5.2 Aboriginal and Torres Strait Islander people's use of and need for bereavement services

*When we grieve extended family comes together – talking, laughing, crying. It is important for people to have the option – a lot of us don't look for someone else. We deal with it in our own way. I wouldn't go to a counsellor.* [community member, Queensland]

*Murris like to talk and laugh!*

The indications from our data are that Aboriginal and Torres Strait Islander people do not take advantage of counselling, even where these are offered as part of the palliative care bereavement service. Several reasons were offered for this, the most common being

*It [counselling] is not the Aboriginal way. The family deals with it.*

Most people we spoke with said they would not use the local AMS emotional and social well-being service for grief and loss counselling. They thought that these services were not resourced to provide an adequate professional grief and loss service. Many also identified a number of difficulties in maintaining privacy in small communities that pose significant barriers to providing a confidential service. The privacy issue is compounded by the fact that many people felt that there was stigma attached to going to a counsellor for many community members. As one person interviewed put it,

*You only go to the counsellor if you are mad or bad.*

AMS staff we spoke with confirmed that there was a perception that emotional and social well being services had a stigma attached and that there was a need to change community attitudes to mental health problems, including grief and loss.

A significant number of Aboriginal people we interviewed said that they thought that there should be trained and qualified Aboriginal and Torres Strait Islander grief and loss counsellors available. Some thought these should possibly be separate from the AMS. Some mainstream service providers we interviewed also indicated that at the request of Aboriginal and/or Torres Strait Islander clients, they had made successful referrals to mainstream counsellors where there was a special need. They had had considerable difficulties finding appropriate counsellors in the absence of Aboriginal or Torres Strait Islander specific counselling services.<sup>11</sup>

In the absence of trained bereavement counsellors, many AHWs are put in the position of providing counselling and support services for which they have no training. This is true even for palliative care services which do not employ Aboriginal workers. For example, one north Queensland palliative care service involves an AHW from the local Community Health Centre in the care of their Aboriginal and/or Torres Strait Islander clients, including a 27 year old Indigenous woman client with two young daughters who presented with advanced symptoms of cancer. She received counselling from an AHW soon after presentation, and this has been ongoing.

### **The burden of grief for bereaved Aboriginal and Torres Strait Islander clients**

What is noticeable about the risk assessment model described earlier in this chapter is the likelihood that nearly any Aboriginal or Torres Strait Islander client would be assessed as high risk because of a burden of unresolved losses, current crisis and other risk factors. Unresolved losses are likely to include not only other recent deaths in the family but other unresolved losses stemming from invasion and stolen generation issues<sup>12</sup>. This underlines the need for action to provide better services for Aboriginal and Torres Strait Islander clients.

*Close relatives and parents pass away and there is no opportunity to deal with it before someone else passes away and there are so many unanswered questions.* [community member, Western Australia]

*Drink, depression, low self esteem follow from the constant death rates. Unresolved grief underlies many of the health issues. This is especially so for depression and psychotic illnesses which result from marijuana use which results from unresolved grief.* [AMS doctor, Western Australia]

*Grief and loss counselling is needed where there are multiple bereavements, no jobs and no self esteem – leads to anger and frustration and to drink and drugs.* [AHW]

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<sup>11</sup> The only Indigenous services we identified (part from those associated with AMSs) were Galang Place in Brisbane, Rosemary Wanganeen's *The Sacred Site Within Healing Centre* in Adelaide and a centre called Yorgum in Perth. Galang Place has qualified staff but does not focus on bereavement care.

<sup>12</sup> A number of grief and loss programs which have been developed incorporate these sorts of losses, including loss of cultural identity, into their programs, eg Rumbalara Medical Service in Victoria list seven stages of grief (The Dreaming, Invasion, Genocide, Protection, Assimilation, Self-determination and Reconciliation); see also processes used by Rosemary Wanganeen (Wanganeen, R. 'Self Healing and Spiritual Reconnection' *Aboriginal and Islander Health Worker Journal* 18(2).)

A counsellor working with Aboriginal clients said:

*No clients don't have grief issues. All the clients we see have an unresolved burden of grief. This comes from recent deaths, from traumatic deaths, from loss and abandonment and from grief of loss of culture and identity. Other people give great support at the time of death but it is 'closed down grief'. [counsellor, Western Australia]*

Because of this there is not only a need for trained Aboriginal counsellors but also a need for research aimed at developing effective treatment programs for Aboriginal clients.

### 5.5.3 How Aboriginal and Torres Strait Islander peoples deal with grief<sup>13</sup>

Most people we spoke with believed that the family would provide support and that funerals were an integral part of the grieving process.

*People are very open about grief – they try to share and support one another. We prefer to see people turn up [to funerals] and we like flowers and all of that.” The group believed that the family would provide support. [field notes, community discussion, Western Australia]*

The importance of family being present and involved before and after death and at the funeral was stressed over and over again, although we recognised a number of significant regional cultural differences in the way this was done.

#### Immediately before death

In the south of South Australia and Western Australia and on the east coast of Australia, community members spoke of how important it was for family to visit the dying person. We were told that hospitals did not cope well with the number of visitors at this time. Similarly, we were told of situations where nurses attending a patient at home had complained about the number of people present. One community member told of a situation where there were many people visiting a person who was dying:

*They were there to honour the dying person. The nurse came in and said that there were too many people in the room. She was speaking down to them. She did not understand the cultural importance of the visitors or why they were there. [community member, Western Australia]*

Aboriginal people who had used hospices were generally more satisfied with their arrangements, as hospices were often able to accommodate larger numbers of visitors (see Section 5.4 Setting of care). We were told that being able to be with the dying person is important to Aboriginal people in dealing with grief, and so it is important that the dying person is in their own country (see further Section 5.3 Place of Death ).

#### Upon death

Cultural patterns vary across the country. On the east coast of Australia and in the south of South Australia and Western Australia, Aboriginal people said it was important for all family members to be able to visit the deceased person, preferably at the same time so they can talk with each other. This has important implications for the design and management of hospital facilities, and for rules about being able to keep a body at home for a time if this is what the family wants.

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<sup>13</sup> This project did not undertake an in-depth study of grief amongst Indigenous peoples. It sought to explore with participants what their experience had been and if (and how) they thought services could be improved to assist.

In other places, or for families from more traditional areas who may be in Perth or Adelaide, the situation is often different and people will have particular needs related to cultural practices associated with death.

*A lady from a remote area died in a Perth hospital. The family members had come to Perth to be with her. The Aboriginal staff from the Aboriginal medical service told the ward staff when she was near death that they should remove solid, moveable objects from the room before she died. They ignored the advice. When she died the waiting relatives began wailing and started hitting themselves with all sorts of dangerous objects that were in the room. The staff had not listened, had not removed the objects and had not found a better room for the lady where the family could be with her safely. [Aboriginal health professional]*

In contrast, a senior Aboriginal health worker in Adelaide explained:

*Some more traditional families cannot stay nearby when a baby dies in hospital for fear that the spirit of the dying child could go into them. So they may leave the child to die in the hospital.*

In some areas of the Northern Territory, South Australia and Western Australia, the bereaved gather in 'sorry camp' upon the death of a community member. 'Sorry camps' usually last for some weeks, from time of death until after the interment. The size of these camps, and the length of time people spend in them may depend on a number of factors, including the age of the deceased, and their standing in the community. The appropriate role of service providers in supporting people in these situations includes assisting with transport, ensuring that those in the camp have adequate food, water and firewood, and providing the medication or medical care the visitors or the bereaved family require.

## Funerals

Funerals (and tombstone openings<sup>14</sup>) are critical to Aboriginal and Torres Strait Islander peoples' bereavement process, and remain among the most clearly delineated and elaborated elements of contemporary Indigenous cultures, even in areas where other ceremonial life has declined since colonisation. From the perspective of bereavement care, they are an important opportunity for the expression of grief, for the public acknowledgment of grief and for being comforted.

Christian (or Moslem) funerals with hymns and flowers are common, often with Aboriginal or Torres Strait Islander flags, and sometimes incorporating smoking ceremonies. These are critical cultural rituals. In some places people have traditional ceremonies as well as Christian burials. Most Aboriginal and Torres Strait Islander people we spoke with told us how important funerals are, and about the increasing difficulties people have in arranging and attending them. Funerals provide an opportunity to renew family and community relationships, and to share grief with family and community members. For immediate family, the funeral preparation is a vital part of the grieving process, providing rich and valuable opportunities for people to express and deal with grief.

In many places funerals are usually followed by gatherings which are often held in a local community or cultural centre. In most areas of Australia these gatherings also follow well defined cultural protocols.

The support offered by some AMSs to the funeral process is a valid and appropriate provision of bereavement support. At one AMS we visited, AHWs work with the bereaved to assist with practical issues (funding and pension payment issues), facilitate preparation of the 'order of service' and the

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<sup>14</sup> for Torres Strait Islander peoples.



eulogies, and liaise with the undertaker or funeral parlour. This very hands-on and practical approach is not only appreciated by the bereaved, it provides opportunities for the AHW to provide informal grief counselling. By being there to talk with family members about the deceased person and about the funeral, they provide a highly culturally appropriate bereavement service. Funerals are not only important to the immediate family but to the whole community. Funerals are central to Aboriginal and Torres Strait Islander grieving and this is reflected in the amount of time people spent telling us about their difficulties in arranging funerals. Section 5.5.8 below outlines some of the difficulties that were reported. The work of AMS staff in assisting with funerals should be a legitimate palliative care expense if staff members have appropriate training to augment their grief counselling capacity.

### After the funeral

There was little comment about what happens after the funeral. Most people apparently cope by talking with family. Several people who had been involved with palliative care services said that they had received follow up phone calls offering support in future if required, but though they felt they needed some help they would not ask for it and would certainly not phone for help. Some would have liked a visit.

Community members in Perth thought that some people might like to go to a bereavement counsellor and others might not. There was agreement that some people don't think they need counselling when they probably should have it. More important for Aboriginal people was *'talking time and sorry time and taking time to yarn'*.

An elderly man in South Australia spoke of his devastation after his wife's death. *'Everything was busy 'til the funeral and then there was nothing'* – he was left alone. We were told that in urban areas until recent times the family would provide support, setting up an informal roster of people to be with the bereaved. However this is not happening now that most people have to work and people live further apart and don't have transport. This illustrates the importance of peer support networks and mechanisms (especially for men) as an alternative to professional counsellors.

Some Aboriginal health workers take on an informal unpaid role, visiting and chatting with people. This is as important after the funeral as it is in the early stages of the illness.

The people we spoke with in focus groups very much valued the opportunity to talk to us about their experience. Some people especially thanked us for providing the opportunity for them to speak with others who had been through similar experiences.

## 5.5.4 What Aboriginal and Torres Strait Islander people said they wanted

### Early counselling

In general, Aboriginal and Torres Strait Islander people who had experience of looking after a family member with a life limiting illness said that there should be more emphasis on early counselling, accompanied by better information about the likely course of the illness and what to expect. This early counselling should be undertaken with the assistance of an appropriate Aboriginal or Torres Strait Islander community member, and should ideally be done in several sessions so that people have time to absorb information and to develop trust and a relationship.

*There is a lot of grief and sorrow. People try to cope within their own family structure but they can't really address the needs of the person. This is partly because they are not given the*

*information and counselling that they need. They need counselling so that they can handle the situation and go out and get the services that they need. [South Australia]*

The need for early counselling of patient and family was identified by community members in rural and remote Western Australia. This was specifically identified as a need where the diagnosis is done in Perth (away from home).

*People are told straight out, and cold hard facts – not told in a supported way. Family is not even there and there is no opportunity to ask the questions that they should ask. They might be offered treatment – might go through all that before they get to talk with any family members. [Western Australia]*

Early counselling was also raised by informants on the east coast.

### **Trained Aboriginal and Torres Strait Islander counsellors**

There is a need for Aboriginal and Torres Strait Islander palliative care workers to provide support – ‘someone to talk to’. An Aboriginal doctor in Queensland said:

*Being Aboriginal is a benefit – having an Indigenous team, people actually seek to see you. Sometimes they would rather talk to me than a white counsellor in the Centre. Sometimes people don’t get the picture straight up – initially they say they are okay and you see down the track they are not all right.*

Clinical staff in one remote community in central Australia reported that last year people spent most of their time attending funerals and this was an ‘enormous part of local culture’.

*People are just dying and grief issues are not being dealt with. It does affect families. We need mental health workers who speak [one major regional] language. We are now seeing people with psychosomatic illness – bizarre behaviour – and a number of women needing medication. We don’t have the resources to sit down with people. There is much confusion between traditional beliefs and Christianity. If professionals have no language skills it is very difficult to communicate. There is only so much support you can give.*

The remote mental health nurse in this community is sometimes accompanied by a male and female worker. Clinic staff commented that counselling is a highly specialised area and language is a huge issue.

*Grief and dealing with death and change – transition between traditional and Western culture – is a huge issue. Counsellors need to have local language skills and be living outside the community so they don’t become overwhelmed by community issues.*

### **Support for cultural protocols**

Palliative care workers in the Northern Territory said the most important cultural issues around death and dying for Aboriginal people are family, country and law. These are entwined with protocols (social rules, ceremonies) that are required when someone is sick, dying, or deceased. Supporting these cultural protocols is important for families to assist in meeting their grief and bereavement needs.

Cultural protocols can be very complex in some remote areas or more simple, as in some urban areas. Whether complex or simple, they should be identified and supported by palliative care service providers, preferably with guidance from a local Aboriginal and/or Torres Strait Islander person as cultural broker. Arranging and attending funerals should be seen as a critical cultural issue and palliative care service providers should play an advocacy or facilitating role where needed (see below Section 5.6).

In the Northern Territory, ‘sorry business’ is considered an important time for dealing with bereavement issues. One Aboriginal service has flexible conditions written into its employment award in recognition of the cultural responsibilities of its staff members and to enable them to attend to such responsibilities during this time.

The high number of deaths in some communities and the cultural responsibilities associated with ‘sorry business’ can give rise to complex management issues for Aboriginal service provider organisations. In some Aboriginal organisations this is partly overcome by employing non-Aboriginal staff. One organisation told us that it recruited/employed staff from different family groups to ensure there would always be Aboriginal and/or Torres Strait Islander staff on duty.

A major Aboriginal organisation said that the whole organisation will shut down in circumstances where a person who is very important in the community has died.

### 5.5.5 Barriers to delivering bereavement services to Aboriginal and

#### Torres Strait Islander clients

As well as the complex cultural issues involved in bereavement for Aboriginal and Torres Strait Islander people and the lack of appropriate services there are some particular barriers to effective service delivery for mainstream service providers:

- the short periods of time spent with Aboriginal clients due to late referral means that ongoing rapport is not established; and
- relocation immediately after death means that follow up is not possible. In some areas people must move house for cultural reasons and may not be easily traceable by service providers;

Most mainstream bereavement services would not be aware of the underlying mental health issues affecting Aboriginal and/or Torres Strait Islander clients.

### 5.5.6 Innovations and/or good practice in bereavement services

This section highlights the few examples of ‘good practice’ in this area that were reported.

A Victorian palliative care team has recommended that bereavement plans be prepared in discussion with the local AMS to ensure that culturally sensitive options are available and used.

The palliative care team in a New South Wales rural town suggests working with the community to develop appropriate bereavement strategies for Aboriginal family members in order to offer appropriate support. They suggest that the support is best offered to an identified family or community member who provides support to the bereaved, hence ‘supporting the supporter’, rather than attempting to directly support the bereaved.

*Check that there is a community member supporting the bereaved and then support the supporter, especially at the six week mark. [palliative care service provider]*

A service in Adelaide uses group counselling where indicated. Counselling is offered on an individual, family or group basis, including groups for widows and widowers, children, and daughters or sons; and groups are sometimes offered for various adult age ranges. There have been no Aboriginal and Torres Strait Islander groups, but community members thought that would be a good idea.

Aboriginal staff in a number of Aboriginal services in South Australia thought there should also be more and better access to traditional healers who may assist with bereavement.

In a remote area of Western Australia, a Community Health representative who was involved in a recent study of Aboriginal people's health needs reported that people did not want the mental health team to visit because of the social stigma attached to mental health. She said people said they wanted grief counsellors who would sit under a tree where people could go and talk to them.

A Community Health coordinator who had been involved in a recent study in the [remote region] commented that during her discussions with Aboriginal people she was told that counsellors should be from outside the community to ensure confidentiality. An Aboriginal woman also said she would prefer counsellors to be 'kartiya' [non-Aboriginal] for the same reason.

The offer of a palliative care nurse in a remote community in Queensland, to assist with the funeral arrangements was very much appreciated by the community member concerned. The nurse stated that it was '*just the way we do it in New Zealand*'. In some places it may be appropriate for palliative care services to offer this sort of assistance to Aboriginal and/or Torres Strait Islander clients as an effective way to provide bereavement care.

An AMS doctor in Western Australia said he believed it was very unlikely that people would take up the offer of formal bereavement counselling (no matter who offered it) and so suggested that bereavement counselling be linked to the practicalities of preparing for the funeral.

Some AMSs assist bereaved families to prepare an 'order of service' and eulogy booklet. This work has had good results but is currently unfunded.

The approach taken by AMSs in assisting with funeral arrangements could be developed and supported by augmenting the skills of staff in bereavement counselling and risk identification, and ensuring that there are adequate staff hours to undertake this work. There is a need for trained staff and funding for bereavement care as an essential element of palliative care.

Strategies for delivering bereavement counselling in a practical and culturally appropriate way should be explored.

#### 5.5.7 Special needs of Aboriginal and Torres Strait Islander health professionals

*When there is a death here in the hospital staff experience silent grief because everyone here is related. We empathise with them. There is no counselling for us. We talk to each other. We also visit the family, share stories and unwind with them. The main thing is to empathise – people don't want sympathy – with sympathy you never find the right words.* [Torres Strait Islander nurse]

A major issue for Aboriginal and Torres Strait Islander people working in the health system (and in palliative care in particular) is that when a member of the Aboriginal or Torres Strait Islander community dies, they are not only a health professional associated with the event but also (usually) one of the bereaved. Whether as a member of the same extended family or as a member of the local community, they will have been in some way related to the deceased person.

These staff members (AHWs, ALOs, Aboriginal counsellors and nurses) also need appropriate debriefing and counselling.

### 5.5.8 Issues and problems reported in relation to funerals

The importance of funerals and their role in the grieving process is described above in Section 5.5.3 *Funerals*<sup>15</sup>. Many people raised issues regarding funerals, including the cost of funerals, difficulties in attending funerals (cost and transport), and transport of the deceased to the appropriate place of burial.

#### **Cost of funerals**

The cost of funerals was seen as a major financial burden, with families often having to go into debt to pay for funerals or tombstone openings. Although many people contribute to various types of funeral funds, there has been a lot of disgruntlement about these funds and uncertainty about what they provide for the money paid.

In remote Western Australia, the cost and the high number of funerals in some remote communities can place a huge financial burden on some families and on the communities. Some cannot afford the cost of the funeral and a body may remain in the morgue for several months until the money is found. In other cases it was reported the community sometimes picks up the cost of chartering a plane and recoups the cost from the family over time.

Funerals are often paid for by pooling family resources ('chuck in') or through a community funeral account.

There was a lot of discussion about the various funeral funds and what they pay for. Some people suggested that there be an enquiry into funeral funds because many people thought that they were being 'ripped off', or being made promises when they signed up only to find out later that what they had been told about entitlements was not correct.

Funerals are so important to Aboriginal and Torres Strait Islander people that they will generally pay what is asked without much question. In Queensland many people contribute \$2-\$3 each week to a funeral fund by direct deduction from their CDEP pay.

Many people reported that notwithstanding costs, they found local undertakers or funeral parlours to be very sensitive to Aboriginal and/or Torres Strait Islander cultural needs, including accommodating special cultural requests.

#### **Accessing funding**

Some special funding assistance for funerals is available but many people reported difficulty accessing these funds.

In South Australia it was reported that assistance is provided by Centrelink or by Family and Youth Services (FAYS), although FAYS funds are not available if even one person in the family is employed. (For example four out of five members of a family may be on a pension, but if the fifth is working they would not receive assistance.) We were told of a 90 year old woman who had to pay for her son's funeral because she had more than \$3000 in the bank – her life's savings.

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<sup>15</sup> and tombstone openings for Torres Strait Islanders.

The following comments were made in Western Australia:

*We need a social worker after the death to help with all the arrangements – prepare eulogy and everything. I needed support to declare my mother dead and all of that – needed to have help in arranging money from Centrelink. [community member]*

*Centrelink will try to talk a family out of the bereavement package (equal to 3 payments of allowance) – so you need to make sure you send the right person. Centrelink and Family Services will try to knock people back in claiming what they should be able to claim. It depends on which worker you get at Family Services. The AMS provides an advocacy service in dealing with this. [AHW]*

### **Timing of funerals**

Funerals often have to be delayed until people can afford to attend. This may have further cost implications for the family as the body must be stored during that time.

### **Attending funerals – travel**

A common complaint was the difficulty of finding transport to attend funerals. In more remote areas people sometimes had to charter flights and were then left with large debts, or were left stranded in communities after the funeral. Similarly, transport to attend funerals was often an issue in urban and rural communities. In South Australia, Victoria and the Northern Territory we were told that community organisations which in the past had permitted their buses to be used for funerals would now no longer do so. It is not clear why this change has come about, but it may be an insurance issue.

*Problem of getting people to funerals – can't use community buses any more and people don't have cars. Funding bodies (eg HACC bus) have now said can't use buses for funerals. Community is very critical about this.*

*If people can't get to funerals then it mucks up the healing process for those who are left behind. [South Australia]*

In the Northern Territory lack of transport was a major problem, especially now that it is no longer possible to borrow vehicles from Aboriginal organisations to attend funerals. This can have serious implications for family members who are unable to meet their responsibilities.

*Organisations will not loan vehicles even for funerals – not allowed to use bus. Before we used to 'throw in' money for fuel to go to funerals.*

*Most families here are on a pension. When some family members go to a funeral and others can't because they don't have transport or can't afford to travel, this can cause troubles within the family.*

In some parts of New South Wales on the other hand, we were told that Community Options Transport was available for local funerals for a gold coin donation. Travel from rural areas to Sydney (and vice versa) for funerals was, however, a major problem.

### Cost of attending funerals

Many people reported having to wait until pension day to travel to a funeral (and to buy good clothes and flowers) and having to wait in the community where the funeral was held until the next pension day to get home. This was a further financial burden on them and the community, and they often had nowhere to stay and no food.

*One of the biggest issues for people around funerals is resources to travel to funerals and then somewhere for the family to stay when they arrive. Often people come back to the area for funerals but have to wait two weeks for their next pension cheque before they can travel home again and they have nowhere to stay. [AHW]*

Some community organisations in central Australia provide food and blankets for funerals.

### Storage and repatriation of deceased

#### *Repatriation*

Health systems in all states and territories increasingly recognise the importance of assisting people to get home to country to die, (Williamson 1996; Willis 1999) however if this does not happen, bodies need to be returned to the right place. An AHW in New South Wales said '*Where a person is buried is almost more important than where they die.*'

Transport of bodies for burial can be costly. If the person died in hospital, PATS (Patient Assisted Travel Scheme) assistance is generally available.

In South Australia there have been problems with deaths of Aboriginal people from interstate. It takes time to locate the family and there is no funding to get the body home across state boundaries (eg to Queensland).

In Victoria, the Victorian Advancement League provides a service transporting bodies home for burial and operates across State boundaries. This service was spoken of very highly.

In New South Wales the State government has provided funds to the Mt Druitt AMS to assist with transport of the deceased. This funding covers the vehicle and petrol but not the driver.

The AMS in Kalgoorlie, Western Australia, has provided transport to retrieve bodies from Perth, but this had not been ideal as the vehicle was not refrigerated. The Western Australian government recently modified its rules so that the State government will now fund the repatriation of bodies (beyond 50 kilometres radius of Perth), provided the deceased has been in the care of a hospital.

In the Northern Territory, PATS covers repatriation costs if a client has been relocated to a larger centre for medical treatment and passes away.

#### *Storage*

Storage of bodies is a problem in remote areas where there are no morgue facilities. In the Northern Territory, local communities can hold a body only for a day or so before it must be flown out. It often takes longer to arrange the funeral (letting people know, time for people to travel to the community, decisions about where the person should be buried and time needed to get money together). This is also a problem on off shore islands.



*One problem might be that there is no place to store the body on the islands so the family or community has to pay for costs of transport. Sometimes the body is flown to other communities for viewing.*

In a remote area in Western Australia, health staff mentioned problems with an undertaker from [town] who got lost finding the community. As a result a body was left in the house for two days, which caused cultural problems. In one region bodies are retrieved from communities or remote areas by a contractor, and there were reports of 'rough handling'. There are no body storage facilities in the Aboriginal communities in the region. They either charter a plane for the undertaker to fly out and take the body back to town or he will drive out.

Delays in holding funerals can cause distress and additional cost. In a palliation situation where death is expected, some non-Indigenous care providers (in northern Western Australia and central Australia) have begun to discuss the benefits of holding a family discussion about the place of burial before the death occurs so that delays and extra costs can be avoided. There are clearly difficulties in raising these issues, given the restrictions on speaking about death amongst some Aboriginal and/or Torres Strait Islander peoples, however these services providers believe that attitudes are changing and the idea of having a 'living will' is something that some Aboriginal and/or Torres Strait Islander people might want to speak about.

## 5.6 Continuity of care: caring at home doesn't mean have to die at home

In the experience of one Northern Territory nurse, the delivery of palliative care has ranged over time from: a) managing people in the community; to b) managing people entirely in the hospital; to c) managing largely in the community up to pre-terminal days and then in hospital.

*I have come to doubt whether all people want to die at home. [Aboriginal people's] perspective is varied. It doesn't appear to be the same case for everybody. There are many and varied ways. [Aboriginal people] have different ways of coping. Whatever approach is adopted should be flexible. Often best-laid plans go astray. Caregivers in remote communities may change their minds and we need to accommodate their wishes. [remote clinic nurse]*

While many people say they want to look after people at home, in fact many Aboriginal people pass away in hospital. The reasons for this may be related to culture and/or capacity. These issues are discussed in Section 5.3 above.

