

# Staying Well

with bipolar disorder

## FINAL REPORT

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Sarah Russell, Margie Nunn and Jan Browne

❖ **Research Matters**

Sarah Russell PhD  
Principal Researcher  
Research Matters  
Phone: 61 3 9489 0742  
Email: sarahrussell@comcen.com.au

[www.researchmatters.net](http://www.researchmatters.net)

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In this report, all text in *“italics and quotation marks”* is a direct quote from a participant. In longer quotes, participants are identified by number, not name.

## "Stay Well" Summary

We are grateful to everyone who participated in the "Stay Well" study. Participants' stories provide evidence that people with manic depression/bipolar disorder<sup>1</sup> can aspire to full lives. This includes having a job, partner, children, friends, hobbies and pets.

This report provides feedback to people who shared their "Stay Well" story with us. We collected 100 stories from people from all around Australia and from all walks of life. These stories provide hope for people diagnosed with manic depression/bipolar disorder, their families and friends. Positive stories also help to dismantle the stigma that is so often associated with manic depression/bipolar disorder.

Listening to people who have learnt how to stay well with manic depression/bipolar disorder may also provide new insights for mental health professionals. For many participants, staying well was not just about seeing a psychiatrist and taking prescribed medication. It was often about so much more.

In this study, "staying well" meant different things to each participant. For some, it meant being free of symptoms. For others, it meant being able to make choices and take control of their illness.

Like others who experience chronic illnesses, participants developed strategies to manage manic depression/bipolar disorder. Many participants described the importance of being "mindful" that they have manic depression/bipolar disorder. "Mindfulness" involved being aware of both themselves (e.g. their strengths and limitations) and the symptoms of their illness. Although participants would undoubtedly like to forget about their illness, they benefited from maintaining an awareness of its presence. By keeping manic depression/bipolar disorder in mind, participants were able to move on with their lives.

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<sup>1</sup> Most participants referred to the illness as "bipolar disorder". Some, however, preferred to use the term "manic depression". In this report, both terms are used together.

## Background

An Australian study found that people with manic depression/bipolar disorder are “4 times more disabled than the general population”, with high rates of suicide, substance abuse, criminal behaviour, unemployment and divorce<sup>2</sup>. According to this study, people with manic depression/bipolar disorder can, at best, aspire to “a relatively normal life”. Another recent Australian study found people with manic depression/bipolar disorder experienced social isolation, the failure of support networks and the breakdown of relationships<sup>3</sup>.

Mental health research often relies on ‘convenience samples’ in which participants are accessed through mental health organisations, rehabilitation programs and consumer groups. People with manic depression/bipolar disorder who are not involved with mental health groups are largely absent from this research. In order to provide a different perspective to recent Australian reports<sup>2,3</sup>, the "Stay Well" study focused only on how people with manic depression/bipolar disorder stay well.

According to the World Health Organisation<sup>4</sup>, health is a state of complete physical, mental and social well-being. It is not merely the absence of disease or infirmity. In the "Stay Well" study, “wellness” is defined as the concept of practicing all the things that keep one well.

**Although the "Stay Well" research does not intend to represent all people who experience manic depression/bipolar disorder, our research fills an important gap in previous Australian mental health research.**

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<sup>2</sup> Access Economics for SANE Australia (2003) “Bipolar disorder: an analysis of the burden of bipolar disorder and related suicide in Australia”

<sup>3</sup> Highet.N and McNair. B “The Impact of Living with Bipolar Disorder” [www.beyondblue.org.au](http://www.beyondblue.org.au) February 2004

<sup>4</sup> Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 1946

## Methods

One hundred people who live well with manic depression/bipolar disorder were recruited from the general community. Recruitment methods included media releases and circulation of flyers via email. People were invited to share their stories about: the changes they make in their lives to stay well; the early signs of things going wrong; and what they do to prevent an episode of illness.

Within one month of launching the "Stay Well" study in the media, 163 enquiries were received. Over a quarter of the initial enquiries came from those with manic depression/bipolar disorder, family and friends seeking some sort of assistance. They were unaware that support and information services existed. Rather than participate in the "Stay Well" study, these people were referred to appropriate services.

