

# **A COMING OUT: MY EXPERIENCE WITH PSYCHOTIC DEPRESSION.**

The frightening, isolating, and stigmatising  
experience of psychosis.

Joyce Vromen, *PhD*



Dedicated to Isabella and Sophia, simply for being you

Dedicated to those affected by psychotic depression -  
for slowly finding your way through the forest of obstacles,  
society's icy silence, and misconceptions about what psychosis is and is not.

# Mental (ill) health

visual depiction of the size of the world population experiencing good mental health, anxiety, depression & psychosis.



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No one would ever say that someone with a broken arm or a broken leg is less than a whole person, but people say that or imply that all the time about people with mental illness.

*Elyn Saks,*

*University professor, lived-experience of psychosis and schizophrenia*

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Long after acute psychotic symptoms have abated, it is the stigma that is the residual source of persisting distress, and functional impairment. For stigma has the power to irrevocably destroy one's sense of self-worth, and to grossly distort one's self-identity.

*Aashish Tagore,*

*Psychiatrist, lived-experience of a brief psychotic episode*

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## Chapter 1: Summary

### Who I am?

I am a caring, creative, and adventurous mother of two, psychologist, (academic) researcher and lecturer in mental health and psychology. I love spending time with family and friends, reading, walking, dogs, pottery, and raising awareness of mental ill-health and wellbeing. I am pretty average in most ways and I could easily be that friend, colleague or family member that you get along with quite well.



### My first psychotic episode & experienced distress.

When I was in my mid-thirties I developed a psychotic episode and was hospitalized in the mental health ward for a week. Initially, my psychosis was classified as a stress-induced brief psychotic episode, but after a year or so it became clear that I was affected by psychotic depression. It was a shock to me and my immediate family and friends that I had developed psychosis as none of us knew much about this illness beyond its stereotypical portrayal. We had never considered someone we knew may experience psychosis. With the help of medication, I initially made a swift and complete recovery and was back to work in just a few weeks.

However, in the months after my psychotic episode, depression and anxiety debilitated me while I processed what had happened to me, how unexpected it was, and what it would mean for my future. My hospital experience was traumatic and I felt like my mind and body were no longer to be trusted entirely. A lot of the information I read in the aftermath of my first psychotic episode about psychosis, pertained to worst-case scenarios and illnesses like schizophrenia. I could not find

much information in general about psychosis, and almost no information and personal stories about psychotic depression.

#### Subsequent episodes of psychotic depression, information & belonging.

Over the next few years, I experienced two more brief psychotic episodes. Both occurred while having tapered off medication in the hope that the vulnerability to depression and psychosis would be manageable without any medication supports. Subsequent recoveries were speedy and complete, but each episode was impactful, traumatic, and in the lead-up impacted my ability to be productive.

During and after subsequent psychotic episodes, I felt a little more hopeful as I knew a little about what to expect, and importantly I had found some information written by Aashish Tagore, a high-functioning psychiatrist who had experienced a stress-induced psychotic episode and described his road to recovery and the stigma that rests on self-disclosure. On top of these he also was a fellow mental health professional and discussed the stigma that even rests on such conditions in our field of work. I also discovered that there was a small, but active community on Instagram sharing their experiences with psychosis, (traumatic) hospitalizations, and stigma.

#### My hopes & aims for this book.

The enormous positive influence that just a few articles and Instagram accounts had on my subsequent recoveries and feelings of hopefulness and belonging, motivated me to write down my own story. If my story can only make one other person experiencing psychosis feel a little less lonely and dejected, it will have been worth it. Furthermore, I'd hope I can play my small piece in breaking down the stigma surrounding psychosis.