Relationships between home-based care providers and hospitals or hospices are generally good, but Aboriginal workers including AHLOs, AMSs, and State and community Aboriginal and Torres Strait Islander health units are not in the loop (see further Chapter 8, Section 8.4.4 *Models of coordination*).

There are a number of continuity of care issues for clients returning to remote communities.

*Big issue for PC medical officers is how to manage patients in outlying centres. When patients return to their community local GP takes over and provides day-to-day management for these patients but there is still confusion about who is responsible. [field notes, Queensland]*

*One community member told us that her husband ended up dying in hospital which was not what they had planned. Her husband had been cared for at home for a long time, then things became bad and he went to the hospital because he needed additional medication in the middle of the night. Unfortunately, despite the fact that this person had been a long term*

*palliative care patient, he was taken to the emergency unit when he presented at the hospital – apparently there were no palliative care beds. He was treated inappropriately, with the emergency staff giving him blood transfusions and trying to ‘make him better’ rather than recognising that he was palliative and probably terminal.*

*All the good palliative care work of the previous months broke down because there was nothing organised at the hospital and so he was not received as a palliative and terminal patient but as an emergency case. He expressed a desire to go home but it was not possible to extricate him from the system. The emergency unit found a separate room for him but it was not in the palliative care unit. In a sense all the good work of the palliative care team at home was undone at the end because of lack of planning for the terminal stage and probably a lack of information and support at home at this crucial time. This was made worse by the fact that the patient was treated as an emergency patient rather than as in need of palliation.*

*His wife was very distressed at their losing control of the situation at the end.* [field notes, South Australia]

The director of a palliative care unit at a hospital said:

*You try to tell people what they should or can do when people are dying: ie that you don’t need to call the ambulance; that you don’t need to call the police etc, but people panic and call the ambulance. Things don’t always go according to plan.*

Palliative care patients at one hospital have an ‘alert’ in their case notes to direct them to palliative care if they are admitted to emergency, so palliative care staff in the hospital will be notified if a palliative care patient is brought in. This system doesn’t always work, however, especially if emergency is very busy.

It is critical that palliative care patients be identified if admitted through emergency units. Systems need to be clear so that palliative care patients do not receive inappropriate emergency treatment, for example, they should not be resuscitated if this is not their desire, or have other non-essential intrusive treatment. This issue is especially important for Aboriginal people who are often very daunted by hospital and medical personnel and procedures. In circumstances such as this they may need advocacy support to ensure that appropriate procedures are followed.

## 5.7 Pain management, medication and equipment

### 5.7.1 Pain management

An Indigenous doctor said that Aboriginal and Torres Strait Islander patients often do not let you know they are in pain:

*We try to make sure they are comfy but sometimes they don’t tell you that they are in pain all the time and it’s sometimes hard to work out – you can sort of work it out if they start to go through a bit of morphine and you say ‘well you must be in a bit of pain’. Sometimes they don’t tell you and you find out from a relative. Then I might talk to people at [the palliative care hospital] and say I think he has had a bit more pain and they get me to increase his medication.*

The director of a nursing home in Western Australia was very concerned about pain management for her Aboriginal clients. She said that Aboriginal people did not seem to experience pain in the same way as other people.

A recent publication explains that cultural differences may account for this. While Aboriginal people do experience pain, they may not complain about it or may behave in different ways from other cultural groups in coping with pain (Fenwick 2001).

### 5.7.2 Cost and perceived cost of medication

The cost of medication was said to be a problem for community members in all States and Territories we visited. Even where medication is on the 'free' list, dispensing charges were seen as a burden. Sometimes people would be prescribed 'second choice' drugs because they could not afford the most effective ones. It was reported that many community members would choose to spend money on other family needs before they would spend money on medications.

Palliative care workers need to check that the family can afford the medication prescribed or facilitate finding financial support for medication.

We were told by Aboriginal health workers that the fear of the cost of medication is probably one reason why Aboriginal people do not seek medical assistance. A palliative care service for Aboriginal and Torres Strait Islander people should include checking to see that medications prescribed will be available and accessible as a key feature. There may be an advocacy role for palliative care providers in relation to medication.

*Low levels of income amongst many Aboriginal families mean that these families cannot afford even basic things like fees for meals-on-wheels or the cost of having a prescription filled. Any money that is available goes into supporting the extended family rather than into medication, equipment costs or other service.* [Western Australia AMS staff member] Note: This person was under the impression that there was a fee for Silver Chain Palliative Care services.

### 5.7.3 Appropriateness of medication

#### Availability and suitability of prescription

A number of community members raised issues concerning availability of medication. Apparently medication may be prescribed which chemists do not necessarily have in stock (and cannot get without notice). It was suggested that palliative care workers could facilitate access to medication by checking with local chemists about availability and by advising carers to phone the chemist in advance to order stock.

*A patient returning from Adelaide was seen getting off a bus in his country town. He had been prescribed Ketamine and Fentanyl via subcutaneous pump. No pharmacy in his home town was able to fill his script.* [reported by a doctor in South Australia]

If the client is returning to a remote or regional centre, it is critical that availability of medication be checked and arrangements made for its supply, or a more appropriate medication arranged.

High mobility affects access to medication. *‘Often when people go to visit family in other communities they take nothing with them, including their medications.’* [Queensland]

We received some reports of some forms of medication being withheld from Aboriginal clients because of perceived safety issues in Aboriginal households. The rules about the administration of drugs should be explained carefully to clients and all the possible options should be explored, not just what can’t be done, but how it could be made to work in the particular situation.

#### 5.7.4 Inappropriate drugs and inadequate monitoring

In some places in the Northern Territory local doctors’ attitudes to pain management and reluctance to use morphine because of legal implications has meant that the palliative care workers have had to ask the palliative care medical officer from a nearby centre to intervene on behalf of clients.

In New South Wales palliative care service providers and nursing home directors reported prescription of inappropriate drugs for terminally ill patients – *‘not the best possible choice being made’* – largely due to the inexperience of GPs.

There were many reports of undesirable effects of the use of MS Contin without adequate bowel care.

#### 5.7.5 Issues about Morphine

##### Fear and misunderstanding

In one rural area of New South Wales a community member explained that there was widespread fear of being given morphine close to the end of life because of a belief that it would hasten death. The common belief was *‘If you go into hospital they will give you the injection and you will die’*. An AMS doctor said that many local Aboriginal people had a great fear of needles generally.

An ALO in Brisbane said she felt for families because a lot of time they have to deliver the morphine and this is very stressful for the daughter/wife/family.

*They [health professionals] come and leave the stuff but you are left to administer the stuff and it’s very hard. Lot of times they are not giving them the full dose because they are too frightened. He’s in pain – just give a little to ease a little bit – not going to give the full dose because that’s going to kill him.*

This ALO also talked about the fear patients have of receiving morphine and was present when a patient who was about to be given morphine said:

*My aunty had morphine and she died so what are you trying to do to me, are you trying to get rid of me?*

She said Indigenous people often do not understand about drugs or palliative care:

*A lot of our Indigenous community don’t understand about drugs – the palliative care side of things. My husband went in for an operation and they were going to give him morphine and he was so worried. He knew his brother had had it, his mother had had it and they both passed away. He freaked out.*

Staff from one palliative care service emphasised how important trust was in the administration of medication. In relation to morphine there was a need for accurate information and there were many myths about morphine which should be dispelled.

In Queensland people spoke a lot about their fear of morphine. One woman told a story of her husband who was dying of cancer:

*He had come home to the local hospital and he sat on the veranda for 2 days and nights receiving visitors and the nursing staff had to try and get him to rest. On the third day he was exhausted. At the end they called the family together and asked about giving him some additional morphine to help with his breathing which had become very shallow. We were informed that his heart was under a lot of strain. He passed away shortly afterwards. That was such a shock and it took my daughter and me a long time to get over it. My daughter felt so guilty – she felt she was part of a decision which killed him. She eventually dealt with this through talking to family and friends. [Queensland regional area 3]*

and:

*When my sister in law was dying of cancer she said she didn't want an extra shot of morphine at the end – she wanted to die naturally. She did but she was fighting hard for her breath right to the last. [Queensland regional area 3]*

*People who go on to morphine die more quickly – without morphine have more days.*

*For many people when they hear the word 'morphine' that means death. It is the last option and they don't want their relative to go on morphine. When they see it going in [being administered] they know they are going to 'go'. It is the end and they are definitely going to die.*

Misunderstandings of and fear about morphine have led to the production of a useful resource in Queensland, *Understanding Morphine*<sup>16</sup> which was compiled by Mount Isa District Palliative Care Service to answer patients' and carers' questions about pain relief in plain language.

### **Access, safety and security**

We were told stories of patients having to receive care in hospital because the service providers would not prescribe drugs for administration at home because of lack of safety and security.

In remote areas, the major issue raised about morphine was the difficulty of access to it and appropriate storage facilities.

### **Administration of morphine in aged care and nursing homes**

In several States, aged care and nursing home facilities reported difficulties in being able to provide adequate palliative care because of rules about the administration of dangerous drugs. The requirement for two registered nurses to be present (when the home was not funded for this) meant that the client had to relocate to a high care facility or to a private home. In some States, palliative care services can and do consult into aged care facilities, however there are sometimes difficulties in palliative care nurses (eg domiciliary nurses) going in to provide medication because of funding issues and drugs administration

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<sup>16</sup> Available from Mount Isa District Palliative Care Service (07) 4744 4828 or Queensland Cancer Fund (07) 3258 2200, it is beautifully illustrated by local Aboriginal artists Harry and Shannon Gertz, and is 'user-friendly' for Aboriginal patients and their families.

rules. Funding rules and drug administration rules need to be modified so that residents of aged care facilities and nursing homes can receive the best possible palliative care (including appropriate pain management and cultural security) in their place of residence.

#### 5.7.6 Equipment

The major issue relating to equipment was that Aboriginal and Torres Strait Islander people looking after terminally ill relatives at home did not have information about what equipment would help them or how to access it. This was especially the case where they had not had the support of palliative care workers. Even where families were receiving palliative care services, access to equipment was sometimes a problem and people had to try to source it themselves.

One of the issues raised was that some service providers were concerned about the eventual return of the equipment because of the mobility of Aboriginal and Torres Strait Islander people or the condition of their houses. Sometimes the housing did not lend itself to accommodating appropriate equipment such as hospital beds. Spaces were too small, for example. Many community members who had been provided with equipment such as proper beds or bedding, lifters, wheelchairs, etc, said it was one of the good things about palliative care and made a big difference.

In New South Wales, service providers also reported that access to, storage of, and transport of equipment was a problem. There are often waiting lists for items such as oxygen concentrators and generally funding is not available for transporting equipment. In the Northern Territory, service providers said that they often did not expect to get equipment back. (For example, especially in remote communities, all resources are valuable and maximum use is made of them. For old people, wheelchairs are valuable for other practical purposes such as to collect firewood). In the Northern Territory the cost of delivering an oxygen concentrator to a remote community was about \$400. Detailed and well coordinated discharge planning could reduce these costs by ensuring that equipment is transported on the same plane as the patient.

In the Northern Territory, a palliative care team has experienced problems of clients running out of medications because they had not understood about getting repeat prescriptions. A number of AMS services dispense medication in order to avoid some of these problems.

In one regional area of Queensland an ALO said:

*Medical aids are a big problem with our Indigenous people here. We have Community Health – we can plug into their resources – and there is a MAS (Medical Aids Scheme) program where you can purchase stuff, but the process takes too long for people to access the medical aids. Wheelchairs – there is often a shortage for mainstream as well. People sometimes die before we can get the equipment. [hospital ALO]*

#### 5.7.7 Equipment infrastructure costs

Many people raised the issue of hidden costs in palliative care such as the cost of increased gas or power consumption for heating or running equipment. Some people said that they were still paying off their energy bills two years after the death of a family member.

## 5.8 Service provider access to palliative care specialists

*The palliative care worker estimated 99% of palliative care work is counselling talking, educating – bringing everyone together [Western Australia rural area]*

Good palliative care is a well coordinated service, where someone (such as a GP or AMS doctor, a palliative care service or a family member) brings together all the various elements necessary to deliver appropriate care (for example, symptom management specialists, ancillary services such as physiotherapists, equipment providers, home help, cultural interpreters and grief and loss support).

### 5.8.1 Symptom management advice

Access to all of these elements is important but for symptom management, specialist advice can be critical. This need has been recognised and many services are set up to access specialist doctors or nurses. In many places, palliative care advice lines have been set up for doctors and/or nurses, however these are not always well known and are often not used by GPs and AMS doctors. Advice lines and personal networks are especially valuable to nurses working in relative isolation in remote communities or small towns. Where specialist doctors are not available in a region and no advice line exists, local palliative care nursing staff will call a big city hospital for advice. Many have developed their own advice networks. Palliative care providers state, however, that GPs who do not recognise that they need advice are the problem – not the lack of advice opportunities.

In Adelaide, an innovative system of outreach has been developed in which doctors from Adelaide palliative care units perform outreach visits to various parts of the State (certain city hospitals deal with certain parts of the state). To an outsider there appears little logic in the way the State is divided for this program. Specialists from Adelaide visit regional palliative care units and provide education programs and consulting advice. It appears, however, that only some palliative care staff are accessing the educational or consulting sessions. In one area where we conducted phone interviews, the community based unit was involved in the program but staff at the hospital (which had a palliative care bed) was not. The staff in the regions value this outreach greatly.

In remote communities in central Australia, clinic staff are only able to provide palliative care because they have phone access to the Territory Palliative Care Service whenever they need it.

### 5.8.2 After hours advice for clients

Client access to after hours palliative care advice varies enormously and service providers have identified this as a critical need. It is especially heartbreaking for family and service providers if the care and comfort provided by a palliative approach breaks down at the end because a crisis occurs at night or on a weekend when no staff are available to deal with it. Carers often panic and call an ambulance, and the client ends up in the hospital emergency unit, receiving inappropriate treatment.

After hours emergency numbers will only be useful to Aboriginal and Torres Strait Islander clients if they have a telephone. In urban areas many Aboriginal and Torres Strait Islander homes do not have phones. Consideration should be given to funding telephone access to service providers for palliative care clients in areas where this is possible. In remote areas, client access to specialist advice is even more difficult since telephones are even rarer and after hours emergency lines are unlikely to be available because of low staff levels.

Some implications of these findings are discussed in section 5.9.8.



## 5.9 Findings and implications

### 5.9.1 Expectations, attitudes and relationships

Past experience has a powerful impact on whether Aboriginal and Torres Strait Islander people will be willing to accept referrals to palliative care. Their underlying experience of and attitude towards the health system and towards non-Indigenous bureaucrats and service providers is a critical constraint on effective service delivery. In general, Aboriginal and Torres Strait Islander people strongly dislike, distrust and fear hospitals and non-Indigenous strangers coming to their homes.

Mainstream service providers should acknowledge these attitudes and the historical reasons for them. ACCHSs exist in order to overcome some of these difficulties and to allow community control of health service delivery. ACCHSs should be invited to become a central part of the specialist palliative care network and/or palliative care service providers should put their specialist skills at the disposal of these units, especially where they have mutual clients.

Service providers, in turn, hold attitudes which affect their behaviour towards Aboriginal and Torres Strait Islander clients. Many people who work in these fields have never met or spoken with an Aboriginal or Torres Strait Islander person and know little, or nothing, about Aboriginal and Torres Strait Islander health services. Unfortunately, many are perceived as highly judgmental by Aboriginal and Torres Strait Islander people. Most, for example, are unaware of complex family relationships or the group nature of many Aboriginal households and do not understand the implications of these when home visiting. Many would not feel comfortable in the conditions of many Aboriginal and Torres Strait Islander households. Concerns about hygiene and personal safety (both perceived and real) were reported. For their part, we were told that many Aboriginal and Torres Strait Islander people feel 'shame' when non-Indigenous strangers visit their home.

The attitudes and expectations of clients and service providers have very real significance for discharge planning and assessment and care planning. The importance of the referral process and the need for cultural advocacy at this time has been mentioned above. In hand with this is the need for the development of trust between clients and service providers. Development of trust requires the development of a relationship. In many cases, because of late referral there is not enough time for this relationship to develop.

Service providers working with Aboriginal and Torres Strait Islander clients should start to develop relationships with the community by beginning a dialogue with Aboriginal and community organisations (including health and home care providers). They need to establish their 'credentials' in the community. Being introduced or recommended by a community member is an almost essential first step to forming a relationship and is particularly critical where time is short.

Immediate action that service providers can take would be to initiate a local dialogue between mainstream and Indigenous service providers to find out what each does, what each has to offer and to work out how the gaps can be filled. The solutions should be developed in response to local circumstances and cultural needs. This action can be taken by individual service providers and/or Indigenous health services. It should be encouraged and supported by State governments and non-government bodies.

### 5.9.2 Discharge planning and assessment

There is a need to develop care pathways for palliative care clients which ensure consistent involvement of the palliative care team, a cultural advocate<sup>17</sup> (AHLO or AHW from AMS or Indigenous staff of the service providers) and appropriate family members in discharge planning.

A question about Indigenous status should be asked on admission as a palliative care client (with an explanation of why it is being asked). Assessment should not take place without the participation of appropriate Indigenous staff. Assessment processes should try to avoid a stream of individual service providers and may need to be done over several visits as relationships develop. The location of the assessment (including the place it is done in the home) and the language and listening skills used are crucial. Understanding the relationships of family members and realising that roles within the family may be culturally determined are also critical. The carer may not be the decision maker. Service providers should work with Indigenous staff and/or community advisers to develop effective assessment processes for their particular situation.

Service providers should ensure that they have ready access to, and funding for, a cultural specialist and should develop ongoing relationships with local Aboriginal and Torres Strait Islander health and community organisations.

National Palliative Care Strategy (NPCS) Goal 3 *Partnerships in care*, would be enhanced by an introductory objective about raising the profile of mainstream service providers in the Indigenous community, including naming specific individuals as contact people for Indigenous clients and services, so that relationships can be developed and so that people can get to first base in developing care planning (see further Chapter 10, Section 10.2.3).

### 5.9.3 Implications of place of death issues for service providers and policy makers

The implications of place of death issues discussed in Section 5.3 above are set out below.

#### **Early information, being prepared and making a choice**

The earlier clients and their families are informed of their condition (in a culturally supported way) and of the options and support services that are available, the better they are able to make an informed choice about where they want to pass away and to put in place the services that will achieve that. The fact that diagnosis and/or referrals to palliative care services are made very late reduces peoples' freedom of choice.

In remote areas, careful consideration should be given to whether to send someone away to the city or regional centre for treatment or diagnosis if there is a chance that they will not be able to get back in time. Better use of telemedicine may assist. Families should be involved in these choices.

#### **Better information**

People need and want better information about the likely progress of a disease, about the process of death and what to expect, about what can happen after death (length of time the deceased can be kept at home) and about the sorts of equipment, services and options that are available. Publications such as *Palliative Caring at Home*<sup>18</sup> should be reviewed and revised to meet the needs of Aboriginal and Torres Strait Islander people and should be made widely available through Aboriginal or Torres Strait Islander health services.

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<sup>17</sup> Unless this is expressly rejected.

<sup>18</sup> *Palliative Caring at Home* (WA), Palliative Care WA, Silver Chain and the Cancer Foundation of Western Australia.

### **Solutions for cultural dilemmas**

Solutions for cultural dilemmas in relation to place of death should be explored where necessary, for example:

- provision of a detached room (with visitors facilities) adjacent to the clinic in remote communities (see above);
- building of a 'care centre' separate from, but possibly adjacent to, a town hospital where family can come to be with a dying person; and
- provision of a suitable comfortable house made available for the duration of the palliation which would allow the family to care for the person and vacate the premises upon death.

### **Advocating on behalf of clients to get them home**

Some service providers do not do enough to help people get home. Palliative care service providers and Aboriginal medical services in cities should actively advocate on behalf of their clients to find a way for them to return home, rather than simply assuming that it isn't possible. Some clients would rather be at home with slightly less effective symptom management rather than away from home with more comfort.

### **Improvement of hospital and nursing home facilities**

Ensure provision of the following:

- separate rooms for the dying person which are large enough to accommodate family groups;
- rooms which are on the ground floor and have outside access;
- special, large family visiting rooms such as that at Goulburn Valley Base Hospital (see Appendix 9); and
- a large pleasant room where the deceased can be visited.

See further Section 5.4.3 Setting of care - care in hospital)

### **Tracking systems**

Development of tagging or tracking systems are needed so that if a palliative care patient arrives at hospital their condition will be known, the palliative care team can be contacted and they will not receive inappropriate treatment (see Section 5.6 Continuity of care).

## **5.9.4 Setting of care**

### **Care at Home**

Care at home was the preferred option of most people we spoke with. Issues identified to improve this included:

- service provider visits should be made in company of Indigenous staff;
- taking the time (and having the skills) to establish a relationship;
- competence in cross cultural communication and practice;
- being sure to establish who are the decision-makers in the household;
- coordinating and reorganising services to reduce the number of strangers coming to the house;

- providing appropriate information on a range of issues and delivering these both verbally and in written form; and
- maintaining confidentiality and being discrete.

Having enough respite care services available to give carers a break is critical to most people's capacity to care at home.

The most appropriate role for the palliative care worker will be determined by the context in which they are working. For home-based care, the model that best accorded with what Aboriginal and Torres Strait Islander informants said they wanted was to act as a coach to support and train the family so that they could undertake the care.

### **Hospital and hospice**

Hospitals are often seen as places of death rather than of healing by many Aboriginal and Torres Strait Islander people and many communities are acutely aware of relatively recent racist practices, such as segregated wards, and labelling of cutlery and linen for Aboriginal patients.

The design and decorations of hospices and hospitals should be reviewed to attempt to implement the many physical improvements that have been identified above.

Staffing and care practices at hospitals should be reviewed to:

- increase the number of Aboriginal and Torres Strait Islander staff at all levels;
- ensure that good quality cultural awareness training (which covers end of life issues) is provided to all staff regularly;
- ensure medical and cultural advocacy for Aboriginal and Torres Strait Islander clients; and
- facilitate the involvement of family in the care of patients.

Hospitals should put in place appropriate protocols for meeting end of life (and post death) requirements of clients.

Familiarisation visits to hospitals and hospices for key members of the community can be effective in dispelling misunderstandings about hospices. Consultation with community leaders about how to make hospitals more comfortable places for Aboriginal and Torres Strait Islander peoples would be appropriate.

### **Nursing homes and aged care facilities**

- There is a need for more flexible and generous funding arrangements to ensure that funding is not a barrier to aged care facilities and nursing homes accessing appropriate palliative care for their clients. The model recently developed in Perth seems appropriate. Silver Chain Palliative Care Service delivers services into nursing homes in the metropolitan area provided the homes do not have 24 hour care. If they have 24-hour care then Silver Chair delivers a 24 hour consultancy service as a five-day package, funded by the State government.
- All nursing homes and aged care facilities should be encouraged to access palliative care services for assistance and advice regarding palliative care clients.
- Mainstream nursing homes and aged care facilities should be encouraged to access Aboriginal and/or Torres Strait Islander health and community services to support their Aboriginal and Torres Strait Islander clients and their families (unless clients do not desire this). It may be appropriate to include

these organisations in the care planning for Aboriginal and Torres Strait Islander clients and/or to broker in their services for family liaison and cultural advocacy. The use of video conferencing with families of remote residents should be explored.

- Local palliative care teams should include residential facilities as part of their support, education and clinical program. Offering in-service training to these facilities may begin a useful relationship.
- Nursing homes and aged care facilities in areas with substantial Aboriginal and/or Torres Strait Islander populations should endeavour to increase the number of Aboriginal and/or Torres Strait Islander staff (at all levels including nursing, caring and domestic) and in some places should develop strategies to ensure that there will be enough staff to back-fill positions when staff have to go on 'sorry' (bereavement) leave. Employment of both male and female workers is important because of cultural avoidance issues which prevent some people caring for others.
- Mainstream nursing homes and aged care facilities which have Aboriginal and Torres Strait Islander clients (or which are in areas that have large Aboriginal or Torres Strait Islander populations) should have positions designated for Aboriginal and Torres Strait Islander staff.
- Nursing homes and aged care facilities should ensure that all staff have undertaken cultural awareness training. Cultural sensitivity should be included as a performance measure in evaluations of service delivery.
- Nursing home staff should have palliative care training (see also Chapter 7, Section 7.6.3).
- People living in nursing homes need to be able to make the choice to go home to country to pass away if this is what they want. They need information to be able to make the choice in enough time to get home. Sometimes people will choose to return to country even though there are no care facilities for them. This is their right.

#### **Need for medically supported hostels and palliative care for itinerant people**

In cities such as Perth and Adelaide and in Alice Springs a need was identified for medically supported hostels for short term accommodation of Aboriginal and Torres Strait Islander palliative care clients visiting for medical treatment (see Section 5.4.6) .

There is a need to develop strategies and funding arrangements to allow delivery of palliative care services to all people in the setting of their choice. This should include itinerant or 'homeless' people who need palliative care and symptom management.

### **5.9.5 Counselling and bereavement care**

The main implications from the findings reported in Section 5.5 are:

- need for more trained Aboriginal and Torres Strait Islander psychologists and counsellors;
- need for AHW post graduate qualifications in grief and loss counselling;
- need for recognition and recompense for work of AHWs that is currently done in their own time;
- need for support groups – both for families of people with life limiting illness and/or for families of who have passed away; and
- need to involve Aboriginal and Torres Strait Islander palliative care workers as part of palliative care team (may be brokered in from AMS or other services) to ensure that early counselling takes place.

