

Learning to live with **schizophrenia**

A companion guide

Produced by GAMIAN-Europe



This guide was developed to be in line with the booklet *Learning to live with bipolar disorder: a companion guide*, copyright © 2011 Bristol-Myers Squibb and Otsuka Pharmaceutical Europe, Ltd

Development of this guide was supported by grants from Janssen and Teva Pharmaceuticals, who had no influence on the content

Support for the independent writing and editing of this publication was provided by Oxford PharmaGenesis Ltd, UK

Copyright © GAMIAN-Europe 2016

Contents

Foreword	iii
Editorial Board	iv
How to use this guide	v

Introduction

Chapter 1	Understanding a diagnosis of schizophrenia	5
Chapter 2	Why me?	11
Chapter 3	Symptoms of schizophrenia	13
Chapter 4	Dealing with the diagnosis: what now?	21

Management

Chapter 5	Finding the right management strategy	25
Chapter 6	Personal relationships	35

Moving on

Chapter 7	Living with schizophrenia	45
Chapter 8	Advocacy	51
Chapter 9	Further information	53
	Key contacts	55
	Crisis card	56
	Advance directive	57
	Glossary	58



Foreword

No two people with schizophrenia are the same. Every individual is different. Every experience is different. The effects of schizophrenia are also felt by caregivers, friends and family members. Each person affected by schizophrenia will have their own story to tell and their own journey to travel. There may be times when this journey is difficult, but it is a road that many have travelled before. Equally, there is no right way or wrong way to live with schizophrenia but, by learning from the experiences of others, it is possible to prepare for what lies ahead and overcome obstacles along the way.

We have developed this booklet through consultation with people with schizophrenia, their caregivers and family members, and healthcare professionals, with the aim of offering practical guidance for people affected by schizophrenia.

It will be up to you to steer your own course, but we hope this companion guide will help you find your way.

Paul Arteel

Chair of the Editorial Board

“Mental health is not a destination but a journey. It’s about how you drive, not where you’re going.”

– Unknown

Editorial Board

Paul Arteel

Executive Director of the Global Alliance of Mental Illness Advocacy Networks (GAMIAN)-Europe

Aadt Klijn

Foreign Affairs Co-coordinator at Anoiksis, Netherlands

Aikaterini Nomidou

General Secretary of GAMIAN-Europe

Ausra Mikulskienė

Treasurer of GAMIAN-Europe

Bill George

Foreign Affairs Co-ordinator at Anoiksis, Netherlands

Dieter Naber

Department of Psychiatry and Psychotherapy, University Medical Centre, University of Hamburg, Hamburg, Germany

Köksal Alptekin

Department of Psychiatry, School of Medicine, University of Dokuz Eylül, Izmir, Turkey

Monika Nemanyte

Board Secretary, Club 13 & Co.

Muazzez Merve Yüksel Avcioğlu

Turkish Federation of Schizophrenia Associations

Rebecca Müller

Board member of GAMIAN-Europe and President of Ups and Downs, Belgium

Yoram Cohen

Chairman of Enosh, the Israeli Mental Health Association



How to use this guide

This companion guide has been designed to provide practical assistance to people with schizophrenia, and their caregivers, friends and family. It contains advice on how to manage situations that commonly arise and a number of practical tools to help in day-to-day life. At the end of the guide are some useful resources that can be kept for different situations.

Reading this booklet as a whole will give you an idea of what the journey through life with schizophrenia will be like. Alternatively, you may find it more useful to dip in and out, and read the chapters that are most relevant to your situation at the time.



Introduction

The first crisis: personal perspectives

"I experienced my first psychosis at the age of 19. I was studying psychology in Utrecht and I started to become depressed and developed delusions. Every time that I sat in the restaurant of the university, I thought that people were laughing at me. I was very scared and did not dare to go to the university anymore. Also everything on TV seemed to be about me. I saw a minister preaching, and while he was talking about hell and damnation he looked very intensely at me and I felt particularly addressed by the whole thing. My father then contacted a psychiatrist at my request. The psychiatrist prescribed an antidepressant for me and made sure that I went into treatment in an outpatient care centre for my depressive symptoms. I stopped with this prematurely; it did not work for me. It was only later that it became clear that I had also been psychotic."

– Aadt

"It was the first time that I had been confronted with schizophrenia. It had an important impact on me. The experience of being psychotic was very difficult for me to understand and, to tell the truth, I still do not really understand it. But I have always tried to be there for my son through the whole experience. There is nothing more that you can do."

