

# Understanding Psychosis and Schizophrenia



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By

Lieuwe de Haan

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## PREFACE

If something is bothering you, it is usually good to know a lot about it. Sometimes that can be confronting, but it can also give you grip. In this book I will present current knowledge about psychosis and schizophrenia spectrum disorders. The book is written for patients and their loved ones, who want to learn more about psychosis and schizophrenia. It is also suitable for others, such as teachers, nurses, medical students or doctors. This book gives you an impression of how psychiatrists and researchers think about psychosis and schizophrenia spectrum disorders and what scientific research has yielded so far. Knowledge about occurrence, symptoms, causes, mechanisms and treatment.

It is important for any reader to know from which perspective this book has been written. After all, medicine, psychiatry, science, and authors are not value-free. That is why I write about my point of view in this introduction. Of course there are other valuable points of view, but you will not find them here. This book is written from a medical, scientific and “Western” perspective. In short, I believe that the scientific method is the best we have to understand and improve the world and our relation with the world. The nice thing about the scientific method is that it is critical, stimulates doubt and (if all goes well) prevents ideological positions. Science, as mentioned, is not value-free, and scientists bring their own beliefs and blind spots with them. But they should be critical of themselves and others. I think that knowledge of biology is valuable, but in my opinion many researchers place a lot of emphasis on it. To better understand psychosis, we need science from different perspectives: psychological, biological and social. And we need quantitative and qualitative research. Furthermore, I believe that medicine can often bring limited, yet significant improvements. I think that psychiatric symptoms are scattered in the population and that we make classifications that are more or less correct and that can be meaningful. I also think that our biological and psychological qualities give us possibilities, but also vulnerabilities. We need to take our vulnerabilities into account. Antipsychotics can help in case of psychosis and schizophrenia, however, they have also disadvantages and other help or support is clearly needed. And, maybe most importantly, I think it matters a lot how someone deals with their possibilities and vulnerabilities.

Now you have an idea of where this book comes from.

Schizophrenia and psychosis are complex, and there is still a lot of uncertainty about them. There is also substantial variation in symptoms: they do not manifest themselves in the same way in everyone. Many of the findings are debated. In addition to uncertainty and differences of opinion, there is fortunately also considerable agreement. My goal is to make the available scientific and clinical knowledge accessible to patients, their loved ones and other interested parties. Mind you, much of the information in this book is about backgrounds and causes. If you especially need more practical information, you can find it in Part 1 Chapter 1 and Chapter 2, and in Part 6 and Part 7.

I hope that the knowledge described helps in understanding and overcoming or reducing problems. And that it helps to make decisions about treatment. So that you can use not only your experiential expertise, but also knowledge based on research.

The word patient is used frequently in this book. I talk about patients with schizophrenia or psychosis and about people with schizophrenia or psychosis. A patient is someone who suffers from a medical or psychological problem that creates difficulties in functioning for which professional help is appropriate. Now, of course, someone is not just, or mainly, a patient. But the role of patient suits all of us. It can also refer to any future status. For example, we are all patients of our General Practitioner. By using the word patient, I absolutely do not mean that someone should wait and see what the professional has to offer. On the contrary, the book is actually aimed at strengthening patients and their loved ones with knowledge.

Not surprisingly the term schizophrenia is common in this book. The concept schizophrenia is discussed in more detail in a number of chapters, but I would like to say a few things about it here. Schizophrenia is associated with stigma. This stigma is linked to the prejudice that most people with schizophrenia do not get better and that many of them are dangerous. Both are wrong. The classification of schizophrenia has been wrongly linked to pessimism. It's not a serious brain disease, and it usually doesn't go from bad to worse. It is also problematic that many psychiatrists and scientists themselves also have a pessimistic view of schizophrenia. This may be because some psychiatrists mainly see people with the most severe form of schizophrenia. This gives them the false impression that things usually end badly. Some patients and their loved ones suffer a lot from the classification of schizophrenia and the prejudices that prevail about it. It has made them



angry or sad. Moreover, it is clear that it is not easy to distinguish schizophrenia from other psychotic disorders. The causes of schizophrenia are not essentially different from the causes of other psychotic (or even other psychiatric) conditions. For example, we are increasingly aware that variation in genes is associated with various psychiatric disorders. In addition, there is also no specific treatment that is only applicable to people with schizophrenia. In short, critics emphasize that schizophrenia is a concept that carries stigma and they argue that schizophrenia promises specificity, but does not deliver on that promise.

So, critics say: get rid of that word, because schizophrenia does not exist. They are right: schizophrenia does not exist. Just like Parkinson's disease or depression doesn't exist. All patients with Parkinson's disease and all patients with depression are different from each other. The causes can differ, the course differs and the therapy differs. Just like with schizophrenia. Diseases are "constructs," that is, they are human-made. On the basis of agreement between experts these constructs are defined. Psychiatrists have a set criteria for classifying schizophrenia, and if a problem someone has meets those criteria, then that person's psychiatric problem is called schizophrenia. It doesn't exist, we invented it. We agreed on the concept.