- need emphasis on early referrals and early counselling, and need to establish what people want, where they want it to happen and to facilitate this;
- palliative care teams should work with local AMSs and other community groups to develop bereavement plan options that are culturally sensitive. These should take into account that
- *‘Aboriginal people won’t ask’* for services,
- *‘We value someone who will take the time to have a yarn’*,
- *‘We might want to talk to someone from outside the community’* – ensure that appropriate ‘third party’ services are available;
- continue strategies to remove stigma attached to attending mental health services;
- service providers should explore the idea of *‘supporting the supporter’*;
- ways to combine professional bereavement counselling with practical assistance and advocacy should be explored, as in the case of the AMS which provides the services of AHWs to help write eulogies and the ‘order of service’. Assistance with family funeral preparations by health workers whose skills have been augmented by grief and loss training should be considered a legitimate health cost;
- recruitment of Aboriginal and Torres Strait Islander people into volunteer programs is needed;
- need for research into best approaches to assist in management of grief and loss for Aboriginal and Torres Strait Islander communities;
- service providers should check that the bereavement services they are offering are appropriate and where possible should make use of, or seek advice from, an AMS emotional and social well-being service or other Aboriginal counselling services; and
- put in place appropriate counselling and debriefing services for Aboriginal and Torres Strait Islander health professionals who deal with death on a regular basis as they are usually members of the bereaved families or are connected with the deceased.

### 5.9.6 Continuity of care

Being cared for at home does not mean that one has to pass away at home, and being cared for in a home or hospital does not mean one cannot pass away at home. Flexible and responsive services should allow for patients and families to be able to choose the options they want, and to change their minds if the situation requires it. Palliative care pathways and patient tracking systems will support consistency of care. NPCS Objective 2.4 should be developed to ensure that systems are developed which deliver consistency of care and which have built into them key points which will identify the need for cultural advocacy.

### 5.9.7 Pain management, medication and equipment

The major issues here relate to how Indigenous people experience pain, the need for information about pain management, and the cost and perceived cost of medication (see Section 5.7). Many Aboriginal and Torres Strait Islander people cannot afford the dispensing fees let alone the cost of medication which is not available on the Pharmaceutical Benefits Scheme. People often go without medication to pay for other family needs.

There were many reported cases of doctors prescribing inappropriate medications, that were either not the most suitable for symptom management, or that would not be available or able to be administered when the patient returned home. There were numerous stories of clients arriving home in remote communities with prescriptions for medication that was unavailable in the community.

There are many issues of concern about the use of morphine. Many Aboriginal and Torres Strait Islander people are fearful of morphine and there are apparently many misunderstandings about its use. There are also safety and security issues about access to this drug by palliative care clients. Issues concerning equipment shortages are reported in Chapter 9 below.

### 5.9.8 Access to palliative care specialists

The implications of the findings in Section 5.8 above are:

- the existence of palliative care service and advice lines should be marketed to GPs and AMS doctors;
- service providers should keep in mind that Aboriginal and Torres Strait Islander clients may not have telephone access and should either advocate for phone access on their behalf or set up emergency procedures that do not rely on phones;
- funding structures should be examined to allow for the funding of telephones for palliative care clients who otherwise would not have them; and
- service providers should budget for the employment or brokering in of Aboriginal and/or Torres Strait Islander cultural specialists who could be on call to provide advice.

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# Chapter 6

## Workforce issues



### 6.1 Traditional healers

As explained in Chapter 4, traditional healers are used quite extensively in some parts of the country and are sometimes consulted by palliative care clients and their families. The use of traditional healers is fairly well supported by community-controlled health organisations and organisations (such as the Ngaanyatjara Pitantjatjara Yankunytjatjara [NPY] Women's Council) in remote areas where traditional practices continue.

We did not find traditional healers working specifically or formally in palliative care; rather they were providing services to sick people either privately or during a special clinic at a community-controlled health centre. In some cases healers may play an important role in confirming to the family that the medical view that the client requires palliation rather than healing is, in their view, correct. They can also have an ongoing role in pain and symptom relief.

No significant barriers to traditional healers visiting clients in hospital were reported, however it is not known whether the hospitals concerned were aware of the nature and purpose of the visits.

In central Australia there is considerable debate about pay rates for traditional healers. In some places they receive 'top up' on their CDEP pay. In others they are apparently fully employed and are paid as health workers. These sorts of debates also raise questions about insurance, equity, accountability and other issues. In the Northern Territory there is a strong view that decisions around the use of traditional healers should be left to the community and that it is not an issue for government.

#### 6.1.1 Western Australia

Aboriginal people use traditional healers and bush medicines to treat illness in many Western Australian communities. One administrator expressed concern about 'medicalising' a practice that exists in many areas anyway and felt that the most important thing was to support the process.

Peter Williamson's 1996 report (Williamson 1996), recommended that *maparn* (traditional healers) in the Kimberley and Pilbara regions should be involved in the delivery of palliative care to Aboriginal people from the early stages of a terminal illness, if that is the patient's wish.

#### 6.1.2 Northern Territory

In many remote communities, traditional healers are involved as a matter of course. At Yuendumu in central Australia, *ngangkari* (traditional healers) were placed at the top of the list of people who should be involved in caring for someone who is 'finishing up'.

The NPY Women's Council employs *ngangkari* in the communities it serves.

### 6.1.3 South Australia

Nganampa Health facilitates the use of *ngangkari*s where this is desired and will also fly them to Port Augusta or Adelaide if this is requested by clients who have had to go away for treatment.

Some other Aboriginal medical services (eg Nunkawarrin Yunti in Adelaide and Pika Wiya in Port Augusta) also engage traditional healers to run clinics or visit clients when necessary or when there is a *ngangkari* available. The healers will visit other service providers in the area as well (eg Wami Kata aged care facility in Port Augusta). Service providers report that it is increasingly hard to gain ready access to these healers.

Traditional healers are also employed at Koonibba (Ceduna) and Umoona (Coober Pedy).

The implications of the use of traditional healers in relation to palliative care are discussed below in Section 6.8.

## 6.2 Aids in nursing

Aboriginal staff working in nursing homes sometimes hold the aids in nursing (AIN) qualification. The director of one Indigenous-specific nursing home expressed the view that AIN training should be expanded to include a palliative care component.

## 6.3 Aboriginal Liaison Officers (ALOs)

### 6.3.1 Role and qualifications

The role of hospital Aboriginal liaison officers is very broad and may include liaison between clients and the hospital, and between tertiary and primary health care providers. Their presence serves to alleviate the sense of isolation that Aboriginal people and Torres Strait Islanders feel in the institutional setting of a hospital. Their continued use was a specific recommendation of the Royal Commission into Aboriginal Deaths in Custody (RCIADIC) (Johnston 1991)<sup>1</sup>, which recommended that their use as part of the therapeutic team be increased.

ALOs are usually employed by hospitals which have significant numbers of Aboriginal and/or Torres Strait Islander clients, though the hospitals' criteria for employment of ALOs was not investigated as part of this study and may vary from State to State.

The ALO's role is generally that of a social worker, liaising between various services, assisting people to get to appointments or fill out forms, sorting out financial issues, transport, family liaison etc. ALOs are not often involved (in a clinical sense) 'as members of the therapeutic team' as recommended by RCIADIC and are seldom involved in discharge planning in any substantial way. In some places we were told that even if they had a comment, their views could not be included in the clinical notes because they were not clinicians.

ALOs are often called on to liaise into the community as well as directly with patients. Some are responsible for cultural awareness training of other hospital staff, a role which some thought was inappropriate<sup>2</sup>. Some are called upon for language translation and some provide advice on cultural issues.

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<sup>1</sup> Recommendation 261: *That the use of Aboriginal hospital liaison officers as part of the therapeutic team is increased.*

<sup>2</sup> There are questions about whether ALOs are the best qualified to provide this training. Most are not skilled trainers. It may also be inappropriate, ineffective or difficult for an ALO to train staff who may be in a more senior or supervisory role.

Many of the ALOs we spoke with had no qualifications, though others had received health worker training and some had degrees in social work. In Darwin, Aboriginal hospital liaison staff have health worker qualifications, but are apparently not permitted to do any clinical work, in contrast to health workers based in remote communities. Most ALOs do not provide 'medical advocacy' (acting as translator to the medical profession) or are not qualified to do so, though some may have AHW qualifications.

Some ALOs spoke of the need for ALOs to accompany doctors on rounds to explain to patients in plain language what their situation is. This does not always happen.

*ALO's gave an example of a doctor wanting to turn off life support [to a young baby] at a particular time and not giving the mother time to consult with appropriate family members. They see it is their role to make sure this sort of thing doesn't happen. [Queensland]*

Some AHWs and Aboriginal health administrators suggested to us that hospitals prefer to describe their staff as 'ALOs' so they would not have to employ qualified AHWs or RNs and pay them more.

In Perth, a hospital liaison team services the major hospitals in relation to clients from remote communities. This team is located independently of the hospitals it serves. These staff all have nursing qualifications which are vital to the role they play in explaining medical issues to patients and their families. Only one member of this team is Aboriginal.

At least one remote community health organisation employs its own (2.5) hospital liaison officers, based in Alice Springs. Their role is to transport patients and their escorts to and from medical appointments, check that flight and bus connections will work and sort out accommodation issues.

On Thursday Island in the Torres Strait there are high numbers of Indigenous staff in the hospital (nurses and ancillary staff) and ALOs are not employed. Any one of a number of people are likely to fill the ALO role, though at the expense of other duties.

Without exception, the ALOs we spoke with were overworked and often unsupported. There is no career structure for ALOs. Many had no access to hospital transport for community liaison work. Some reported difficulty accessing funds for certain purposes, such as to provide sandwiches for family visitors who may have travelled all day to reach the hospital. Some complained that they had no office space and no private area to take a family in the event of a death in the ward.

Some hospitals employ a male and a female ALO, but this is not the norm and in many places the ALO is the only Aboriginal or Torres Strait Islander employee in the hospital. In these circumstances they feel very isolated.

ALOs generally reported being very stressed by their workload and by the deaths of clients (who were often family or friends). They do not receive adequate debriefing or support to deal with grief issues associated with their work. There is a very high turnover of ALOs.

### 6.3.2 ALOs and palliative care

ALOs are generally not involved in liaison with palliative care units, either in the hospital or in the community, nor in discharge planning for palliative care clients. Unless funding were to be made available for additional hours or staff, ALOs would not have the capacity to be involved and in general they do not have the training to fulfil these roles.

Although hospital-based ALOs are very overworked, one might have expected a greater degree of liaison between them and palliative care services. In fact we often found that the palliative care service (even hospital-based units) had no contact with the ALO at the hospital and some were even unaware of their existence.

Sometimes palliative care staff claimed that the ALO would be involved if there were Indigenous clients, but the ALO said this did not occur. (Several of these discussions took place with both the ALO and the palliative care staff present and provided useful opportunities for an exchange of views and identification of needs.)

Some ALOs thought that it should be their role to let families know what palliative care services are available but this could not be done without more staff. Some spoke of the need for both male and female ALOs and, in the Northern Territory, of the need for ALOs working in palliative care to be 'neutral' (for example the Aboriginal worker for the Top End palliative care service comes from Western Australia) to avoid cultural restrictions which would prevent them from working with some people. In Perth a need for Wongi and Kimberley ALOs, as well as local Noongar staff, was reported. Many people stressed the importance of employing local people who have good links with the local community.

Some ALOs said that palliative care should not be part of their duties because they already have too many roles to play. Many said that they should be involved but could not do so without additional hours or more staff. ALO working hours are 9.00 – 5.00 only and some work only two or three days per week.

At a major base hospital in Queensland, the palliative care unit spoke of the importance of their relationship with ALOs for development of relationships with the community.

The implications for the role and participation of ALOs in palliative care are discussed in Section 6.8 below.

## 6.4 Health and Community Care (HACC) Workers

Indigenous HACC workers who often the first Aboriginal or Torres Strait Islander workers to come in contact with Indigenous clients who need palliative care.

Aboriginal homecare coordinators in several locations in New South Wales reported that they are often asked to provide personal care, home care or respite care for palliative care patients (who were not clients of palliative care services), usually after being approached by the family or by the AMS. Wagstaff (1997) documented similar occurrences in Victoria, as did Williamson (1996) in the Kimberley and Pilbara. In New South Wales, one hospital ALO stated that she regularly referred clients to the Aboriginal home care service rather than to the palliative care service because she thought that people would not want to use a service that *'doesn't have a black face'*.

One Aboriginal domiciliary care worker in Adelaide provides services to palliative care clients as well as other clients.

Many HACC services reported difficulties in providing services to clients who do not fit the HACC criteria (or who have become palliative and are no longer covered by the funding guidelines) but provided the service anyway. *'We find the money somehow or we do it in our own time.'* Palliative care is generally no longer covered by HACC funding arrangements (see Chapter 9).

In some Indigenous HACC programs, especially those run out of AMSs, the HACC workers are often involved in caring for palliative care clients (regardless of whether they fit the HACC criteria). As well as

providing home care services, the HACC workers act as counsellors and coordinate other services. They are often not in contact with palliative care services, are not trained to undertake this work and often work in their own time.

Indigenous HACC programs in which Aboriginal and Torres Strait Islander workers provide home services have been very successful in servicing Aboriginal and Torres Strait Islander clients. These programs are often able to coordinate well with a range of mainstream services. One reason is that funds have been provided for Indigenous staff in HACC and CACP programs and in some places have also been provided for the employment of Indigenous HACC development officers. These development staff work across a number of (usually mainstream) services providing cultural awareness training, checking that Indigenous clients are receiving adequate services, and advocating on behalf of Aboriginal clients when needed.

For example in a regional centre in Victoria, the HACC Aboriginal liaison officer/ Development worker not only provides direct liaison to clients but also works with mainstream services to check the suitability of their policies and procedures, and regularly runs cultural awareness training programs.

It is also noted that the HACC National Reference Committee has been instrumental in bringing Indigenous HACC issues to the attention of policy makers.

The implications of the role of HACC workers in relation to palliative care are discussed in Section 6.8.

## 6.5 Aboriginal health workers (AHWs)

AHWs work for AMSs, community clinics, community health centres and in some cases, in hospitals as ALOs. Their roles vary from State to State. Many Community Health AHWs undertake health education and disease prevention; in some AMSs and community clinics they undertake community liaison and patient transport roles; and in some areas they have clinical roles.

In remote areas, AHWs, together with clinic doctors and nurses, provide the only palliative care services available. Fried (2000) (209f) examines the role of AWHs in palliative care in Central Australia in some detail, outlining the broad scope of their role and the complexity of cultural issues they face. In some towns Aboriginal health workers from the AMS provide an informal (and untrained) palliative care role, often in their own time as AMS hours are 9.00 – 5.00, five days per week.

Many AHWs, especially those in remote communities, spoke of the huge personal cost involved in their work. For many, nursing Aboriginal clients is like nursing their extended family. Due to the high number of deaths, there is insufficient time to deal with each death as there are still other clients to look after. This was clearly culturally, spiritually and emotionally very difficult for these workers.

Many coordinators spoke of the need for additional resources to backfill positions so that AHWs could take the emotional and cultural leave they needed. The coordinator of a social and emotional well-being program suggested:

*Recently four clients died and it would be great for the program to be structured so the worker could take leave – to backfill positions. It's very stressful to be providing emotional support to client and family as well as coordinate the requirements of other chronically ill patients.*

In some communities there are quite large numbers of trained health workers who choose not to work in this role because of disillusionment or in some cases because of difficult cultural issues.

Health workers in remote areas reported feeling unsupported and overworked with regional staff not understanding what it is like for remote area workers.

### 6.5.1 The need for AHWs in palliative care

The need for trained Aboriginal and Torres Strait Islander staff to work in palliative care was repeated again and again by community members and AMS staff. AHW training needs to include a palliative care component (see Chapter 7). Funding is needed to employ and broker out trained workers as needed (see below).

In areas where traditional values are held and 'blame' is an issue, some have suggested that AHWs from outside the area should be employed. Others have argued for local AHW training so that people can work in their own communities. Fried (2000) has also canvassed the idea of providing some training to older Aboriginal people living in the remote communities to increase the capacity of communities to provide personal care. Such improved capacity may reduce the personal care aspect of the role that AHWs and nurses find themselves filling.

### 6.5.2 Some models of employment

Community members and AMSs suggested various models for employment of trained palliative care workers. It was widely suggested that they should not work exclusively for one organisation, nor exclusively in palliative care. Some suggested regionally based staff.

*It would be good to have a palliative care AHW on staff who could work across the whole of western Sydney. They could be based in the AMS to help them keep the link with the community and the support they would need, but they could work with both the palliative care services. They don't need to be especially highly trained as long as they can work in partnership with the palliative care nurses. They should go to home visits with nurses. [AMS]*

Health workers suggested that a palliative care trained health worker could work throughout the sub-district or even the region, and could possibly be employed by the division of GPs, with their services brokered out to the palliative care team, hospice, Homecare and the ACAT, etc. It is especially important to have Aboriginal workers present at the time of client assessment and early in the development of a relationship.

AMS staff in one area of the Northern Territory commented that it was vital for the local palliative care team to include ALO's and suggested that a male and female Aboriginal health worker should work with the palliative care team but be physically located in an Aboriginal organisation such as an ACCHS so they would not be working in isolation.

## 6.6 The need for cultural and linguistic interpreters

There is a notable lack of interpreters and interpreter services. It appears more likely that you will be able to get an interpreter if you speak a foreign language than if you speak an Indigenous Australian language. There is a desperate need for trained interpreters in places such as Perth and Adelaide and also in many remote areas.



## 6.7 Other Aboriginal and Torres Strait Islander health professionals

Very few Aboriginal and Torres Strait Islander nurses, doctors, psychologists and social workers are involved in palliative care. Strategies to raise the awareness of these groups and to solicit their input into the development of culturally appropriate practice should be pursued through their professional associations (eg CATSIN and AIDA).

## 6.8 Findings and recommendations

The findings about workforce issues are supported by the recommendations of a recent report into Breast Cancer Screening Diagnosis Treatment and Care for Aboriginal Women and Torres Strait Islander Women in Queensland – (Kirk, McMichael *et al.* 2000) which state:

- initiatives of government and non-government organisations need to be supported, eg the Queensland Health Indigenous Workforce Management Strategy, to increase the number of Aboriginal women and Torres Strait Islander women employed in cancer services, including screening, management and treatment, palliative care and support services to increase community trust and acceptability;
- the training of Aboriginal and Torres Strait Islander health workers should be promoted and supported, especially in rural and remote areas, in counselling, domiciliary and palliative care; and
- the number of Aboriginal and Torres Strait Islander health workers employed in palliative care and domiciliary care services should be increased.

### 6.8.1 Aboriginal and Torres Strait Islander staff in palliative care

Aboriginal and Torres Strait Islander health professionals and community members spoke about how important it is ‘*to have a black face*’ present (ie to have Aboriginal and/or Torres Strait Islander workers). It is very important that home-based services (and doctors making referrals to palliative care services) have trained Indigenous staff and/or buy in the services of such staff for advice and liaison.

Employment of Aboriginal and Torres Strait Islander staff would go a long way towards developing relationships between mainstream service providers and the community and would assist in the development of culturally appropriate services. It is important to ensure that Aboriginal and Torres Strait Islander staff working in this area are not isolated in mainstream services. It may be more appropriate to locate them in, or share them with, an Indigenous health service.

Where there is a significant Aboriginal and Torres Strait Islander population, trained Indigenous palliative care workers are needed either as full-time palliative care workers or to undertake additional duties. How these positions are funded should not necessarily affect where they are based, which would depend on the local situation. The following have been suggested:

- hospital ALOs (with AHW and palliative care qualifications);
- AMS-based AHWs who may be brokered out to other providers;
- AHWs based with a palliative care service; or
- Community Health based AHWs.

They could be regional workers, working throughout a health district with a number of service providers (mainstream and Indigenous), or they may be community-based, or located with service providers.

Two sorts of roles are needed: development and promotion roles to improve existing services; and more hands-on or face to face roles dealing with cultural and/or medical advocacy. Sample duty statements for these roles are given in Appendix 14.

There is a need for medically trained Aboriginal and Torres Strait Islander advocates (such as AHWs, enrolled nurses, registered nurses) to be employed by hospitals, health services and/or brokered in by palliative care services.

It is important that, wherever they are based, they should not be isolated from other Aboriginal and Torres Strait Islander workers and they should be professionally supported and supervised. Part of that support should include provision of interpreter services where necessary. Local Indigenous and palliative care service providers should be encouraged to work together to find the best local solution.

### 6.8.2 Implications in relation to HACC workers

- The skill and knowledge of HACC workers in delivering care to palliative care clients should be acknowledged and they should receive appropriate training and counselling.
- Funding barriers to the involvement of these workers in palliative care should be removed.
- The task of involving trained Aboriginal and Torres Strait Islander workers in palliative care may be more complex than getting Aboriginal and Torres Strait Islander workers involved in HACC programs, but the HACC model may offer some lessons.

### 6.8.3 Implications in relation to ALOs

- ALOs should be more actively involved in discharge planning
- Job descriptions, workloads, staffing levels, working conditions and qualifications should be examined to prevent exploitation of these workers and to ensure that Aboriginal and Torres Strait Islander clients receive the best service possible.
- In some places the demarcation between the hospital ALO and the community based AHW is not clear and causes problems. Increasing ALO involvement in palliative care would require some clarification of these roles. Local rather than global solutions would be appropriate.
- ALOs should be better supported through formal supervision and emotional or counselling support.
- If ALOs were to be more involved in palliative care support and liaison roles, then more would need to be employed or they would need to work more hours; they should also receive some medical training (AHW, EN or RN), because of the need for medical advocacy, as well as palliative care training.
- All ALOs should receive basic training in the nature of palliative care and the services available in the area.

### 6.8.4 Implications in relation to traditional healers

The use of traditional healers is regarded as Aboriginal and Torres Strait Islander 'business'. We were advised that it would not be appropriate to try to integrate these 'service providers' into the health system. They are part of a complex cultural and social system which may be endangered by trying to co-opt services into the western context.

Policy makers and service providers should be aware of the work of these healers and facilitate access to them when necessary. Funding might be supplied for fares and/or brokering in these services if needed. Consultation with these healers is usually a family matter. Palliative care service providers should support the family in consulting them if needed. AMS and other Aboriginal and Torres Strait Islander community organisations may have their own arrangements to facilitate access to traditional healers.

Traditional healers should be seen as an important adjunct to palliative care services where families want to have them involved. Funds should be available for use in the event that facilitation of access to the healers requires it.

### 6.8.5 Language and culture interpreters

All palliative care services should have the capacity to engage the services of language interpreters where the family involved does not speak English. Funding is needed for brokering in these services and in some places may be needed to establish them (eg a service offering various Aboriginal languages in Perth). These interpreters will require the same orientation as cultural advocates and should receive supported debriefing as part of their engagement (see further Chapter 3, Sections 3.2.8 and 3.3.2).

All palliative care teams should have the capacity (service delivery design and resources) to engage cultural advocates for their clients. Cultural advocates need orientation in the objectives and methods of palliative care (especially in respect for the individual's wishes) as well as cultural awareness training (in respect of the mainstream medical culture in which they will be working). Cultural advocates should receive supported debriefing as part of their engagement.

### 6.8.6 Other Indigenous health professionals

Strategies to raise the awareness of Aboriginal and Torres Strait Islander nurses, doctors, psychologists and social workers and to solicit their input into the development and delivery of culturally appropriate practice should be pursued through their professional associations (eg CATSIN and AIDA).

Training issues are discussed in Chapter 7.

## References

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- Williamson, P. (1996) *'Let me die in my country': palliative care needs of Aboriginal people in the Kimberley and Pilbara regions of Western Australia, final report*, July 1996. Broome, Australia. Dept. of Human Services and Health., Western Australia. Health Dept., National Palliative Care Project (Australia): xi, 59.

## Chapter 7

# Information, education and training



*Clients at home – there are no support services for them. Some people are asking ‘What about our Health Workers? Why aren’t they trained in this area?’ – then we have to explain to them why they can’t come in. We need Indigenous workers in the palliative care team who can go out into the community and be there ‘hands on’ in the homes. One old lady didn’t have a drink for 24 hours because the family was too frightened to give her a drink because they thought she would choke. They didn’t have a sucker in the house – no one would know how to use it. [Queensland ALO]*

### 7.1 Providing Information to the Indigenous community at large

#### 7.1.1 ‘People don’t know about palliative care’

In the interviews we conducted most Indigenous people had never heard of palliative care and did not know about palliative care services. This applied as much to health workers, HACC and CAACP workers as to the general public. Some hospital ALOs do not know of community based services.

Most mainstream palliative care services have simple brochures about their services, however these were often not available in the foyer of the services (either community health centre or hospital information stands). The information is not available in AMS waiting rooms. At least one service provider we spoke with had a policy of explaining its brochure face to face and so did not make copies freely available.

People generally don’t consider palliative care until they need it, however palliative care services should make their leaflets more widely available in health information outlets and in Indigenous health and carer service centres. Copies should be available to Indigenous service providers.

In the Northern Territory, it was suggested by one person that promoting palliative care to the broad community could have a negative effect as death was the last thing people wanted to hear about.

*When people have to go to Adelaide for tests they know it is serious and you see them give up [HACC Worker]*

However in several places people pointed out that other issues, such as incontinence, used not to be spoken about, but now after successful strategies there was much more awareness.

It is important to explain that palliation is about relieving symptoms.

### 7.1.2 Existing information on palliative care for Aboriginal and Torres Strait Islander audiences

We did not discover any Indigenous-specific general information brochures about palliative care. There were four examples of information about palliative care that were specifically targeted to or prepared for Aboriginal and or Torres Strait Islander audiences.

1. A poster produced by the South Australian Palliative Care Council. The only people who spoke about this poster were service providers, not community members. The comments we received about it were that while it was colourful, it was not very informative and ‘...if you wanted to actually find out what it was about you would have to stand up and go right up to it to read it which might be embarrassing.’ We were told the South Australian Palliative Care Council has undertaken its own studies on the effectiveness of this poster, but the results are not yet available.
2. The Alice Springs Central Australian Palliative Care Service has a promotional poster, developed from a set of four promotional paintings by four Aboriginal artists representing major language groups of the region. They found the poster worked well in conveying the message in Alice Springs but not so well in other regional centres because it was not relevant to the Aboriginal language groups in those regions.
3. *Bessie’s Story* (Lowe and Floyd 1998), is a small booklet about palliative care for remote communities which has a limited distribution in the region for which it was developed.
4. A booklet from the Indigenous Carers’ Kit produced by the Australian Government Department of Health and Ageing was mentioned to us as being an important source of information about palliative care. This is a general aid for carers, but is not specific to palliative care and does not list palliative care services.

