On the Same Wavelength

Episode 1: True connections

Elise: Hello, and welcome to *On the Same Wavelength.* I'm Elise, a PhD candidate, psychologist, and researcher with an interest in how we can make a better world for people living with complex mental health issues.

This is a new podcast created in collaboration between the University of Melbourne School of Psychological Sciences, and SANE, Australia's leading national mental health organisation for people with complex mental health needs.

I've been working in research and the mental health field for the better part of a decade, and I have my own lived experience. In that time, a lot has changed. We're talking about depression and anxiety more than ever, and it's definitely more acceptable in the general community to get mental health support these days. It's an issue that we're talking about more and more, especially as COVID-19, bushfires, and other national issues have highlighted how we need to better support Australians' mental health.

It's estimated that around 800,000 Australians experience recurring, persistent, or complex mental health issues, like schizophrenia, bipolar disorder, OCD, personality disorder, and complex trauma. These experiences can affect anyone regardless of age, gender, or cultural background.

Unfortunately, many of these Australians still experience stigma and discrimination. But what does stigma this look in real life? How does it affect people? And how can we make things better for people with lived experience?

So each episode, you'll hear from a Peer Ambassador – a person with lived experience of complex mental health, who works with SANE to share their story and contribute the wisdom that comes from real experiences. They speak candidly about stigma they've faced, and how we can improve things, in their own language. You'll also hear from other advocates, policy experts, and health professionals.

I hope you get something out of these stories.

In this episode, we're focusing on relationships. Yeah… it's a pretty big topic.

Odds are that you know someone personally who has lived experience. By 'lived experience', I mean someone who has personally experienced psychological distress, trauma, or mental illness. Maybe that person is a friend or a colleague. Or a family member. Or even an intimate partner. Maybe it's you. Mental health affects not just one person, but our communities are affected in many ways.

The National Stigma Report Card was a large study of nearly 2000 Australians who have lived experience of complex mental health issues. This study found that nearly every participant – a whopping 96% – had experienced some level of stigma or discrimination in their relationships in the previous year.

You're about to meet Evan, who will be sharing his story. I'll also be chatting to Amaya from Mental Health Carers Australia and Tandem Carers. Just a quick note that this episode touches on topics including schizophrenia, relationship breakdowns, and multicultural mental health. So please only listen today if it feels right for you.

Evan: My name is Evan, Evan Bichara. I'm 64 years old. I reside in a Northern suburb of Melbourne called Bundoora. I'm of Greek Egyptian background. I speak both languages and have done most of my schooling here in Melbourne graduating in a Diploma of Community Development.

Elise: Evan was born in Egypt, and moved to Australia when he was six years old. He grew up around the northern suburbs of Melbourne. He enjoys reading biographies and books on theology, and catching up with friends and family. He's also been working in the mental health advocacy space for many years, in a number of paid and unpaid roles.

Evan told me about the autumn of 1977.

Evan: I entered a Bachelor of Science degree at Melbourne Uni here and yeah, just symptoms started to arise. And they flared up further down the track, and they got problematic.

Elise: Evan struck me as a person who has taken control of his own story. He reflected back on those early years with self-compassion and gratitude.

Evan: I always like to be positive as possible. My mental health illness, even though it has been a setback in my life, I managed to grow through it, creating all sorts of coping strategies. It humbled me as a person. It led me to a job with a vision and mission in helping others, the dream that I had as an early kid. And helping organisations as well, and helping government along the way.

So it wasn't as bad as many people perceive a mental illness to be. With the slight symptoms that developed in me, paranoia, slight delusions, and even a bit of depression, sadness in me… all were controlled well through talking therapies, through medication. And most of all, I have to add this, the willpower of me wanting to get better.

I was diagnosed with schizophrenia, with a slight depression on it. Though I managed to overcome them and carry on with my life, like any other person in the community, listening and heeding upon multiple advice given by caring health professionals, my family as well, and some close dear friends who all wanted to help me to get better.

Elise: Evan's family and friends provided critical support to him in those early years – encouraging him to get advice, and seek treatment.

Evan: It wasn't an individual aspect. It was a collective process that got me better.

Elise: He told me about some of the key relationships in his life – the people who play a huge role in supporting his wellbeing.

Evan: I have a fine network of caring and loving people in my life. Firstly, my wife, Tammy. Secondly, my family that grew me up through my life. My dad, who has passed away now, my loving mom, who I have high respects for, growing me up to what I am today. My two lovely sisters and their families, though one sister has passed away. And my close associate friends who I have either from my church community, or I happened to grow to, or through, the networks of work in advocacy.