However, should we stop using the word "schizophrenia"? Does that solve the problem of stigma? Do we no longer have any difficulty in distinguishing between the different problems of different people? Is "psychotic disorder" a better term? Can we convince the rest of the world to get rid of the word schizophrenia?

I think the answer to all these questions is negative. We don't improve patients' prospects if we rename their problem. People are very different from each other and we have to take this into account in the treatment. Psychosis is common, with other conditions or without causing problems. Placing all psychotic disorders, including schizophrenia under the heading of "psychotic disorder" ignores an important feature of the problems of people who now meet the criteria of schizophrenia. Namely: that they have been suffering from psychotic symptoms for quite some time. And that that indicates a rather persistent and substantial vulnerability.

From previous research, we know that schizophrenia is variable and sometimes difficult to define. Still, it is good that researchers continue to work on schizophrenia. It is an advantage that recently the concept of "schizophrenia spectrum disorders" has been introduced and that more attention is being paid to different symptom dimensions and that we are aware

of the problems with the term schizophrenia. But internationally the term schizophrenia is still used and there is still no agreement on a better term.

“Schizophrenia” describes a psychotic disorder that has existed for more than six months and is associated with obvious problems in functioning. The long-term burden is built into the classification. We know that for people who meet the criteria for schizophrenia that the risk of a psychotic relapse is high. And therefore, we know that it is worth taking this into account in the treatment.

In short, schizophrenia is seen as a term that describes vulnerability. Something to keep in mind. Recognizing that for many patients the outlook is quite good, but that a significant proportion of them require continued support and that for the vast majority of patients the vulnerability remains.

Finally, a few less tricky points. “He” and “she” are used interchangeably. Furthermore, I have tried to avoid technical concepts as much as possible. Sometimes I couldn’t avoid it. Then I tried to describe these terms as clearly as possible.

What is this book not about?

It is also important to clarify what the book is not about. It is not about how you cope with feelings, emotions, worries and meaning. It’s not about dealing with loss, or how exactly you build or regain your confidence. These questions are very important, but they are also very personal. I do not consider myself able to write about that in general sense. This book is also not about assistance with housing, education, work, finances or relationships. All very important subjects, but not the focus of this book.

In addition, I would like to emphasize that findings from research often only apply to average patients, while hardly anyone is “average”. Sometimes the text is too rosy. Sometimes the text is too gloomy. The book is not exactly about you. If you are left with questions: discuss them with your friends or professional caregiver.

December 2023, Lieuwe de Haan

## **PART 1.**

### **INTRODUCTION PSYCHOSIS AND SCHIZOPHRENIA**

# CHAPTER 1

## PSYCHOSIS

### **What is a psychosis?**

Psychosis can be a lot of different things. Psychosis is captivating, special, terrifying, fantastic, terrible, funny, serious, deadly, reassuring, impressive, admirable, sick, incomprehensible, scary, original, annoying, maddening, beautiful, depressiony, handsome, lonely, inspiring, understandable, and moving. Of course, it cannot be all that at the same time. One thing is clear: psychosis varies considerably and the differences between people with psychosis are enormous.

### **What are the characteristics of a psychosis?**

So many people, so many psychoses. Psychosis concerns what we think, how we think and what we perceive. A psychosis is a state in which the belief, thinking or processing of perceptions differs from normal. But that does not immediately make it clearer. Because what is normal? Is it normal to think that young people should always listen to the elderly? Is it normal to think that healthcare does not have to be accessible to everyone? Is it normal to think that you should make as much money as possible? Is it normal to believe in telepathy? Is it normal to think you have to kill unbelievers? Is it normal to believe that horoscopes provide valuable information? Many people do not think so, but many others are fully convinced of it. What is true or normal for one person, is not true or normal for another.

When do we consider a thought, a way of thinking or an observation as normal and when as a psychotic phenomenon? Psychosis has a number of characteristics. None of these features allow an absolute distinction between what is and what is not psychotic. But taken together, these features are used to determine that a thought or perception is psychotic. These characteristics, which I discuss below, are:

- 1 You stand alone in your thought or perception.
- 2 Your thought or perception is considered not to be realistic.

- 3 You remain convinced of your thought or perception, despite evidence to the contrary.
- 4 You or others are hindered by your thoughts or perceptions.

Incidentally, not only “what” you think can be psychotic, “how” you think can also be psychotic. Criteria for this are:

- 1 Others do not understand what you mean, they cannot follow you properly.
- 2 Your way of thinking is illogical or you form new concepts that have never been conceived by anyone else.
- 3 Your way of thinking remains difficult to follow for a longer period of time.
- 4 Your way of thinking is disturbing to yourself or to others.