Although most people said that they thought ‘word of mouth’ information would be most effective, it was also suggested that simple information leaflets should be available to Indigenous clients and that it would be good to have an ‘Indigenous version’ printed, using the Aboriginal (or Torres Strait Islander) flag or another design.

An AMS in a remote community said ‘*Written information needs to be in local language with lots of pictures. Posters don’t convey education.*’ Others suggested simple English leaflets which give information about:

- who is eligible;
- what palliative care can offer;
- where you get it and what it costs;
- what happens next [steps]; and
- what happens if you don’t take tablets.

In some states (such as South Australia) there are booklets in many languages yet there are none specifically for Aboriginal people.

There is a need to explain to Aboriginal and Torres Strait Islander peoples what palliative care is – that it does not only mean a hospice, aged care facility or nursing home and that it is not only for cancer. If there is no fee that should be made clear as there are great misunderstandings about costs.

### 7.1.3 Word of mouth information

Overwhelmingly, Indigenous people said that the only effective way to spread information about palliative care was by 'word of mouth'. They also suggest that such strategies should be backed up by written information (preferably with an Indigenous cover design or logo) which would usually only be required once people were aware that they had a need.

The implications are twofold: there is a need to develop 'word of mouth' strategies and medical referral needs to be supported by appropriate information materials.

'Word of mouth' communication will most likely occur through:

- people who have used these services mentioning it to others;
- Aboriginal and/or Torres Strait Islander health and care workers who are aware of palliative care services passing on information to potential users of these services as they come into contact with them; and
- medical referrals supported by Indigenous liaison staff or cultural advocates who are aware of palliative care services.

'Word of mouth' strategies could be implemented by:

- providing opportunities for Indigenous people with experience of palliative care services to tell their story;
- providing opportunities for people to find out about services (eg open days); and
- providing training and information for AHWs, ALOs and Indigenous HACC workers.

### 7.1.4 Telling stories of good service delivery

*When you get to know each other the links are stronger – be very supportive and approachable and always follow up with clients who go back into that community – the community then gets a better level of care. It [information] all starts with individuals and then goes to groups and then the community benefits. [ALO, Queensland]*

A number of community members suggested that videos could be shown on a loop in the foyer of AMSs. Some suggested creating opportunities for people to hear the stories of others, for example by placing media items in the Indigenous or local press (especially during palliative care week) and/or producing videos. In Mount Isa an article appeared in the local paper when the Indigenous palliative care worker was appointed and that was why many members of the community knew about palliative care.

### 7.1.5 Information days and 'yarning' sessions

Information days or gatherings for community leaders, elders, and health and care workers are effective. Two hospices (one of which also provides outpatient clinics and works closely with a community based team) successfully held information sessions or open days. We heard about these from community members who had attended and they were clearly valuable to these people who later used these services. In both cases the local ALO had made the arrangements. Involving community opinion leaders was clearly important in one case. Information days may be easier for facility-based care services to arrange, however it should be noted that many people we spoke with who had had experience of palliative care were happy to speak about their experience and some may be willing to take part. In the Northern

Territory one person suggested that informing Aboriginal church leaders in the region might be useful. In Queensland ‘yarning’ sessions were suggested:

*Black fellas and forms don't get on. Bits of paper won't be read. The best way for passing on information is by 'yarning' in an informal way. In [ ] have set up a women's group which meets once a month as an opportunity for sharing information and airing views – they work out what they want and how they will go about getting it. Aboriginal health worker comes along and brings latest health information.*

### 7.1.6 Informing key Indigenous health and care workers

As explored in Chapter 6, Sections 6.3-6.5, HACC workers, AHWs and ALOs are very likely to come into contact with people who require palliative care services. People in these roles are well placed to learn about palliative care and are also members of the community, likely to share information with family and friends. They are likely to be the main source of ‘word of mouth’ information.

Many of the health workers we spoke with thought that undergraduate AHW (Primary Health Care Certificate) and Aged Care Certificate courses should include sections on palliative care that would cover:

- ‘what is palliative care?’;
- what sorts of services and benefits palliative care can offer and how cultural sensitivities might be accommodated;
- how these services can be accessed; and
- what sorts of services exist in the State and region.

Where possible, the courses should present opportunities for AHWs and Indigenous aged care students to meet with palliative care service providers.

For workers who have already graduated, palliative care information and awareness programs should be developed. These might include:

- local service providers identifying and making contact with these workers and providing in-service training, information sessions and work experience opportunities;
- publishing articles in journals such as the *Aboriginal and Islander Health Worker Journal*; and
- developing mailing lists and networks of ALOs, AHWs (in both AMS and State government health centres), or using existing networks such as the Indigenous HACC reference group, to provide information about palliative care.

An ALO in Queensland suggested appointing an ALO as a resource person to develop awareness in the community and the hospital system.

In the short term, until undergraduate training programs take effect, information strategies targeting ALOs, HACC workers and AHWs should be developed. This might include the development of networks and newsletters and using existing associations or journals. Locally run information or training sessions would be appropriate.



### 7.1.7 Volunteer training

Strategies to inform Indigenous communities might also include offering volunteer training programs in venues and formats that would appeal (see below in Section 7.8).

## 7.2 Information for Indigenous clients

Indigenous palliative care clients and their families have special information needs (see Chapter 3 which outlines some of the socio-economic and cultural contexts). The underlying issues which give rise to these special needs include:

- cross cultural communication difficulties;
- literacy and education levels;
- difficulties in understanding medical terminology;
- lack of capacity to source information independently; and
- feeling uncomfortable about asking questions or asking for clarification, due to feeling intimidated or 'shamed'.

Indigenous people who had experienced palliative care consistently said that they had needed more information, earlier. In general the information needs identified included:

- Being supported when being told about the life limiting nature of the illness and the nature of palliative care:

*My sister was diagnosed in December and died in August. We were not prepared for what we were in for. It would have been good to have had an Aboriginal person at the Cancer Clinic. There is an ALO at the hospital but not at the clinic. [Community member, NSW] (This woman was not introduced to the palliative care service until her sister was actually dying, despite having been diagnosed 7-8 months earlier and having been treated with radio- and chemotherapy. This story does not accord with what the palliative care service claims to be their practice.)*

*A health worker said it is important the patient has someone with them when the doctor tells them about their sickness. One client was carefully told by a doctor, the registrar, nurses, but still did not understand until the health worker talked to her. [Queensland]*

- Written information about services available at that time, presented in a way that Aboriginal and Torres Strait Islander people can understand and relate to:

*Don't know where to go – for example for modifications – one family got things done thinking palliative care would pay for it, but that didn't happen. People are not accessing respite. They don't know about having access to equipment like commodes – wives are carrying their husband to the toilet. Sometimes people are too ashamed to ask. Will we have to pay for this? We don't have the money. Even when I do home visits I have ladies who will have been up since 5am getting their house cleaned for the visit. Still that perception they have to clean the house. [ALO]*

- Written information about the nature of palliative care, the likely course of an illness, the process of death, carer issues, legal and administrative issues to be considered, information about grief and loss, etc:

*It would be really good if there was a booklet that covered what to expect – what to expect at the time of death – and there are also things that you don't know, like what to do after a person dies – where you can get support, where you can get help with a funeral, who you need to contact – like the tax office, the electoral office etc. [community member]*

- Information specific to their situation at any given time, presented in such a way as can be understood, or provided with appropriate advocacy and interpretation. This requires the development of an ongoing and trusting relationship where service providers give information and reassurance, and continually check that the information has been understood.

Being able to meet these information needs will require different solutions in different settings, including:

- Language interpreters;
- Service providers being prepared to spend the time to check that people have understood. Training and guidelines in cross cultural communication should be developed for mainstream service providers;
- Cultural and medical interpreters and advocates. Mainstream service providers should be accompanied where possible and the client and service provider should have the services of a cultural advocate available if needed;
- Preparation of general literature for an Indigenous audience. For example, one of the most useful booklets that we came across was *Palliative Caring at Home* produced by Palliative Care WA Inc, Silver Chain and the Cancer Foundation of Western Australia<sup>1</sup>. It is a small and comprehensive booklet which explains palliative care and covers the practical issues involved in caring for the patient at home. The booklet includes contact numbers of a range of organisations in Western Australia (including health regions outside of Perth), that the carer may need to contact, including where to get equipment, counsellors, resources and more information. This is a very practical booklet which closely matches the sorts of information which Indigenous people said that they wanted.

It should be a high priority for this booklet to be reviewed and edited for an Indigenous audience. The language is plain and should not require substantial editing. Additional information about the legal situation regarding reporting of death, how long the deceased can be kept at home and a section on what to do if the patient should end up on hospital would also be useful. The booklet should have a cover that will appeal to an Indigenous audience and should include State specific information about palliative care services and Indigenous support services. It may also be appropriate to produce a picture version for remote communities where literacy rates are low.

### 7.3 Information exchange between mainstream and Indigenous health care providers

Our research identified the need for better communication between mainstream and Indigenous health providers so that positive changes can take place and to ensure that Indigenous people can access the palliative care services they need.

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<sup>1</sup> This booklet was adapted from the South Australian booklet *Palliative Caring at Home* prepared by the Palliative Care Council of South Australia.

Most palliative care services had little or no knowledge of Indigenous services and no contact lists for services such as Indigenous home care or HACC services, the Community Options Program, AMSs or other Indigenous groups or organisations in their regions.

Palliative care services need to have this information not only so they can provide it to Indigenous clients, but in order to begin a dialogue with these services. This project's Newsletter no.3 outlined ways that service providers and community organisations could begin such a dialogue.

A dialogue is also needed at senior policy level, between palliative care policy makers and Aboriginal health policy makers at State and Australian Government levels.

## 7.4 Education and training programs

### 7.4.1 Introduction

Our brief required us to identify available palliative care training and its relevance to Indigenous palliative care service provision. The following areas were explored:

- What palliative care courses are available for nurses, especially community nurses and remote area nurses? Is palliative care a standard part of nursing training? If not, how do nurses find training in this area? Where is it offered?
- What sort of cross cultural awareness training (or Aboriginal and or Torres Strait Islander cultural issues training) is available for nurses and where is it offered?
- What sort of information exists about Aboriginal health worker training and palliative care components of it?

Identifying the palliative care training available (except at post-graduate level) is not easy as there are no comprehensive listings. It is hard to tell which courses may include some elements of palliative care because course descriptions, even of relevant courses, often do not include the term 'palliative care' but use other terminology. As a result of many telephone calls, emails, internet searches and literature searches, we identified the training opportunities at various levels outlined in the following sections.

### 7.4.2 Tertiary training

Information from the Royal College of Nursing and curriculum searches on the internet revealed that, in general, palliative care training is usually available only for nurses at post-graduate level. For instance at La Trobe University, palliative care can be taken as a subject in a post graduate diploma or in varying degrees of specialisation as a graduate certificate, post graduate diploma, a master's degree or at doctorate level.

Flinders University has recently added a graduate diploma course to its existing post-graduate program (Graduate Certificate, Master of Palliative Care and Master of Science (Palliative Care)), beginning in 2002. This will allow students to complete the diploma after two years' part time study. Numerous short courses are also offered by the International Institute of Hospice Studies (allied to Flinders University) for registered nurses, enrolled nurses and care workers.<sup>2</sup>

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<sup>2</sup> Other courses include short courses held at the Peter MacCallum Cancer Institute and a graduate diploma at Melbourne University (personal communication Cathie Pogott).

In the Northern Territory palliative care services based in Darwin and Alice Springs offer education to health practitioners in community and hospital settings, as well as to clients, carers and families in urban Darwin, Alice Springs and rural and remote settings. The urban program concentrates on nursing homes, hostels, hospitals, community health centres, families and HACC workers. The rural team provides education for the rural hospitals and remote community health centres as well as aged care facilities and HACC workers.

In 1999 an agreement was made between the Territory Palliative Care Service and the Northern Territory University (NTU) to transfer the main part of the training course into the tertiary sector at the NTU as part of undergraduate nursing training. The course includes topics relating to Indigenous palliative care and service delivery to rural and remote regions, as well as more typical training in management of symptoms, pharmacology, grief and bereavement, occupational therapy, pastoral care and other therapies.

Other training providers include the Mercy Health Service based in Albury which has developed a VET-accredited training program with three strands for:

- community peers (volunteers);
- enrolled nurses and allied health workers (eg social workers); and
- registered nurses.

Apparently none of these courses are directly suitable for HACC or Health Workers although some of their elements would be. The courses were developed in order to shift the focus of the medical practitioner away from medical provision to focus on the person.<sup>3</sup>

Meadowbank TAFE has developed a training program for enrolled nurses.

#### 7.4.3 Palliative care training in the mainstream system

Our interviews with mainstream palliative care providers indicate that the level of palliative care training of nurses providing these services is not high. Many of the nurses we spoke with had little or no specific training. Palliative care services are set up with one or two CNCs who usually have postgraduate qualifications in palliative care and who provide advice to generalist nurses who do most of the hands-on work. Some nursing services provide their own short courses on palliative care, such as the five day training program which is run by the RDNS in Adelaide once or twice year for its generalist staff. Most nursing homes do not have palliative care trained staff. It would be very rare to find a nurse trained in palliative care in a remote clinic setting.

Most of our respondents commented that there were not enough trained staff, not enough training programs and not enough money to release people for training.

#### 7.4.4 Training in palliative care for Aboriginal and Torres Strait Islander health workers

Various Aboriginal community-controlled health services across Australia provide accredited vocational training for Aboriginal and Torres Strait Islander health workers.

The mainstream Kimberley/Pilbara Palliative Care Network has *'liaised with the Aboriginal health workers school in Broome to increase palliative care content in their course'*.

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<sup>3</sup> Pers Com Camilla Rowland.

Bachelor College (a major Northern Territory Aboriginal College) now offers an undergraduate, post graduate and certificate course in palliative care which has been developed by the Top End Palliative Care team.

The Education Centre of the Cancer Foundation of Western Australia (Cottage Hospice) has run a training program for care aides and personal carers from Marr Mooditj<sup>4</sup> and are holding discussions regarding the development of post graduate courses.

Aboriginal health worker training has recently been the subject of a review (Health Workforce Section OATSHI):

*Currently a health training package is being developed with funding through the Australian National Training Authority. The expected outcomes of this work include the identification of a framework for skills based on competency standards, improved career mobility, and a flexible and efficient vocational training framework.*

The prospect of a new national framework of competency-based health qualifications offers some significant opportunities and issues for these training providers.

[<http://www.health.gov.au/oatsih/pubs/trainpk.htm>]

#### 7.4.5 On-line training and tele-health

On-line education in palliative care was reviewed in Palliative Care Australia Summer Edition 2001 (Education in Palliative Care). The review did not reveal many specific on-line palliative care courses, though the point was made that most universities tend to design courses for flexible delivery. The article mentions the Australian Catholic University's new on-line units (two units) in its post-graduate course.

A palliative care educator (rural and remote areas) at the Cancer Foundation of Western Australia is based at Cottage Hospice. This Education Centre recently introduced tele-health to provide regular palliative care education sessions, however until now has done no specific training for Indigenous palliative care. The educator believes they could have a role working alongside or with the AMS to develop an appropriate training package. The tele-health service is mostly accessed by medical staff in more remote areas who have no other access to training.

The Royal College of Nursing developed a Distance Education Palliative Care course for enrolled and registered nurses which was run once. The College believes this course could be successfully modified for delivery to Indigenous health workers.

#### 7.4.6 Volunteer training

Various courses are available for volunteer carers, though we have not identified any which are specifically designed to be culturally appropriate for Indigenous carers.

One of the roles of the mainstream Kimberley/Pilbara Palliative Care Network is to coordinate education for the region as a priority at both the community and professional levels. They have conducted community forums on death and dying, held talks for community groups, and organised displays, newspaper articles, radio sessions, visits to Aboriginal communities and participation at regional aged care workshops.

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<sup>4</sup> Marr Mooditj is a major provider of Health Worker training in Perth.

#### 7.4.7 Training for service providers in delivery of palliative care to Indigenous clients

We have not identified any of this type of training. Many nursing courses and palliative care courses contain some elements of cross cultural training however we understand that these are not intensive and do not specifically deal with Indigenous issues. The Australian Government funded the National Guidelines project will provide some materials for this purpose. Mungabareena Aboriginal Corporation and Wodonga TAFE, in association with Mercy Health Service, are working together to produce national guidelines for service providers who provide palliative care to Aboriginal and Torres Strait Islander peoples.

The overall aim of this project is to help palliative care professionals to provide culturally appropriate palliative care to Indigenous peoples and communities. As well as the national guidelines, the project will produce a national education and training resource, and recommendations on how the guidelines and education and training resource can be implemented. The education and training devised will be nationally accredited and will support the philosophy and principles of palliative care practice. The project will use the findings of this study and other research.

### 7.5 Training Indigenous staff

There are very few Indigenous staff formally working in palliative care. These include one AHW in Mount Isa and one in the Top End Palliative Care Service. There is one ALO in the Domiciliary Care service in Adelaide, whose work is not exclusively with palliative care clients. There is one Indigenous nurse (Indigenous Clinical Advisory Nurse) in Royal Perth Hospital who works with palliative clients, though not exclusively. The work of other Indigenous staff who work informally or more peripherally with palliative care clients is described in Chapter 6. No training programs are currently available for these staff.

Given the enormous stresses communities are under due to their primary health status and because of the impact of sudden death, education and training about palliative care may not be a high priority for some Indigenous health providers. While the need for trained Indigenous staff in this area is recognised, it is not the highest priority. Palliative care was not identified in any of the regional plans prepared in relation to the Primary Health Care Access Program (PHCAP). One informant who had been involved in the development of such a regional plan said that was not because there were no needs in relation to palliative care, but that '*palliative care was not in people's consciousness*', and so was never considered.

#### 7.5.1 Post graduate training for AHWs

There is clearly a need to involve Indigenous people in palliative care service delivery. Indigenous people should be employed in various ways, including:

- as development staff (to monitor and improve the services of palliative care providers such as domiciliary nursing services, hospices etc.);
- to accompany home visits to provide cultural and medical advocacy;
- to liaise between AMSs and palliative care service providers;
- to assist service providers to coach families in providing care at home; and
- to support families through grief and loss in a number of ways, including assisting with funeral preparation.

In order to perform these roles Indigenous staff need training in aspects of palliative care and in grief and loss counselling. Discussions with some AHW education providers raised the possibility that the most appropriate way to accomplish this might be to develop a post graduate Certificate in Palliative Care and or a post graduate Certificate in Mental Health (Palliative Care).

Some work has already begun at an undergraduate level. The Cancer Foundation of Western Australia (Cottage Hospice) Education Centre has run a training program for care aides and personal carers from Marr Mooditj.<sup>5</sup> Both Marr Mooditj and the Education Centre thought that this had been very successful and discussions have been held about working to:

- integrate palliative care component into the Health Worker Certificate 4 training;
- develop a post graduate diploma in palliative care in health worker training; and
- integrate a palliative care/bereavement/grief and loss component into the Diploma in Aboriginal Mental Health or develop a separate diploma focusing on this.

A number of people spoke of the importance of trying to deliver AHW training locally so that local people can be trained to work in their own community. An Aboriginal medical service representative said that:

*Any palliative care training needs to be local because we want to ensure that Aboriginal people are trained to be able to deliver services. There is such a high turnover of non-Indigenous staff, by employing and training local people, the project won't stop. [remote town in Western Australia]*

This was suggested even though it appears that in some areas employing AHWs from outside the community may be important in avoiding blame and payback. Fried (Fried 2000) also writes of the importance of training local older people in their own setting.

### 7.5.2 Need for more Indigenous nurses

Many people spoke of the need to have ‘*more black faces*’ in hospitals and for medical advocacy – ie, someone who is culturally attuned and who can also understand the medical issues involved. Every effort should be made to encourage and fund the training of Indigenous nurses.

### 7.5.3 Qualifications and training for ALOs

The findings reported in Chapter 6 suggest that the role and qualifications of ALOs should be examined to ensure that they have appropriate skills, working hours and support to undertake the work asked of them. All ALOs, whether they have a social work background or an AHW qualification, should have an understanding of palliative care (see above Sections 7.1 and 7.2). If these positions are to be part of or brokered into palliative care services, then they need adequate training in palliative care and relevant training to enable medical and cultural advocacy.

### 7.5.4 Aids in nursing (AIN) training

Aids in nursing are often employed in nursing homes. The director of an Aboriginal nursing home suggested that AIN training should also include a component on palliative care. This would raise staff awareness of issues and may equip these staff to be more supportive to family and patients.

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<sup>5</sup> Marr Mooditj is a major provider of health worker training in Perth.



### 7.5.5 HACC workers

Palliative care should be included in Certificate 3 courses for HACC workers.

### 7.5.6 Psychologists and grief and loss stuff

The need for trained Indigenous psychologists and counsellors is discussed above in Chapter 5, Section 5.5 (*Counselling and Bereavement Care*). Consideration should be given to providing special scholarships for Aboriginal and Torres Strait Islander people to undertake psychology degrees. The AHW Mental Health Diploma should also be reviewed to include a component on palliative care and bereavement.

### 7.5.7 Cultural and/or linguistic interpreters

Cultural or linguistic interpreters should undertake orientation training in the principles of palliative care and the importance of respecting and reporting individuals' wishes in the palliative care context, irrespective of the cultural norm.

### 7.5.8 In-service and other training measures

Palliative care units could explore opportunities for delivering in-service programs to AMSs and other relevant service organisations.

For example, the palliative care unit at a base hospital in Queensland called a meeting with local Indigenous health workers and asked them to complete a questionnaire about how they could improve their service. They requested education specifically for Indigenous workers. The hospital is about to begin a program of getting the email addresses of the Indigenous health workers and encouraging them to email requests for information. The CNC's response will be emailed back to all health workers.

Given that curriculum development takes time, it may be useful to examine existing courses, such as the TAFE Volunteer training programs or the five day training programs in palliative care delivered by RDNS in Adelaide, to see if they would be appropriate (with or without modification) for AHWs or ALOs employed to work in palliative care.

## 7.6 Education and training for other health professionals

### 7.6.1 Education of GPs and medical specialists

The need for GP education about palliative care is well recognised. GP education programs should be encouraged and should be expanded to include: cultural awareness information or training about 'giving bad news'; the need for cultural advocates; and that assumptions about Indigenous people's wishes should be avoided.

We were often told that oncology specialists, renal specialists and others are not as aware or supportive of palliative care as they should be. These specialists would also benefit from training in how to 'break bad news' and how to involve cultural advocacy for clients and families at critical times. In remote areas there is a constant training need due to the high turnover of doctors.

All palliative care service providers thought there was a need to train general practitioners in palliative care, what it can offer, how it can be delivered and how it may be made suitable for Indigenous clients. The comment that '*GPs are not very available and not very skilled*' was made. Some GPs are very knowledgeable and skilled in palliative care, but these are in the minority. Palliative care educators say that when they run programs for GPs they are usually attended by those who have already had training: '*We are preaching to the converted.*'

One GP spoke about her work with Aboriginal clients: '*We do our own palliative care...*' GPs appear to be reluctant to use palliative care services and many do not have a good understanding of what is offered.

In particular, GPs need to be trained to offer a range of choices to all clients, rather than assume that Aboriginal people will not want to access mainstream services, and to seek out appropriate Aboriginal liaison support.

### 7.6.2 AMS Doctors

Like other GPs, many AMS doctors are generally uninformed about the nature and benefits of palliative care services. By their own admission they do not make use of these services (where they know of them) because of a belief that clients may not wish to use them. (see Chapter 4). GPs in general require information and training about palliative care and this special sub-group of GPs could be specifically targeted.

There are opportunities for OATSIH, NACCHO and the College of General Practice to work together to develop and provide training programs which inform GPs (and AMS doctors in particular) of the services and benefits of palliative care, to suggest strategies for working with palliative care service providers to deliver an integrated and sensitive service to Indigenous clients.

### 7.6.3 Nursing homes and aged care facilities

The findings reported in Chapter 5 point to the need for the development of strategies, including funding strategies, to encourage more in-service training and to facilitate the release of staff to undertake specialised palliative care training and cultural awareness training.

### 7.6.4 Community nurses

Generalist community nurses often provide services to palliative care clients, calling in a CNC only when necessary. All community nurses should undertake cultural awareness training specifically designed for people delivering services in the home. Community nurses should also have some palliative care training. They are in a unique position to identify clients in need.

### 7.6.5 General nurses

Undergraduate courses could include material to increase awareness of palliative care and cultural issues, and training in when palliative care specialists and cultural advocates should be called in.

### 7.6.6 Training for decision makers

An AMS staff member in the Northern Territory suggested that administrative staff also need training: *‘organisations can’t make management decisions relating to palliative care unless they understand about palliative care – organisations need to be resourced properly to address palliative care issues. If positions are unsupported staff will not be willing to stay.’*

### 7.6.7 Awareness for other Aboriginal and Torres Strait Islander health professionals

The peak organisations representing other Aboriginal and Torres Strait Islander health professionals such as nurses, psychologists, social workers and doctors should be engaged to assist in the information strategy.

## 7.7 Cultural awareness training

*The major outcome of cultural awareness training should be to have service providers listen to what they are told and really hear it. Teaching people to develop the skills of listening and hearing is as important as cultural awareness.* [community member in Perth]

### 7.7.1 Not enough cultural awareness training

Despite the fact that cultural awareness training is mandatory in many state health systems (eg New South Wales) the view of ALOs, community members and Aboriginal health workers is that it is very inadequate. The training is generally very superficial (sometimes only 15 minutes in a general induction program) and even where there are enough programs available, they are not taken up at adequate rates (for example, staff shortages may mean that people cannot be released from duties). In some places where additional training has been delivered (such as the ICU of a western Sydney hospital), improvements have been marked, with staff becoming far more accommodating of the needs of Aboriginal people at the time of death.