Several other enquiries were received from people working in mental health organisations and other health care settings who had only ever experienced people with manic depression/bipolar disorder who were unwell. They questioned the underlying premise of the study. They questioned whether it was possible for people with manic depression/bipolar disorder to stay well.

A number of people shared stories about not staying well. For the purposes of the "Stay Well" study, these stories were excluded. Other exclusions were the stories submitted by mental health workers on behalf of clients.

One hundred people diagnosed with manic depression/bipolar disorder were included in the "Stay Well" study. Their stories were either written by the participant or collected through a personal interview with the researcher.

**The next stage of the "Stay Well" study involves a forum. At this forum participants with manic depression/bipolar disorder and health care professionals will discuss the findings and make recommendations.**

## Findings

Participants found that their wellness depended on a number of things that were within their control. However the data indicated that there was not a simple ‘one fix fixes all’ approach. In the "Stay Well" study, most participants:

- recognised the importance of taking their illness seriously
- demonstrated that staying well was within their control
- made changes in their lives to stay well
- learnt to get on with their lives whilst remaining mindful of their illness

Participants in the "Stay Well" study were mostly professional people over the age of thirty (the age range was 18 – 83 years). Sixty three participants were female; thirty seven were male. The majority had been living with manic depression/bipolar disorder for more than 5 years. Participants mostly had jobs (76% of participants were in paid employment) while 7% were receiving the disability pension. In addition, 36% of participants were parents. Many participants described “*living life to the full*”.

*“With bipolar illness controlled, I have had a wonderful quality of life and live life to the full”. (Participant 52)*

Participants identified a number of factors that helped them to stay well and live life to the full. Not surprisingly, these factors were things that help all people to stay well. We all benefit from eating healthy foods, exercising, drinking less alcohol/caffeine, sleeping well, spending time with loved ones, having quiet times, managing stress, laughing and so on. However, participants also described the need to make specific changes to stay well. With the assistance of their support networks, participants learnt to set limits and boundaries, establish safety nets and set up harm minimisation strategies.

Participants learnt (often through trial and error) what worked for them, and what did not work. For some participants, sleep deprivation could trigger an episode of illness – these participants were particularly mindful about sleep. For other participants, drinking alcohol or caffeine “*sent them right off*” – these participants modified their eating and drinking habits. Several participants found that smoking marijuana was a trigger. To avoid episodes of illness, they stopped smoking marijuana. A few participants, however, found marijuana helped them to manage their illness.

## **Staying well concept**

Staying well is not just about mental health. It also includes physical, social and emotional wellness<sup>5</sup>. Wellness is a state that allows people with manic depression/bipolar disorder to live life to the full.

In this study, “staying well” meant different things to each participant. For some, it meant being free of symptoms and behaving “normally”. For others, it meant being able to make choices and take control of their illness. Taking control and being free of symptoms did not, however, mean being cured.

*“One of the best things I can say about my illness now is that I am not scared of it anymore. I believe that I have the power to control it. I have learnt how to manage my symptoms.” (Participant 67)*

Although the illness could not be cured, episodes of illness could be prevented. Participants felt it was far better to prevent episodes of illness than to live with the consequences of a breakdown.

*“It is a long way back from a breakdown. A breakdown is a huge thing.” (Participant 106)*

Several participants had developed plans to keep them well. These so-called “action”, “stay well” and “crisis management” plans were often developed in conjunction with partners, family and friends.

*“My intention is to never go to hospital again so when I see these signs coming, I have my own action plan. This action plan has been constantly revised and updated throughout my illness. This action plan assists in preventing me from sliding further.” (Participant 67)*

For many participants, staying well involved separating themselves from their illness. This separation allowed them to forgive themselves for their behaviour when they were unwell. They accepted that it was the illness not them.

*“I see the problem as the manic depression and not me. I separate the two and see the need for me to be in control of the manic depression, so that it doesn't influence my life too much.” (Participant 97)*

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<sup>5</sup> According to the World Health Organisation, health is a state of complete physical, mental and social well-being. It is not merely the absence of disease or infirmity.