## Chapter 2: The need to de-stigmatize psychosis.

### Attitudes towards mental ill-health.

Acceptance of mental ill-health has increased over the past decades due to the hard work of many individuals and organizations. However, there is still a long way to go in lifting mental health stigma. Encouragingly, depression and anxiety are becoming more normalized and accepted in many societies. Many of us may be able to imagine feeling low in mood or anxious. However, perception of mental illness like psychosis remains largely unchanged. Contrary to popular belief, psychosis is not rare either and



worldwide affects a group of people equal to about 4 times population of the UK. Those affected by psychosis are often treated with suspicion and incorrectly perceived as dangerous or seen as unable to live a fulfilling and productive life. Many people struggle to imagine that they could lose touch with reality in any way, one of the hallmarks of psychosis.

### A lack of information on & personal stories of psychosis.

The picture of psychosis that most people hold in their minds does not look like themselves. It looks darker, dangerous, impaired, and unfulfilled. After I experienced my first brief psychotic episode, I noticed some of such unconscious, negative biases in myself too. I feared my life as I knew it was over and that I wouldn't be able to hold down a job or earn a decent income, that friends would walk away, and I would end up alone, poor, and unfulfilled. It was incredibly difficult to find much information on psychosis to educate myself and information that I could find often covered worst-case scenarios, including ongoing psychotic symptoms and schizophrenia. Even my



medical healthcare professionals at the time were surprised how well I recovered. Implicitly conveying the message that having experienced psychosis meant I could only hope for a suboptimal life going forward.

#### Two sources of hope and belonging in my psychosis journey.

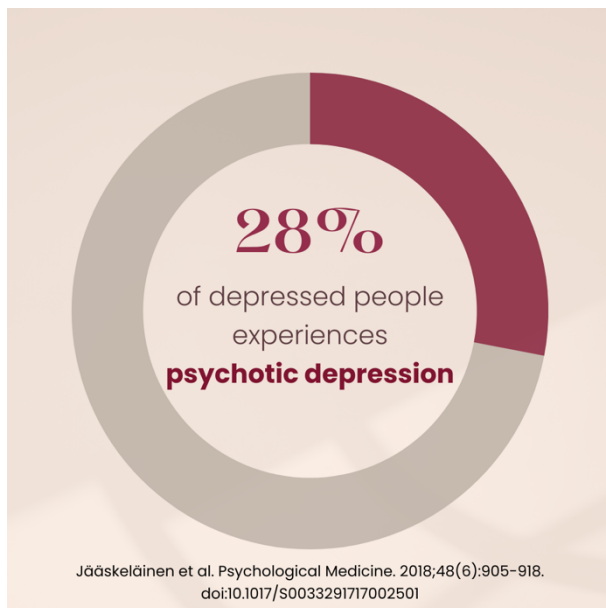
Only when I stumbled on a beautifully written article by UK-based psychiatrist Aashish Tagore, who experienced a psychotic episode himself, this heavy load of dread and stigma significantly reduced. His article helped me feel that working towards achieving my goals and dreams was not outrageous. Around the same time I also found a small but active group of people on Instagram who had personal experience with psychosis and who did not seem to fit the narrow stereotype society at large holds of psychosis.

#### My skills, experience, and goals.

As I have worked for more than 20 years as a researcher in the field of mental health, am currently working as a psychologist and university lecturer, and have lived-experience of psychosis, I feel it is my duty to combine all these skills and experiences. My hope is that my writing and advocacy can assist at least one person experiencing psychosis to not experience the same initial loneliness that I experienced and feel optimistic they can live a meaningful, high-quality life. Moreover, it is my hope that I can contribute to educating people on psychosis and what it is and isn't while relying on high quality research, statistics, and personal experience.

### Psychosis & psychotic depression.

About three percent of the world population will experience at least one psychotic episode. If we put numbers to psychosis, about 234 million people currently alive worldwide will experience a psychotic episode in their lives. Schizophrenia, one of the most impactful and well-known conditions involving psychosis, carries a lifetime risk



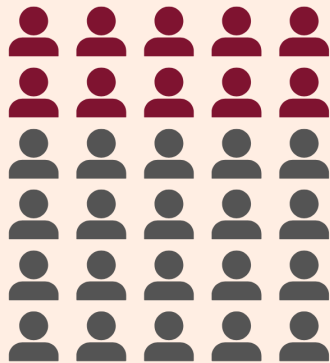
of about one percent. This is three times as common as rheumatoid arthritis, but nevertheless psychosis remains something that is rarely discussed openly. Furthermore, worldwide, the World Health Organisation (WHO) estimates that 5% of people are affected by depression and that psychotic symptoms occurs in 28% of cases of depression. Nevertheless, you rarely hear about psychosis as a symptom of depression.