Training does not appear to be mandatory in some hospitals. The palliative care team in one Perth hospital were unaware of any specific cultural awareness programs, though they thought that most of their staff would have *‘picked up a day here or there’*.

High staff turnover is a major problem in many hospitals: *‘As soon as you get some staff trained they move on.’*

In hospitals in remote areas such as Kalgoorlie, a very high number of agency staff are used because of staff shortages and these are often foreign nurses who have received no Indigenous cultural awareness training at all.

*One of the major problems however is that there is a very rapid turnover of staff. Most of the nurses at the hospital are agency staff and they are there on a short term basis. They all need additional training and they are not here long enough to develop experience. Many of the agency staff are from overseas – so they really need cultural awareness training. There is a need for better orientation for short term staff – a day’s training would be time well spent.* [local doctor]

Most home nursing service staff (eg Blue Care) have not had any cultural awareness training or have not had Indigenous-specific training. This is especially problematic when they are caring for clients in their own homes.

The perspective of an AMS in the Northern Territory is that palliative care team members need greater awareness and the ability to engage with the family so as to involve them in the care. Service providers also need to have ongoing interaction with cultural leaders in each local community, not just generalised 'awareness' courses.

### 7.7.2 Cultural blindness

Palliative care service providers need to acknowledge the difficulties inherent in cross cultural communication and take opportunities to develop awareness of their own attitudes and values and how these may differ from that of their clients.

*The 'culture' which informs our thinking and world view includes our gender and many other aspects of our background, personal experience and professional socialisation. We become relatively blind to the ways in which our experience differs from that of others. The wider the 'cultural gap', the more likelihood there is of communicative distortion when we attempt to cross that gap. [(Fried 2000) p110]*

Cultural awareness training is a first step. Cultural awareness training really needs to go beyond 'awareness' to deliver cognitive change resulting in changed behaviours and effective cross cultural practice.

### 7.7.3 Course intent and content

Generalised cultural awareness training is inadequate to equip palliative care workers for the cross cultural practice they engage in with both Aboriginal and Torres Strait Islander clients and other culturally and linguistically diverse groups.

Cultural awareness courses should be tailored for palliative care workers and should provide:

- a learning environment in which participants can candidly review their own beliefs, value systems and communication practices as a basis for acknowledging and accepting other world views;
- more information about Aboriginal and Torres Strait Islander death and end of life issues (ie a course especially developed for palliative care workers);
- more information about how to establish contact and build relationships with Indigenous organisations, communities and individuals;
- more about the limits and dangers of cross cultural communication, especially in the context of unequal power relationships (such as Indigenous versus non-Indigenous status, health system versus patient, expert versus family). Courses should emphasise that participants should be aware how little they know;
- emphasis on the cultural variations that may exist within an area or region. Some hospitals, such as Royal Perth, employ Indigenous people for three major Aboriginal cultural groupings, as well as Torres Strait Islanders; and
- resulting in cognitive change.

Generalised courses are often inadequate preparation for dealing with the particular culture of the area in which one is working, and especially with the complexities of communicating about end of life issues. An AMS perspective in the Northern Territory is that palliative care team members need greater awareness of local issues and an increased ability to engage with the family to involve the family in the care.

Courses should aim to improve competency in effective cross cultural practice. This will require the delivery of cognitive change, rather than mere 'awareness' Research into the competencies required for cross cultural practice and a review of the effectiveness of current cultural awareness training in health systems would be timely.

#### 7.7.4 Context of cultural awareness training and worker exchange

Several AMSs suggested that cultural awareness training should take place in the local AMS or in an Aboriginal community organisation. It should take place on 'Aboriginal turf'. Opportunities for work placement (work experience) in Aboriginal health organisations should also be pursued.

#### 7.7.5 Resources and skills available for training

Delivery of effective training for cross cultural practice requires adequate time and the service of a skilled trainer.

Aboriginality is not a training qualification *per se*. The task of leading people to a consciousness of their own beliefs and values – a starting point for beginning to understand the values and beliefs of others – requires considerable training. It is unfair and unrealistic to expect junior staff such as ALOs to attempt such a task unsupported by qualified trainers.

#### 7.7.6 Cultural awareness and assertiveness training for Indigenous staff

Indigenous staff working in mainstream organisations may need some cultural awareness training to inform them of the social and cultural context in which they will operate.

In some areas, Indigenous staff also need cultural awareness training. For instance in Perth most of the Indigenous staff are Noongars, and need orientation for Wongi and Kimberley Indigenous cultures.

#### 7.7.7 Not a substitute for Indigenous staff

Cultural awareness training should not be seen as a substitute for the employment or brokering in of Indigenous staff. Conversely, employment of Aboriginal liaison staff does not abrogate the need for cultural awareness training and cross cultural communication skill development. ALOs and AHWs are too often left to bear the burden of communicating complex western or medical concepts to Indigenous clients. All members of the team need to work together as a team to bridge the cultural divide.

## 7.8 Volunteers programs and support groups

### 7.8.1 The role of the volunteer

Nearly all home-based palliative care services and some residential palliative care units have volunteer programs. The role of volunteers ranges from the 'caring neighbour' role (keeping company, helping with transport, occasional shopping, and supportive listening) to a greater focus on bereavement care.

### 7.8.2 Coordination and training of volunteers

Most programs employ a full or part-time paid coordinator and offer training programs that range from 24 to 40 hours, given either in a week long block or for several hours a day over several weeks. Some training programs are conducted by TAFE. Most include information about the nature of palliative care, the course of death, the nature of grief and loss, reflective listening skills and occupational health and safety issues. Volunteers and their co-ordinators should have cultural awareness training.

### 7.8.3 Recruitment of volunteers

Recruitment of volunteers is usually done by advertising and screening. Some are recruited from experienced hospital based volunteers. None of the services we spoke with had recruited or aimed to recruit Indigenous volunteers.

### 7.8.4 Volunteer manuals

One volunteer group uses a *Volunteer Training Manual*, by P.A. Gallasch, which was developed and trialled as part of a national palliative care grant secured by the Murray Institute of TAFE. The manual does not include information about providing palliative care in a cross cultural environment.

Volunteer manuals need to be revised to include sections on working in cross cultural environments.

## 7.9 Aboriginal views about volunteers and support groups

Most of the community members we spoke with thought that it would be a good idea to have some community members 'trained up' so they could help. Some thought that support groups of people who had been through the experience would be more useful. Community members in a remote town in Western Australia were keen to develop such a support group, and the idea was also raised in Queensland and South Australia.

Some people thought that volunteers gave better care than nurses because they were more committed.

Only one person we spoke with had had a volunteer to assist her while she was looking after a dying family member. She had found it very useful, however after some months the volunteer had been unable to continue for personal reasons.

Few Aboriginal people would be able to volunteer in the same way as those who are generally involved in volunteer programs, who are in a position to volunteer their time free of charge. Most Aboriginal people need to work and have many family commitments already. There is also an underlying feeling that

people should not be asked to provide services for nothing and should be paid. Nevertheless, many community members expressed the view that '*it would be good to have some people trained up*', because although they do not have 'free time' to enter into volunteering programs, the reality is that they often help out family and friends within their close knit community in a way that does not often occur in mainstream communities. Lack of access to vehicles and disposable income would limit the volunteer activities that could be undertaken. In Perth people said that they thought it would be good to develop a 'home visiting group'.

If attempts were to be made to recruit Aboriginal or Torres Strait Islander people into mainstream volunteering programs, 'word of mouth' would be the most effective approach to recruitment, and special attention would need to be paid to arranging a 'buddy system' for training programs so volunteers would not feel isolated in a largely non-Indigenous environment. Training courses may need to be modified in some areas to accommodate literacy and education levels of participants. There may be scope for Indigenous participants to educate their colleagues in Indigenous perspectives of care.

### 7.9.1 Informal volunteering

In the Torres Strait we spoke with a woman who had cared for three family members who had died from cancer. The informant works in an ancillary service at the hospital. No information or advice about palliative care is available on the island and because people know her interest they seek out her advice about what they can do, what sort of food can be eaten, and so on. She says the hospital is unaware that she provides this advice.

## 7.10 Findings and implications

Employment and training of Aboriginal and Torres Strait Islander staff to work in palliative care should be a central and immediate target at all levels. Palliative care services need to employ trained Aboriginal and/or Torres Strait Islander staff to assist in the development of their services. These positions are needed at State level (in government and/or in Palliative Care Associations) and in services in regions with high Aboriginal and Torres Strait Islander populations.

### Awareness at policy level

Policy makers at State and Australian Government levels should be encouraged to consider and incorporate palliative care for Indigenous clients in policy and funding documents (eg State / Indigenous health partnerships, state strategic plans and OATSIH funding formulas). The challenge here is not only to raise awareness of policy makers about palliative care for Indigenous peoples but to do so in such a way as to ensure that local Aboriginal communities will be engaged in advising on their particular needs. Decision makers in ACCHS and State-run Aboriginal and Torres Strait Islander Health units must be specifically targeted. (See further Section 7.6.6).

### 7.10.1 Information for the community at large

Most Aboriginal and Torres Strait Islander people and Aboriginal and Torres Strait Islander service providers (AMSs, HACCs, CACP and AHLOs) are not aware of what palliative care is or what services might be available. Information strategies are needed which address these issues.



For community information, ‘word of mouth’ strategies are best and AHWs, ALOs and HAACC workers will be the key to the success of such strategies. Introduction of information about palliative care into undergraduate training programs for these workers will assist in the long run, and in the short term, other information strategies should be developed. Finding ways to encourage people to tell stories of good service, arranging information days and ‘yarning’ sessions were some of the strategies suggested to reach the community (see Section 7.1).

Communication strategies for Aboriginal and Torres Strait Islander communities and for decision makers working in Aboriginal and Torres Strait Islander health should be developed.

### 7.10.2 Information for Indigenous clients

Aboriginal and Torres Strait Islander community members who had experienced palliative care clearly identified the kinds of issues about which they wished they had received more information, and indicated that the earlier the information was available the better. As well as information about the range of services available (including Indigenous specific services), the clearest need was for the kind of information that has been provided in the *Palliative Caring at Home* booklets produced by the South Australian and Western Australian Palliative Care Associations (see Sections 7.1 and 7.2). These booklets could readily be reviewed and revised to meet this need.

### 7.10.3 Information exchange between mainstream and Indigenous health care providers

Mainstream and Indigenous health providers tend to work ‘in parallel’ and they often do not relate to each other. They may be unaware of how the other providers operate, what services they provide, and how they could work together (see Chapter 4, Sections 4.3 and Section 7.3 above). Initiatives which build relationships between all relevant service providers should be pursued.

Local planning workshops are needed so that Indigenous health and home care services can find out what palliative care services do, and vice versa, and then work out how best they can work together. Local colleges of GPs should be involved in these workshops.

There is a need to raise the profile of mainstream service providers in the Indigenous community, including naming specific individuals as contact people for Indigenous clients and services, so that relationships can be developed and so that people can get to first base in developing care planning. Such relationships currently do not exist in most places, however before partnerships can develop basic relationships need to be in place to establish a basis for trust (see further Chapter 5, Sections 5.4.2 and Section 7.3 above).

A number of protocols then need to be developed on a local and regional basis to allow adequate care planning to develop (eg see guidelines in Appendix 12).

### 7.10.4 Education and training programs

#### **Lack of palliative care training**

There is an urgent need for development and provision of training for Aboriginal health workers – for example, including a component in undergraduate courses; creating post graduate certificate courses in palliative care and in mental health and bereavement (see Section 7.5).

There is an urgent need for trained Indigenous psychologists and mental health workers to provide support or counselling in grief and loss (see Section 7.5).

#### 7.10.5 Training for Indigenous staff

Indigenous health workers (Hospital ALOs, Aboriginal primary health workers and HACC workers) need training and awareness programs about palliative care and palliative care services in their State and their own region (see Chapter 6 and Section 7.4). Other Aboriginal and Torres Strait Islander health professionals including nurses, psychologists and doctors may also benefit from such programs.

The peak organisations representing Aboriginal and Torres Strait Islander health professionals such as nurses, psychologists, social workers and doctors should be engaged to assist in an information strategy (see further Section 7.6.7).

Aboriginal health worker undergraduate training needs a palliative care component to explain what palliative care is and to explain what services are available in each State. (see further Section 7.1.3).

Aboriginal and Torres Strait Islander community controlled health organisations (and other Aboriginal and Torres Strait Islander health services) need education about palliative care and its benefits, and how they can get help from palliative care specialists for their clients (see Section 7.6.2 and Chapter 4, Section 4.3.2).

There is a defined need for a post graduate Certificate in Palliative Care for health workers and a need for a component on grief and loss associated with palliative care in the Mental Health Certificate (see further Section 7.6.1/2).

#### 7.10.6 Education and training for other health professionals

##### **Education of medical practitioners and health services**

Professional development curricula for GPs, nurse practitioners and registered nurses in the Aboriginal and Torres Strait Islander health sector need to include issues related to palliative and bereavement care. For GPs this could be facilitated through CME programs coordinated by professional colleges, and for nursing graduates, through the development of specific post graduate certificate level courses. A specific module on Indigenous issues in palliative and bereavement care should be included in undergraduate training curricula for all doctors and nurses as part of their education in Indigenous health.

Mainstream palliative care workers need specific cultural awareness training, tailored for palliative care workers, which will translate into effective cross cultural practice and competence. Cultural awareness courses for palliative care workers need to be revised to deal with issues of death and dying for Indigenous people and to provide safe learning environments where practitioners can review their own belief and value systems and communication practices. Professionals delivering care at home need special skills in developing relationships with the local Indigenous community and with individual clients. This is critical given the high frequency of late referral of Indigenous clients to palliative care (see further Section 7.7).

In the first instance, this education might look at basic issues of developing cross-cultural partnerships with Indigenous organisations in the community. Such education could be attended by both mainstream palliative care organisations and Aboriginal and Torres Strait Islander health services in each local region.

General practitioners (GPs) and specialist doctors may not be aware of palliative care services and the associated benefits to their patients. Education is needed to increase doctor awareness and encourage earlier referral to palliative care. Referral to palliative care does not have to mean that the GP stops caring for the patient (see Section 7.6.1 and Chapter 4, Section 4.3.2).

#### **GP and AMS doctor education**

It is extremely important that GPs who work with Aboriginal and Torres Strait Islander clients<sup>6</sup> have the opportunity to learn more about palliative care and cultural issues surrounding death and dying. It is important that AMS doctors come to see palliative care as a special service which they can access for their clients and in which they can take a central role. It is suggested that a CME package (Continuing Medical Education) on these issues be developed for GPs. Assistance might be sought from the College of General Practitioners to sponsor such programs in areas of high Aboriginal and Torres Strait Islander population.

#### **Professional awareness**

Strategies aimed at government and community-controlled Aboriginal health services to develop the awareness of health professionals working in them (doctors, nurses and health workers) about palliative care are needed. These groups should be specifically targeted and included in programs such as GP palliative care education. The support of NACCHO, OATSIH, and bodies such as CATSIN and AIDA should be enlisted (see further Section 7.6).

#### **7.10.7 Cultural awareness training**

All palliative care workers and community nurses should have regular cultural awareness training and related work experience opportunities to develop competence in cross cultural communication. Cultural awareness training needs to be developed to deliver effective cross cultural communication and practice as well as to deal with issues specifically related to Indigenous death and dying. Cultural awareness training of hospital staff should be reviewed and improved, especially where large numbers of agency staff are used in areas of high Aboriginal and Torres Strait Islander population (see Chapter 7).

The effectiveness of cultural awareness training needs to be reviewed and competencies in cross cultural communication and service delivery developed and delivered (see Chapter 7).

#### **7.10.8 Volunteer programs and support groups**

A number of Aboriginal and Torres Strait Islander people spoke of their desire for support groups for families coping with the life limiting illness of a family member. Some were interested in becoming volunteers within their own communities. No mainstream volunteer programs have previously recruited within Indigenous communities. There is scope for these programs to be made more effective, however coordinators of volunteer programs would need cultural awareness training and guidance from Aboriginal and/or Torres Strait Islander advisors about recruiting within Indigenous communities (see further Section 7.9).

It appears that the sort of training available to volunteers could be easily adapted and upgraded for delivery to AHWs and enrolled nurses.

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<sup>6</sup> including those who work in ACCHS or AMSs, and those who work in regions with high Aboriginal and/or Torres Strait Islander populations.

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# Chapter 8

## Some aspects of good practice



### 8.1 Introduction

As outlined in Chapters 2 and 4, there are few, if any, Indigenous-specific palliative care services and Aboriginal peoples and Torres Strait Islanders have a low level of access to mainstream services. During the scoping phase and in the field work we sought to discover examples which might be considered to be good practice. We also heard from community members and service providers about the sorts of things that needed to make services more accessible and appropriate to Aboriginal and Torres Strait Islander people. These are described in Chapters 5-7.

In the course of our investigation we discovered aspects of practice which we considered to be innovative or 'good'. This chapter highlights some of these (without going over ground covered in previous chapters) and describes some models of service delivery.

### 8.2 Practice highlights

#### 8.2.1 Palliative care provider as coach

In one palliative care service we found an approach that stood out as being exactly what many Aboriginal and Torres Strait Islander community members were asking for. Here the service providers viewed themselves as coaches for the family, providing them with training and support so that they could look after someone at home. They also provided specialist advice and coordinated other needed services (including access to residential facilities if required). This approach enables family members to feel they are in control of care.

#### 8.2.2 Some key elements of good practice

As outlined in Chapter 5, key elements of good delivery of care include:

- early referral;
- cultural advocacy and brokerage;
- good communication and relationship development;
- clear coordination (e.g. everyone's role is clear);
- regular case management meetings, including cultural advocates;
- continuity of care; and
- flexibility and responsiveness which recognises individual needs.

### Residential or in-patient palliative care

Aspects of good practice in relation to residential settings of palliative care (hospitals and hospices) are detailed in Chapter 5. See also Appendix 8 and Appendix 9.

### Good practice opportunities in regions where passing away at home will present a cultural problem

The need for a comfortable and ‘neutral’ place where people can pass away that is readily accessible to family members, is discussed in Chapter 5, Section 5.3. Three key possibilities were raised:

- the development of care centres separate from hospitals where people and families could come for the terminal phase;
- in remote communities, a room and family accommodation near the clinic that could be used during the terminal phase; and
- public (or Aboriginal) housing authority to make a house available for the duration of the palliation when deemed necessary, so that appropriate care could be given, family members could stay and families would not have to vacate their own home after the death.

### Behaviours

Community members appreciate the kind of behaviour and approach from palliative care service providers given in the following example:

*Dr [ ] ... wanted to provide a better service and wanted the best for everybody. She wanted Aboriginal people to be able to exercise culture. She would sit on the floor, squat down under a tree. While she was working here she kept ALO's informed and would give us all a run down on that person. She attended funerals of patients. [ALO]*

### Bereavement

At one AMS, AHWs were actively involved in assisting families with practical issues at the time of death, for example, working with families to develop the ‘order of service’ and prepare eulogies. This process is an important and practical bereavement support activity which is currently not funded.

In South Australia one palliative care service provider had set up peer support groups as part of its bereavement program. Community members independently talked about the need for these groups (especially for men). Innovations and good practice in bereavement care are discussed further in Chapter 5, Section 5.5.

## 8.3 Staffing and training matters

The need for Aboriginal and Torres Strait Islander staff in palliative care services has been commented upon throughout this report. The study found only two mainstream palliative care services that employed an Aboriginal or Torres Strait Islander staff member. We found AHWs and HACC workers delivering informal services in many areas without adequate training or support. Where Indigenous staff are involved in palliative care service or as hospital ALOs, they are under-resourced and unsupported (see Chapter 6).

In residential care facilities with large numbers of Aboriginal or Torres Strait Islander staff, the atmosphere is noticeably different. In these places the presence of a high percentage of Aboriginal or

Torres Strait Islander workers, both in domestic as well as health professional roles, was important.

Good practice requires:

- employment of men and women of Aboriginal and/or Torres Strait Islander descent;
- that Aboriginal and/or Torres Strait Islander staff are not isolated (ie they should be located in or associated with Indigenous organisations or associated with other Indigenous workers);
- adequate support and supervision, and professional debriefing (especially around grief and loss); and
- appropriate training.

The need for a review of the employment conditions of hospital ALOs was raised with us more than once. Some organisations have flexible award conditions to enable ALOs to attend to cultural responsibilities in 'sorry' time.

Training needs have been outlined in Chapter 7, and examples of training initiatives are given in that chapter.

Royal Perth Hospital has recently made an innovative appointment of an Aboriginal nurse in a position described as Indigenous Clinical Advisory Nurse. Creation of this position recognises the need for a combination of medical and cultural advocacy in the hospital. The position works closely with the palliative care team in the hospital.

An interesting model for improving service delivery was discovered in the position of HACC development worker. In this model a development worker/ALO is appointed to an organisation in a town or region but works across a range of HACC services, providing advice about their service delivery from an Aboriginal or Torres Strait Islander perspective, undertaking hands on liaison and also providing regular cultural awareness training for mainstream services, including provision of information about Indigenous services.

## **8.4 Access and coordination issues**

### **8.4.1 ALO involvement**

We came across several examples where a hospital ALO had been actively involved in promoting the use of hospices and had arranged familiarisation visits to these facilities for community leaders and client families. These activities seemed to have been very successful in promoting the use of the facilities and expanding the choices of community members.

### **8.4.2 Care pathways**

Hospitals with discharge facilitators who involve both palliative care services and the ALO or other cultural advocate are considered to be demonstrating good practice. There are very few of these. Those that also involve the family are even rarer.

The need for some sort of palliative care pathway into which cultural liaison or brokerage could be built was raised by several service providers. Two examples of pathway development in other (non-palliative) areas were discovered. The Hospital to Home Pathways (HOP) pilot project being run in Adelaide has the goal of:



*Improving the continuity of care for HACC eligible patients of The Queen Elizabeth Hospital (TQEH), by developing, piloting and evaluating a collaborative and effective pre-admission and discharge planning process with Metropolitan Domiciliary Care – Western Region (MDC–WR), Royal District Nursing Service (RDNS), Adelaide Western Division of General Practice (AWDGP) and the Centre for Allied Health. [HOP Project Plan August 2002]*

This project targets Indigenous clients and builds Indigenous HACC service providers into the loop. The Pathways Committee has a representative from an Aboriginal and Torres Strait Islander service provider.

The second example is the *Management of Diabetes Mellitus in Adults – Queensland Standard Care Pathway* (2000), where the primary care coordinator is the GP or the Indigenous health worker. The pathway documentation includes a wall poster / flowchart. Such a pathway flowchart or checklist, including 'built in' elements of cultural advocacy could be developed for palliative care.

Accessibility and responsiveness of palliative care specialists to requests from AMSs were highly valued where these occurred.

### 8.4.3 Coordination between settings of care

Chapter 5, Section 5.3 described the need for a 'tagging' system to prevent palliative clients receiving inappropriate treatment in emergency wards. Two examples of such systems were discovered. One involved a 'tag' or 'alert sheet' in the hospital file, similar to an allergy tag. The other involved a registration booklet given to the client on admission to the palliative care service which described key features of the care plan, contact details for palliative care team members, and could include the patient's directions regarding resuscitation.

### 8.4.4 Models of coordination

*There needs to be better communication between the service providers about who is dealing with what, eg there should be agreements about communication protocols between the Aboriginal liaison staff of the hospital, the Aboriginal health unit and the domiciliary care and other service providers. In general, more communication is better. Talk to each other and check that the matter is being dealt with appropriately. [domiciliary care worker]*

Models of coordination vary. In many places weekly team meetings between all key service providers are held. Aboriginal or Torres Strait Islander service providers are not usually involved, even when there are Indigenous clients.

In many places, coordination between hospital and home-based palliative care service providers is quite good and care is coordinated by case management meetings. Aboriginal or Torres Strait Islander health service providers and AHLOs are not usually involved, however.

In one New South Wales health service district the community nurse coordinates relationships between service providers. Care reviews and meetings take place on an 'as needs' basis. (Apparently this does not work perfectly because the coordination role of community nurses is sometimes forgotten by the hospital team). There is no regular contact with the ALO and no contact with Aboriginal health organisations except in NAIDOC week. The community health palliative care staff are aware which hospitals have ALOs but have no regular contact with them. Discharge planning had not included the ALO, but this is

changing, and the ALO is now invited to explain palliative care to Aboriginal clients and arrange familiarisation visits to the hospice. This coordination model could easily accommodate involvement of the local AMS on a regular basis, rather than the AMS having to contact the palliative care unit for help on occasion.

In a regional centre in the Northern Territory, the palliative care team and community care team meet with the Aboriginal health service on a monthly basis. The AMS says this team approach works well but could be improved, as it is not clear who is the team leader and it is confusing to clients because three service providers are involved. The AMS also said there is a lack of feedback from each of the organisations.

In another regional centre in the Northern Territory, monthly palliative care meetings also include representatives of Indigenous and non-Indigenous organisations.

The high turnover of staff in small regional towns often means that new staff members may not be aware of local processes. For example when we met with hospital staff in one Northern Territory town, they reported the AMS no longer attended discharge planning meetings and assumed they were no longer interested. When we met with the AMS and mentioned they no longer attended these meetings, the AMS doctor who was relatively new was not aware they had ever attended the meetings.

*A major example of breaking down barriers and building relationships between Indigenous organisations is in [2pop3] region where the [2AB] Cultural Health Service, [2AF] Health Service and the community have recently formed a partnership to provide an integrated, culturally appropriate health care model for the communities of the [major river] Valley in order to avoid duplication of services and to foster continuity of care. [Western Australian regional area]*

Relationships once developed need to be maintained, especially in areas which experience high staff turnover.

There were also good examples of services working collaboratively.

