Lived Experience: Mick’s Story

Mick is a SANE Australia Speaker and has treatment resistant bipolar. He is sharing his story to raise awareness of complex mental illness and the benefits of online support and connection.

“I’ve known there was something different about me for many, many years - even when I was 13 or 14 years old. As my younger self, I never thought I’d find someone to accept me as I am, warts and all. But it did happen. And now I have a wonderful wife and two amazing children. I also have treatment-resistant bipolar disorder.

“I was diagnosed officially about 10 to 12 years ago. I knew something was wrong, but wasn’t sure what it was. At the time, I had no idea about bipolar. It was just a word, so I did a lot of my own research.

“Growing up, I’d never had many friends. I would come home from school, go to my dark room and listen to music. I was fortunate that I was good at sport which kept me really busy and also gave me a social life. But when I got older and couldn’t play sport any more, I really struggled. I found it hard to stay in contact with the people I’d associated with. And then I isolated myself.

“I remember telling my wife very early on that I was ill. I’d had bad experiences before when I’d told people. It was just like a movie scene where the camera moves away and you’re left sitting there. You could just see, that was it. It was all over right there and then. So rather than just let it go, I thought I’ll tell her. She was fantastic, she’s still fantastic. I wouldn’t be here without her.

“I’m medically retired due to my illness, but I really hope to work again one day. In my previous work life, I found the understanding wasn’t there regarding mental health. I wasn’t treated very well at times. I found I was the one having to educate people, having to find the information and explain reasonable adjustment to my employers and the rights I had with my disability.

“There’s very little education about mental illness at the managerial level. It’s such a massive undertaking, but things need to change. It would make a huge difference for people with a mental illness to just be able to work and be supported at work, without the added responsibility of having to educate their employers.

“When I’m experiencing mania, one of the biggest indicators is that I’ll speak loudly, not letting anyone get a word in, talking over everyone. Of course, people don’t like that... And then you crash. And your bipolar depression comes in. And it’s worse than anything you can imagine.

“Suicide is a very real problem in our society. In fact, suicide awareness is one of my biggest passions. It’s something we shy away from acknowledging, even though the statistics are frightening. We don’t talk about it unless we’ve had somebody close to us take their lives. We’re not doing enough about it. It’s as simple as that.

“When you’re living with a mental illness, having a respectful and anonymous place like the SANE forums to go to makes a real difference. You don’t have to participate. You can just go and have a look. Or you can share your small wins like being able to get to the shops today – for someone with a mental illness that can be huge, and you’ll get encouragement for that. From time to time, you’ll see something really resonates with you and that can really help.”

Mick’s story was originally published on the SANE Australia website: www.sane.org/people-like-us

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Lived Experience: Stephanie’s story

Stephanie is a SANE Australia Speaker and has Borderline Personality Disorder. She is sharing her story to raise awareness of complex mental illness and the benefits of online support and connection.

“People say cancer takes over your body to kill you. I believe mental illness takes over your mind to kill you. And the only way to get better is to make a choice. But it’s very difficult to even want to choose that when your illness takes over every single thought. You just don’t have the capacity to do that. You don’t have the rationality to do that because it takes over your mind to the point where you can’t do anything.”

“I love my life and have been quite privileged. I have also struggled with different mental illnesses for almost a decade. I was diagnosed with bulimia at 18 and had my first suicide attempt just before my 23rd birthday. It was just after this that I received my diagnosis of borderline personality disorder (BPD) and was able to seek treatment and support.

“It was actually quite a relief for me and my family to be able to put a name to what I was experiencing and to learn my triggers. While the symptoms of borderline personality disorder can be quite diverse, for me it was an irrational and impulsive response to different situations. I was very black and white. One minute I could be totally fine then something would trigger me into a complete suicidal episode and a 24-hour downward spiral. BPD generally also is a co-morbid self harm type illness. In my case it was an eating disorder – a sort of combination of anorexia and bulimia.

“I’ve felt the stigma and discomfort around mental illness both in the workplace and in my personal life. There have been times I’ve had to take sick days for mental illness issues and it hasn’t been viewed as a proper sick day. I’ve also been excluded from certain social situations. I had quite a large group of friends and was sometimes not invited to things because I might have an episode. I’ve also isolated myself from events when I’ve known people would be there who have certain views on mental illness. So I’ve felt quite alienated at times.

“I don’t blame anyone, as it’s such unfamiliar territory. People can identify with a broken arm, because they can see it. They can’t see mental illness so they can’t sympathise with it. They can’t comprehend the way your mind can change itself into thinking such deep and dark thoughts.

“I feel there just isn’t enough accessible education around mental illness. There’s a lot of information about it, but you have to look for it. It hasn’t been as saturated in mass media the way other illnesses with the same statistics are.

“Supporting someone with a mental illness is definitely challenging. Your family and closest friends feel they should be able to support and love you no matter what, but you really test that. My loved ones have been amazing and I am so grateful. My partner has been incredibly patient with me and he’s taken the time to learn my triggers. He’ll hide under the blankets with me until I’ve calmed down. He knows not to say anything. He knows just to be there.