– Aadt's father



Chapter 1

Understanding a diagnosis of schizophrenia

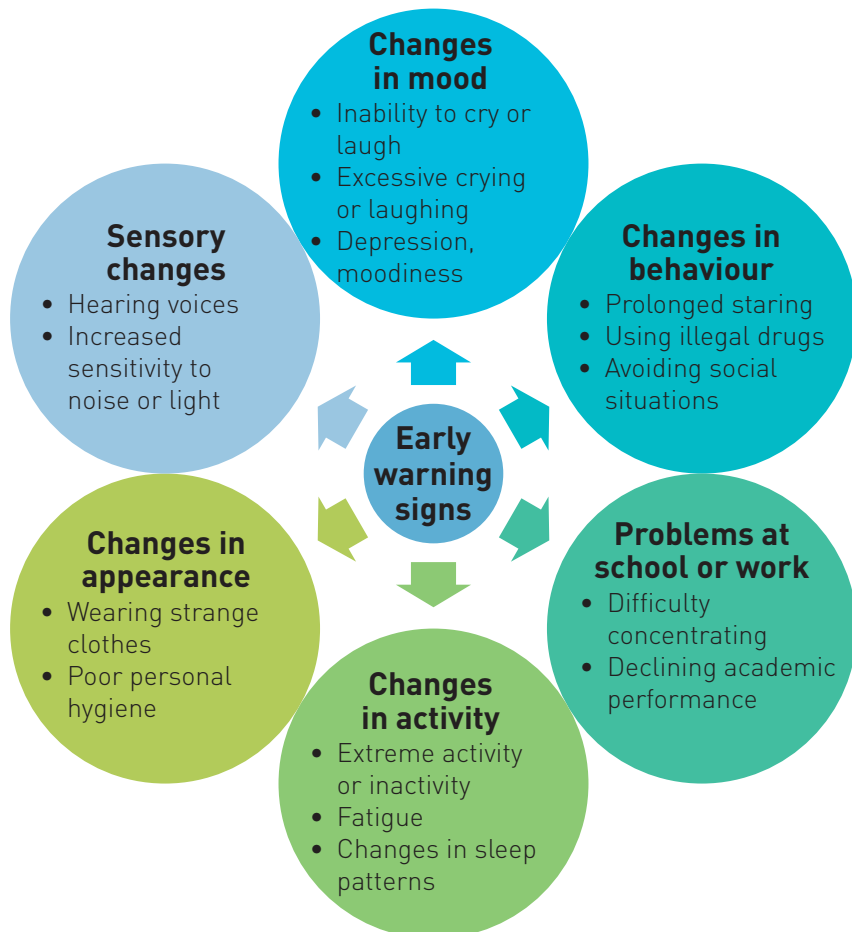
Seeking a diagnosis

If you have experienced hallucinations, delusions, severe paranoia or disorganized behaviour leading to a crisis, it may be time to think about seeking help to identify whether or not there is an underlying mental health condition. These could be the symptoms of a condition called schizophrenia; however, the symptoms of many mental illnesses overlap, so your first step towards getting help should be to consult your doctor. He or she can advise you on whether it is necessary for you to see a psychiatrist.

A diagnosis of schizophrenia should only be made by a qualified psychiatrist. There is currently no test that can be used to show that a person has schizophrenia so, to make a diagnosis, the psychiatrist will need to talk with the person and their family or friends about the symptoms they are experiencing. The psychiatrist will also need to observe the person's behaviour over several weeks to identify any signs of the condition.

Early warning signs

The early signs of schizophrenia vary from person to person and can be very difficult to recognize. Depression, compulsive behaviour, decreased motivation and asocial behaviour may be mistaken for normal changes that take place during adolescence or linked to drug abuse. As the following figure shows, however, these symptoms may be early warning signs of schizophrenia. A more detailed description of the symptoms of schizophrenia can be found in Chapter 3 of this booklet.



What is schizophrenia?

If you have noticed the signs of schizophrenia in yourself or received a diagnosis, one of the first questions you will have is “What is schizophrenia?” This section explains what schizophrenia is and, importantly, what it is *not*.

Schizophrenia is a long-term condition that results from changes in the mind and causes a range of different psychological symptoms. People with schizophrenia do not choose their illness, any more than people with a physical illness do. Importantly, there is no known cause – no one is responsible for a person developing schizophrenia and no one is to blame. Schizophrenia is a treatable mental illness and many people with the condition lead completely normal lives; however, it is often sensationalized in the media, which has led to a range of misconceptions about the nature of the illness.