*The mainstream HACC service and Indigenous HACC service often share clients. This sometimes happens when there is a staff shortage (often due to 'sorry business') in the Indigenous service. Recently the mainstream HACC service outsourced four CACPs to the Indigenous HACC service. [Northern Territory]*

## Identified need

An AMS in a metropolitan area would like to work out a way to support the AMS doctor and community nurse to provide palliative care support at home, should they have a client who refuses to be referred to mainstream palliative care services. They reported a case where a client (who would have nothing to do with mainstream services) was dying at home and, at the last minute, the doctor had to go in the middle of the night to access drugs and other needed items (which would normally have been available through the palliative care service). The AMS wanted to know whether a patient could be admitted to a palliative care program without seeing one of the palliative care team? This also raised the question of whether family members could get palliative care support if the patient had refused to see the mainstream palliative care specialists. This latter question was also raised in other places.

### 8.4.5 Opportunities for the funding coordination of service

Enhanced Primary Care (EPC)<sup>1</sup> multidisciplinary care planning involves team-based management of a patient's complex care needs. An EPC multidisciplinary team care plan is a written, comprehensive, longitudinal plan for the care of patients with one or more chronic conditions and complex care needs, developed and managed by a multidisciplinary team comprising the patient's GP and other health and care providers.

EPC items provide Medicare rebates for, among other things, '*care planning and case conferencing for people of any age who have chronic medical conditions and have complex care needs*'. Such case conferencing can lead to better quality of care and better collaboration between doctors and other care providers and is highly appropriate for palliative care clients.

EPC multidisciplinary care planning provides added incentives for GPs and AMS doctors to work with palliative care providers as a member of the care team, since a Medicare rebate is available to the doctor, provided that the client is enrolled in Medicare.

### 8.4.6 Missed opportunities for coordination and cooperation

Several practices or approaches need to be avoided in order to achieve well coordinated services that include appropriate Aboriginal and Torres Strait Islander participation.

#### Rivalry between service providers

We found some examples where 'possessiveness' over clients prevented the delivery of good service. This may take place between GP and palliative care service provider, between hospital and community based service provider, between an AMS and palliative care provider, between consulting oncologists,<sup>2</sup> or even between ALOs from 'rival' hospitals.

#### 'Gate-keeping' by AMSs

Concern for loss over control of the client's interests is said to be one reason why 'gate-keeping' behaviour occurs, although some AMS doctors admitted that it was sometimes based upon an assumption about the wishes of clients (i.e. that the client would not want to use a mainstream service). It is unlikely that this occurs in other fields. Do AMS doctors not refer clients to other specialists, for example to cardiologists, because they are mainstream service providers and their clients may not want to go?

The example of the Queensland doctor (cited in Chapter 4, Section 4.4.1), who did not refer clients to palliative care services because he was under the impression that palliative care was 'life prolonging' and believed that Aboriginal people accepted death with equanimity, is extremely serious. It underscores the importance of training about palliative care for GPs and the need for more robust cultural awareness training so that practitioners will not make simplistic assumptions on behalf of their clients.

'Gate-keeping' behaviour also underscores the need for more trained Indigenous staff who can support clients to access services.

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<sup>1</sup> See the EPC Website at [www.health.gov.au/epc](http://www.health.gov.au/epc) or contact the Medicare Enquiry line on 13 20 11.

<sup>2</sup> In one remote town it was reported that a city-based oncologist from a particular city hospital consults to the local base hospital. If clients have visited a different city hospital and their specialist is unwilling to pass them over to the consulting oncologist, they will miss out on being referred to the palliative care coordinator who gets most of her referrals from the visiting consultant.

### State health boundaries

We found some examples where Aboriginal and Torres Strait Islander clients were not receiving the best palliative care services available because of Health District boundaries. Patients might attend a hospital in one district but live in another and palliative care services may not be coordinated across these boundaries.

#### 8.4.7 An example (recommendation for) of an integrated service

Kirk, *et al* (2000), reporting on a study of breast cancer, recommended that Aboriginal women and Torres Strait Islander women should have equitable access to a range of culturally appropriate palliative care services. Key activities identified to implement this recommendation included:

- women's cancer screening services should work with existing cancer support and palliative care services to identify and develop strategies to improve services to better meet the needs of Aboriginal women and Torres Strait Islander women;
- cross cultural literature and audiovisual material about the later stages of breast cancer and loss and grief should be developed;
- opportunities for existing cancer support and palliative care services should be identified, to improve services to better meet the needs of Aboriginal women and Torres Strait Islander women;
- initiatives of government and non-government organisations need to be supported, for example, the Queensland Health Indigenous Workforce Management Strategy to increase the number of Aboriginal women and Torres Strait Islander women employed in cancer services, including screening, management and treatment, palliative care and support services in order to increase community trust and acceptability;
- the training of Indigenous Health Workers should be promoted and supported, especially in rural and remote areas, in counselling, domiciliary and palliative care; and
- the number of Indigenous health workers employed in palliative care and domiciliary care services should be increased.

#### 8.4.8 Working together – making it happen

At the suggestion of an Aboriginal HACC worker from an AMS in a rural town in Victoria, all the palliative care services in the region came together to develop a set of local protocols or regional guidelines to take account of cultural issues. These draft guidelines are shown in Appendix 12. Newsletter No 3 outlined a process for developing such guidelines.

## 8.5 Standards for the delivery of palliative care

### 8.5.1 Whose standards?

Recently there has been considerable discussion about the development of standards for the delivery of palliative care (see for instance Jellie and Shaw (1999) and PCA *Standards for Palliative Care* (1999)). Development of standards for delivery of care to Aboriginal and Torres Strait Islander clients should be approached with extreme caution. Practice standards must be reviewed to check their applicability to all

Indigenous situations. In some cases the best palliative care for a person may involve their return to an environment which would not be regarded as meeting medical or personal care standards. Practice standards developed must give due weight to emotional, social, cultural and spiritual issues.

Willis (1999) states *'the issue is not simply to modify elements of palliative care so that cultural differences in belief and practice around death are accommodated, but to recognise that different cultures 'do death' in different ways, and that institutions for the provision of palliative care are bound up on the 'way of dying' of the culture in which they originated.'* (p 427). He goes on to discuss the concept of a 'good death' (as defined in terms of modern hospice practice), as opposed to what he terms an 'acceptable death' (p 434) as defined in terms of the desires and expectations of the patients and their families. The implication is that one person's 'good death' may be another person's 'bad death'. Willis also points out that changing minor details of service delivery such as food or the numbers of visitors, or the time allowed for visits (though they may be necessary) are inadequate responses to cultural differences in the underlying assumptions of care.

The setting of standards in relation to these matters is not simple.

Whilst it may not be practicable to set prescriptive standards for the delivery of culturally appropriate palliative care, it should be possible to set standards for appropriate cross cultural communication and practice. These should ensure, for example: effective input into policy and cross cultural practices by appropriate Indigenous organisations; employment or participation of Indigenous staff where possible and appropriate; effective communication between Indigenous and non-Indigenous service providers, and so on. Ultimately the effectiveness of such standards must be determined by consumers – palliative care clients and their families – so observance of these standards would need to be monitored or measured by (culturally knowledgeable) third party interview of consumers.

Objective 2.1 of the *National Palliative Care Strategy* (2000) suggests that resources should be tied to good practice. There is a danger in tying resource allocation to good practice because this may disadvantage those who are already disadvantaged. Where consumers are not well served by existing services, action needs to be taken (and resources applied) to ensure that those services are improved (or replaced) rather than withdrawn because they do not meet standards.

### 8.5.2 Monitoring service delivery

There is a need for effective quality control and improvement. Specifically, mainstream palliative care providers should develop systems to check on the quality of their service to Indigenous clients. Scheduled service reviews, for example conducted six months after a death and using an Indigenous reviewer would be a useful way for providers to discover how their services could be improved.

## 8.6 Some service delivery models

The models described in this section were selected because they are said to work well in the communities where they operate. It is probable that none could be directly 'transported' to another region, however they may contain elements that would be appropriate in other places.

### 8.6.1 Remote community with multipurpose funding (central Australia)

In this model, care is provided in the home by the family with support from clinic staff (doctors, nurses, health workers) with whom the family are familiar. Clinic staff are supported by a specialist palliative care nurse who can provide advice and equipment (mattresses, mosquito nets, etc). When the person is about to pass away the family arranges for them to be transferred to the clinic which has an overnight stay room for the patient.

After the person passes away, the deceased can remain at the clinic mortuary for 24 hours and then must be either buried or flown to Alice Springs (as the mortuary is not suitable for long term use). When funeral arrangements are made the deceased is flown back to the community at the expense of the family. If members of this community have to fly to Adelaide or Alice Springs for treatment, arrangements can be made for a *ngangkari* to visit them. In Alice Springs a community representative liaises with the hospital and patient. People are usually flown back to the community when they are close to death if this can be achieved (this may not always be possible due to limited flights).

Elements of this system that were thought to be best practice were:

- the clinic staff are known to the sick person they are visiting;
- the clinic staff are supported by a specialist palliative care nurse who has access to appropriate (though limited) equipment; and
- the palliative care nurse has access via her network to advice from another palliative care specialist.

The aspect of this system that did not always work well was that there were not always enough family members with the ability to make a sustainable commitment to look after the person. It was very hard on families. The fact that a palliative care nurse was employed in the community was a 'lucky accident' and had not been planned.

### 8.6.2 Aboriginal controlled medical service in rural-regional setting with registered nurse and HACC worker

As well as town-based clients, many Indigenous people from throughout the region (often travelling long distances) come to this rural town for health care.

HACC workers provide home care, cleaning and linen for clients who need palliative care at home, while the medical centre nurse looks after medical needs. The nurse is always accompanied by an Aboriginal worker. There is no special funding for this.

Weekend work is not funded. If the nurse or HACC staff give their phone number for contact over the weekend, they provide the additional service in their own time.

The Aboriginal housing and hostels unit arranges accommodation for clients from out of town but often there is no furniture for them. HACC workers will often try to help with this.

Although there is a hospital in this centre, some Indigenous people do not like to go there. A mainstream palliative care team operates out of the hospital. Many Aboriginal people prefer to attend the AMS rather than go to the mainstream service where they often have communication problems. People especially don't like going to the palliative care room where people have died.

Patients from out of town would usually prefer to go home but there is often no hospital or no culturally appropriate facility where they live and their families may not feel able to provide care. There is no funding for transport for people to go home.

We were told by an Aboriginal health worker that:

*Some time ago, an old man from out of town died. The senior men from that town came in and wanted to blame the medical centre staff – it was very difficult but it was all right in the end. There hasn't been any more of that sort of trouble, but the accountability put on Aboriginal workers is a constant pressure.*

*Palliative care is added on to what you can do. There is no funding for it. We should be able to provide 100% care not 50% care. [AHW, South Australia]*

### 8.6.3 City hospital with Aboriginal liaison officer (ALO)

The ALO in this hospital provides a number of services:

- assists with communication and explaining medical terms, helping with travel arrangements for family and extended family;
- arranges appropriate space in the hospital to accommodate family visitors;
- ensures there is a culturally sensitive environment for children and family that allows for their cultural practices (many patients come from remote and traditional communities);
- coordinates with the local community to find appropriate accommodation and support for families visiting from outside the metropolitan area;
- makes contacts to arrange for appropriate mortuary and funeral arrangements; and
- puts families in touch with a range of mainstream services if they want to access them.

### 8.6.4 Metropolitan Indigenous aged care facility with flexible funding

This facility has 'high care' and 'low care' beds and will be gaining some community aged care packages. It is flexibly funded and so can provide some palliative care for residents who are approaching death, although this stretches available resources.

The facility is not funded for the additional nursing care required when people need high level pain management or other palliative care. Housing and accommodation for family members, many of whom come from some distance, also stretches the resources of the facility. Although as much palliative care as possible is offered, people usually pass away in hospital where they are moved at the last minute.

This service identified certain dilemmas and needs. They do not want to use the label 'palliative care' because it is like making a decision that people will die. They need extra resources to help clients through this time at the end of life, but they want to build it in without labelling it. This is a cultural issue. There may also be a dilemma about the legitimacy of this use of funds and so a reluctance to raise it with funding bodies. A possible solution suggested by the service provider is to develop a relationship with an existing mainstream palliative care provider that could provide the extra medical support for their clients.



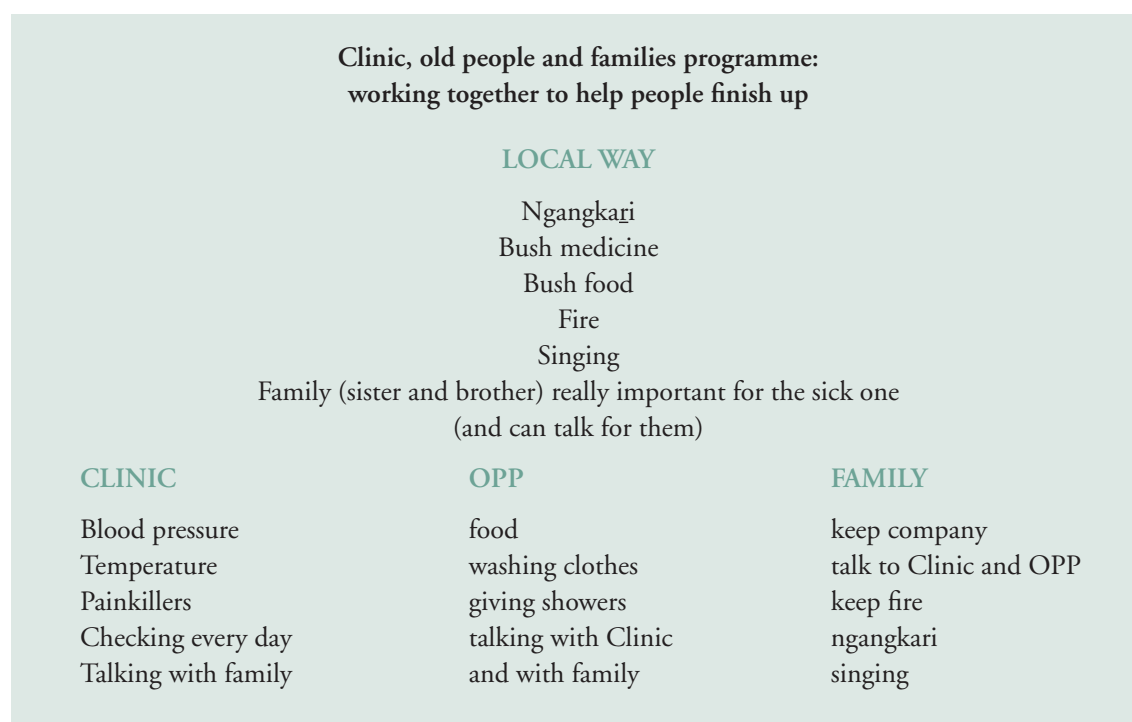
### 8.6.5 Metropolitan community-controlled health centre working with a mainstream service provider

This metropolitan health centre has been actively involved in the palliative care of several clients in recent years. They have played a key role in explaining palliative care options and available services to clients and their families. While the centre staff are as involved as they can be, and recognise the importance to the client of a familiar provider, they have been instrumental in facilitating the use of mainstream service providers. They have worked with the Royal District Nursing Service (RDNS), which has an Aboriginal liaison officer, to provide appropriate care and support. This was essential because the community controlled health centre is a 9.00 – 5.00 operation.

This organisation has identified the need for an Indigenous coordinator attached to their centre who can assist with communication and liaison between the centre, the client and the mainstream provider. As well as providing information about palliative care and what it can offer, the liaison officer would need to build trust and facilitate the development of a relationship between the family and the service.

### 8.6.6 A Northern Territory model

In the model depicted on the following page, the people in a large remote community describe how the clinic, the aged care program and the family work together to provide care according to local traditions. The diagram and notes presents the model as the community see it.



The following are the principles involved in palliative care as identified by this community:

**Finishing up when people cannot get better**

- Old people and sick people need to pass away in their own country with their own family
- It is really important people be brought home to finish up. Families need to gather, camping around and say goodbye
- Really important people stay at home and doctors and nurses don't send them last minute to hospital
- Airplanes are really frightening for old people
- We don't like seeing our old people going through cruel things like kidney machines
- It is not right for our people to have tubes and too much different medicine at this time
- People need help to settle down properly and be happy – it is important they have no pain, pain medicine is all right
- It is important in our way that we see the passing with our own eyes

### 8.6.7 The empowerment models – remote communities

#### **Northern Territory**

The Central Australian Territory Palliative Care service provides a model of empowerment. It offers education and support to health clinic staff in remote Indigenous communities who carry out most of the day-to-day care of clients and advises on symptom management. This model allows local staff to work out local solutions and relies on the health clinics and aged care workers to work closely together with the client, the traditional healer and the family.

#### **Western Australia**

Because of the vast distances, scattered population centres and the difficulties some communities have in accessing medical services, the palliative care network developed a decentralised model for the delivery of palliative care. Local medical practitioners and hospitals in larger centres are responsible for primary medical care and the community nurses and Aboriginal health workers are responsible in remote centres. Because of the wide cultural diversity of Aboriginal groups throughout the region they have developed a flexible model to accommodate local cultural and social needs.

### 8.6.8 Two case studies from central Australia

The Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council (NPYWC) provided the following case studies. They illustrate how communities deliver palliative care services without palliative care funding.

### **Mutitjulu Disability House 29.04.01 – 03.06.01**

*A frail aged man at Mutitjulu who was wheelchair-bound was in Alice Springs Hospital and returned to his home at Mutitjulu. The family had a meeting with the clinic at Mutitjulu and he decided that that if he got sick again, he didn't want any invasive treatment but antibiotics were OK, and that he didn't want to be taken back into Alice Springs. If he was to get very sick and pass away he wanted to be in the community where all his family were.*

*His carer was finding it difficult to look after him as his health was failing and winter was approaching. His house had no heating and he was sleeping in a room with many other people. They decided he should go to Hetti Perkins in Alice Springs for respite. There were no beds available and he did not want to go to Alice Springs. He wanted to stay close to family members in his home community, Mutitjulu.*

*His carer suggested he stay at the Mutitjulu Disability Respite House (MDRH) where he could have a room to himself and paid carers but still be in his home community. His granddaughter and her husband came along to the house and acted as primary respite carers.*

*The MDRH is primarily a respite facility for people with disabilities but can cater to frail aged people when needed. Under normal circumstances respite is restricted to two weeks. He stayed at the house for five weeks.*

*One morning he had a talk with his family and told them how he was happy and knew that his family would be OK. He also had conversations with his family with regards to his possessions. He requested that the MDRH not be closed for an extended period and for the family to continue to live in his house and that only his personal possessions are destroyed.*

*He passed away a few hours later.*

*The house was closed for one week out of respect.*

Funding for this respite opportunity came from NPYWC Cross Border Carer Respite Centre.

### **Palliative care case study AP lands**

*In December and January of 2000/1 the NPYWC Aged Care Support Project for AP lands (the project) was able to facilitate the provision of palliative care for a frail aged client on the AP lands.*

*With an elderly and sick husband and no other appropriate family to care for her, Nganampa Health clinic staff had sent our client to Alice Springs Hospital (ASH) for observation. The project liaised closely with our client and her husband, with ASH and Nganampa Health staff, and ascertained that her condition had progressed to a palliative care situation. Her wish, and that of her husband, was that she return to her community and be attended there by clinic staff. Unfortunately, the inappropriateness of her usual accommodations, a swag on the ground under a makeshift wiltja, and the staff shortage at the community clinic over the Christmas period, meant that the clinic was unable to ensure an appropriate quality of care on her return to the community and therefore recommended against it.*

*The NPYWC project staff worked quickly to negotiate a solution to this situation. We were able to employ a qualified and appropriate care attendant through a nursing employment*

*agency, who was willing to travel with our client and project staff from Alice Springs back to the Lands. We were able to locate temporary accommodation in a neighbouring community where our client's husband had family and which was therefore an appropriate place for them to stay. The care attendant resided with our client and her husband, and in liaison with the community clinic staff, monitored and administered patient medications, provided daily personal care, including meals, and ensured the last weeks of our client's life were comfortable. The importance of the palliative care that NPY was able to facilitate for this client cannot be under-estimated. She was provided with the medical attention and personal care that she needed whilst being able to be with family, speak her language and see her country. She passed away quietly on January 3, 2001 aged 79.*

Funding for this respite opportunity came from a combination of two NPYWC HACC programs (South Australian Office for Ageing, Department Human Services): the Aged Care Support Project on the AP lands and Carer Respite Program.

## 8.7 Findings and implications

### 8.7.1 Good practice highlights

Key elements in good delivery of care include: early referral; cultural advocacy and brokerage; good communication and relationship development; clear coordination (i.e. everyone's role is clear); regular case management meetings, including cultural advocates; continuity of care; and flexibility and responsiveness which recognises individual needs.

In the course of our investigation we discovered aspects of practice which we considered to be innovative or 'good'. Some highlights are listed below:

- Employment of Aboriginal and Torres Strait Islander staff;
- Palliative care services in which the providers view themselves as coaches for the family, providing training and support so that they can look after a family member at home (see Section 8.2.1);
- The provision of a comfortable and 'neutral' place where people can pass away that is readily accessible to family members, and will not result in cultural avoidance problems after the death;
- Good design and management of in-patient and residential palliative care facilities to accommodate cultural practices (see Sections 5.4.3 and 5.4.4 and Appendix 8 and Appendix 9);
- Pathways of care (see Section 8.4.2) which include checkpoints for cultural advocacy and cultural safety;
- Workshops and planning sessions in which mainstream and Indigenous service providers develop regional network guidelines to assist them to communicate with each other and deliver more integrated services (see Appendix 12); and
- Provision of valuable practical assistance to families by assisting in the funeral arrangements and the preparation of the 'order of service' and eulogies at the funeral service. Other innovations and good practice in bereavement care are provided in Section 5.5.

### 8.7.2 Standards and monitoring

In some cases the best palliative care for a person may involve their return to an environment which would not be regarded as meeting usual medical or personal care standards.

It may not be practicable to set prescriptive standards for the delivery of culturally appropriate palliative care, however it should be possible to set standards for appropriate cross cultural communication and practice, such as ensuring effective Indigenous input into policy, ensuring employment or participation of Aboriginal and/or Torres Strait Islander staff where possible, and ensuring effective communication between Indigenous and non-Indigenous service providers.

Practice standards must be reviewed to check their applicability to *all* Indigenous situations. Practice standards must give due weight to emotional, social, cultural and spiritual issues. From an Indigenous perspective, an initial starting point for any standard may be that a local Indigenous cultural broker or patient advocate, acceptable to both patient and family, is included in palliative care planning for Indigenous patients.

Observance of these standards would need to be monitored by culturally knowledgeable third party interviews of consumers (see Section 8.5).

There is a need for effective quality control and improvement. Specifically mainstream palliative care providers should develop systems to check on the quality of their service to Indigenous clients. A program of service review conducted 6 months after a death and using an Indigenous reviewer would be a useful way for services to discover how their services could be improved (see Chapter 8, Section 8.5.2).

If services are not up to standard then action needs to be taken to ensure that those service are improved rather than withdrawn because they do not meet standards.

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# Chapter 9

## Resources, fees and funding



### 9.1 Funding

#### 9.1.1 Australian Government funding for Indigenous palliative care

The *National Palliative Care Strategy* was endorsed by the Australian Health Minister's Advisory Council (AHMAC) in October 2000.

The Australian Government made a total of \$162 million available for palliative care throughout the five years of the current Australian Health Care Agreement (1998-2003). Of this, \$151 million has been broadly allocated on a per capita basis to States and Territories for continued service provision, and \$11 million for the Australian Government to implement a national program of initiatives.<sup>1</sup>

In May 2002, the Australian Government committed a further \$55 million over four years for Australian Government activities to support improvements in the standard of palliative care offered in local communities.

This total of \$66 million funding for national activities, known as the National Palliative Care Program, is intended to improve the quality of palliative care through the provision and coordination of a national program of initiatives. The national program is being implemented across the following six broad priority areas:

1. Provision of an expanded range of medications for palliative care in the community;
2. Assistance for families and increased support to other care networks;
3. Education, training and support for the primary care workforce;
4. Increasing the range and reach of palliative care services;
5. Capacity building in the palliative care research community; and
6. Performance information development.

#### Indigenous palliative care projects funded by the Australian Government

Some of these funding initiatives will have outcomes which flow indirectly to Indigenous service users. Two major initiatives of the *National Palliative Care Program* were directed toward Indigenous Palliative Care: this study of the palliative care needs of Indigenous peoples; and the *Guidelines and education and training resources in Indigenous Palliative Care Project* which is jointly coordinated by Wodonga TAFE and the Mungabareena Corporation. The Guidelines project has three major components:

- to develop national guidelines for staff at all levels who provide care to terminally ill Aboriginal and Torres Strait Islander peoples in mainstream palliative care services or hospices;

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<sup>1</sup> Funding information drawn from Australian Government Department of Health and Ageing, *Overview of Commonwealth Funded National Palliative Care Initiatives as at November 2002*.

- to develop a national education and training resource about caring for terminally ill Aboriginal and Torres Strait Islander peoples, for staff at all levels in mainstream palliative care services or hospices; and
- to recommend ways that the guidelines and the education and training resource can be implemented.

The Guidelines project will make use of the information gathered by this study.

In the Northern Territory, the National Health and Medical Research Council (NHMRC) has funded a multi-disciplinary research project called *Innovative Models of Palliative Care Health Service Delivery to Rural Areas* which is exploring service delivery to Indigenous people living in rural areas of the Northern Territory. The expected outcome is the description of an innovative model for rural and remote palliative care service provision to Indigenous people based on an understanding of what is presently available, which models work most effectively and what is needed. The project is being directed by the University of Queensland.

In 2000, Ngaanyatjarra Health Council secured funding through the Commonwealth Office of Rural Health (Regional Health Services) for a two-year palliative care project, including the development of a manual for health professionals. The project was based in the remote Wannarn community in the far eastern region of Western Australia where the Ngaanyatjarra Health Council employed a palliative care nurse with extensive experience working with Indigenous clients. The position has been developed to include general support/education and clinical work. This made it easier for nurses to go into homes and not to be seen as just the 'dying nurse'. The project was expected to conclude in June 2002 and no further funding was expected through this program.

