



What recovery means to us: understanding real-life recovery.

Stories from people
travelling on their
recovery journey.



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Content warning:

This book contains discussions surrounding drug use, trauma including abuse and domestic violence, and thoughts of self-harm and suicide. If the information triggers an emotional response please connect with your support workers, family or friends or contact Lifeline on 13 11 14.

Support Services are listed in the back of this booklet.

Recovery is generally considered to be:
Living a meaningful and contributing life with or without the symptoms of mental ill-health

- (William Anthony, 1993)

In this booklet we have brought together stories from a group of people who are at various stages in their recovery, to understand what recovery has meant to them in their lives.

The stories in this booklet are real-life. They show the ups and downs of recovery which can often be difficult but still reveal moments of hope.

When people share their recovery stories or experiences, they help us to better understand the barriers as well as the things that helped. While different people will find different things helpful and unhelpful, some of the stories and experiences might be useful to you.

The quotes from people who shared their stories are in inverted commas and sometimes we have added words to help make it easier to read. When we have done this we have put our extra words in brackets like (this). When we have cut out some words, you will see a few dots like this ...

When you have taken some time to read the stories, we suggest that you use them to raise questions with your support worker or counsellor, and that you think about how these stories might relate to your journey.

The images in this book were all created by people with mental ill-health who are living in Western Sydney. The images were made and shown as part of the 'See Me Hear Me project' funded through Partners in Recovery and run by the Benevolent Society.

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The image on the front page is by Tim Smith who produced this beautiful work as part of See Me Hear Me project funded through Partners in Recovery and run by the Benevolent Society.



‘Thursday’ - Doug Walker

The stories in this booklet

The University of Sydney, in partnership with Western Sydney Partners in Recovery, undertook a project in 2015-2016 to develop stories of recovery for people living with mental ill-health.

Thirteen people, who at the time of the interviews, were receiving help from Western Sydney Partners in Recovery, took part in the project. Two men and eleven women aged between their mid-20s to retirement age took part. People shared stories with the researcher in their homes, some in coffee shops or bowling clubs across Sydney and others in offices of their support facilitator, who checked in with them afterwards. Names have been removed to protect their privacy.

We would like to thank all those who so generously shared their valuable stories with us

After speaking to this group of people going through recovery, we found that...

Recovery is an individual journey

We uncovered some shared ideas, by asking people what personal recovery meant to them. Most previous writing on recovery focuses on people further along in their journey, where life might be less chaotic or crises further apart. These stories give us an insight into a time where things might still be tough, but a time where hope exists.

The stories have common themes of hopeful times, and of difficult times.

People talked about times of sadness, and the gaining of wisdom, a process of understanding what worked for them, what helped, and learning how they could live well.

The people we spoke to talked about hope; hope to be loved, hope to have satisfying relationships with others, and being included in day-to-day life within their local communities. Thinking about the possibility of recovery was hopeful in itself, people explained that there was not always a ‘and so they lived happily ever after’ story about recovery but that getting close was good enough.

How do people 'do' recovery?

“(Recovery and support) are like a tree; I’m trying to get all the branches to align and grow leaves at the same time. So I’m trying and I’m doing that with every different facet. My support facilitator, she’s in this main trunk, sort of thing. Other branches would be services - Salvos, St Vinnies, all those places that have provided me with food parcels or vouchers - basically that help you live not just exist, because I existed for a long time. I still am sort of existing, I feel, but now that I’ve got that bit of faith and hope back again ”

Early recovery was full of ups and downs for the people who shared their stories with us. People spoke about physical health, support from others, medication, working and volunteering and the importance of looking after themselves.

“I’m a nature person and I love to go for nature walks ”



Untitled - Garth



Depression in Sydney – Robert Powell



The importance of looking after yourself

One woman explained that learning to accept her own mental ill-health was like understanding that her life was like the trunk of a tree, where you have to feed the roots that hold you up. Finding ways to learn about yourself, the way the health system works, and to be gentle with yourself, while you were unwell, was the key to recovery.