Elise: Though Evan has a solid network around him now, things weren't always that way. There was one relationship in particular, which, sadly, became very unsupportive.

Evan: After 20 years of marriage through my first wife an unbearable transformation occurred. My first wife no longer had that caring attitude, and wanted a separation and a divorce due to her claim of not being able to look after me because of my mental illness. We had two kids at the time.

Elise: This event affected Evan to a great degree.

Evan: My first wife could no longer cope with me living with her. I did not have an opportunity to find out why, what made this happen? Could something be done to mend it? No, nothing of this nature occurred. She just wanted me out.

Elise: As a result of the separation, Evan moved back with his family. Who, thankfully, were very supportive.

Though most people generally are caring, unfortunately, Evan has also met many people over the years who aren't very supportive or understanding.

Evan: Well, people in general, you know, I wouldn't say very close friends, but just people out in the community, who knew I had a mental illness… and they based negative attitudes, because I had the mental illness.

Many times I remember I was brushed aside because of my mental health condition. Comments like 'he would not know what he's talking about, he has a mental illness' or 'keep away from him, he could be dangerous'. Or, 'do not listen to him, he's thinking irrational and does not know what he's saying'.

Elise: Evan spoke about the impact of being brushed aside, disrespected, or even treated as dangerous.

Evan: In the beginning, it was tricky. Yeah. It was hard. It was hard.

But over the years, after trying to change my mindset by other people talking to me as well on this, my mindset changed. And what really matters is how this may affect me. So I don't allow it to affect me that much. And if it's a distasteful word or attitude, it's their problem and not mine. And that's what I say. I always put it down to their problem. And I don't internalize that stigma attitude that they have, that negative attitude towards me. I don't internalize it, and allow it to affect me.

Elise: Evan also spoke about how his cultural background intersects with his experience of mental health issues.

Evan: My cultural background, Greek-Egyptian is a very, very collective culture, right? What I mean by that is that if a person goes sick, it's not up to the individual on his own to get better. Everyone around him gets a little bit sick with that individual. So everyone around him tries to get better and, and that person gets better with them as well.

In their understanding of mental health, though, there still contains that minority that believe that the mental illness is still caused by superstitious happenings or the devil's intervention, or even a punishment from above. Obviously, more education needs to be done to these communities, to unfold and remove these false beliefs or myths, and replace with actual evidence-based information.

Elise: While speaking with Evan, I was thinking about how complicated relationships can be. I wanted to speak with other people who also understood the needs and challenges faced by families, friends, and others who support people living with mental health issues.

Amaya: My name is Amaya Alvarez. I'm based in Melbourne, Victoria. And currently I'm sort of wearing two hats. I work for a mental health carer organization in Victoria called Tandem Carers. And I also work part-time at Mental Health Carers Australia.

Elise: Mental Health Carers Australia is a national peak body for organisations that support families, friends and carers. Tandem is a Victorian-based organisation providing information, support and advocacy, and a member of Mental Health Carers Australia.

Amaya: My own experience is supporting a family member. So I've got a young adult daughter who has been struggling with quite complex mental health since her early teenage years, she's now in her mid-twenties.

Elise: Amaya has two other children, who would have been in grade six when her daughter first became unwell. As a result of her experience, and the people she's worked with, Amaya understands how mental ill-health can affect a family.

Amaya: When it became acutely obvious that she was very unwell and it was, it was... there's a lot of fear and anxiety and stress about what's going on, what's happening. There was a kind of a strange feeling of still being in the normal world, but not being in it, in a way.

Elise: At this time, Amaya found herself withdrawing from her own social world. She was spending a lot of time researching and planning to support her daughter, trying to work with her daughter's school, while still supporting the rest of her family.

Amaya: But I do think that I did go through a stage of feeling like it was the result of something that was inadequate in the family, and therefore something inadequate in my parenting.

I mean, right from the start, I really tried to understand what was happening, but I still think that you do reach points along the way where you're just wanting it to finish ... and I think for my partner, I think for men often in these spaces, and I don't wanna generalize, but that 'fix it' idea. 'I just wanna 'fix it'. You know, 'I'll throw all this stuff at it and then she'll be sorted out'. Like it'll be sorted [laughs] which is a very Australian thing as well, I think. You know, like, 'well just sort it, you know, just fix it'.

And once I accepted that I didn't control what was happening, and couldn't necessarily... all I could do was be present, and maybe try and manage and assist in different ways, then I was able to be much more accepting of what was happening.

Elise: She's known others with similar experiences, who have been unsure how to help, and experienced feelings like stress, guilt and confusion. Plus, a lot of families might not know a lot about mental health in the first place. This can lead to a lot of negative thoughts and assumptions relating to the person with lived experience.