### 9.1.2 State funding for Indigenous palliative care

State informants told us that most of their palliative care funding comes from State funds (for example, in Victoria \$44.5m is funded by the State government<sup>2</sup> and \$7m comes from the Australian Government through the Australian Health Care Agreement (AHCA). Other Australian Government funds flow from the Medicare schedule.

None of the States has made any specific allocation for Indigenous palliative care with some exceptions related to specific projects:

- The Western Australian Health Department has allocated a one off payment of \$100,000 to Aboriginal and Torres Strait Islander initiatives in palliative care. They have also allocated approximately \$40,000 to Gascoyne Health to develop 'creative' palliative care initiatives for a number of AIDS clients (including Indigenous), in the Gascoyne area;
- In Victoria, \$30,000 has apparently been provided by the Department of Human Services to the Centre for Education in Grief and Loss which is working with VACCHO on a project investigating Indigenous grief and loss;
- In New South Wales, funding has been allocated to a project in the New England region to study the needs of the Aboriginal community in relation to palliative care (this project is just getting underway); and
- In Broken Hill, the New South Wales Government has funded (with some additional Australian Government funds) a project which aims to increase access to and awareness of mainstream palliative care services and is investigating ways of integrating mainstream and Indigenous services. The project is developing protocols for cultural and clinical services to allow community-controlled and mainstream services to work together. An advertising campaign using local media is planned.

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<sup>2</sup> Note that the \$44.5m quoted above includes funding of two Chairs of Palliative Medicine.



In South Australia a research project funded by the non-government sector is underway: The Royal Flying Doctor Service and the South Adelaide Palliative Care Service have supported a project to examine access to palliative care for people in remote areas of South Australia. Negotiations have commenced with the remote Indigenous community which will be the focus of the project. The project is also supported by Apex.

Apart from these projects, no funding is set aside for Indigenous-specific palliative care initiatives.

In New South Wales each health region has developed (or is in the process of developing) a palliative care strategic plan. Those we have viewed identify Indigenous people as a special target group. These plans are general documents and do not have specific or costed Indigenous initiatives. Only one of the three documents (of 16) which we viewed had had active involvement of Aboriginal Health regional directorates.

Overall, State funding for specific Aboriginal and Torres Strait Islander palliative care has been limited and piecemeal. The approach of developing regional plans for palliative care is to be commended, however the components of the plans for Aboriginal and Torres Strait Islander clients need to be based upon identified local needs if they are to be effective.

Local and regional officials from:

- mainstream palliative care service providers;
- State run, Aboriginal and Torres Strait Islander local health units (including community health);
- the ACCHS; and
- Indigenous HACC or CAAP or home care programs

need to come together to identify priority actions and initiatives. These initiatives need to be funded and the outcomes monitored.

### 9.1.3 Structure of funding

#### **Structure of mainstream services funding**

Palliative care services are funded by State governments and through the Australian Health Care Agreements. These funds cover palliative care beds in acute care facilities as well as community based services. The private sector also provides services (hospices, nursing homes, community nurses, bereavement services) which are sometimes either partly funded by government or are brokered in by government.

#### **Structure of Indigenous services funding**

##### *OATSIH funding*

Indigenous health services are provided either directly by governments or are delivered by the community controlled health services (ACCHSs or AMSs) (120) which are funded by OATSIH. Most of these services provide only limited and informal palliative care services, with no trained and dedicated staff and no identified funding source.

AMSs receive grant funding on a global budget basis and can also access funds via Medicare or pharmaceutical funds either through the Pharmaceutical Benefit Scheme or under Section 100 of the

National Health Act (if they are remote). These organisations may also receive some State grants and access other Australian Government funds through special programs.

#### *Primary Health Care Access Program Funding*

A major new funding initiative in Aboriginal health is the Primary Health Care Access Program. This program was announced in the 1999-2000 budget and is now being rolled out. It has three objectives:

- to increase the availability of appropriate primary health care services where they are currently inadequate;
- to reform the local health system to better meet the needs of Indigenous people; and
- to empower individuals and communities to take greater responsibility for their own health.

*PHCAP will establish a framework for the expansion of comprehensive primary health care services, including clinical care, illness prevention and early intervention activities and management and support systems, in a planned and coordinated manner in line with regional planning.* [www.health.gov.au/OATSIH/pubs/phcap/]

The scheme is dependent upon completion of regional planning processes. Essentially it provides top-up funding (pooled and untied) to fill gaps in service delivery.<sup>3</sup> Advice from the Health Financing Section is that all the regional plans are now complete; that none of them identify palliative care as an issue<sup>4</sup> and that palliative care has not been identified as a priority in any of them. This would appear to be a serious missed opportunity with far-ranging implications for the future of palliative care in Indigenous communities.<sup>5</sup>

The reason(s) why palliative care has not been identified as a priority is not clear. It may be that palliative care is not a high priority, however it is also likely that the definition of primary health care used during regional planning did not recognise palliative care as part of primary health care, as palliative care is neither curative nor rehabilitative (see further below) and/or that those at the planning table are uninformed about palliative care.

Discussions with some Indigenous health professionals who were involved in the development of the regional plans upon which the PHCAP funding is based believe that lack of consciousness of palliative care and lack of awareness of what it is and what it might offer was the main reason that it does not appear as a need, rather than that there are no needs for palliative care services. That is not to say that if there were greater awareness, it would necessarily be the top priority in Indigenous health. Indeed several AMS doctors we spoke with said that they would not regard delivery of palliative care services as a high priority. Doctors' views of course do not necessarily reflect the view of Aboriginal and Torres Strait Islander people.

The fact that palliative care is missing from the regional plans is partly due to the diversity of programs that PHCAP funds, and partly due to a lack of priority and profile for palliative care.

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<sup>3</sup> The PHCA funds available for Aboriginal and Torres Strait Islander health in a region are worked out by subtracting the amount already spent on primary health care and subtracting that from the PHCA funding base.

<sup>4</sup> Personal Communication, Barney Lee, OATSIH (02) 6289 5292.

<sup>5</sup> Planning at the sub-state level (eg strategic palliative care across five zones in the Northern Territory) is presently underway and this gap may be identified at that level.

### *Other sources of funding for palliative care*

The following sources of funds for palliative care for Indigenous clients were identified by informants. Not all of these are legitimately accessed for palliative care.

- Multipurpose funding;
- Indigenous Flexible funding;
- Residential Care funding;
- Community Aged Care Packages (CACPs); and
- Home and Community Care (HACC) funding.

The multipurpose funding model appears to provide excellent opportunities for remote communities to gain access to funding for integrated palliative care services (see below). These funding schemes are described in Appendix 13.

### **Opportunities for additional funding of ACCHS in palliative care delivery**

The Enhanced Primary Care items (see Chapter 8 Section 8.4.5) provide Medicare rebates for, among other things, ‘*Care Planning and Case Conferencing for people of any age who have chronic medical conditions and have complex care needs*’. As noted above, case conferencing is intended to achieve better quality of care and better collaboration between doctors and other care providers, and is highly appropriate for palliative care clients.

## **9.2 Structural funding issues**

### **9.2.1 No specific funding**

Virtually no funding has been made available specifically for Indigenous palliative care service delivery, capacity building or access programs. State–Australian Government framework agreements on Indigenous health do not pick up palliative care.

*We are so busy just keeping our heads above water. The Framework Agreement with the Australian Government, State and [Indigenous health organisation] is not seeing changes happen on the ground. Funding needs to happen – we are asked to jump through hoops with all the data and information we are expected to provide. Shortage of staff means that there is no time to complete required paperwork. Palliative Care doesn't rate a mention in the Agreement.* [hospital administrator of 25 years in remote area, Queensland].

State health departments advise that palliative care is not identified in Australian Government / State Indigenous Health Framework agreements, although these are very general documents that do identify the need for better access to and coordination of mainstream services as an issue for action.

### **9.2.2 Funding formulas – ‘cancer as proxy’**

Funding for palliative care is based on numbers of cancer patients. 80-90% of palliative care clients are currently cancer patients. Renal, respiratory and cardio cases may be under-represented in palliative care numbers because traditionally these clients have not been referred to palliative care services. Because the

State funding formula is based on a cancer proxy it may not pick up the needs of high concentrations of HIV/AIDS, renal, cardio, and respiratory condition palliative care clients. Aboriginal and Torres Strait Islander people are highly represented in these client groups.

While the incidence of cancer amongst Aboriginal and Torres Strait Islander people may be similar to the mainstream population (lower for men in some areas), the death rate from diabetes is eight times as high and the death rate from respiratory and circulatory illness is three times as high (see Chapter 3, Section 3.2.3). Renal, respiratory and cardio cases need to be recognised as conditions likely to require palliative care (see Chapter 4 Section 4.5) and palliative care funding formulas need to recognise the prevalence of these conditions in Aboriginal and Torres Strait Islander populations.

### 9.2.3 HACC funding not available

HACC funding is no longer available for palliative care except where there were specific programs running in the past, and these have been set as a 'no-growth area'. This is explained in more detail in Appendix 13. Despite this, in many areas Indigenous HACC programs are delivering quasi palliative care services because either there is no suitable alternative available or none which people know about or are willing to access.

This is a critical issue for Indigenous palliative care. There are effective and vigorous networks of Indigenous HACC workers in all states and these HACC workers are a vital link between the community and the health system. The importance of 'a black face' in a palliative care team was stressed again and again. Currently HACC workers are undertaking palliative care work without funding or training. Their potential role as referrer and/or coordinator is very substantial, but is not being developed or supported.

### 9.2.4 Palliative care and Primary Health Care – the gap

Palliative care does not fit easily into the Primary Health Care definition, despite the fact that it is increasingly delivered in a primary rather than in a tertiary setting.

The World Health Organisation Alma Ata Declaration for Primary Health Care (1978), while extolling community participation and involvement, does not include palliative care in the range of services to which it applies. The Australian primary health care system accordingly includes a '*comprehensive range of preventative, promotive, curative and rehabilitative services*'<sup>6</sup>, however palliative care does not fit comfortably into this range of services.

*Better Health Care*, the major document written to explain and promote the primary health care model for Indigenous Australians<sup>7</sup>, does not mention the term palliative care anywhere and uses the word 'palliation' only once in an introductory section. There are no examples of palliative care in the documents, except for an example of how end-stage renal disease is being managed although this is not portrayed as palliative care.

The primary health care focus of Aboriginal and Torres Strait Islander health funding, and the poor fit of palliative care into the '*preventative, promotive, curative and rehabilitative*' modes of service delivery may be in part responsible for lack of funding for Indigenous palliative care programs. The importance of

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<sup>6</sup> (2001). *Better Health Care - Studies in the successful delivery of primary health care services for Aboriginal and Torres Strait Islander Australians*, Department of Health and Aged Care: 1-104.

<sup>7</sup> Ibid.

palliative care being recognised as part of the primary health care system has been identified by Prior (1997). Funding for palliative care may be one funding gap which PHCAP will be unable to fill within current definitions.

### 9.2.5 Aged care and nursing home funding issues

There may be several issues in funding structures for aged care and nursing homes which stand in the way of effective delivery of palliative care. These include:

- adequate funding for end of life care in aged care facilities and in nursing homes. Service providers report that cost peaks for additional nursing at this time are not adequately covered by funding even if high care beds are available;
- aged care facilities with no high care funding cannot offer 24 hour care without family assistance;
- appropriate medication may not be available in these institutions if there are not two registered nurses present, although the same drugs could be administered in a private home with no nurses present;
- flexible funding schemes are available under the Indigenous Aged Care Strategy, although these do not seem to be used as effectively as they could be for palliative care provision. Flexible funding appears to be available for nursing homes as well as aged care hostels, some of which also have community-based packages. It is unclear whether it is legitimate to use aged care money for palliative care in these settings (see Appendix 13). Some Indigenous service providers may be reluctant to describe the service they provide as 'palliative care' for cultural reasons and therefore may not be accessing the funding they could, or it may mean that funding is not used strictly in accordance with the rules; and
- There is a need for funding to allow aged care facilities and nursing homes to broker in palliative care services for symptom management advice, cultural advice and support, and additional nursing care under some circumstances.

### 9.2.6 Multipurpose funding scheme not used by remote communities

Multipurpose service (MPS) funding (designed for rural and remote communities of less than 5,000 people) provides opportunities for the provision of funding for palliative care. It is used in only one Aboriginal community in Australia and there would seem to be scope for this type of funding to be used more widely. This funding provides a flexibility which facilitates appropriate palliative care service delivery.

The future of many mainstream community palliative care services (which either provide services to, or have the potential to provide services to, Indigenous clients) seems to be in doubt as Australian Government funding under current Australian Health Care Agreements (1998-2003) comes to an end. The Australian Government is in the process of negotiating new agreements with the States and Territories and an announcement is reported to be due in the near future.

### 9.2.7 No mechanism for palliative care services to buy in cultural advocacy services

This study has identified a need for mainstream palliative care services to have the capacity to purchase the services of appropriate Indigenous service providers, Aboriginal Health Workers and liaison staff, and cultural advocates and language interpreters.

Cultural advocates should be recognised as one of a suite of ancillary services which may be required. Funding needs to be provided to buy in these services as needed if they cannot be justified on a permanent basis. Service providers identified a need for a brokerage mechanism (and supporting funds), similar to the arrangements available for community aged care packages.

### 9.2.8 Gaps in funding due to lack of local coordination and poor regional planning

In one large town in Western Australia, we found major gaps in funding. As a result there were no home-based palliative care services except for an untrained volunteer service and a coordination position for cancer clients. In this town funding is provided to the hospital to provide a three bed in-patient service and a clinical management support role into the community, however there is no funding to provide the community with a 'hands on' nursing service. Silver Chain is no longer funded to provide palliative care nursing or personal care. As a result of staff shortages at the hospital, there is no 24 hour nursing service for palliative care clients and even the clinical management consulting role is not currently filled. There is no integration of services (bereavement, counselling, information). The only coordination role is jointly funded by Community Health and the Cancer Foundation of Western Australia and so can work only with cancer clients, not other palliative care clients. These services do not reach Aboriginal clients unless they have come through the oncology ward of the local hospital. Many Aboriginal patients diagnosed in Perth return to the community without appropriate referral.

This example points to the need for local service providers (including ACCHSs) to have a collective say in developing funding priorities in their communities. Without coordination, piecemeal applications for funds by individual service providers tends to result in major funding gaps.

## 9.3 Resource issues raised by participants

A number of resource issues were raised in the course of our exploration of needs and unmet needs. Not all of these are specific to the care of Aboriginal and Torres Strait Islander peoples; some are relevant to service provision generally.

### 9.3.1 Aboriginal and Torres Strait Islander staff

The need for Aboriginal and Torres Strait Islander staff is discussed in several sections of this report (see Chapters 4 and 5). There are only two services in Australia which employ an Indigenous staff member as part of the palliative care team. The experience of one of these was that the number of Aboriginal and Torres Strait Islander clients immediately rose once there was an Indigenous worker:

*...relationships with remote communities have improved and there is an increase in Aboriginal clients. This has meant that the health worker is over-worked and we estimate that they need an additional 3 Aboriginal workers.* [Palliative Care Manager]

### 9.3.2 AMSs not funded for palliative care

Aboriginal medical services do not have funds for palliative care. Any resources they use come from other sources. 'Resources come out of OATSIH clinic money, which places increased financial and staffing demands on the program.' AMSs have no funds to pay Aboriginal health workers for out of hours work.

### 9.3.3 Home care and home support and shortage of respite services

Many mainstream service providers complained that there were not enough home care hours for palliative care clients. Many home care providers were said to 'close their books' (i.e. decline to accept more clients) if they were approaching funding limits. This was reported in New South Wales, Queensland and in the Northern Territory (where this was especially mentioned in relation to town camps).

Aboriginal home care is only available for patients who meet the HACC criteria. Aboriginal and Torres Strait Islander clients often don't fit the HACC criteria because funds cannot be used to help relatives who might be caring for someone.

Many people, especially in remote areas, spoke about the lack of support which often meant that they had had to take a family member to hospital and/or had difficulty in accessing equipment.

Shortage of respite beds was identified as a major problem, especially in remote areas. There appears to be a shortage of respite services everywhere.

### 9.3.4 Difficulty accessing allied health services

#### **Unacceptable allied health waiting lists**

Ancillary services (eg speech pathologists, domestic violence counsellors, financial planners, hearing services, physiotherapists, occupational therapists) are inadequate, especially in country areas. Palliative care clients are sometimes placed on waiting lists for up to three months. This was considered unacceptable for someone who has only months to live. This issue is doubly important for Aboriginal and Torres Strait Islander clients who may have been referred late. In remote areas, these services are only located in major regional centres and without transport, access to them is impossible.

In Victoria, the length of time it took to access allied services was reported as a common problem, especially in country areas. For instance, there was a three months' waiting period for a speech pathologist.

#### **HACC criteria and ancillary services**

Young people apparently have difficulty accessing ancillary services because funding is not available for them from aged care sources. If clients cannot meet the HACC criteria then the services have to be paid for by the client or by the palliative care service provider. The funds available to palliative care services for these services (for example, in Victoria, unassigned funds of \$2,000 per month) are totally inadequate to cover most clients' needs.

#### **Home modifications**

In New South Wales we heard of a case where it had taken a month for the occupational therapist to visit the house to authorise modifications and by the time the work was done (three months later) the patient used the installed ramp only once, on his final trip to hospital.

#### **Equipment**

The equipment available is limited and there are no resources for delivery of equipment. In very few places was there enough equipment to meet the need.



### 9.3.5 Not enough funds for palliative care services

Palliative care services reported that there were often insufficient funds for:

- adequate bereavement and counselling support; and
- community awareness, especially multicultural (including Aboriginal and Torres Strait Islander) outreach;

*‘The service has been chronically under-funded since its inception.’* [director of a palliative care unit, South Australia]

#### CNC hours

In one place in New South Wales the recent reduction of CNC hours is likely to impact on capacity to deliver services in rural areas.

#### Lack of weekend hours for CNCs and palliative care nurses

There were several stories of clients who had a weekend crisis because there was no access to trained palliative care staff at that time. Patients or their carers had had to call a GP who did not know about medication, or called an ambulance and sent the patient to a hospital emergency unit.

#### Home visiting nurses

In two adjoining health districts in New South Wales the shortage of resources for home visiting was evident in different ways. One district provided after hours and weekend visits and had a three week waiting list for people to be visited for assessment; the adjoining district had no waiting list but provided no after hours visiting, though it did have a phone line.

In the Northern Territory a (non-Indigenous) palliative care nurse, based in a hospital and employed part-time Monday to Friday, described her situation as very stressful because there are no other services to provide nursing care on weekends or whenever she was sick or on leave. Instead clients would have to go to hospital for care or HACC workers would check on the client when delivering meals and medications.

#### Eligibility issues and funding levels

Some services said that they would be able to provide services to a larger range of clients (eg motor neurone disease and cystic fibrosis) if they had more resources.

In Queensland, it is apparently difficult to access palliative care funding without a medical prognosis of under 3-6 months. Patients often have to be discharged and re-admitted.

A palliative care service based in a major base hospital in Queensland has run over budget for the past three years and has had to cease providing services for the last three months of each financial year.

The integration of palliative care services into end stage renal management (see Chapter 4 Section 4.5 ) will require funding adjustments.

### 9.3.6 High turnover of staff in regional areas

This is a major issue for Indigenous clients, as replacement staff are not culturally aware and do not have a relationship with the Aboriginal and Torres Strait Islander community.

### 9.3.7 Remote area staff are overworked

Several Indigenous and non-Indigenous workers providing services to remote communities spoke of feeling overworked, under-resourced and unsupported. An Indigenous worker who had spent three months working in a remote community clinic said she had received no support from the regional office during that time and believed that regional office management staff had no understanding of the difficulties and working conditions of remote area workers. She said that even a phone call once a month would have helped.

A non-Indigenous remote area worker spoke of the unrealistic expectations of senior management in regional areas, particularly about workplace health and safety issues in areas where all the clients are Indigenous and many are living in bough shelters. She suggested that policy makers and management needed to appreciate that the situation for people working out bush was different and difficult. Remote area staff need to be supported and to feel that they are supported.

### 9.3.8 Need for more high care beds in Indigenous specific aged care or nursing homes

In several places where Indigenous aged care facilities exist, there is frustration at the lack of high care beds and the inability of facilities to offer adequate palliative care (see also Chapter 5).

## 9.4 Fees

In most areas there is no fee for palliative care services, however there is a wide belief amongst Aboriginal and Torres Strait Islander people that they will be charged a fee. This belief may discourage many Indigenous people from seeking out these services. One reason for this perception appears to be that there fees are usually charged for home nursing services (eg Silver Chain in Western Australia) even where there are none for the palliative care arm of the service.

In some States there is a fee for palliative care home nursing and home care but there are waiver systems if people can't afford to pay. Waiver systems may raise problems for Aboriginal and Torres Strait Islander clients who may be embarrassed (feel 'shame') by having to ask for a fee waiver, and/or may not have the social and communication skills to seek a waiver.

Many home care services now ask for a contribution from clients that is likely to be beyond the capacity of most Aboriginal and Torres Strait Islander households (see Chapter 3 – *Capacity* and Chapter 5 – *Medication*).

While most palliative care services are free, they have limited budgets to buy in allied health services and equipment. If the palliative care service has reached the end of its budget or equipment stocks, the only way clients can access some services is to pay for them themselves.

Hospital based palliative care is free to public patients and is reimbursed by private health funds.

Some (very few) health funds offer limited cover for home based services and while the number of funds doing this should be increased, this is largely irrelevant to Aboriginal and Torres Strait Islander clients who are unlikely to have private medical insurance. Where fees are charged by home nursing services it would be beneficial to Aboriginal and Torres Strait Islander clients if these could be reimbursed through Medicare.

## 9.5 Findings and implications

### 9.5.1 Structural funding issues

New initiatives in Indigenous funding focus on filling gaps in the delivery of primary health care. Palliative care does not fit the definition of primary health care (being neither curative nor rehabilitative) even though it is often (and increasingly) delivered by primary health care providers.

HACC funding guidelines now identify palliative care as a 'no growth' area.

The use of cancer as a proxy by most funding formulae for palliative care means that the needs of Aboriginal and Torres Strait Islander people who are highly represented amongst HIV/AIDS, renal disease, and cardio-vascular and respiratory disease palliative care clients may be overlooked.

Funding for Indigenous specific initiatives appears to have been piecemeal to date.

The multipurpose funding model appears to be an effective way of ensuring a flow of funds to meet identified local palliative care needs.

Funding packages similar to CACP packages may allow service providers to purchase cultural advocacy services when required for Indigenous clients.

Enhanced Primary Care Items should be marketed to palliative care and Indigenous health providers as a strategy to encourage the participation of Indigenous health providers into a more integrated (and better coordinated) service delivery for Indigenous clients.

In some circumstances, the funding arrangements for aged care facilities and nursing homes appeared to present barriers to clients receiving the best palliative care service in these facilities. Funding arrangements are needed that will allow aged care facilities and nursing homes to broker in palliative care services for symptom management advice, cultural support and additional nursing care when needed (see Section 9.2.5).

### 9.5.2 Some resource issues

Some key resource issues were repeatedly raised including:

- need for funding for Aboriginal and Torres Strait Islander staff;
- in general ACCHSs are not funded for palliative care, have no specialist staff and only operate 9.00 - 5.00, five days a week;
- there is a serious and widespread shortage of respite services, especially in places where Aboriginal and Torres Strait Islander people live;

- there are inadequate funds for personal care and home help services, which are not funded to provide palliative care and sometimes have to 'close their books' to palliative care clients;
- there are equipment shortages and inadequate funds to access equipment;
- funding restrictions have prevented some services admitting clients such as end stage renal clients;
- lack of funding for Indigenous liaison positions;
- insufficient funding for out of hours visits by palliative care specialists; and
- in some areas (eg Perth) there are no Indigenous-specific aged care nursing home facilities and/or where they exist, too few or no high care beds are available.

There are culturally determined needs which should be recognised as legitimate palliative care costs. These may include the cost of:

- temporary housing for the duration of the palliation (for cultural and/or socio-economic reasons);
- transport to take the client home (with adequate care);
- locating and accessing traditional healers;
- return of deceased to their home country or community;
- support to families and assistance with funeral arrangements as an essential part of bereavement; and
- support for cultural advocacy and language translation services.

### 9.5.3 Flexible funding

Funding needs to be flexible so that palliative care packages can be purchased where needed, for example, additional resources to allow people to be cared for in a remote community or in an aged care facility, or so that Indigenous staff with palliative care training or relevant cultural knowledge can be bought in (see Section 9.2.7).

### 9.5.4 Fees

In most States fees are not charged for palliative care services, however there is a widespread belief amongst Aboriginal and Torres Strait Islander people that these services do attract fees. Hidden costs of caring for family members at home, medication, home modification, equipment and power for heating and equipment, were all costs that most could ill afford to pay.

The absence of fees (and fee waiver schemes) needs to be better publicised, and funding support schemes should be developed to assist people in hardship who cannot afford the 'hidden costs' of caring for someone at home.

## References

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# Chapter 10

## Findings and conclusions



### 10.1 Key findings

Generally, the Aboriginal and Torres Strait Islander people we interviewed said that they thought palliative care was a good idea. Palliative care could give them the support they needed to look after family members in their own way and could provide the knowledge and advice they needed and allow them choices about how (and where) they wanted the last precious weeks to be.

In most regions, however Aboriginal people and Torres Strait Islanders have poor access to palliative care services. Although the specific reasons for this may vary from State to State and region to region, there are a number of common factors that are widely experienced throughout Australia.