Myths and misconceptions

Myth	Fact
People with schizophrenia have multiple or split personalities	People with schizophrenia do not have multiple personalities
Schizophrenia is caused by bad parenting	There is no known relationship between parenting style and schizophrenia, and there is no reason to blame the parents or family of a person with schizophrenia; however, tension in the family may add to the stress of having a mental illness
People with schizophrenia are lazy	A lack of energy can be a symptom of the illness
People with schizophrenia are violent and/or dangerous	People with schizophrenia can act strangely, but are rarely violent towards others
What people with schizophrenia see or hear is not real	What people with schizophrenia experience is very real to them, no matter how unbelievable or unrealistic others may find it
People with schizophrenia will never get better	Symptoms of schizophrenia improve in many people, and some people recover completely
Medication for schizophrenia will stop all of the symptoms of schizophrenia	Medication can drastically reduce some symptoms of schizophrenia, but may not prevent them all
People with schizophrenia cannot work	Many people with schizophrenia are in employment; doing something productive can help people to feel better about themselves
All people with schizophrenia experience the same symptoms	Symptoms vary widely from person to person; no two people with schizophrenia will have exactly the same experience

Stigma associated with schizophrenia

There is a lot of ignorance and prejudice surrounding schizophrenia, which can affect both those with the condition and those who care for them. Many people believe that a person with schizophrenia will switch frequently between normal and bizarre behaviour, as if he or she has multiple or 'split' personalities. This promotes a perception that people with schizophrenia are unpredictable and should be feared.

It is important for a person with schizophrenia to avoid internalization of these misconceptions, as this can lead to 'self-stigmatization', and for family members of a person with schizophrenia not to allow others' perceptions to influence how they feel about that person.

The importance of the name

"I have schizophrenia. I am not schizophrenia. I am not my mental illness. My illness is a part of me."

– **Jonathan Harnisch**, An Alibiography

The name 'schizophrenia' is derived from the Greek verb *skhizein*, 'to split', and *phren*, denoting 'soul, spirit or mind', and originally described a group of 'schizophrenias'. Although the current language suggests a single, uniform condition, there is great variety in the severity of illness and types of symptoms experienced by people with schizophrenia. There have been many suggestions for alternative names that better describe the diversity of symptoms apparent in people with schizophrenia. Indeed, a new term, 'Togo Shitcho Sho' or 'integration disorder', was adopted in Japan in 2002. Patient groups in the Netherlands are also taking steps towards realizing a name change in their country. The Dutch patient society, Anoiksis, has suggested a new name and new concept for schizophrenia, with the aim of reducing the stigma associated with the condition.

A personal perspective on stigma

"Being an active carer to my brother, and seeing the problems faced by families trying to cope with the consequences of mental illness and the unfairness of the situation service users find themselves in, prompted me to become actively involved in the mental health issues that affect society as a whole. Thanks to my brother and 'the before', I am now active in advocating against stigma, discrimination and prejudice surrounding mental health conditions."

– Katerina

Who gets schizophrenia?

Schizophrenia is a common mental illness, affecting about 1 in every 100 people.¹ Anyone can develop schizophrenia. It is seen in people of all cultures across the world, and affects equal numbers of men and women. It can also affect people of almost any age, although the symptoms of schizophrenia usually first appear when a person is in his or her late teens or early twenties.

There have been a number of notable people with schizophrenia: John Nash, the mathematician and Nobel Prize winner; Lionel Aldridge, the Super Bowl-winning National Football League player; Vincent van Gogh, the artist; and Tom Harrell, the jazz musician. These examples show that people with schizophrenia can achieve great things.

¹Schizophrenia. 2014. Available from: <http://www.nhs.uk/conditions/Schizophrenia/Pages/Introduction.aspx> [Accessed February 2016].

Chapter 2

Why me?

If you are affected by schizophrenia, you may wonder at some point whether it is your fault. The answer to that question is 'No' – no one is to blame for schizophrenia. The reasons why some people develop the condition and some do not are currently unknown, although there are some factors that are thought to increase a person's susceptibility to the condition.