“We make the future, but it’s like you can’t see beyond it. You can’t see to tomorrow. It’s horrible for someone with depression. I didn’t know I was depressed. I never understood it. Now I can see it, I can actually recognise it”

Another person who shared her story said that finding ways to manage the way she cared for herself and accept the help of others was important:

“Each time that I was feeling down, I had counsellors in the hospital. They more or less showed me that I do have a reason to live. I have my family and that (I have) positive things like going for walks. I’m a nature person and I love to go for nature walks and stuff like that. I (also) sing out loud. Pop music, country music. That’s the kind of music I like listening to. As long as it’s not heavy metal!”

People talked about finding their own ways to reduce stress:

“I meditate a lot now, but my anger was just over the top. I think clearer, I’m more self-aware of what I’m feeling and why, I can think better. Apart from the ADHD, meditation grounds me. I’m doing (meditation) regularly, because I found I had to.”

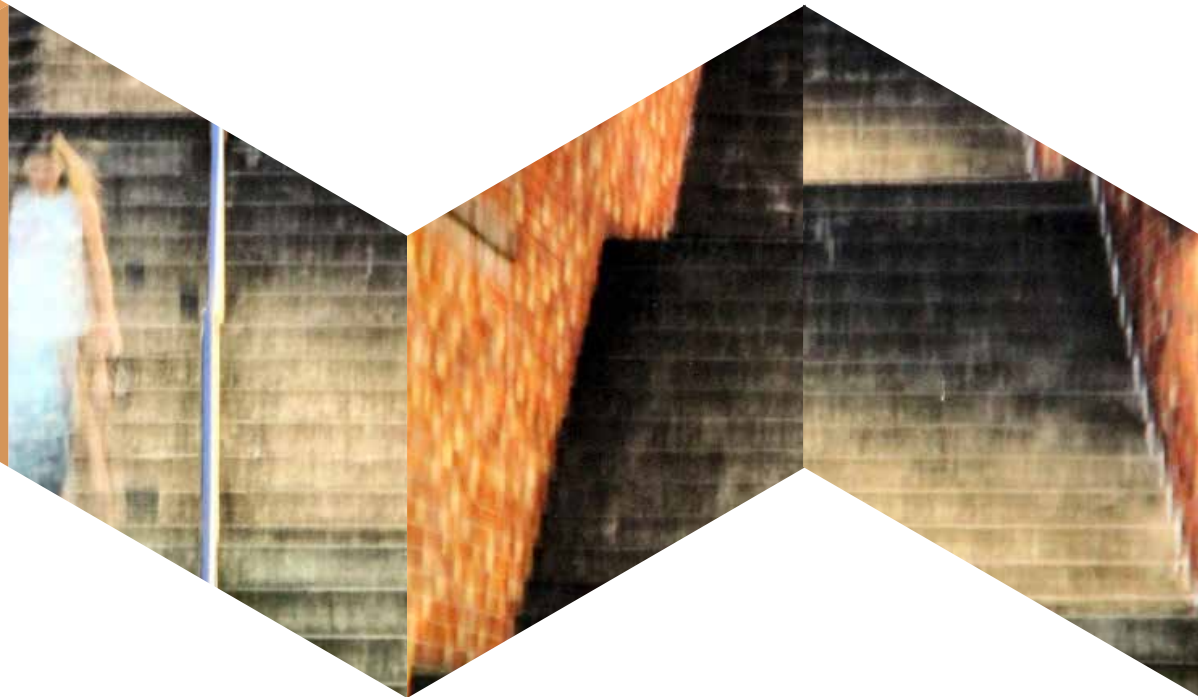
Recovery is an individual journey. You will work out the best way to look after yourself, and what works well for you.

“Walking helps me. Just eases my mind a bit. I don’t get stressed out or think too much.”

Understanding how you feel physically and what that means for your emotional wellbeing.

We know from looking at the health problems faced by people with mental ill-health that a lack of physical health care can cause significant problems for people's health. You should speak to your GP regularly about your physical health problems or ask to get a check-up.

“I was involved in a work injury incident, which led to a significant neck, back, shoulder and leg injury. I guess that was where the depression first started. I started to become very anxious and started having panic attacks... It's very hard because the rheumatoid arthritis is very out of control and very treatment resistant, so I struggle a lot with the of physical loss of function and the fact that I'm no longer the same as everybody else; ... I use the walker... [and] have a shower chair because I can't stand up in the shower... I have a hoist to help me get out of bed, which are all wonderful. They're all-wonderful and make my life easier...”