## Strategies to Stay Well

**Participants learnt what worked, and what did not work for them. Although there were some common themes, participants' strategies were based on their individual needs and social contexts.**

### Diagnosis

For many participants, the first step in “staying well” was getting the correct diagnosis. Those participants who received the wrong diagnoses found the diagnosis of manic depression/bipolar disorder “*a relief*”.

*“Once you know what it is you can deal with it. I’ve had manic depression/bipolar disorder all my life, but it was not until I knew what it was that I could deal with it.” (Participant 4)*

For many other participants the diagnosis of manic depression/bipolar disorder came as a shock. Many described “*a period of denial*” in which they did not accept a medical diagnosis or a mental illness label. Once they “*came to terms*” with the diagnosis, several participants described “*getting on with living*”.

*“I believe the sooner you can accept your illness, and can learn about it, the better chance you have of managing it.” (Participant 67)*

*“Acceptance is a key aspect to being able to live well. When I was able to accept the illness, it made it easier for me to move on with my life.” (Participant 71)*

*“People with bipolar have to realise that they have a disease which requires treatment for the rest of their lives. Once this is accepted, they can get on with living.” (Participant 44)*

Two participants did not use the diagnosis of manic depression/bipolar disorder. Participant 121, for example, did not like defining himself with “*medical language*”. He preferred psychological therapies to stay well. Participant 80 also “*queried the diagnosis*”, though he continued to accept treatment.

*“It is nearly 20 years since I have seen a psychiatrist and other than being told by my local GP that I should continue taking lithium each day as a precaution, I have not sought nor, in my opinion needed, any medical treatment”. (Participant 80)*

## Education

For most participants, the management of manic depression/bipolar disorder required learning about manic depression/bipolar disorder. It also required learning more about themselves. Knowledge about self and illness equipped participants to understand their own response to the illness.

*“I've become more familiar with manic depression, and become more knowledgeable about my illness in particular.” (Participant 77)*

Participants learnt about themselves through such things as their life experiences, relationships, reflection and ‘self talk’. Participants learnt about the illness through books, health care professionals, mental health organisations, seminars, support groups, internet and talking with people. Rather than rely only on professional understandings of the manic depression/bipolar disorder, most participants also valued hearing about others’ experiences of the illness.

*“I found it very important to know and read about how others experience the illness.” (Participant 41)*

*“The most reliable information about medications and managing symptoms came from discussions with others who experience the illness.” (Participant 76)*

## Identifying triggers

Participants identified a number of factors that may trigger an episode of manic depression/bipolar disorder. These included stress, sleep deprivation, fatigue, jet lag, hormonal fluctuations, change of seasons, all night partying and recreational drugs.

*“If enough of these "triggers" occur, especially in a relatively short space of time, then I'm vulnerable to extreme mood swings.” (Participant 77)*

Participants also described “paying attention to little things”. In particular, small changes in sleep patterns, energy levels, moods, thoughts, speech, spending habits. The changes may be small, but they may also be significant. Although participants were mindful of triggers, they felt it was important not to obsess about them.

*“I need to be very conscientious about my commitment to taking my medication and turning up for appointments with psychiatrists and psychotherapists. I also need to be informed on broad issues surrounding bipolar. But at some point I must loosen the tag on my forehead that says 'bipolar' and just 'get on with it'. Otherwise I become obsessed about my disease and then I become my disease.” (Participant 93)*

Many participants were able to identify specific things that triggered their episodes of manic depression/bipolar disorder. The most commonly mentioned triggers were stress and sleep deprivation. The relationship between these two triggers was complex. In some cases stress caused disruption to sleep. In other cases, a lack of sleep caused a low resilience to stress. Either way, participants were quick to intervene. They were simply not prepared to “*take risks*”. Several participants described “*self medicating*” sometime between 2am and 4am.

Insight into manic depression/bipolar disorder involves knowing your own “triggers”. For many participants, it took time, sometimes years, to develop the experience and wisdom to manage manic depression/bipolar disorder.

*“Many people hope for instant recovery. It takes time to learn how to control it. We learn to monitor ourselves and accept what our bodies can do.” (Participant 35)*

Participants described self understanding and learning about their “*own triggers*”. They described always having a “*finger on the pulse of how you feel*”.