So, one of the characteristics of a psychosis is that there is really only one person who has a certain thought or belief, or perceives something in a certain way. You are alone in your thoughts and/or observations. No one else shares them. No one else can track it. Nobody else believes you. That is very lonely. You are on your own. But this characteristic, standing alone, is not conclusive either. The first to think that the earth was round was also completely on his own. Still, he had no psychotic idea, but, on the contrary, was right. And on the other hand, sometimes a charismatic person has strange or dangerous ideas that are completely adopted by a number of followers. For example, there have been sects whose members killed themselves because they believed, like their leader, that the world would end on a specific date. We then think that that group of people have all adopted a delusion. But this is rare. The vast majority of people with a psychosis are on their own. No one can follow what you experience, no one else shares your beliefs.

Another characteristic of psychosis is that the thought or perception are not real. According to others, the psychotic thought or perception cannot be right. You are not chased by the intelligence service, others cannot read your mind, the neighbor does not talk to you when you hear his voice. But you can sometimes argue about that characteristic too. Because what is reality? How do we know for sure that telepathy doesn't exist? Moreover, people often see how you feel from your face or posture. At least, they think they know your feelings. Then, you could argue, it is only a small step to being able to read someone's thoughts? Sometimes it is clear: if you think half of your brain has been pulverized, then almost everyone thinks that is

unrealistic. But often it is less clear: some people talk behind your back, but it is very unlikely that very large groups of people are talking about you.

According to the two characteristics discussed, in a psychosis you have individual thoughts or perceptions that others label as unrealistic. But we all have unrealistic ideas every day, and they are not counted as psychotic ideas. A characteristic of a psychotic idea is that it is an important idea to you and that it is not possible to be dissuaded from it. Others can try, but you remain convinced. In fact, the more others try to convince you that your idea is wrong, the more convinced you become that your idea is really true. As a result, you will increasingly be alone. This characteristic - the unshakable conviction - is also common among people who hold certain beliefs, for instance religious ideas. But often they share it with others. These people usually never change their minds, but as said: someone with a psychotic idea has a strong conviction and is alone in it.

The last characteristic is that you or others are hindered by your beliefs, your way of thinking or your perceptions. For example, you may avoid contact with other people because you think they can read your mind. Or you can destroy your phone because you think it has been hacked. Or you can no longer concentrate on a conversation because you keep hearing voices.

To summarize, a psychotic thought, way of thinking or perception must simultaneously meet four characteristics:

- 1 You stand alone in your thought or perception.
- 2 Your thought or perception is not realistic.
- 3 You hold on to your thought or perception, despite attempts to convince you otherwise.
- 4 You or others are hindered by your thought or perception.

None of these characteristics in itself allows an absolute distinction. And the assessment is arbitrary. It is work of humans. Psychiatrists sometimes also discuss whether a phenomenon is psychotic or not.

### **What kind of psychotic symptoms are there?**

Psychosis can manifest itself in three different phenomena:

- 1 It can be the content of your thoughts. So, what you think. Psychotic thoughts are called delusions.

- 2 It can concern your experiences. You can perceive something while your senses are not receiving stimuli. Such experiences are called hallucinations
- 3 Finally, it can concern your way of thinking. So, how you think. Your train of thought cannot be followed by others. Your train of thought may suddenly stop. Or your associations are difficult to follow by others.

### **What are delusions?**

Delusions are beliefs that are unrealistic, not shared by those around you, and cannot be dissuaded. There are different types of delusions. Paranoid delusions are common. You have the idea that others are chasing you, are bad for you or are forming a conspiracy. With delusions of grandeur, you are convinced that you are very special, have special gifts or will soon become famous. That is a nice dream, and it does not have to be so much of a nuisance to yourself. In delusions of reference you think that all kinds of things you see or hear have a special meaning for you. You think that messages on television or billboards have a special meaning for yourself. You can also be convinced that someone or something interferes with your thoughts. Or that thoughts are inserted in your head, or withdrawn from your head. Or that your thoughts are broadcasted. Sometimes people think that a chip has been inserted into their head or body that affects them. With somatic delusions you are convinced that something is wrong in your body. For example, that you have sharp objects in your blood vessels or that your brain is swelling. With nihilistic delusions you are convinced that you are worthless or even not exist. In melancholic delusions you think you are guilty of misery and accidents in the world.

### **What are Hallucinations?**

Hallucinations are experiences of a perception without the relevant sense being stimulated. So, you hear a voice (or music or some other sound) while no sound vibrations come to your eardrum. You hear that you are being spoken to, but no one around you is speaking.

Hallucinations can also involve other sensory experiences. You can see images while no light hits your retina. Or smell a scent when there is no volatile substance reaching the nerve cells in the back of your nose. Or you can taste a flavor without your taste buds coming into contact with a particular substance. Or feeling something without being touched.

A hallucination is a real experience of a perception. You really hear, see, smell, taste or feel something. Only the corresponding sense is not stimulated. Your brain is kidding you. They register an observation and that is why you experience it. That experience feels real.