“People might say they support mental illness, but most don’t want to talk about it. Being part of a community who have had similar struggles can be a big help. Mental illness is not a convenient thing – it’s not 9 to 5, Monday to Friday. So it’s really important to have somewhere to go any time of day, such as the online SANE forums. Reading about others’ experiences or having someone empathise with your own can give a lot of hope during your darkest moments.”

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Jo is a SANE Australia Speaker and has been a carer for over 30 years. She is sharing her story to raise awareness of complex mental illness and the benefits of online support and connection.

“A lot of people think carers are saints, they don’t think of them as human beings. But they are real people who absolutely do suffer from isolation, stress and burnout. Carers never stop looking after their loved one. They let themselves go, they don’t do anything for themselves because they don’t have time. When they go to bed at night they lie awake worrying. As a carer, it is very important to try to look after yourself and stay connected. I know this from personal experience.

“I started caring in the late 1970’s for my sister, a gifted artist who developed schizophrenia. At the time my sister first starting exhibiting symptoms, there wasn’t really any information out there and I didn’t know what to do. She shifted next door to me and I tried to help her. But I couldn’t understand what was happening. It took many, many months to get a diagnosis. It was very difficult.

“She took herself off medication as it affected her art, and as a result she wasn’t very well. As a single mother of three, I was now also responsible for caring for my sister and her little boy, who subsequently developed schizophrenia as well. The caring went on for many years, around a decade. My nephew ultimately took his own life, and my sister died eight weeks later. It was like a nightmare. I don’t think there are words to describe it. My son then developed depression and bipolar disorder and I have been his carer on and off ever since.

“Attitudes are improving slowly, but the stigma surrounding mental health issues does have an impact on carers. I run workshops and meet a lot of people who are still afraid to be honest about what is wrong with the person they’re caring for. They’ll often say they have cancer or something else to avoid being alienated. Many people in society are embarrassed, ignorant and fearful of mental illness, and carers do not get the support they need. They’re invisible people.

“Caring is constant and can be very hard. At first, I didn’t know how to cope. I was a single mum with three children looking after my nephew and sister as well. I started to drink at night. This is not uncommon. Thankfully, I learned healthier ways of dealing with things – journaling and meditation. Then it all got too much again.

“This happens to a lot of carers; you experience burnout but you have to keep going so you slip into a dissociative state. You go about your daily life like a robot, it’s almost as if you’re in a dream. I suffered that. I was driving home after visiting a family member in hospital late one night and I drove through a few red lights on autopilot. I have a carer friend who found herself driving on the wrong side of the road. Worryingly, instances like this are more common than you’d think.

“This is why it’s so important for carers to be able to connect with others going through similar situations by using resources like the SANE online forums. There is one specifically for carers and it’s completely anonymous, so you don’t have to put on an act. You can share your experiences, seek advice, or just read about what other carers are going through. It’s an opportunity to be completely honest, and even share some unique carers’ black humour to lighten the load and realise you’re not alone.”

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Lived Experience: Denielle’s story

Denielle is a SANE Australia Speaker and and has first-hand experience of mental illness from both the carer and lived experience perspectives. She is sharing her story to raise awareness of complex mental illness and the benefits of online support and connection.

“From the outside, my life looks pretty idyllic. I live in a beautiful part of country Victoria with my three wonderful children. But, as with many people, I’ve faced my share of demons. Mental illness has played a huge role in my family since my father was first diagnosed with depression over 15 years ago.”

“A strong, independent country bloke, his diagnosis came on the back of an illness. As his body started breaking down, so too did his mental state. My own struggle started when he took his own life. My experience has made me acutely aware of the stigma and lack of understanding that still surrounds the issue of mental health in this country.

“This was particularly the case for my father – he was suffering depression at a time when there was very little support and awareness, in a community more remote than mine. As a family we found there were so many road blocks to get Dad the help he needed. There was a resounding attitude of ‘You’ll be right mate’. And his inability to deal with his perceived weakness, particularly when he was used to being the man of the house, was incredibly tough on him.

“I knew it wasn’t just a bad day or a bad week. I was emotional all the time and unable to ‘snap out of it’, crying in the middle of the day for no apparent reason. Any time I would go to sleep I felt like I was being sucked down to the bottom of the ocean, further and further from the sunlight and down into the cold. I was diagnosed with depression and eventually tried to take my own life.

“I don’t think people understand how debilitating a mental illness can be – it takes over your whole life. I really believe as a society we need to break down the stigma and say it’s okay to have a mental illness. It doesn’t make you weak or less of a person. I often compare mental illness to cancer as it can affect anyone, regardless of whether you have the best job or the best friends or the biggest house. When someone has cancer we rally around and support them; we need to approach mental illness the same way.

“Mental illness is complex, and it can often be frustrating and isolating not being able to get the understanding and help you need from family and friends. Using something like the SANE online forums is a fantastic way to connect with a supportive, non-judgmental community. It’s completely anonymous and you can simply read what others are going through, or actively ask questions and seek advice at any time of the day or night.

“Now that I’ve come out the other side, I am passionate about putting the topic of mental health in the spotlight. I look forward to a day when it’s no longer a taboo subject, it’s a dinner table conversation in every household. And if I were to go back and talk to my younger self in the depths of her depression? I would tell her she’s loved and to breathe through it, it’s just a moment.”

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