*“Now, finally, I listen to what my mind and body is ‘telling me’. I know myself. I respect my limitations.” (Participant 38)*

*“I now understand it and my body like the back of my hand and more swiftly intercept a mood swing.” (Participant 52)*

*“I am able to assist in my wellness by observing what is happening to me and making changes to stay well.”(Participant 127)*

A few participants described worrying whenever they felt happy. They worried that their happiness would “*spill over into manic euphoria*”. Although some participants longed for that “*wonderful feeling of mania*”, most acknowledged the damage their mania had caused (to both themselves and their loved ones). Hence, they did “*everything within their powers*” to avoid episodes of mania. Others accepted that their “*fast times are times when I am most creative and have incredible thoughts*”. Likewise, they accepted “*bad days*”, knowing that it did not mean they were “*falling into a depression*”. These participants accepted that ups and downs were a normal part of life.

## Warning Signals

Most participants were vigilant about warning signals. These warning signals were not merely due to the ups and downs of normal life. They were warning participants that an episode of illness may be on the horizon.

*“If I let it slide, I can’t stop it and I become unwell.” (Participant 16)*

Most participants did everything in their power to avoid an episode of illness. One participant, however, developed strategies to live with “*moments of mania*” in ways that were acceptable to herself and others.

*“The other day, I recognised that I was becoming manic. I felt a strong desire to shop. Rather than go home and take medication, I decided to continue shopping. I spent a lot of money on credit. I bought jewelry that I would not normally buy. Later that night, I took an increased dose of medication. A few days later, I phoned my psychiatrist to let him know that I was OK. I love my new jewelry, even though I really can’t afford it.” (Participant 7)*

Participants provided lists of warning signals for both depression and mania. For depression, the early signs of things going wrong were such things as sleeping too much, loss of interest in things, decreased energy, inability to concentrate, loss of appetite and overwhelming sadness. One participant said he suffered a “*drooping libido*”.

The warning signals for mania included obsessive thoughts, talking very quickly and doing one hundred things at once, binge drinking, impulsive behaviour, reckless spending, increased desire for sex, unsafe behaviour, agitation, frenzied house cleaning, partying, racing thoughts, indecisiveness, increased energy, over-committing, inappropriateness, increased selfishness and aggressiveness. Not surprisingly, the list just went on and on:

*“Repeatedly not sleeping well, incredible confidence with women (I’m normally pretty shy around them), lots of creative ideas that are not fully acted upon, probably acting as if I was drunk (i.e. losing inhibitions to say things to people - forgetting the social niceties of what happens when you say socially ‘un-nice’ things to people which you just think are authentic and true!)”. (Participant 93)*

When these warning signals occurred, participants recognised that they were “*close to the edge*”. In many cases, it was only a short step to flying over the edge. To prevent an episode of illness, participants needed to intervene. At such times, participants often worked closely with their support networks. Intervention may simply involve canceling a few appointments, getting a few good sleeps, increasing their medication, or making an appointment with a health care professional. With experience, participants learnt how to respond to warning signals to ensure they avoided episodes of illness.

## **Managing stress**

For some participants, managing manic depression/bipolar disorder required making significant changes in their lives. These changes included moving out of the city, adopting a quieter lifestyle, avoiding “*passionate activities*” (e.g. protest marches, football games) and changing jobs. Several participants employed in senior positions chose to “*downsize*” – they worked fewer hours or moved down the career ladder. Some changed careers completely.

*“I have had to make huge changes in my life to stay well. Taking medication religiously would be the smallest of these changes. I now lead a different but full life.” (Participant 113)*

*“Changes I have made include moving from a “party house” in the city (which I thrived on) to living by myself on the Mornington Peninsula close to the ocean; leaving a very highly paid, stressful and “social” job in the city to becoming a “poor” student; giving up marijuana; learning to take my pills without resentment; limiting my social activities and my involvement in other projects (I have finally realised you can’t do everything!!); moving away from people who were not good for me; setting regular sleeping times and other routines and many others.” (Participant 67)*

No matter what lifestyle participants adopted, or where they chose to live, it was not always possible to avoid stress. Participants, therefore, developed a range of strategies to minimize the impact of stress. One participant, for example, made sure that events that may cause stress were not close together. Another took regular holidays and made time for relaxation. Others chose to increase medication during particularly stressful periods.