### **What is confused thinking?**

Confused thinking or disorganization means that your thinking is no longer logical. At least not easy to follow for someone else. These problems are also referred to as “formal thinking disorders”. Of course, psychiatrists cannot really judge your thinking. They only can listen to what you say, and on that basis, they judge how you think. You may be jumping from one subject to another, it is not clear how or why you switch from one topic to another. Or your thinking may seem chaotic or go too fast or too slow. Sometimes your train of thought can suddenly be interrupted. The formation of new words is also counted as a formal thought disorder. Sometimes people with schizophrenia come up with very powerful, striking new words. One patient told a colleague, whom he was apparently not very satisfied with, that he was not a psychiatrist, but a “psych hater”. In this case you could also say that someone is very creative with language. In addition, the disorganization can also manifest itself in confused behavior.

### **With what can you compare psychosis?**

A psychosis is a state in which the processing of information is disturbed and which leads to psychotic symptoms: delusions, hallucinations and/or confusion. You could compare psychosis with fever. Fever is a phenomenon that can occur with various illnesses. Fever indicates increased activity in your body. Psychosis can also occur in various psychiatric conditions and indicates increased mental activity and disturbed processing of information. People with depression can become psychotic, just like people who use cocaine. And if you have had surgery and are still drowsy from the anesthesia, and if your hearing aid is off and you miss your glasses, you can also get psychosis. When the psychotic state has a physical cause and your consciousness is disturbed, we speak of a delirium.

However, you can also have psychotic symptoms without causing problems. For example, some people occasionally hear voices when no one is speaking to them. But they don't suffer from that; they don't find it disturbing. In fact, they often take what is being said as a good advice. Then these psychotic symptoms do not occur in the context of a disorder. So, you can have psychotic symptoms without having a psychiatric condition.



## **What is the difference between psychosis and schizophrenia?**

There may be confusion about the distinction between psychosis and schizophrenia.

Psychosis, as explained, is a state in which the processing of information is disturbed and which leads to psychotic symptoms: delusions, hallucinations and / or confusion. Schizophrenia is a classification in which someone suffers from a psychosis impacting on social functioning, with a number of other characteristics and a duration of the problems of at least six months.

The comparison is not entirely correct, but you could say that psychosis is “fever” and schizophrenia is “pneumonia”. Psychosis is a phenomenon and a symptom. Schizophrenia is an indication of a certain “vulnerability or condition”.

## **What is meant by Positive Symptoms?**

This is a somewhat strange term. You may initially think of something beneficial. But it simply means that there are symptoms that are not normally present in someone. It is something new, something extra on top of the normal state. Consider, for example, delusions, hallucinations or symptoms of disorganization: normally someone does not have these kinds of problems, but they do now. If one or more of these symptoms are present to a sufficiently severe degree, we speak of positive symptoms.

## **What is meant by Negative Symptoms?**

Unlike positive symptoms, negative symptoms do not indicate excess, but rather a deficiency, something that is missing. Something that is normally there, is now less present or absent altogether. Normally you see emotions on people's faces. Normally people use gestures. Normally people move. Normally people are motivated. Normally people worry. There are negative symptoms when these kinds of normal things are no longer present. For example, people with negative symptoms show less initiative, barely speak, have difficulty taking action and show little emotions. They are often bored and feel a void. Their urge to do something is limited, they hardly have spontaneous thoughts or they experience a decrease in creativity. Lying in bed for a long time, looking straight ahead without thinking, not going to school or work, paying little attention to grooming are all examples of the consequences of negative symptoms.

## CHAPTER 2

### PEOPLE WITH SCHIZOPHRENIA

This chapter is about how people with schizophrenia view schizophrenia. To this end, I have compiled an anthology of impressive stories I encountered. I changed names and circumstances, to avoid recognition. These stories show how different people think about the difficulties and the possibilities, and they give an impression of important themes in their life. Finally, I will mention some famous people with schizophrenia.

**What is schizophrenia according to people who have experience with it?**

**Paul:** “The stigma on schizophrenia is huge. You can overcome that by being open. But schizophrenia is also one of the most cruel illnesses out there. I got depressed and had bad voices a lot. I was also extremely anxious, and I didn’t even dare to leave the house because of the voices. I heard several, both from acquaintances and strangers. They said, “We’re going to do bad things to you.” Sometimes the voices make me seem absent, because I have to have two discussions at the same time. One in my head and one with an outsider. I have learned to handle voices better and I don’t pay a lot of attention to it anymore. It is a short circuit in the brain, no more, no less. Nowadays the voices are more in the background and are more positive. I am stronger than the voices!

In my opinion, doctors have a duty to engage in psychoeducation and recovery. Prescribing pills alone is absolutely not the solution: you have to look for the right treatment together with the patient.

Fortunately, I am doing very well. This is largely due to my mentality and the fact that I have developed myself as a person. I also have a close circle of friends and have received a lot of support from my family. Recently I was hired as a sponsor recruiter at a tennis club. My job is to maintain existing relationships, recruit new sponsors and receive sponsors at the club. So, a lot of social contact, and that goes well for me. “

**Jennifer:** “The alarm clock rings at 7:30 in the morning” or actually four different alarm clocks go off. And yet that doesn’t mean I’m waking up, no matter how badly I want to. Because of the medication I sleep very deeply.