Amaya: There are points there where you look at someone who's suffering from mental health issues and you think, why isn't it that they can't manage this? You know, why is it they can't get out of bed? ... or perhaps, you know, are they really as unwell as they seem? Or, you know... so that sense in which you're trying to think about, well, maybe the behaviours are deliberate rather than being an expression of the illness, or the mental health distress.

There can be this sort of swirling uncertainty... and also sometimes the behaviours can be really challenging. So, you know, it's really easy to see the behaviours as just bad behaviours when people are, you know, in high levels of distress ,or in high levels of fight and flight.

I think where we look at stigma, and families that might stigmatize the person they support, we need to be really careful of not then seeing that as a failing of the family. It might well be a failure of what sits around the family in these circumstances that they're not used to, and they don't have a lot of understanding of.

Carers and supporters that I speak to feel the lack of that. They feel the lack of a place to talk about what's happening, to be able to reflect on how it's making them feel, without feeling guilty about that.

Elise: Plus, families and friends need practical support too, including getting the right information, developing communications and mental health first aid skills, and in some cases, financial support. There's definitely a need for mental health providers to better recognise the role that families and friends play in supporting people with lived experience, and for families and friends to be able to access the right supports.

I asked Evan about how he's travelling these days: how his mental health has affected him over the years, and what's helped his recovery. He spoke about positive relationships with healthcare professionals, and the benefits of the treatment he's accessed, and the role of families and friends.

Evan: Look, mental illness affects me, yes, but in a positive way. In a positive way, it's not at all seen as negative. It's come to me for a reason. And I've made that reason to be as positive as possible, yeah.

Elise: Plus, Evan found love again, with his second wife, Tammy.

Evan: My second wife came to my life. I met her in the church. She's from the same cultural background. She's from the same religion. And she also has the same mental health condition as me. So it was... call it what you want. I called it a miracle.

Elise: He also feels that, in general, community attitudes towards people with lived experience are improving.

Evan: I think the understanding bit has tremendously improved. Through the many channels of communication to the wider communities about this topic, mental health illness is no longer a taboo in society... hopefully as a trend continues, we may have this stigma, community stigma eliminated for once and for all.

Elise: These days, Evan is still working in the advocacy space, though his role has changed.

Evan: Well, currently because I'm at that age of 64, I sort of, have retired from the St Vincent's role there and gave others the opportunity to do that role. So I don't do as much as before.

In my role, as an advocate, I meet a lot of people like myself with mental health conditions. A lot like me have done things, have been able to achieve things in the community where others who don't have a mental illness find very hard achieving. Right? Many of them have started businesses. Many of them have gone back to schooling. Many of them have gone back to professional occupations, jobs. And many of them have been caring, sensitive people.

Elise: He's also working with Greek and Egyptian communities, including speaking in schools about his experiences.

Evan: You know, more work needs to be done in that space. And I think with getting that network of people with lived experience from those cultural backgrounds to develop their own networks and, and get some dialogue happening among their community, from a positive perspective about mental health.

I would advise that people who are worried about these things, these mental health issues of their loved one to attend information sessions around our community, on mental health and learn the up to date information on the topic, dialogue with those of similar situations. There are multiple resources, and multiple tools and services that family and friends can link through and update their knowledge, and knowing what to do in situations which could happen and you may not know how to react.

Elise: Ultimately, I was touched by Evan's call to see each other as individuals, worthy of respect and understanding. To celebrate each other's strengths.

Evan: Treat people such as myself with dignity, with respect. As if I was an ordinary person wanting all those things that ordinary people want: love, care, understanding, and all those good things we all want out of life.

Elise: *On the Same Wavelength* is a collaboration between the University of Melbourne School of Psychological Sciences, and SANE, Australia's leading national mental health organisation for people with complex mental health needs, with the support of the Paul Ramsay Foundation. It is hosted by me, Elise Carrotte, and edited by Chris Hatzis. Special thanks to SANE Peer Ambassador Evan, and Amaya Alvarez from Mental Health Carers Australia and Tandem Carers, for their contributions to this episode. If you're interested in learning more about these organisations, and online resources for families and friends, I've included links in the show notes.

This podcast was recorded on the unceded lands of the Wurundjeri Woi Wurrung people of the Kulin nation, and we wish to pay respects to elders past and present, and extend our respects to any Aboriginal or Torres Strait Islander listeners.

If this podcast has brought up any challenging feelings for you, please consider reaching out to SANE's free counselling support via 1800 187 263, or Lifeline via 13 11 14.