The ghostly walker - Megan Hammond

Physical health, and how it impacts on a person's mental health, can make a difference on a daily basis. People we spoke to told us how important it was to understand the impact that physical health can have on their daily life and mental well-being.

People also said that the 'roundabout' of doctors that they had to visit for physical health problems did not always understand their mental health needs. People said that health workers weren't always looking at you as a 'whole person', just what 'problem' you were seeing them for.

We were told that health workers needed to understand the barriers to accessing help – things like not being able to find transport or not being physically able to move around or when you were having a bad day.

“(You) battle your head against – ‘okay, you’ve got to get up and do this’ I’ve learnt to be strong. But then there’s times when I just break down and I just go to a certain spot and it’s just so easy to just keep walking and walking.”

People also spoke about how important it was to have a support worker who they speak to or meet with on their own terms. We talk more about this later in this booklet.



The journey between two minds - Sue

How the support from others can help and sometimes not help...

Some of the people who shared their stories spoke about both helpful and difficult relationships with people like their parents, friends and ex-partners.

The people who spoke to us said that as they got older, they learnt to manage their reaction to their family and worked out ways to stop any negative relationships from upsetting their recovery journey.

“Part of getting stronger is realising her words [my mother's] are useless, her words are meaningless. I guess that's probably the biggest thing that I have to work on, is now you're up, everything's going hunky dory, you're fine, but then something triggers and you go backwards. It comes back to that two steps forward, three steps back, and that's life. Nobody has an easy life”

People also spoke about the fear of being judged and how it made them feel frozen at times. People made choices about who to share their health information with and who not to.

“I haven't discussed (my wellbeing) with a lot of people. I go to a church and mental health within church circles isn't always widely accepted as a 'thing'. They can deal with a broken leg or a broken back but mental illness they don't deal well with. They ignore (it) a little bit of it, they tend to sweep it under the carpet, 'she'll be right!' but it's not that simple”

“Validation is massive. Getting feedback from people in the community...”

It was important to look out and spend time with people who were positive:

“Validation is massive. Getting feedback from people in the community, like on Facebook and stuff. When I post my pieces of graffiti that I do I get a good response to it. People tell me they like it and that I'm good and stuff like that. I think I'm crap and I constantly tell myself that with everything I do; 'oh, that's shit, redo that'. But other people say how great it is and how much they like it. I'm trying to find out who I am and what my purpose is here, because as a kid my dream wasn't to travel or have a great job; my dream was to have a husband and kids and that's what I've wanted since I was little.”

Try to surround yourself with people who will listen to you and give you support, and are willing to validate or support your individual choices about what works for your own recovery. These may be friends, family or support workers.



Medication and treatment choices

Talking with health workers about the 'right' medication and being part of decisions about medication, helped people as they recovered:

“Living well means I'd go to bed at night and sleep. My doctor knocked me out at night time with my anti-depression medication, it's a fair dose, but it makes me sleep and I'm able to function the next day. But I've also been able to (monitor) my own medication dosage. If I've had a shit day I need to take two tablets, if I've had a good day I take one. I don't like being phased out. I didn't like being out of control.”

Others, especially those who had lived with their mental ill-health for a long time, said that there was a 'new breed' of mental health workers who listened to how medication impacted on their quality of life. One person said that changing medication so that they could lose weight was really important for their recovery:



Voids - Ruby Divine

“(Losing weight makes me feel better). Today my health is back. Nine kilograms by now I lost. I know I'm not fit. Being fit is different. He (my doctor) said changing (medication) you will lose weight.”

Being listened to and having your questions about medication and treatment answered is essential. You have the right to a medication review or second opinion if you don't think your medication is right for you.





People said that that 'getting back to work' helped recovery. Some, who had to let go of their careers because of being unwell, felt like they had lost part of their identity and were looking forward to getting that part of life back again.