At the station I am always a bit anxious about whether the trains will run that day. The tones that always sound just before an announcement follows, already makes me nervous. I quickly get upset when things don’t go according to a set pattern. The filter in my head that separates important impulses from unimportant impulses doesn’t work as well as it does in other people. I quickly get tired of many impressions.

I work one half day a week as a board member of a patient association. We used to say we were the nationwide patient association for people with schizophrenia. Today we call it psychosis sensitivity. Our members feel more comfortable with this new name. All the people who work for the patient association have a psychotic disorder themselves. As a result, we understand each other very well. When I tell other people that I work for such an association, I sometimes experience that people think that I am a kind of social worker who supports the organization. People often cannot imagine that our association is run by fellow sufferers, and that for about twenty years! People with schizophrenia can do more than most people think.

Sometimes I am also asked to lecture on schizophrenia. I like to do things like this, because I notice that a lot is still unknown about schizophrenia and that a lot of nonsense is also written and told in the media. I have made it a kind of mission for myself to contribute to a better image of schizophrenia. That also gives direction to my life; I have the feeling that I contribute something. That is why I have also written a book for young people who in one way or another come into contact with schizophrenia.

It remains amazing how a few pills can make a whole psychosis disappear! And moreover, since I started talking about childhood trauma with my psychologist, I have less burden of the symptoms of schizophrenia. But of course, that could also be due to the fact that I am approaching forty: it seems that symptoms are getting milder then. “

**Thomas:** “I quit my history studies. I was no longer able to attend lectures, because people could read my mind. Just think how awful that is. I completely lost my privacy. Everything you think is on the street. If you think “He has a lot of pimples” or “That’s an attractive girl” or “I do want to have sex”, it is immediately public. I therefore tried to control my

thoughts. Not to think what could be offensive. But that got me completely stuck. I went to the psychiatrist and was persuaded to take antipsychotics. My fear that people could read my mind diminished. I resumed my studies, went back to playing basketball and felt good. At one point my psychiatrist spoke to me about my psychotic period. But we didn't understand each other when he talked about "reading thoughts as a phenomenon of psychosis." There was confusion with both of us. Then I suddenly got it "Oh now I get what you mean: people can only read my mind when I'm psychotic. The belief I had about reading minds is so impressive that it must have been true. I see psychosis as a vulnerability in which my thoughts can be read. "

**Jessica:** "I see messages related to me everywhere. Those messages tell me how I am doing. It's always right. I see it in advertising and hear it from people on the street, and what I see or hear fits exactly with how I feel. It annoys me, it keeps racing in my head. I've been taking antipsychotics for a long time. It does muffle a bit, but I keep seeing all those things. It is not always bothersome or unpleasant, I also learn things about myself from the things I see. But it is not good for my self-confidence. I think I have schizophrenia. It is a handicap. It makes me feel lonely. "

**Barbara:** "My parents are very bad for me. They use a lot of drugs and alcohol. My mother especially yells at me. I don't trust anyone anymore. I don't want to go back home, but I don't want to be admitted either. In the evening I hear voices. Usually, they say shitty things. I turn up the music. That helps. A little. The social workers are in league with my parents. Then I have to take pills, while the problem lies with my parents. I don't have schizophrenia. They just say that to hold on to me and make money off me."

**Patrick:** "Health is a sliding scale. Hearing voices is just as exhausting as a child pulling your sleeve 24 hours a day and asking, "Why?" Or, "When are we going there?" Or: "Are we there yet?" In the early years the voices came from outside forces and often left me defeated. How did they know and why had I not thought of it before? My psychiatrist certainly helped me by making things clearer to me. But in the end, I am the one who knows myself best. I could see the voices more and more as my own. Now the voices advise me: they urge me to run, sometimes stubbornly, but now I believe it is me. I sometimes wonder: What if I got even healthier, would I miss the voices?

**Michael:** "I am afraid that I will spread a terrible odor. I only dare to go outside with a lot of deodorant. When I hear people talking on the street, I always think they are talking about me. When I concentrate heavily on my work, it fades into the background. But that does not always work.

Sometimes I spend hours listening to what people say on the street. I don't want pills. The doctor says I have a psychosis. Maybe so. I also quit smoking. I no longer use drugs at festivals either. I want to keep thinking clearly."

**Emily:** "I think I have schizophrenia and it is a brain disorder. But that is not the whole, and certainly not the most important, story. Because the psychotic symptoms have meaning and they have helped me to organize my new life. I have seen that some patients can really get better from antipsychotics, but others get worse nevertheless. Antipsychotics only treat part of the problem. I heard many voices. I was chaotic, often depressed. I was on antidepressants, but I remained depressed. One day I heard voices from birds saying, "We love you Emily." Later I heard a clear voice: "Believe in Jesus and everything will be all right." Since then, I had a direction in my life and people started helping me. And I became less chaotic. I think God can speak to you through psychosis. Atheist psychiatrists don't believe that, but they are wrong. My psychosis made me know which way to go. "