To stay well, many participants regularly assessed their “workloads”. Those inclined to do “*too much*” developed strategies to keep their schedules manageable. Sometimes it was as simple as keeping an appointment diary. Others needed to regularly reassess their workloads and its impact on their health and wellbeing.

*“I’ve had to make many changes in my life to stay well, which have mostly revolved around regularly re-assessing and re-evaluating my workload, whether that has been at university, in the world of work or in my personal life.” (Participant 77)*

Most participants recognised the importance of making sure they received an adequate amount of sleep. Some watched their sleeping patterns “*like a hawk*”, keeping regular bedtimes and avoiding too much stimulation at night. Other participants did not maintain such strict sleep patterns. Instead, they were more flexible about going to bed (and getting out of bed). However, sometimes they needed to make sleeping a priority.

*“I sometimes have to acknowledge that I am not getting enough sleep. I convince myself that whatever I feel I have to do can wait another day. Sleep at that particular time is more important.” (Participant 92)*

## **Medication**

Eighty five participants in the "Stay Well" study took medication to help them control their illness.

*“First and foremost I take the medication without which I can’t stay well. I have tried, believe me. Like most people, I dislike having to rely on pills.” (Participant 12)*

Some participants described “*learning the hard way*” that they needed to take medication.

*“Sometimes I simply believed that I was cured, or never really had anything wrong with me in the first place, and therefore I stopped taking my medication. I learnt the hard way that I need to take my medication, no matter how much I sometimes believe I no longer need it.” (Participant 92)*

For many participants, medication was an important ingredient in staying well. To be more precise, the right medication at the right dose. Several participants endured years of trial and error with many different combinations of medication and many unpleasant effects. They described feeling like a “*guinea pig*”. However, once the right medication for them was prescribed, their lives improved.

*“I took lithium for 20 years. As a result, I have renal failure and a parathyroid gland tumour which was recently removed. My GP wrote the lithium scripts but did not observe me closely. I had irregular blood tests. I changed doctors 10years ago and switched to Tegretol. My life changed overnight. I felt well for the first time in 20 years.” (Participant 106)*

For some participants, lithium did “more harm than good”. Others described lithium as their “saviour”.

*“To me lithium is a wonder-drug. I fought against taking it but I have learnt bipolar is due to a chemical imbalance.” (Participant 52)*

Rather than take a regular daily dose of medication, a few participants chose to take medication only when they felt warning signals. One participant always carried prescribed medication in his pocket, just in case. Others chose to take a low dose and increase the dose as required.

*“If I feel myself getting too high, energetic or flighty I will dose up on lithium. Instead of taking three tablets I will up the dose to four. Just until I feel myself righted, and in balance again.” (Participant 14)*

For fifteen participants in the "Stay Well" study, the best medication was no medication. These participants accepted that they had manic depression/bipolar disorder but preferred to use other avenues to stay well. One participant stayed well for 5 years with orthomolecular treatment while another had remained well for over 30 years with brewers yeast. One teaspoon per day of brewers yeast had the same effect on her as lithium.

Several participants believed that manic depression/bipolar disorder was caused by poor nutrition and took nutritional supplements as well as, or sometimes instead of, medication. The most common supplements were Vitamin B and Omega.

Several participants used complementary treatments such as naturopathy, cognitive behavioural therapy (CBT), psychotherapy, diet, minerals, Traditional Chinese Medicine, homeopathy, kinesiology, massage, reflexology, aromatherapy, cell salts, colour and crystal healing, herbs, natural healing, qigong, reiki, shiatsu, tai chi and yoga. Their decision to use complementary therapies, however, was not always supported by other health care professionals.

*“I wanted to explore alternative therapies. However, my psychiatrist was not supportive. He was very dismissive of other options. He just pumps me with drugs.” (Participant 130)*

## Support

Many participants acknowledged that “*self-management includes a willingness to access the assistance of others*”. These participants relied on support networks to stay well. This included partners, parents, children, brothers, sisters, friends, colleagues, pets, churches, community and mental health groups and health care professionals.