“(Recovery means) probably just getting back to work and just having a normal day-to-day life. I already feel like I’m recovering, I’m ready to take the next step, which is going back to work and just re-joining.”

“I’ve been quite isolated, besides (being) with my kids. (It’s) coming up to a year-and-a-half in July this year (since I worked). Your network’s very much your children and work, so when I took the work away and all my friends work and things like that, there was just me at home with the kids.”

Researchers have found that doing paid work or volunteering is really important for recovery. There are support services who will help you find work. You should speak to your support worker for information about how to access those services.

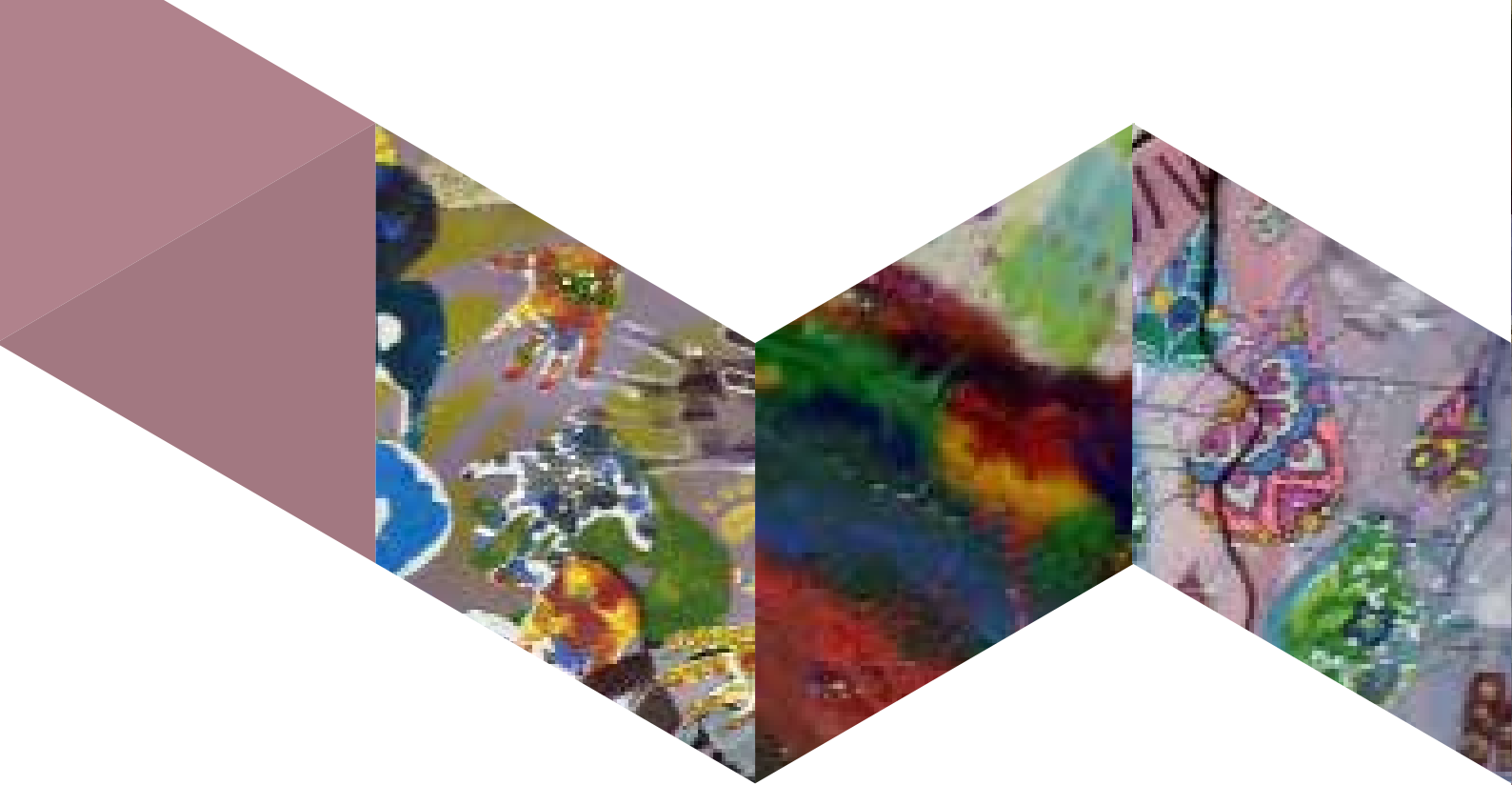
Hear me - group artwork from the See Me Hear Me group

The value of work and volunteering

Some of the people who shared their stories wanted to work as a volunteer or in peer support roles. Two people were also planning, with the help of their support facilitators, to return to the paid workforce. They spoke about how the goal of returning to work filled them with hope.