**Sarah:** "After my divorce, I started to notice that the neighbors looked in a special way when I walked by. Often, they turned around quickly. I also heard them laugh behind my back. When I wanted to go to sleep, they started making noises on purpose. I think they also entered my house. Then they moved things in my house. I couldn't find anything anymore. My doctor says I am confused. It may be, but I think you better be on your guard. He consulted a psychiatrist, and now I am on antipsychotics before sleeping. I sleep better. Whether I have a psychosis? I do not know. In any case, I want to keep living on my own. "

**Susan:** "Making friends is as difficult as landing a capsule on Jupiter. I know all the ingredients. But maybe I'm too shy, they think I'm boring, I can't keep the conversation going... When I'm on medication I'm stable and balanced. I benefit a lot from my family. They accept me as I am. And I also have some friends that I see a few times a year. But I don't really have someone I see every week or just call me to go out. And if that doesn't work, how am I supposed to find a partner? Do I want children? Of course, I want children. But I'm also afraid they could get schizophrenia. Can I raise them without damaging them? I am happy with everything I have, although I am often afraid of losing it. I wish I had more, enough to land a capsule on Jupiter."

**Nancy:** "My son jumped off a building just before his 34th birthday. I miss him so much. He grew in me and I have always cherished him. He liked to

surf. We lost him since he was 21. He withdrew. Threw away the food I brought because he was afraid of being poisoned. He took his medication. He wanted to get better. But nothing helped. It also made him desperate. He shouted, "I'm not taking my medication because I'm sick, I'm sick because I'm taking medication!"

**Musaf:** "I have schizophrenia. If I don't take clozapine, my thoughts get restless, I start paying more and more attention to all the insidious things that happen. This is going from bad to worse. I then pace, feel furious and helpless. I used to be separated. I have had severe psychosis three times. I never want to experience that again. That's why I take clozapine. It bothers me nevertheless. I sleep around the clock and it takes quite a long time in the morning before I feel a little clear. Do agree with my psychiatrist. I am really sensitive to psychosis."

**Linda:** "I want to emphasize the importance of psychotherapy. My previous professional caregiver gave me too much antipsychotics, and he was judgmental. Now I use a lot less drugs, and my psychiatrist is calm, open and friendly. My psychoses have a lot to do with trauma that I have suffered. Also, psychological trauma. Precisely everything I've been through has made me more suspicious. It helps me a lot to be able to talk about this. That I'm being listened to. I don't dare to do that with people I know. It took a lot of time. You cannot quickly recover from broken trust. But through psychotherapy I work on myself. My psychiatrist doesn't have to do much, just ask the right questions, support me, and be patient. Then I get better. "

**Daniel:** "I am now 44 years old and fully recovered from schizophrenia. From the age of 20 I have been admitted to a psychiatric hospital ten times. I have not used antipsychotics since I was 37. I thought my thoughts could influence things in the world. My train of thought was difficult for an ordinary mortal soul to follow. I was very sensitive to everything that was going on around me. I dropped out of college and they told me I would never recover. But that's nonsense: I've recovered. You can be cured of schizophrenia. I became an artist and I still have special gifts.

Changing my lifestyle brought about my recovery. I have slowly tapered off the drugs and am on a vegetarian diet. A lot of fat helps me: I usually eat 250 grams of French cheese and two avocados a day. I should avoid proteins. I also run a lot, and I always visit friends by bike. And it was important that my friends and family supported me. I am a living proof that you can recover from schizophrenia. "

**Aaron:** “Belief in Atheism. That’s what I’ve learned. I used to make the choice for life. I did this by not opting for a university study: then I would have become psychotic and suicidal again. So, I chose life and became a social worker. And my belief is that I can mean something to other people and to the world. That belief is my life. I sometimes think that others speak ill of me or that items in the news relate to me. But through yoga and through my faith I get over it. Life without faith is worse than death. “

### **Which famous people met the schizophrenia classification?**

**Vaslav Nijinsky** (1889-1950) was a famous ballet dancer who was asked to perform all over the world. People were moved to tears by his dance. He married and had two daughters. At the age of 28, he became confused and had fits of rage. He was diagnosed with schizophrenia by Eugen Bleuler and was repeatedly admitted to psychiatric hospitals. In later life he became more balanced.

**Eduard Einstein** (1910-1965) was the son of Albert Einstein. He was very smart and musical. He started studying medicine because he wanted to become a psychiatrist. At the age of 20 he was admitted with the symptoms of schizophrenia. He continued to write letters to his father, but Albert Einstein (who emigrated to the United States) never saw his son again. Eduard remained interested in poetry and could play the piano beautifully, but his memory and ability to remember was severely damaged by the many electroshocks he received, according to his brother.

**John Forbes Nash** (1928-2015) was a genius mathematician. He is the only person to have won both the Nobel Prize in Economics and the Abel Prize (a kind of Nobel Prize in Mathematics). Nash received many honorary degrees and spoke at many congresses.