### *Personal support*

People who were close to participants (partners, parents, children, brothers, sisters, and friends) often gained insight into manic depression/bipolar disorder. This insight provided a level of understanding that was often welcomed. For example, good friends fully understood the need to sometimes cancel arrangements when participants needed some “*quiet time*”. In addition, many participants enlisted the help of partners, children, brothers, sisters, friends and sometimes work colleagues “*to help monitor moods*”. These participants wanted someone close to them to check their behaviour, particularly if they were “*speeding up*”. However, for some participants, this personal surveillance became oppressive.

*“I had to stay calm around my relatives. If I was arguing with them, they thought I might have missed my tablets. It was annoying for me. I couldn’t put my views across. They didn’t realize that I was getting better, taking my tablets, and all I wanted to do was get on with my life.” (Participant 49)*

### *Pets*

For some participants, pets played a loving role in their staying well. These participants mentioned the enjoyment of walking their dogs every day, taking time out to sit and play with cats and unconditional love. For those with dogs, the daily dog walk helped with their mental, physical and social wellbeing.

### *Church*

For many participants, religion and spiritual belief was a source of great strength, comfort and support. For many, attending church was part of their “Stay Well” strategy.

*“My local pastor is my mentor. Attending church has been a major turning point in my life. Prior to that, I was going no-where. All the counseling, hospitalisation and support group meetings did not work long term with me. But church seems to work.” (Participant 131)*

### **Community and Mental Health Groups**

Participants in the "Stay Well" study joined writing groups, book clubs, music groups and sport clubs. Several participants described themselves as *"too busy living to get involved in a support group"*. Nonetheless, several participants felt support groups were valuable, particularly for those who were newly diagnosed. Support groups can help people to get over the *"post episode hump"*.

*"I think it is important to distinguish between strategies for the immediate post episode and hospitalisation times and those for maintaining ongoing health."* (Participant 98)

For some participants, support groups were a source of camaraderie and information about manic depression/bipolar disorder. Support groups helped them to realise that they were *"not the only person in the world with this rotten disease"* and *"establish a network of other sufferers"*. Other participants, however, felt that *"support groups keep you sick"*.

*"You mix with the same people as in hospital. You drink coffee, smoke and talk about the same things – hospital admission, drug reactions and Centrelink. These groups do not encourage you to get on with your life and get back to work."* (Participant 91)

### **Professional support**

According to participants, the quality of professional psychiatric support varied enormously. Many participants shopped around to find the type of professional support that best suited them. They found the process of choosing their own health care professionals affirming.

*"I sacked my first psychiatrist and found another in the yellow pages. That was one of the best decisions I have ever made, because I am now blessed with a psychiatrist who returns my calls to his pager on the same day if it is urgent, and whom I now really trust. It is important to remember that some people clash."* (Participant 105)

*"After twenty five years of treatment, I eventually gained the courage to seek opinions and treatments from other psychiatrists and a sleep disorder specialist. This resulted in better management of my situation."* (Participant 89)

In addition to shopping around for the most suitable health care professionals, several participants preferred to work with a number of different mental health professionals (GPs, psychiatrists, case managers, psychologists, social workers, counselors), acknowledging that each professional had different expertise. Several participants used private therapists. They did not raise objections about the additional costs of private therapists. They considered their mental health as *"valuable"*.

*“My visits with the psychiatrist are quick, short and infrequent. I see him every year, around my birthday so I remember to make the appointment. He just prescribes medication and arranges blood tests. If I need extra scripts, I organize them through his receptionist. I have developed a nice relationship with the receptionist. My psychologist is more instrumental in helping me to get well. We talk things through.” (Participant 59)*

Several participants in the "Stay Well" study saw a psychiatrist only once or twice a year. However, if they felt themselves sliding up or down, or if they had a sleepless night or two, they would make contact with the psychiatrist. This indicated a level of trust between themselves and the psychiatrist. It suggested that the psychiatrist trusted the participant to make contact, and the participants trusted the psychiatrist to respond. Several participants had been referred from a psychiatrist back to their GP.