“My social worker was there for me even though I didn’t want to be there for myself. I have my psychologist helping, at the same time I’ve got my support facilitator from Partners in Recovery. I need stability; once I have stability I’m fine. I’d love to drop my daughter to school at 8:30, dressed up. Wake up at seven o’clock, six o’clock fresh, have a little breakfast, watch the news. Drop her at school. Feel good. Go to work. Come back and she’s going to after school care. Come back and get her, have a laugh with her, go home and that’s it. Call it a night.”





Seeking help

People talked about different supports. One of the supports they found really helpful was from other people who could talk about their own experiences of mental ill-health and recovery.

“Most of the time in our life you just need people that believe in (you), we need professional help. Education is good but experience is good when someone who has gone through the same thing and came out of it and they tell you that they did it. That’s different to someone (who has) never been there, never done that.”

Seeking help

Recovery was described as sometimes being ‘two steps forward, three steps back’. People shared what was helpful and unhelpful in their journey when getting and receiving support. Different support is useful at different times in their recovery journey.

The people we spoke to told us that recovery can sometimes be a lonely life because you have to ‘pull the handbrake up’ and really look at the people that surround you and ask if they are a help, or a hindrance. Many of the people we spoke to said that during those early years of recovery you had to try a few support services or reach out for help a few times before you found the right ‘fit’ for you. As the quote on the previous page shows there is value in professional support and education but also personal support through listening to peers.

Support from others who have gone through recovery, or are on their recovery journeys has shown to be really helpful for personal recovery. Peer support is available through support groups, online mental health forums, or through peer support workers employed within mental health services because of the valuable knowledge that they hold and have gained through their own recovery journeys.



See me - group artwork from the See Me Hear Me group

Life after diagnosis

People who told their stories found that receiving a diagnosis was both a benefit and a challenge. Some people felt that labels, about their mental health, were given to them too quickly and that in those cases it took a long time to “**shake off the labels**”.

Others felt a sense of freedom from being diagnosed. One said that her diagnosis was a “**light bulb**” moment because it provided a name or list of symptoms that validated how unwell she had been feeling. Another said “**it was a relief**” to be diagnosed, but that poor follow up and medication side effects made it difficult to continue seeing his psychologist especially as he was homeless at the time.

Take from your diagnosis what is helpful to you. You should be able to get the individualised support you need whatever your diagnosis and whatever is happening in your life, even if your life is impacted by drugs, alcohol or homelessness. Services should not judge. They should be here to help you and meet your own needs.



Waves of depression - Robert Powell

Help in times of crisis

“I want to be seen as a whole person with a mental health issue”

Even in times of crisis, people said that it was important to be recognised as an individual. “I want to be seen as a whole person with a mental health issue” explained one person. For some, hospitalisations were seen as a time when their mental health was positively “turned around” because of the care they received. Access to crisis services when they were unwell led to them being connected to services that might help as they got better:

“I ended up homeless for five years... (At) four o'clock in the morning one-night Parramatta Mission. Outreach saw me sleeping in the streets. They told me the service they offered and that's how I got linked up with all the services that I have.”

One person, who had a very negative experience, after spending almost 40 years in several mental health facilities, and was now only beginning his recovery journey after recently leaving the last facility. He said that moving from service to service created anxiety about what might happen next. He said that to ‘tell’ a doctor or mental health worker that he was unwell, was hard because there was a fear that he might be hospitalised, or misunderstood, or have control taken away from him.

Help from services in your community

The people we spoke to said that getting help was a good experience, but that they needed to try out a number of services before they found a ‘good fit’. Some said it was important that services really listened to them and that they could tell the difference between ‘bad days’ and a relapse.