### Psychosis stigma & its consequences.

Widely held stigmatising beliefs about psychosis and psychotic experience continue to contribute to social exclusion and distress endured by people who experience psychosis. Stigma and the risk of social exclusion are also known to be major barriers to seeking help. Many people developing psychosis are reluctant to engage with support services and experience high levels of anxiety and shame (World Health Organisation, 2001). As Aashish Tagore aptly wrote: “Long after acute psychotic symptoms have abated, it is the stigma that is the residual source of persisting distress, and functional impairment. For stigma has the power to irrevocably destroy one’s sense of self-worth, and to grossly distort one’s self-identity.”

Stigma is something that I also worry about in speaking out so openly about my past experiences. Will it affect my ability to get certain jobs in the future to tie my name and face to psychotic depression experience or will clients walk away or mistrust me?

**Currently, only 36% of people with a mental health condition access supports.**

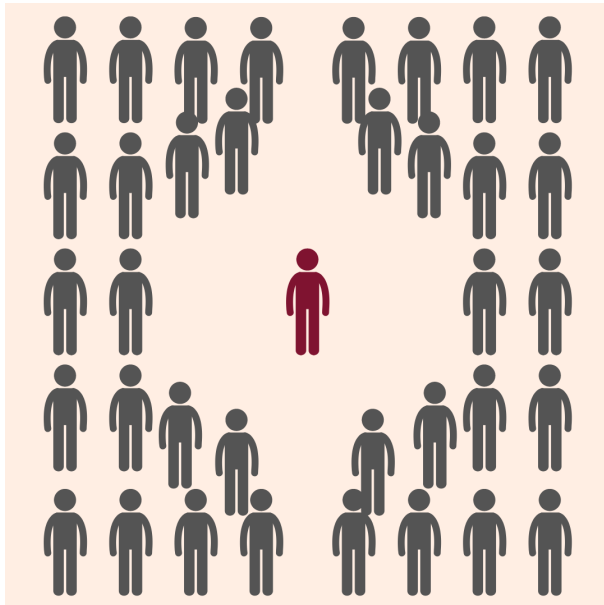


The seemingly easiest option is to remain tight-lipped about my experience with three episodes of psychotic depression. We have a long way to go in finding more effective treatments for mental illness, 3 out of 4 people experiencing mental illness are confronted with stigma, and up to around 70% of people suffering from mental illness do not seek treatment. I don't see how I can become

a more effective psychologist or researcher and advocate for mental health if I carry my own experience with shame and secrecy.

In the early days following my first psychosis I felt terrified. I was lauded by my wonderful outpatient support team as the most successful recovery they had seen in years. I'd like to think I have always been an empathic person and open-minded about mental illness. However, my psychotic experience has made me realize I was probably understanding of some illness like depression and anxiety, but less so of a psychotic episode or schizophrenia. It is possible that my decision to speak out about my experience will have a negative impact on my career or how I am regarded in my wider social circle. I am concerned that my career may be negatively affected by openly linking my name to this story, but if I would do so anonymously I would contribute to maintaining the stigma and shame. I would like to think though that my episode of mental illness, whilst I would have wished to avoid it, has allowed me to grow beyond where I would be without it. I like to think of it as a valuable asset for a career in mental

health to have first-hand experience with stigma, fear, and uncertainty that comes with mental health issues.



In the early days following my psychotic episode, I felt very lonely and could only find a few gloom and doom stories about psychosis. It was only when I stumbled on an article about the personal struggle with a psychotic episode by the UK psychiatrist Aashish Tagore that I felt a renewed sense of hope for a high-functioning life, career, and future. I think as a society we would benefit from

more stories in which mental illness is not the end of a meaningful life but can be a part of it. My hope in sharing my story with you is that it will help one person feel less alone and more hopeful, as Aashish's story did for me.