#### 10.1.1 Variations in delivery and experience of palliative care

The experience of individuals and families is influenced by a variety of significant factors, including:

- models of service delivery vary in each State and Territory, and in some cases from region to region. Hospital or hospice care usually complements home care to some extent, but the way these elements are combined varies (see Chapter 2);
- diversity of Indigenous peoples and families and their social and cultural circumstances, which vary from region to region and between States and Territories (see Chapter 3);
- the health services available to Aboriginal and Torres Strait Islander peoples varies in different regions – for example, some areas are serviced by community controlled Aboriginal medical services; others may have only mainstream medical services (see Chapter 2); and
- the quality of palliative care available varies and depends on the capacity and willingness of service providers to ask and to listen (see Chapter 5).

#### 10.1.2 Lack of knowledge of palliative care and what it means

In general, Indigenous people have not heard of palliative care, or if they have heard the term they understand it only to mean going to a nursing home, hospital or hospice (see Chapter 4, Section 4.4).

Indigenous people are not generally aware of the different kinds of palliative care services available (eg, home based care, pain management, access to special equipment, changes in the home, etc) (see Chapter 4, Section 4.4).

There may be a perception amongst service providers and in the wider community that palliative care is only for people who have cancer. Not enough attention is given to the special needs of Indigenous people with other life-limiting conditions, including those with kidney disease, respiratory disease and heart conditions (see Chapter 4, Section 4.4.1).

### 10.1.3 Factors contributing to lack of access to palliative care services

Mainstream and Indigenous health service providers tend to work ‘in parallel’ and often do not relate to each other. They may be unaware of how the other providers operate, what services they provide, and how they could work together (see Chapter 4, Sections 4.3 and Chapter 7 Section 7.3).

Palliative care services are generally provided by mainstream service providers which often do not have knowledge of, or relationships with, Aboriginal and Torres Strait Islander health services, community networks or Aboriginal and Torres Strait Islander cultures (see Chapter 4, Section 4.4 and Chapter 5, Section 5.4.2).

Indigenous people may not be referred to palliative care services by their health service or may not receive the support they need to understand medical information and information about palliative care (see Chapter 4, Section 4.3).

Indigenous patients are often diagnosed quite late in their illness and as a result are referred to palliative care services at a late stage (see Chapter 4, Sections 4.3.3 and 4.4.5).

Palliative care workers are likely to have had little contact with Indigenous communities and may have difficulty developing good relationships with Indigenous clients, especially if the client is referred late, and they may not understand or appreciate cultural differences. This will not only impact on their capacity to deliver effective palliative care services but will discourage Indigenous people from using or seeking out their service (see Chapter 4, Section 4.4.10).

### 10.1.4 Education of medical practitioners and health services

General practitioners and specialist doctors may not be aware of palliative care services and the benefits they could offer their patients. Education is needed to increase doctor awareness and encourage earlier referral to palliative care. GPs may not be aware that referral to palliative care does not mean that they have to stop caring for their patient (see Chapter 7, Section 7.6.1 and Chapter 4, Section 4.3.2).

Aboriginal and Torres Strait Islander community controlled health organisations (and other Aboriginal and Torres Strait Islander Health Services) need education about palliative care and its benefits, and how they can get help for their clients from palliative care specialists (see Chapter 7, Section 7.6.2 and Chapter 4, Section 4.3.2).

Indigenous health workers (Aboriginal hospital liaison officers, Aboriginal primary health workers and HACC workers) need training and awareness programs about palliative care and palliative care services in their State and their own regions (see Chapter 6 and Chapter 7, Section 7.4). Other Aboriginal and Torres Strait Islander health professionals including nurses, psychologists and doctors may also benefit from such programs.

### 10.1.5 Issues for palliative care policy makers and service providers

There are a number of issues and areas of need where policy makers could initiate action and/or palliative care service providers could provide advocacy on behalf of Aboriginal and Torres Strait Islander clients.

- Housing (eg, ability to relocate a patient during the period of palliation, or relatives after a death in the family) (see Chapter 5, Section 5.3 and 5.9.3).
- Ensuring that palliative care and Indigenous health providers are involved in hospital discharge planning (see Chapter 4, Section 4.3.6 and Chapter 5, Section 5.2.1).

- Development of ‘tagging’ or registrations systems that ensure that palliative care clients admitted to emergency wards are identified on arrival and are not given inappropriate treatment. This is especially important for Aboriginal and Torres Strait Islander clients who might not ‘speak up’ about what they need (see Chapter 5, Sections 5.6 and 5.9.3).
- Changes in hospital facilities and practices:
  - attitudes and expectations;
  - appropriate spaces for visitors;
  - allowing space and time for families to be with the deceased if it is required; and
  - design of palliative care facilities that can meet the cultural needs of local Indigenous people (see further Chapter 5, Section 5.3.3/4).
- Development of culturally appropriate grief and loss counselling strategies and services (see Chapter 5, Section 5.5).

#### 10.1.6 Lack of resources

There are insufficient resources for the provision of palliative care services to Aboriginal and Torres Strait Islander people and there are some major gaps in the services that are provided. (see further Chapter 9). For example, there are regions where:

- there is no home-based care;
- services exist but they are not provided on a 24 hour basis;
- services exist but home-based care is not available on weekends;
- funding for personal care and home help services is inadequate, and they are not funded to provide palliative care and sometimes have to ‘close their books’ to palliative care clients;
- funding for purchase of equipment is inadequate;
- there is funding for equipment, but no funds for transporting it;
- there is no funding for Aboriginal and Torres Strait Islander liaison positions;
- the local Aboriginal medical service does not operate on a 24 hour basis, or does not provide home-based care; and
- there is no Indigenous-specific counselling service.

Availability of palliative care specialists may be inconsistent. Where available, specialist knowledge and skills are highly valued (see Chapter 5, Section 5.8).

Funding needs to be flexible so that palliative care packages can be purchased where needed (eg additional resources to allow people to be cared for in a remote community or in an aged care facility), or so that Indigenous staff with palliative care training or relevant cultural knowledge can be bought in (see Chapter 9, Section 9.2.7).

#### 10.1.7 Lack of palliative care training

There is an urgent need for development and provision of training for Aboriginal health workers, for example, by including a component in undergraduate courses and/or creating post graduate certificate courses in palliative care and in mental health and bereavement (see Chapter 7, Section 7.5).

There is an urgent need for trained Indigenous psychologists and mental health workers to provide support or counselling in grief and loss (see Chapter 7, Section 7.5).



### 10.1.8 Indigenous employment in palliative care

There is a need for mainstream palliative care services to employ Aboriginal and Torres Strait Islander health workers who have received training in palliative care or to be able to broker in services from Indigenous health services. These skills could also be provided through consultancy arrangements with local Indigenous health services (see Chapter 6, Section 6.6).

There is a need for medically trained Indigenous advocates (such as Aboriginal health workers, enrolled nurses, registered nurses) to be employed by hospitals, health services and/or brokered in by palliative care services (see Chapter 6, Section 6.6).

There is a need for adequate supervision and debriefing of Aboriginal and Torres Strait Islander staff working in palliative care, particularly where staff are related to the deceased (see Chapter 5, Section 5.5.7).

### 10.1.9 What community members want

Early information and support (see Chapter 5, Section 5.5.7).

More information about life-limiting illness, the course of the illness and what to expect, especially at the final stage (see Chapter 7, Section 7.2).

More information about the services that are available (see Chapter 7, Section 7.1).

Respite care, both in the home and short-term residential (see Chapter 5, Section 5.4.2).

## 10.2 Implications for the National Strategy

The brief (see Chapter 1 Section 1.1) called for identification of '*areas that could be enhanced or developed under the National Palliative Care Strategy*' (NPCS) (2000). An analysis of the Strategy indicates a general congruence between the current National Strategy and the needs and issues identified during this scoping study.

The Strategy has three major goals, each with a number of objectives:

Goal 1: Awareness and understanding

Goal 2: Quality and effectiveness

Goal 3: Partnerships in care

Objectives under Goals 1 and 3 have the greatest levels of congruence. Some aspects of the objectives under Goal 2 are potentially problematic.

Some of the strategies should be strengthened or added to and it may be appropriate to develop a set of outcomes for Indigenous palliative care which mirror or can be set against the objectives. The areas for attention following on from the findings of this study are detailed below.

### 10.2.1 Goal 1: Awareness and understanding

There are major issues regarding lack of awareness and understanding of palliative care in Aboriginal and Torres Strait Islander communities. These were discussed in Chapter 4.

### **Objective 1.1: Community awareness and capacity**

Devise strategies aimed at developing word of mouth information implemented through key members of Aboriginal and/or Torres Strait Islander communities. The strategy should include information, training and education for Aboriginal liaison officers, Aboriginal health workers and Aboriginal HACC workers, and should be supported by appropriate printed information for the community (see further Chapter 4, Section 4.6).

### **Objective 1.2: Families and communities of care**

Develop a strategy which will deliver the specific sorts of information identified as needed by Indigenous community members. For example, the information booklets prepared by the Palliative Care Associations of South Australia and Western Australia provide a useful framework and should be reviewed and reproduced for Indigenous audiences with the inclusion of some additional practical information (see further Chapter 7 Section 7.2.2).

A number of Aboriginal and Torres Strait Islander people spoke of their desire for support groups for families coping with the life limiting illness of a family member. A number of people were interested in becoming volunteers within their own communities. No mainstream volunteer programs have previously recruited within Indigenous communities. There is scope for these programs to be made more effective, however coordinators of volunteer programs would need cultural awareness training and guidance from Aboriginal and/or Torres Strait Islander advisors about recruiting within Indigenous communities (see further Chapter 7 Section 7.9).

### **Objective 1.3: Professional awareness**

Develop strategies aimed at government and community-controlled Aboriginal health services to develop the awareness of health professionals working in them (doctors, nurses and health workers) about palliative care. These groups should be specifically targeted and included in programs such as GP palliative care education. The support of NACCHO, OATSIH, and bodies such as CATSIN and AIDA should be enlisted. (see further Chapter 7 Section 7.6).

Aboriginal Health Worker undergraduate training should include a palliative care component to explain what palliative care is and to explain what services are available in each State. (see further Chapter 7 Section 7.1.3).

The peak organisations representing other Aboriginal and Torres Strait Islander health professionals such as nurses, psychologists, social workers and doctors should be engaged to assist in the development of information strategies aimed at increasing professional awareness (see further Chapter 7 Section 7.6.7).

### **Objective 1.4: Professional education**

Consideration should be given to strengthening this objective by specifically mentioning Aboriginal and Torres Strait Islander health professionals (nurses, psychologists, social workers, doctors and Aboriginal health workers). There is a defined need for a post graduate certificate in palliative care for health workers, and a need for a component on grief and loss associated with palliative care in the Mental Health Certificate (see further Chapter 7 Section 7.6.1-7.6.2).

As well, professional development curricular for GPs, nurse practitioners and registered nurses in the Aboriginal and Torres Strait Islander health sector need to include issues related to palliative and bereavement care. For GPs this could be facilitated through CME programs coordinated by professional

colleges, and for nursing graduates, through the development of specific post graduate certificate level courses. A specific module on Indigenous issues in palliative and bereavement care should be included in undergraduate training curricula for all doctors and nurses as part of their education in Indigenous health.

Mainstream palliative care workers need specific cultural awareness training, tailored for palliative care workers, which will translate into effective cross cultural practice. Such training must go beyond awareness to deliver competencies in practice in cross cultural environments. Cultural awareness courses for palliative care workers need to be revised to deal with issues of death and dying for Aboriginal and Torres Strait Islander people and to provide safe learning environments where practitioners can review their own belief and value systems and communication practices. Such courses need to deliver cognitive change not just awareness. Professionals delivering care at home need special skills in developing relationships with the local Indigenous community and with individual clients. This is critical given the high frequency of late referral of Indigenous clients to palliative care. (See further Chapter 7, Section 7.7)

In the first instance, this education might look at basic issues of developing cross-cultural partnerships with Indigenous organisations in the community. Such education could be attended by both mainstream palliative care organisations and Aboriginal and Torres Strait Islander health services in each local region.

#### **Objective 1.5: Awareness at policy level**

This objective should be strengthened to encourage policy makers at State and Australian Government levels to consider and incorporate palliative care for Indigenous clients in policy and funding documents (eg State / Indigenous health partnerships, state strategic plans and OATSIH funding formulas). The challenge here is not only to raise awareness of policy makers about palliative care for Aboriginal and Torres Strait Islander peoples but to do so in such a way as to ensure that local Aboriginal and Torres Strait Islander communities will be engaged in advising on their particular needs. Decision makers in ACCHS and State-run Aboriginal and Torres Strait Islander Health units must be specifically targeted (See further Chapter 7, Section 7.6.6).

### **10.2.2 Goal 2: Quality and effectiveness**

#### **Objective 2.1: Standards**

This strategy must be approached with extreme caution. Practice standards must be reviewed to check their applicability to all Indigenous situations. In some cases the best palliative care for a person may involve their return to an environment which would not be regarded as meeting medical or personal care standards. Practice standards developed must give due weight to emotional, social, cultural and spiritual issues. From an Indigenous perspective, an initial starting point for any standard may be that a local Indigenous cultural broker or patient advocate, acceptable to both patient and family, is included in palliative care planning for Indigenous patients. Standards are discussed further in Chapter 8, Section 8.5.

Willis (1999) states *'the issue is not simply to modify elements of palliative care so that cultural differences in belief and practice around death are accommodated, but to recognise that different cultures 'do death' in different ways, and that institutions for the provision of palliative care are bound up in the 'way of dying' of the culture in which they originated.'* (p 427). He goes on to discuss the concept of a 'good death' (as defined in terms of modern hospice practice), as opposed to what he terms an 'acceptable death' (p 434) as defined in terms of the desires and expectations of the patients and their families. The implication is that one person's 'good death' may be another person's 'bad death'. Willis also points out that changing minor details of service delivery such as food or the numbers of visitors, or the time allowed for visits

(though they may be necessary) are inadequate responses to cultural differences in the underlying assumptions of care.

The setting of standards in relation to these matters is not simple.

Whilst it may not be practicable to set prescriptive standards for the delivery of culturally appropriate palliative care, it should be possible to set standards for appropriate cross cultural communication and practice. These should ensure, for example: effective input into policy and cross cultural practices by appropriate Indigenous organisations; employment or participation of Indigenous staff where possible and appropriate; effective communication between Indigenous and non-Indigenous service providers, and so on. Ultimately the effectiveness of such standards would need to be determined by consumers – palliative care clients and their families – so observance of these standards would need to be monitored or measured by (culturally knowledgeable) third party interview of consumers.

This objective suggests that resources should be tied to good practice. There is a danger that tying resource allocation to good practice will disadvantage those who are already disadvantaged. At the same time, bad practice should not be fostered simply because of a practical absence of better alternatives. Where consumers are not well served by existing services, action needs to be taken (and resources applied) to ensure that those service are improved (or replaced) rather than withdrawn because they do not meet standards. Services should be strongly encouraged to develop local models of good practice for Aboriginal and/or Torres Strait Islander patients, in partnership with other local service providers in Aboriginal and Torres Strait Islander health or palliative care.

#### **Objective 2.2: Resource allocation and administrative support**

This objective should explicitly recognise that some culturally determined costs which in the past may not have been seen as the province of palliative care funding should be recognised as legitimate palliative care costs (see also Chapter 9). These may include costs for:

- temporary housing for the duration of the palliation (for cultural and/or socio-economic reasons);
- transport to take the client home (with adequate care);
- locating and accessing traditional healers;
- return of deceased to their home country or community; and
- providing support or assisting with funeral arrangements as an essential part of bereavement.

#### **Objective 2.3: Accountability and reporting**

The administration of the Indigenous status question in relation to palliative care clients is a major issue, not only for consistent reporting and monitoring but also for delivery of appropriate care. Our research shows that the question is often not asked, but is assumed in many health admissions and that most palliative care assessment processes do not usually ask or record this information (see further Chapter 4) . While most palliative care assessment instruments ask clients about cultural issues, most do not ask about Indigenous status. There are often poor links between systems that record Indigenous status information and systems that record palliative care.

#### **Objective 2.4: Service development**

A number of our findings are likely to have implications for this very broad and all-encompassing objective. Some immediate additions are obviously needed, such as the addition of end stage renal disease to Strategy 2.4.4 of the National Palliative Care Strategy (NPCS) (see further Chapter 4, Section 4.5).

The relevance of some of the strategies to Indigenous issues should perhaps be highlighted. For instance, the development of palliative care pathways (NPCS Strategy 2.2.3) (particularly incorporating referral processes) would allow the triggering of appropriate cultural support and advocacy at key times (see further Chapter 5, Sections 5.9.3 and 5.6.5). The use of video-conferencing (NPCS 2.4.4) has particular relevance to remote Aboriginal and Torres Strait Islander peoples. Early tele-medicine conferencing should help prevent unnecessary transfer of remote patients to city hospitals, and use of video conferencing to facilitate family access and family meetings for remote community members is very important. This might also be used in Aboriginal-specific nursing homes on the east coast where relatives live long distances away, but most AMSs have video conferencing equipment which families could access (see further Chapter 5, Section 5.9.4).

There is a need for effective quality control and improvement. Specifically mainstream palliative care providers should develop systems to check on the quality of their service to Aboriginal and Torres Strait Islander clients. A program of service review conducted six months after a death and using an Indigenous reviewer would be a useful way for services to discover how their services could be improved (see Chapter 8, Section 8.5.2).

Some specific targets or outcomes could be developed in relation to NPCS Strategy 2.4.5.

#### **Objective 2.5: Research and evaluation**

Section 10.3 below identifies several particular target areas for research. One relates to the delivery of 'bad news' by doctors and another to research into the best approaches to grief and loss and the development of effective treatment programs for Aboriginal and Torres Strait Islander clients. Research into competencies to be delivered by effective cultural awareness training and into the development of palliative care pathways is also needed.

### **10.2.3 Goal 3: Partnerships in care**

#### **Objective 3.1: Partnerships in care coordination**

This goal requires an introductory objective about raising the profile of mainstream service providers within Indigenous communities, including naming specific individuals as contact persons for Aboriginal and/or Torres Strait Islander clients and services, so that relationships can be developed and to facilitate care planning. Such relationships currently do not exist in most places, however before partnerships can develop, basic relationships need to be in place to establish a basis for trust. A preface to this effect should be added to this goal. (See further Chapter 5, Sections 5.4.2 and Chapter 7, Section 7.3)

A number of protocols then need to be developed on a local and regional basis to facilitate the development of care planning (eg see guidelines in Appendix 12).

#### **Objective 3.2: Partnerships in service planning and delivery**

Issues that are relevant here include the need for local relationships and partnerships and the need for Aboriginal and/or Torres Strait Islander staff (see further Sections 4.3 and 7.3 and Appendix 12).

Local planning workshops are needed so that Indigenous health and home care services can find out what palliative care services do, and vice versa, and then work out how they can best work together. Local colleges of GPs should be involved in these workshops.

Palliative care services need to employ trained Aboriginal and/or Torres Strait Islander staff to assist in the development of their services. These positions are needed at State level (in government and/or in Palliative Care Associations) and in services in regions with high Aboriginal and Torres Strait Islander populations. Two types of positions are envisaged although in some places they may be combined: *Development positions*<sup>1</sup> which primarily aim to develop services within a region and *Service Delivery positions* which would work more directly with clients. Sufficient trained Indigenous palliative care positions (or days) need to be funded so that these services can be bought in as needed. A strategy more specifically directed at Indigenous employment may have resulted in this issue being dealt with, or at least pointed out, in the Palliative Care Australia Planning Guide (2002). (See further Chapter 6, Section 6.6, Chapter 7 and Appendix 14.)

### **Objective 3.3: Partnerships in policy development**

Much of the comment above in relation to Objectives 3.1 and 3.2 applies to this objective, but at State and Australian Government level. Employment of Indigenous palliative care development staff in key places will ensure that policy makers engage with palliative care issues. Until now, most Indigenous health bureaucrats (State, Australian Government and in the community controlled sector) have not been well informed about palliative care and as a result it is not raised in policy development (see also Objective 1.5 above in Section 10.2.1).

## **10.3 Conclusions**

The implications of the findings of our study are recorded in more detail within the relevant chapters of this report (as cross referenced above) and these sections should be considered by service providers and policy makers. Some of the immediate and medium term actions needed and some key targets are outlined below.

### **10.3.1 Demonstration projects and resource shortfalls**

It is clear that an infusion of funds is required in the short term to:

- develop the capacity of Aboriginal and Torres Strait Islander communities to access and take part in delivery of palliative care services. Immediately, training for Aboriginal and Torres Strait Islander health workers, nurses, psychologists, social workers, doctors and allied health professionals is needed.
- develop services to provide culturally sensitive delivery of palliative care by improving the design and coordination of services, employing Aboriginal and Torres Strait Islander staff and improving the cultural competence of mainstream staff. Coordination must involve ACCHS and/or Area Health Boards.

This process could be 'kick started' by the establishment of a number of demonstration projects, some at State or regional level and some at a local, hands on level. Such projects should give high priority to training issues and planning and coordination.

It is estimated that 5 years' funding is required to develop pilot and demonstration projects which will set up the infrastructure so that the States and Territories could deliver needed services in a prioritised way.

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<sup>1</sup> See Appendix 14 Model Duty Statement – Indigenous Palliative Care Development Worker.

A mechanism by which these projects might be managed may be the establishment of a committee of each of the State or Territory Partnership Forums to develop State palliative care strategies for Aboriginal and Torres Strait Islander peoples. These committees could use the demonstration projects to develop models of coordination and service delivery and at the same time identify resource shortfalls on a regional basis. Clearly the community controlled health sector will have to be involved in this process.

It is extremely important that the non-government sector (for example the Palliative Care Associations and the Cancer Foundation) and are involved in and take some ownership of this process.

### 10.3.2 Some key targets

Many of these targets are relevant to other culturally and linguistically diverse groups as well as to Indigenous peoples.

#### **Employment and training of Aboriginal and Torres Strait Islander staff to work in palliative care**

This should be a central target and is discussed in Chapters 6 and 7.

#### **Information strategies**

Communication strategies for Aboriginal and Torres Strait Islander communities and for decision makers working in Aboriginal and Torres Strait Islander health are discussed in Chapter 7.

#### **GP and AMS doctor education**

It is extremely important that GPs who work with Aboriginal and Torres Strait Islander clients<sup>2</sup> have the opportunity to learn more about palliative care and cultural issues surrounding death and dying. It is important that AMS doctors come to see palliative care as a special service which they can access for their clients and in which they can take a central role. It is suggested that a Continuing Medical Education (CME) package on these issues be developed for GPs. Assistance might be sought from the College of General Practitioners to sponsor such programs in areas of high Aboriginal and Torres Strait Islander population (see further Chapter 7).

#### **Cultural and linguistic advocacy**

All palliative care teams should have the capacity (in service delivery design and resources) to engage cultural advocates for their clients (both Indigenous and Culturally and Linguistically Diverse (CALD) clients). Cultural advocates need orientation in the objectives and methods of palliative care (especially respect for the individual's wishes) as well as cultural awareness training (in respect of the mainstream medical culture in which they will be working). Cultural advocates should receive supported debriefing as part of their engagement.

All palliative care services should have the capacity to engage the services of language interpreters where the family involved does not speak English. The implication of this is that funding is needed for brokering in these services and in some places may be needed to establish them (eg a service offering various Aboriginal languages in Perth). These interpreters will require the same orientation as cultural advocates and should receive supported debriefing as part of their engagement. (See further Chapter 3, Sections 3.2.8 and 3.3.2.)

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<sup>2</sup> including those who work in ACCHS or AMSs, and those who work in regions with high Aboriginal and/or Torres Strait Islander populations.



### **Cultural awareness training**

All palliative care workers and community nurses should have regular cultural awareness training and related work experience opportunities to develop competence in cross cultural communication. Cultural awareness training needs to be developed to deliver effective cross cultural communication and practice as well as to deal with issues specifically related to Indigenous death and dying. Cultural awareness training of hospital staff should be reviewed and improved, especially where large numbers of agency staff are used in areas of high Aboriginal and Torres Strait Islander population (see Chapter 7).

### **Hospital and hospice design and management**

Chapter 5 outlines some key issues for hospital and hospice design and management in relation to Aboriginal and Torres Strait Islander people. These issues have wide applicability in the Australian context. Many of the needs regarding facilities at the time of death identified by members of Aboriginal and Torres Strait Islander communities are applicable to other culturally and linguistically diverse groups.

### **Research targets**

Four areas of research need present themselves:

- State or regionally-based research into how ‘bad news’ is usually delivered, how it should be done, the roles of family and cultural supporters, and links between the initial or subsequent advice of diagnosis and follow up actions, such as referral to palliative care. The way in which ‘bad news’ is delivered is critical to Aboriginal and Torres Strait Islander people accessing palliative care services. People need to be told in a way that is appropriate to their culture and in a way that will support them in making informed choices about their future options. What is appropriate will vary from place to place (see Chapter 4). Bodies representing Indigenous health professionals such as nurses (CATSIN), doctors (AIDA), psychologists and social workers should be consulted in the development of this research;
- Contemporary Aboriginal and Torres Strait Islander modes of dealing with grief and loss, and the development of effective and accessible methodologies and programs in this area (see Chapter 5, Section 5.5);
- A review of the effectiveness of cultural awareness training and development of competencies in cross cultural communication and service delivery (see Chapter 7); and
- Development of model palliative care pathways which include checkpoints for cultural advocacy and cultural safety (see Chapter 5, Sections 5.6 and 5.9.2).

### **10.3.3 Immediate actions that would help increase Indigenous people’s access to palliative care**

- Initiate a dialogue between mainstream and Indigenous service providers in your region or local area to find out what each does, what each has to offer and to work out how the gaps can be filled. The solutions should be developed in response to local circumstances and cultural needs. This action can be taken by individual service providers and/or Indigenous health services. It should be encouraged and supported by State governments and non-government associations.
- Development of an Aboriginal and Torres Strait Islander palliative care network and ongoing Indigenous palliative care newsletter.
- Employ Aboriginal and Torres Strait Islander people in local palliative care services (see model duty statement, Appendix 14).
- Schedule a planning workshop for the region involving all relevant parties.

## References

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