“Support services need to listen to you, because sometimes you might just be having a crap day or a crap time. If they listen to you, they can know, ‘okay, she’s having a bad day, let’s just let it go.’ Or, ‘come on, I think this is more than just a bad day, what are your options?’”

Almost all of the people we spoke to said a good GP was so important. One person spoke of being taught the ‘tricks of the trade’ from other health professionals like breathing techniques, and mindfulness. Others said that the benefits of talking to a counsellor made life easier, as long as they felt included and decisions were personalised to their recovery.

“I do go to counselling with my support facilitator. She’s been very, very helpful. Since I’ve met her, things have changed and I have started doing new things. Like changing eating habits, changing things for my younger kids.”

Some people spoke about the costs of seeking support. Using Medicare was important so people could focus on finding a psychologist without having to find the money to pay for it.

“Until the psychologist helped me, like a conversation. Like taking off everything from the chest. God sent (this) and it opened the other doors. Government approved of (with Medicare) I can have psychologist for free. It took me 12 years (to find someone to talk to). The specialist psychologist is Persian. He’s from my background. He knows (about) Persian background. The psychologist helped me.”

Help from your support worker

Mental health workers were a really important part of people's recovery.

“People like my support facilitator who are ringing me and texting me and enquiring if I'm okay, that's massive. That's like a miracle to me because nobody cared if I'm okay. ”

It is important that you have around you a range of people to support you formally. This would include a GP, counsellor or other support workers who you feel that you can speak to and receive understanding support from.

People said that the key to a good relationship between them and their support worker was sticking around and learning how to get on with each other. One person shared that her support workers bought her 'back down to earth' when she was overwhelmed with all of the tasks she had to complete day to day.



Untitled - Tim Smith

“My support facilitator from Partners in Recovery sort of took the bull by the horns or put that little ring through my nose and was guiding me to what services were out there. I never knew (they) even existed, I didn't know they were even around! ”

Respect between you and your support worker is important. The people who shared their stories said being given space when they wanted to limit contact, but also, 'chasing people up' when they hadn't made contact for a while and being flexible with appointment locations, all showed genuine care and respect.

One woman spoke about feeling respected when the support worker agreed to meet at a coffee shop rather than her home, and that "buying me a coffee made me feel like 'wow I'm important!'"





Your own thoughts on recovery

These stories of recovery show that recovery can be both a murky and a positive path – a journey of finding hope but being realistic about the challenges ahead.