## Chapter 3: What is psychosis?

### Psychosis as a set of symptoms.



Psychosis is not an illness, it's a set of symptoms that can have many different causes and be part of many different mental health conditions. Psychosis can be characterized by so called positive symptoms and so-called negative symptoms. The term positive does not refer to something nice or likeable, but rather indicates the addition of something that is not present in our

healthy, non-psychotic state. Positive symptoms are behaviours and cognitions like delusions and hallucinations. Negative symptoms are those behaviors and cognitions that are present in health but absent or diminished in psychosis. Examples are reduced social engagement and reduced or flat affect during a psychosis (Blanchard et al., 2020; De La Lune, 2020). The commonly held belief that people with psychosis are dangerous and violent is unfounded and people with psychosis are actually at an increased risk of becoming the victim of violence.

Generally, psychosis include changes in behaviour, thinking, and mood. However, there is large heterogeneity in symptoms across people and across the course of a psychotic episode. According to Yale University, the most characteristic symptoms of psychosis can be categorized as follows:

**Confused Thinking.** Thoughts are muddled or unclear and it may be difficult to follow the person's train of thoughts when they are speaking. Psychosis often causes difficulty concentrating, following a conversation or remembering things. It may lead to one's mind racing and often processing irrelevant information to a detailed level. Simultaneously, processing of important



information may be slowed down and people experiencing psychosis may struggle to make simple decisions. For example, I struggled to make simple decisions like 'eat an apple or a banana', 'walk or be driven' as I was very worried that making the wrong decision would leave me being sent to jail.

**False Beliefs.** False beliefs are usually referred to as delusions and are extremely common in psychosis. Often, people experiencing psychosis can be so convinced of their delusion that logical arguments cannot change their minds. For example, during the few days of my psychotic episodes, I believed an international police organisation was investigating me as I feared I was a bad mother, employee, and friend.

**Hallucinations:** In psychosis, people may see, hear, feel, smells or taste things that are not actually present or perceived by others around them. For example, during psychosis one may hear voices or sounds which no one else can hear, or see visuals which aren't actually there. For example, during my first psychotic episode I perceived some knocking sound that I think wasn't really present and I perceived an occasional flicker on TV and computer screens that originated in my brain.

**Changed feelings:** During psychosis, and especially psychotic depression, people's feelings may change for no clear reason. Often people with psychosis may feel cut off from the world and mood swings are common. Psychosis may also lead one to feel unusually excited or depressed. Often, a person's emotions may seem flat and reduced in intensity. For me, I felt quite flat and hopeless as I truly believed I would be sent to jail because of choosing a 'wrong' fruit and felt like nothing I did would make a positive difference.

**Changed behavior:** Psychosis may impact the way a person behaves and leave them behaving differently from their usual ways. Psychosis may cause people to be very active or lethargic, laugh inappropriately, become upset, or scared without apparent cause. For me I felt extremely scared, did not understand what was happening, and just slept a lot.

### **The stages of psychosis.**

Evidence from research and clinical practice indicates that a psychotic episode occurs in three stages. The length of each phase varies from person to person and from time to time.

**Stage 1: Prodromal stage.** During this early stage of psychosis, signs may be hardly noticeable. Subtle changes behaviour and cognition and energy-levels may take place and each person's experience will be different. However, some common changes include: a reduction in concentration and motivation, lowered mood, sleep difficulties, anxiety, suspiciousness and social withdrawal, subtle impairments in functioning, and some odd beliefs.

**Stage 2: Acute psychosis stage.** The acute psychotic stage is when clear symptoms of psychosis start to emerge, such as hallucinations, delusions or confused thinking.

During this acute stage, people experiencing psychosis can become very distressed by what is happening or behave in a out-of-character manner.

