

Clinical Toolkit

“My Experience with Psychosis” – Sam

In order to get a better idea of what it's like to experience and be diagnosed with psychosis, we asked a young person with lived experience. Here are her answers.

Tell us about what kinds of symptoms or problems you were experiencing before your diagnosis

Stress has always been a precursor to me becoming unwell. Before I was diagnosed I was having problems within my friendship group. I felt a pressure to be someone I wasn't and when I couldn't measure up I felt extremely isolated.

The first symptom I noticed were voices. I heard my family screaming and yelling every time I was alone. These were less frightening and more confusing. When I told my mum she wanted to take me to see my GP but I assured her I was okay.

Years later and my symptoms became frightening. I experienced sleep disturbances where I couldn't sleep for up to 8 days in a row. I experienced rapid mood cycles which were exhausting – I had no idea why one minute I was chronically suicidal but the next minute I thought I could conquer the world. I saw apparitions coming to attack me and I sensed spirits watching me. I saw piles and piles of maggots on the carpet, huge spiders crawling on the walls and felt bugs crawling on me in bed, which led to copious amounts of bug spray and in turn terrible skin rashes. I had a feeling of impending doom and thought my family were going to die at any second which led to frequent phone calls just to check in. I couldn't read or watch movies or tv shows because I thought that everything I would read or watch would be predicting my future. While all of this was distressing, the most detrimental thing about it for me was the fact that most of these symptoms occurred in the evening and during the day I was relatively okay.

How old were you when you were diagnosed and who made the diagnosis?

I was 22 when I was diagnosed properly by a psychiatrist after being referred to one by my school counsellor.

What did it feel like to have this diagnosis- did you agree with it or accept it- what about now?

For many years I couldn't understand that I had ever been unwell. I think it had to do, in part, with the fact that most of my symptoms occurred at night. During the day I could kind of function. It also didn't help that I experienced things like rapid cycling moods. When given psychoeducation I was handed brochures that didn't explain that symptoms could disappear or that people could be okay for some parts of the day or even that rapid cycling was an actual thing and I wasn't a fantastic actress who deserved an Oscar for 'crying on cue'. These things made me think that I was making symptoms up. How could someone possibly be truly suicidal, crying, so distressed one minute and then fine the next and then crying again in the third minute. And more importantly isn't true psychosis and schizophrenia something that plagues people day and night. It would have been so helpful if someone could have taken then time to tailor their psychoeducation to exactly what I experienced.

Were there any benefits to being diagnosed to understanding what was going for you/ any negatives of receiving the diagnosis in particular did you experience any discrimination?

When I was diagnosed and was able to kind of believe it, I felt a sense of mourning and grief. How could someone tell me that my personality, my moods, my experiences are wrong. Why would people want to tone down how I am supposed to experience the world?

Tell us about your experience of seeing GPs (what has helped the most/ the least)

While trying to sort out a medication regime that was right for me I gained 70kg in under 8 months. As this process was happening I was begging my psychiatrist to change my medications or to do something, anything, to help me with my weight.

It wasn't until I found an awesome GP, one that actually took my blood pressure when I complained of fainting spells and not just pass it off as being 'just a girl thing – she is trying to lose weight', that I was able to get some assistance with my weight. My GP delved deeper into my history and realised that I could possibly have an eating disorder so she referred me to a specialist eating disorder clinic where I have been receiving treatment for the last few years. My GP has also helped me take care of health issues that get overlooked in the mental health clinic such as my sexual health and has me up to date on my contraceptive and pap smears.

As a person with a mental illness but more importantly a human being, I needed a GP that would take the time to really listen to me. To ask me how things are going and to care about my answer.

What has happened since, what has changed, what are you doing now?

I've spent time living in a CCU as well as supported residential services and am now living independently in my very own apartment with a balcony full of thriving succulents. I am also studying a dual Cert IV in mental health and alcohol and other drugs.

What do you have to say about recovering from this diagnosis?

Hope is an integral element in recovering from this diagnosis. Not only do I need to have hope for recovery but the team of professionals who support me need to remain hopeful, no matter how many times I come off my meds, no matter how many times they need to repeat the same things to me, hope is important.

What are your hopes and plans for the future?

My hopes and plans are written on a whiteboard hanging from the back of my front door. It's a drawing of a house with a fence and a big yard with a dog. It also reminds me that I want to keep taking my medication so that I can get off the DSP, get out of commission housing and into meaningful work.