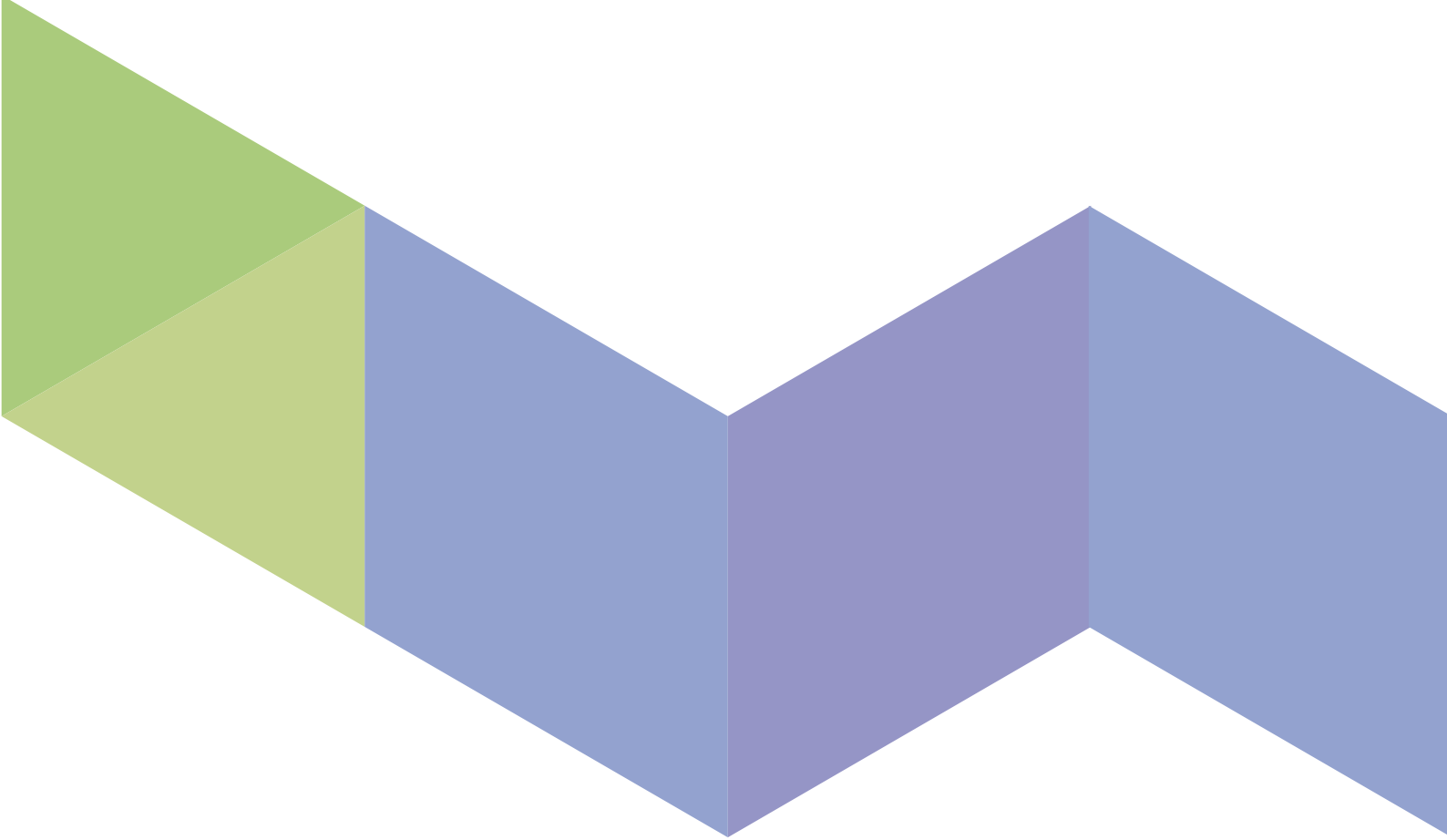
Here are a few of the ways that the people who shared stories with us described recovery. They might be useful to you or they might give you some ideas to help progress your own recovery journey:

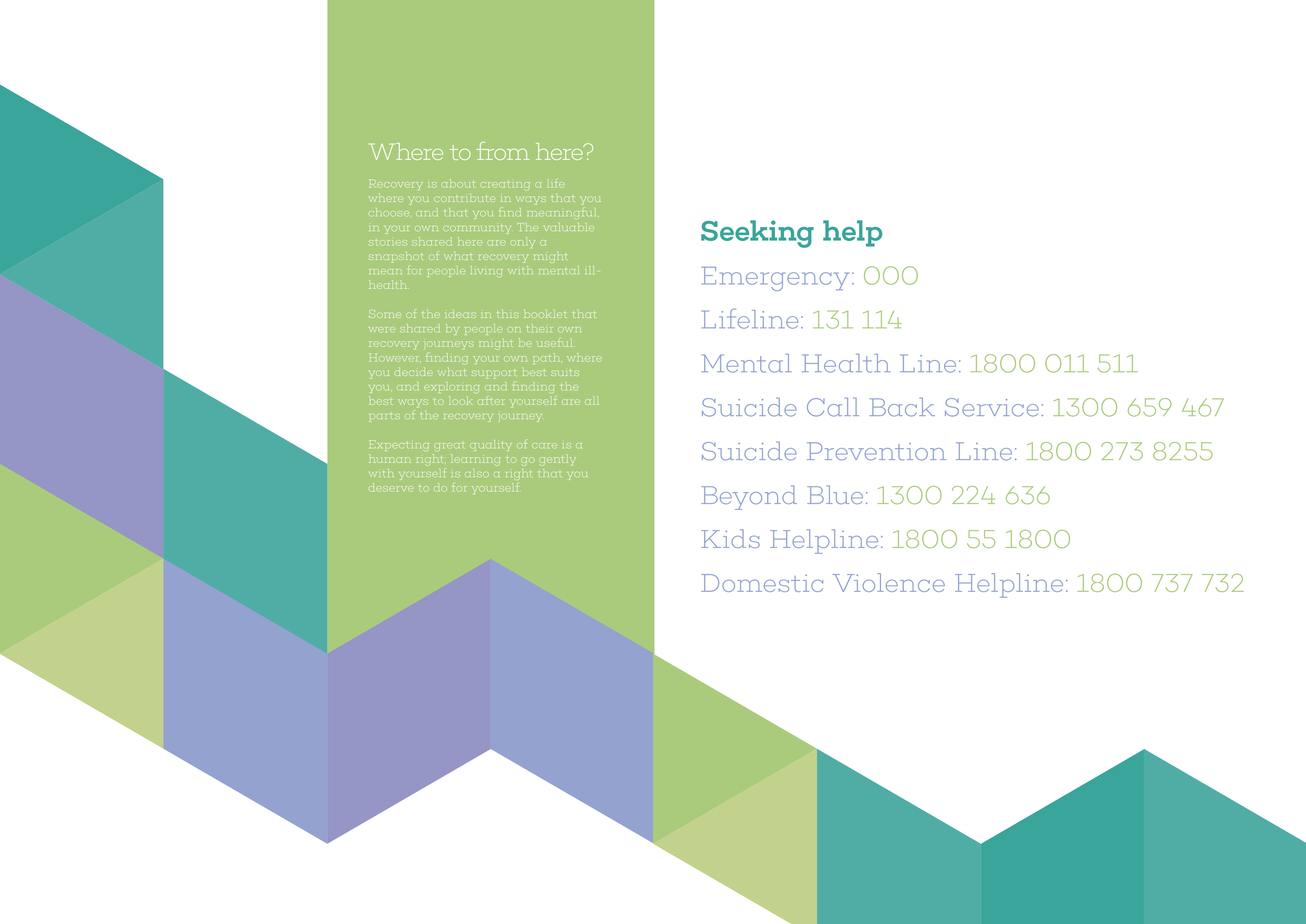
“I want to get (all the branches of my recovery tree) growing leaves at the same time so that I can put it all together, mesh it together and then I will grow from that..”

“You are always recovering when you’re mentally ill... I believed I could go to a doctor or see somebody, and I’d walk away thinking, ‘why don’t I feel different?’ I believed there was a magic pill. The only magic pill is from within, once you get used to that, you’re not angry. When you’re depressed, you don’t want to help yourself, you want someone to come in and help you. You have to realise (that) before you can get better.”

“Happiness (means recovery to me), just to find happiness. Not all the time, but happiness, and fulfilment. I remember someone said to me when I was 18, what do you want to do with your life? I looked at him and said ‘be happy’. He looked at me like I was a weirdo, but that’s all I wanted. I’m finding it now that I’m older.”

“There are stages of recovery (At first) it’s isolation, you just want to be (on your own). You don’t relate. (Then there is) anger, frustration, abandon(ment), stress and anxiety. One of the last stages is the most beautiful thing - all of a sudden (you) wake up to yourself. You realise how beautiful that little thing has been in your life, holding onto you the whole time that you’ve been depressed.”





Where to from here?

Recovery is about creating a life where you contribute in ways that you choose, and that you find meaningful, in your own community. The valuable stories shared here are only a snapshot of what recovery might mean for people living with mental ill-health.

Some of the ideas in this booklet that were shared by people on their own recovery journeys might be useful. However, finding your own path, where you decide what support best suits you, and exploring and finding the best ways to look after yourself are all parts of the recovery journey.

Expecting great quality of care is a human right; learning to go gently with yourself is also a right that you deserve to do for yourself.

Seeking help

Emergency: 000

Lifeline: 131 114

Mental Health Line: 1800 011 511

Suicide Call Back Service: 1300 659 467

Suicide Prevention Line: 1800 273 8255

Beyond Blue: 1300 224 636

Kids Helpline: 1800 55 1800

Domestic Violence Helpline: 1800 737 732



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