**Stage 3: Recovery stage.** With effective treatment and support the majority of people recovers from their first psychotic episode. Some may never experience another episode. But even for many people who do experience subsequent episodes, psychosis is a treatable condition. Some of the symptoms from the acute stage may still linger in the recovery stage, but with appropriate treatment many people successfully recover and return to their normal, everyday lives.

#### Mental health conditions with psychosis.

Mental health conditions with psychosis, just like any other mental illness, are classified using the Diagnostic and Statistical Manual of Mental Disorders (DSM-5-TR) or International Classification of Diseases (ICD-11), our two main current psychiatric classification systems. Nine psychotic disorders are recognized in the DSM-5 and seven in the ICD-11. This indicates that there is no complete consensus on how to distinguish presentations that fall within the psychotic spectrum. Some examples of diagnoses that include psychosis are brief psychotic disorder, schizophrenia, schizophreniform disorder, schizoaffective disorder, delusional disorder, and psychotic depression.



## psychosis

People can experience psychosis as part of a range of mental & physical health issues.

#### Psychosis risk factors.

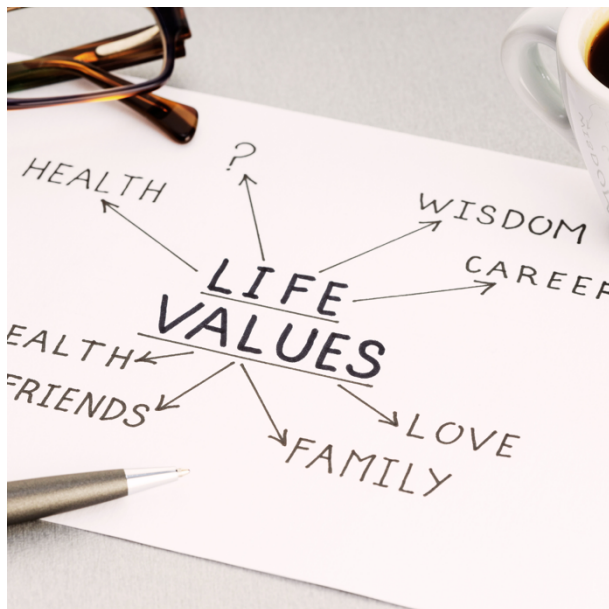
Psychosis is a serious set of symptoms that will need to be treated by qualified professionals and often will require at least temporary, targeted medication support.



Relatively little is known about the risk factors for psychosis, but likely a combination of genetic vulnerability, early adverse life experiences, and recent stressors play a role. There is a strong genetic basis in psychosis, with identical twin studies showing a fifty percent risk of psychosis in one twin if the other has experienced it. Nevertheless, the cause of psychosis is more complicated and these biological influences interact with environmental influences like prenatal exposure to infection and socio-economic disadvantage (Fletcher & Frith, 2009). Psychotic symptoms fall on a spectrum in terms of severity as well as persistence of psychotic symptoms.

### Living a valuable life with psychosis.

The idea that experiencing psychosis needs to be the end of one's productive and value-driven life is incorrect in most cases. Yes, the experience of psychosis will impact you and your future life, to a larger or lesser degree. Doesn't every illness impact the person who suffers from it? However, we would be unlikely to think that someone who has diabetes cannot live a worthy, valuable life. Contrary to popular belief, even



if your psychosis is part of a long-term psychiatric condition like schizophrenia or a condition with high chance of relapse, like psychotic depression, you can live a rich and meaningful life with adequate treatment and support. Examples of people who experienced psychosis and achieved extra-ordinary things are John Nash Jr. who won the Nobel Price in economics, university

professor and mental health advocate Elyn Saks, and Cecilia McGough, mental health advocate, who gave a TED talk about her psychotic experiences during college. Most people experiencing a first-episode psychosis are everyday people like you and me. It is in part due to the barriers in accessing evidence-based, best-practice treatment,

difficulties with adhering to antipsychotic medication due to severe side effects, self- and social-stigma, and lack of adequate supports that life quality can be significantly reduced in those with recurrent or ongoing psychosis as early and ongoing intervention is critical according to research.