From the age of 32, he became suspicious and has been repeatedly hospitalized. Nash said his “mental disorders” started when his wife was pregnant. The scientific rationality of his thinking changed to the idea that he saw a messenger or had a special function himself. He felt haunted. A few years later he started to hear voices. He only took antipsychotics when forced to. From the age of 52 his condition improved and he gradually returned to academic work. He later said, “I would not have had good scientific ideas if I had thought more normal.” Nash saw schizophrenia as an unacceptable way of thinking. He emphasized the evolutionary benefits of human diversity and apparently absurd behavior.

Nash and his wife had a son. Nash lived with his wife in between psychiatric admissions, even after their divorce. They later remarried. Nash and his wife were killed in 2015 when the taxi they were in crashed.

**Syd Barrett** (1946-2006) was the founder of Pink Floyd. His father was a famous pathologist. Syd was the singer and main author of the songs that the band released in the early years of its existence. With the first success came the first problems. Barrett's behavior became unpredictable, probably because he used a lot of LSD. David Gilmour, a childhood friend of Syd's, joined the band. It was hoped he could get Syd back on track. In vain: Syd started to use more drugs, got a burnout, heard voices and withdrew from publicity. The last time the members of Pink Floyd saw Syd was when he entered the studio while recording the song "Shine on you crazy diamond," a song about Syd. Coincidence does exist, you would say. Eventually, Syd went back to live with his mother.

**Peter Green** (1946-2020) is the founder of Fleetwood Mac. He wrote many songs that were also performed by others (Santana, Aerosmith, Status Quo), such as "Albatross" and "Black Magic Woman". Later he suffered from psychosis and was admitted several times, and in the 1970s he received electroconvulsive therapy. After this he regained his balance.

**Donny Hathaway** (1945-1979) was an American soul singer who could sing beautifully. When he was only four years old, he already performed as a gospelsinger. Hathaway was seen by his colleagues as one of the very best, on par with Aretha Franklin and Ray Charles. He has sung beautiful duets with Roberta Flack, such as "Where is the love" and "The closer I get to you". He also suffered from schizophrenia. During his psychoses he was afraid of being killed by white people and thought his brain was connected to a device that controlled him. At that time, he was smoking a lot and used cocaine. This sometimes made him violent. The relationship with his wife broke down, and after a failed recording day, a day when he also suffered from delusions, he committed suicide at the age of 33. His daughter Lalah Hathaway also later became a famous singer.

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## CHAPTER 3

# BRIEF WESTERN HISTORY OF PSYCHIATRY AND SCHIZOPHRENIA

This chapter focuses on the history of schizophrenia in Western medicine and science. I will not discuss non-Western ideas or cultures. This is certainly not to say that views from other times and cultures cannot be fascinating or helpful. “Madness” is timeless and an impressive phenomenon about which many views and stories exist and existed. Some visions attach importance to prophets, seers, witches, punishment from gods, enchantment and forces of nature. For many people such ideas are meaningful. They can also be supportive for patients and their loved ones, because they do not assume a disease or a disability, but rather something extra that the patient has, something special. That can be a comfort or a confirmation of how they experience it themselves.

### **How did people feel about psychiatric disorders from ancient times to the eighteenth century?**

In ancient times, four natural elements — air, earth, fire, and water — were thought to correspond to bodily fluids: blood, black bile, yellow bile, and mucus. Illness was seen as a disruption of the balance between those fluids. An excess of black bile caused depression or melancholy (literally: black bile). In addition, “phrenitis” was distinguished, in which patients had incorrect sensory perceptions (van den Bosch 2018). Mania was diagnosed when someone was excited and at the same time had a lack of judgment. Until the eighteenth century, three psychiatric disorders were distinguished. They were respectively called melancholy, feverish light-headedness, and madness. The similarity between the different psychiatric conditions was that patients destroyed things that were dear to them or threatened dear people (Haslam 1809).

### **How did scientific psychiatry start?**

As the influence of religion on thinking began to wane, scientists began to describe delusions and hallucinations as symptoms of disease. This was not possible before, because it was believed that experiences and thoughts originated in a supernatural world whose existence was not in question. Gradually there was interest in the inner world and psychology. Some understanding of the functioning of nerve cells was gained and physicians began to accurately describe pathologies and their course. A less strict distinction was also made between “insane” and “normal”. Patients could be gripped by a strange passion, but also have moments or periods when they thought normal. Psychiatric illness was thought to arise because the nervous system was unable to maintain proper balance (van den Bosch 2018).

### **How did scientists and professional caregiver feel about psychological and physical causes in the early eighteenth century?**

There was a clear split at the time. Some of the professional caregiver/scientists belonged to so-called romantic speculative psychiatry. They saw no role for physical factors and attached great importance to classifying patients’ views. Another part of the professionals was convinced that physical factors were the cause of psychiatric syndromes. Eventually the latter group became more dominant: psychological illnesses came to be viewed in the same way as physical illness and speculative ideas faded into the background. These professionals provided us with careful descriptions of the symptoms and course, and thought that causes of psychiatric disorders could be found in physiology and anatomy (van den Bosch 2018).