*“I am no longer seeing my psychiatrist. My drugs are managed by my GP. But if I was ever in need, I would not hesitate to call my psychiatrist.” (Participant 109)*

## **Stigma**

Many participants had dealt with the stigma of manic depression/bipolar disorder since they had received the diagnosis. For some, the stigma was worse than the illness.

*“The stigma of bipolar had an incredibly deep adverse effect on my self confidence, self image and my major fear and uncertainty of what my life was going to be like.” (Participant 101)*

Several participants described only hearing negative accounts of manic depression/bipolar disorder. These negative accounts gave participants the impression that it was not possible to stay well.

*“During years of going through acute illnesses, I was very aware that I didn't know, and couldn't even find out about, anyone who'd gone through a course of the illness as disruptive as mine and come out 'okay'. Apart from the odd famous figure of the distant past.” (Participant 63)*

Several participants believed that they were destined to suffer episodes of mania and depression for the rest of their lives.

*“I am generally stable with minor "blips". This seems to be a miracle as I thought I was doomed to be chronically ill for the rest of my life. I have finally reached the stage where I, my family, psychologist and psychiatrist are fairly certain that, if I keep doing what I'm doing, I will never go back into hospital or become significantly ill again.” (Participant 67)*

The lack of positive stories of manic depression/bipolar disorder also gave people in the community the perception that people with manic depression/bipolar disorder were “*complete social misfits*”. It was not surprising that many participants felt unable to disclose their illness, particularly to work colleagues. Those who chose to disclose their illness knew they risked encountering prejudice.

*“I used to tell people at work that I had the illness. But not anymore. I experienced extreme prejudice from my colleagues.” (Participant 66)*

Many participants in the "Stay Well" study felt that their friends, colleagues and acquaintances would be “*very surprised*” to know they were “*a sufferer of this devastating illness*”. This may be due to the fact that these participants did not present as “*sufferers*” nor had the illness “*devastated them*”. Although episodes of illness were often traumatic and disruptive (due to both the illness and inadequacies within the mental health system), participants found ways to minimize, or end, their suffering.

*“Although both my son and I have endured unbelievable suffering because of bipolar disorder, we both try to use this as a positive experience and truly appreciate the joy of being well.” (Participant 41)*

Although participants recognised that much of manic depression/bipolar disorder’s stigma was due to ignorance and fear, they felt people in the community needed to hear more hopeful stories. This conviction prompted many to participate in the "Stay Well" study. They also felt people who were newly diagnosed would benefit from hearing positive stories.

Although the illness was one of the most distressing things to happen in their lives, several participants felt the illness helped to make them “*a better person*”. Several participants found that manic depression/bipolar disorder had enriched both their personal and professional lives. In many cases, manic depression/bipolar disorder had given them greater personal insight and compassion for others.

*“In so many ways it’s a bit like cancer. People don’t talk about it or get too close just in case they may catch it. Once you get close to manic depression, you understand it. With every day, you fear it less.” (Participant 50)*

## Conclusion

The data in the "Stay Well" study demonstrates that people with manic depression/bipolar disorder can, and do, stay well. Participants do not aspire to live a "relatively normal life"<sup>6</sup>. They aspire to so much more.

By actively managing manic depression/bipolar disorder, participants were able to take control of their lives and stay well. Although there was no "one fix fixes all", participants learnt what worked for them. With time and experience, participants found that staying well was often within their control. For many participants, controlling manic depression/bipolar disorder involved:

- adequate amounts of sleep
- insight into triggers and warning signs
- manageable levels of stress (at both work and play)
- suitable medication for them
- compassionate social and professional support networks

In addition to the above list, staying well involved participants being mindful of their illness. Sometimes it was necessary to be more mindful than others. When participants were feeling well, the illness was in the back of their minds. It did not play a large role in their lives, but they knew it was there. On the other hand, when participants were feeling 'early warning signals', participants became more vigilant. Sometimes they needed to intervene. Intervention may simply involve a few good sleeps, a walk along the beach with a dog, or making an appointment with a health care professional. With experience, participants learnt what worked best to keep them well.

*The "Stay Well" study was funded by beyondblue.*

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<sup>6</sup> Access Economics for SANE Australia (2003) "Bipolar disorder: an analysis of the burden of bipolar disorder and related suicide in Australia" p11