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Shame, stigma, losing touch with reality but hope and healing too – what it’s like to live with psychosis

Niamh Jimenez speaks to young people who have suffered psychotic episodes about their battle to shake the stigma that comes with it



Conor Gavin hopes to pursue post-doctoral research in the field of psychosis. Photo: Ray Ryan

Conor Gavin is hoping his own experience with psychosis can help



Niamh Jimenez

Thu 8 Jun 2023 at 02:30



"If people went through it, they'd come out and say: 'God, that was really mind-bending,'" says Jack (who would prefer not to disclose his last name), a microbiologist who experienced an episode of psychosis in the summer of 2018.

At the time, he was just 19 years old and at the end of his first year of a degree in biomedical science.

"I remember the World Cup was on during my episode," he says, "Watching the match in front of me, a goal could go in and I wouldn't notice because of this disorganised thinking. It's hard to describe, it's just [like] racing, you can't concentrate or process anything."

Now 24 years old and working at a pharmaceutical company, Jack admits that, for several years, he did not disclose his experience to close friends for "fear of being seen differently".

Lisa Callaghan, a 32-year-old clerical officer and postgraduate student at the University of Galway (UG), felt a similar pressure to remain silent after she experienced an episode of psychosis two years ago.

"I've been told by some people that I should keep my mental-health history to myself because they were saying that people might judge me," she says. "It was almost like you have to kind of hide this part of yourself."

She highlights that this expectation of secrecy is not present for other medical conditions, such as diabetes or depression, likely due to a general lack of understanding of psychosis.

"I had never heard of psychosis before I was diagnosed," Lisa says. "I think it's important for people to know about it in case they get it or experience it, so that they understand what it is."

In Jack's view, many have heard of schizophrenia, but fewer are familiar with the umbrella term of psychosis. "I remember telling a friend I had psychosis and they said: 'Is that a skin condition?'" he says.

Dr Karen O'Connor is the National Clinical Lead for the HSE's Early Intervention for Psychosis (EIP) programme and a consultant psychiatrist for RISE, an EIP service in South Lee, Co Cork.

She says that increased use of the umbrella term represents a shift away from "rigid diagnoses" towards a "broader, more inclusive" approach.



Conor Gavin is hoping his own experience with psychosis can help other people. Photo: Ray Ryan

Psychosis, according to the consultant psychiatrist, refers to a collection of mental health conditions that affect the brain's "ability to process information".

During psychosis, people experience a "loss of touch with reality," which may present as auditory hallucinations, such as hearing voices or ringing phones, or delusions, such as the belief that they are being followed or watched.

These "positive symptoms," as defined in medical terms, are often what drive the 1,500 new annual cases in Ireland to seek treatment, since they tend to have a significant impact on a person's daily functioning.

Conor Gavin, a 25-year-old engineer who had an episode of psychosis almost 10 years ago, notes that even after recovering from a first episode of psychosis, individuals may still have to manage "deficits in mood, concentration, cognition and sleep".

"One of the misconceptions that I see for me and others around me is an expectation that you'll be better right away," he says.

Each individual's experience of psychosis, which exists on a spectrum, is unique. Although negative symptoms have traditionally received less attention from both mental health services and the media, Dr O'Connor emphasises that they too can have a "big functional impact".

"Taking the medication prevents the major positive symptoms, whatever they may be, [such as] a delusion or auditory hallucination or disorganised thinking — the main episode, essentially," Jack says.

"But they don't necessarily treat negative symptoms, such as anhedonia, which is the loss of pleasure in things that maybe you once enjoyed, motivation or emotional flatness."

In Dr O'Connor's view, medication can be critical, especially during the acute phase, but it is not a cure-all solution for everyone. She believes that people should also have the option of "doing specialised psychological work" to address negative symptoms, which tend to be less responsive to medication.

Conor Gavin attributes much of his self-awareness and resilience to regular therapy, revealing he "found out a lot about [himself] through that avenue".

Having not only overcome, but gained, valuable insights from his experiences, he says he has developed "fortitude" and everyday obstacles often seem "more manageable".

For both Conor and Jack

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Jack was initially reluctant to tell others about his experience, but says the episode ultimately brought him closer to his family.

“As corny as it sounds, they [family] would have been more watchful of me and I would have been more open after what happened, to speak about my day-to-day struggles. The discussion of mental health opened up a bit,” he says.

Similarly for Lisa, the involvement of her family in the EIP programme fostered a new level of openness and support.

“To be honest, being open with my friends and family if I’m ever even just having a bad day, like speaking to someone about it [really helps], I’m very lucky that I have that support there,” she says.

“And sometimes I might just go for a walk and have a phone call with a friend, but by talking to someone, you actually kind of realise that actually everyone’s in the middle of something and that grounds you in a way. It helps put things in perspective.”

Conor says: “There’s a bit more understanding of mental health in general. And people sometimes can treat each other in a kinder way.

“People are more aware of feelings, emotions, how people think, not just because of me, but maybe because they spent some time in psychiatric ward hospitals, and they’ve been talking to mental-health nurses and doctors. Through those conversations, people can gain more awareness.”

Lisa, who is receiving support from the Sligo/Leitrim EIP team, credits the resources she has accessed with helping her return to work — for her, a source of much-needed “structure and routine”.

She explains that after feeling like she had “lost part of [herself]” following her first episode, finding meaning and enjoyment outside of work has also been integral to her recovery process.

“I was finding it difficult to get back to where I was [before the episode],” she says. “But then one of my friends suggested to go to try printmaking, as there’s a local studio in Manorhamilton where we’re from. And I just loved it because it was totally different. That’s given me this whole other sense of purpose and meaning.”

Passionate about the connection between art and mental health, Lisa is contemplating a part-time master’s degree in creative arts. In the future, she hopes to be involved in community arts projects for people with mental health difficulties.

Similarly, Conor derives hope and motivation from his peer support work as part of UG’s PSYcHE, a programme funded by the Health Research Board and led by Professor Gary Donohoe, which focuses on psychological interventions in youth mental health.

“I had a brainwave that maybe this lived experience could actually do some good for other people,” he says. “Maybe I can throw down a ladder behind me for other people. And that’s just filled me with so much hope going forward in my career.”

Following his master’s degree in clinical neuroscience starting this September, Conor hopes to pursue post-doctoral research in the field of psychosis.

It is clear that, despite the persistence of outdated stereotypes and myths — such as the notion that people with lived experience of psychosis are in full-time psychiatric care — the vast majority of people with these conditions lead normal lives.

According to the latest Irish research, 35pc of people who have experienced an episode of psychosis have recovered fully and 65pc have achieved symptom remission.

Lisa stresses the importance of dispelling the shame that so often accompanies these diagnoses, especially for those who are just embarking on their recovery journey.

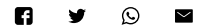
“I remember one of the psychiatrists saying to me and my family, it could literally happen to anyone,” she says. “He was like, this could happen to me. This could happen to your parents at any time.”

“You do feel like there’s something wrong with you and you can have a lot of guilt and shame about it because you feel like you’ve done something wrong... Like there’s so much guilt that goes along with it, but it’s not your fault.”

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