### **How did people think about psychotic disorders at the end of the eighteenth century?**

In the late eighteenth century, it was thought that there was one underlying psychotic disorder that could manifest itself in different ways. They tried in vain to classify them on the basis of brain anatomy. It was the German psychiatrist Emil Kraepelin (1856-1926) (see figure 3.1) who suggested distinguishing syndromes on the basis of their course. Kraepelin was strongly influenced by the now outdated idea that there are psychiatric disorders characterized by increasing degeneration (the so-called “degeneration theory”). Kraepelin distinguished dementia praecox from manic-depressive psychoses (Kraepelin 1899).

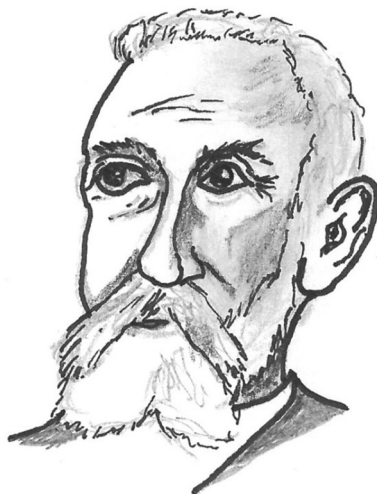
Figure 3.1 Emil Kraepelin

**Who introduced the concept of schizophrenia and what did it mean?**

Eugen Bleuler (1857-1939) (see figure 3.2) introduced the term schizophrenia and by that he meant the splitting up of psychic functions. He thought the core problem was that correct associations get disturbed, derailing the train of thought. The associations become too much at the mercy of emotions, which makes thoughts too much of the center of attention, reducing the integration of different thoughts (Bleuler 1908, 1911). Daily reality also has less influence on ideas. Bleuler hypothesized that a number of basic symptoms, which all happen to start with an A, are always present in schizophrenia: association disorder, affect disorder, ambivalence, autism, attention and will disorder. He considered delusions, hallucinations and catatonic phenomena as additional symptoms, which therefore do not occur in all patients or always.

Bleuler emphasized that there was a wide variation in severity. That is why an attempt was made to make a categorization within schizophrenia (Bleuler 1908, 1911). Kraepelin distinguished, for example, hebephrenia (with many negative symptoms and an unfavorable course), catatonia (with deviations in posture or speech) and paranoia (with delusions and hallucinations). Later he realized that this strict division did not last and he focused more on distinguishing psychic reaction patterns (Kraepelin 1899).

Figure 3.2 Eugen Bleuler

**How did the concept of schizophrenia develop in the first half of the twentieth century?**

Psychiatrists looked for characteristic symptoms that separate schizophrenia from other psychiatric conditions. They thought of a “thought disorder” or “will disorder”, or “a certain sense of alienation that a patient evokes in the researcher”. Despite this, the broad label of schizophrenia became applicable to more and more people. Meanwhile, some psychoanalysts developed theories about the cause of the symptoms and the development of schizophrenia, including very erroneous and harmful theories, such as the idea of the sickening role of the mother or the family (van den Bosch 2018).

**How did the concept of schizophrenia develop in the second half of the twentieth century?**

The Diagnostic and Statistical Manual of Mental Disorders (DSM) was developed in the United States in an effort to achieve greater consensus on different classifications. However, the 1968 DSM-II contained a very broad definition of schizophrenia: Conceptual changes that can lead to misinterpretations of reality and sometimes to delusions and hallucinations (American Psychiatric Association 1968). It was then found that in the United States, many more people are diagnosed with schizophrenia than in

Europe, and stricter diagnostic criteria were proposed. Delusions or hallucinations were characteristic, but not enough.

Psychiatrist Kurt Schneider (1887-1967) (see Figure 3.3) emphasized the importance of the patient's subjective experiences and described what he considered to be the so-called first-order symptoms, i.e. symptoms of which he thought that they were characteristic of schizophrenia: hearing thoughts out loud; voices that speak to or about the patient; thoughts that are entered or removed (Schneider 1959). These ideas influenced the DSM-III-R (the revised version of the third edition of the Diagnostic Handbook), which came out in 1987 (American Psychiatric Association 1987). Another change in the DSM-II-R was that, in contrast to the DSM-II, it was stated that the course of schizophrenia had to be chronic.

Figure 3.3 Kurt Schneider



### **What are the ideas about schizophrenia in the early 21st century?**

In general, professional caregiver and scientists are now aware that schizophrenia is a diverse collection of more or less circumscribed conditions, and that there are no characteristic symptoms that occur only in schizophrenia. We now know that it is sometimes difficult to distinguish

schizophrenia from other conditions and from normal functioning. The criticism of the concept of schizophrenia is discussed in the next chapter.

The DSM-5 speaks of a spectrum of disorders and attention is paid to different dimensions of symptoms that may be present in schizophrenia spectrum disorders: hallucinations; delusions; disorganization; abnormal psychomotor skills; negative symptoms; cognitive impairments; depression; and mania (American Psychiatric Association 2013).

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