Genes and environment

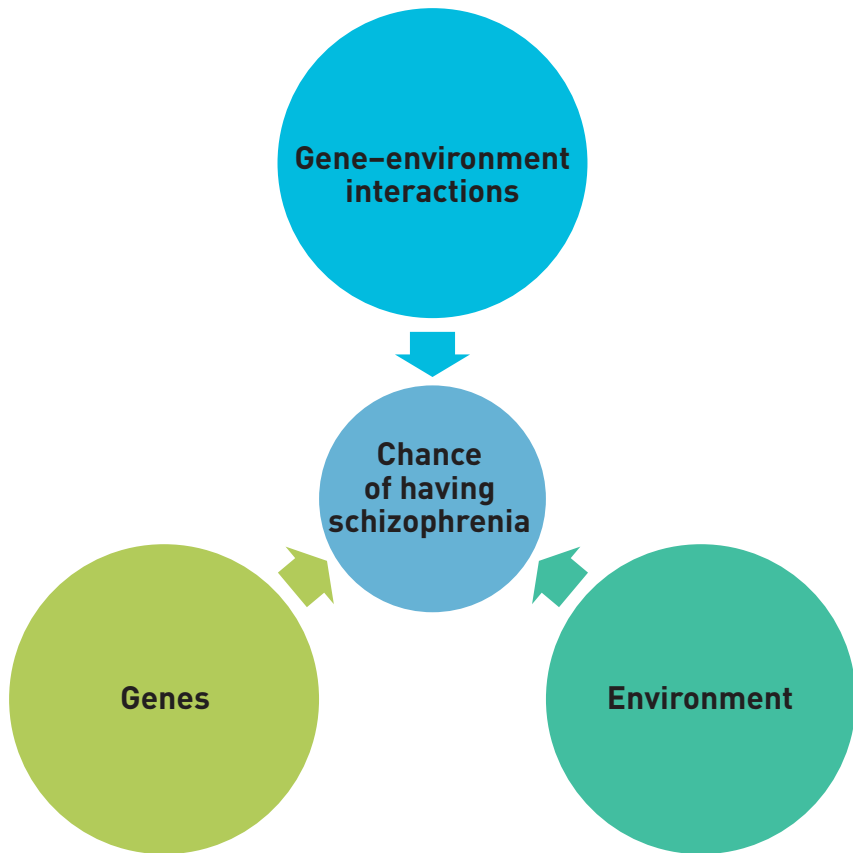
Schizophrenia is sometimes referred to as a heritable condition, which means that if there are certain genes in a person's DNA their risk of developing the illness is increased compared with people without those genes. The chance that a person will develop schizophrenia is increased from about 1 in 100 to about 1 in 10 if one of their parents has the condition. In identical twins with exactly the same genetic make-up, however, the chance of one twin developing schizophrenia if the other twin has the condition is only 50%, and so we know that genetics are not the sole cause of the condition.²

Likewise, there is no single environmental factor that is known to cause schizophrenia, although there are certain factors that can increase a person's chances of having the illness: these include growing up in a city centre, abusing drugs such as cannabis and amphetamines, and experiencing stressful life events.

There is some evidence that the environment a person is exposed to can interact with their genes. Research into this phenomenon is ongoing, but not enough is currently known to say who will or won't develop schizophrenia.

²Schizophrenia. 2015. Available from: <http://www.rcpsych.ac.uk/healthadvice/problemsdisorders/schizophrenia.aspx> [Accessed February 2016].

A key feature of schizophrenia is that different combinations of symptoms are seen both between individuals and within an individual over time – whether this has anything to do with an individual's genes and/or environment is still unclear.



Chapter 3

Symptoms of schizophrenia

“The only thing you have for measuring what’s real is your mind... so what happens when your mind becomes a pathological liar?”

– **Neal Shusterman**, *Challenger Deep*

Schizophrenia affects the way you think, feel and act. Each person with schizophrenia will have different combinations of symptoms, making one individual’s experience very different from another’s.

It can be difficult to link the way you are feeling to the way in which doctors describe the symptoms of schizophrenia. Medical professionals often divide the symptoms of schizophrenia into three categories: positive, negative and cognitive. The following pages explain what these categories mean and give some examples.

Positive symptoms

This term is used to describe feelings or experiences that do not correspond to reality, such as hallucinations, delusions or paranoid thoughts.

- **Hallucinations**

- This means hearing, seeing, feeling, tasting or smelling something that is not really there.
- Hearing voices is a common hallucination; some people may find the voices non-threatening or even comforting, while others may find them disturbing and frightening.

- **Delusions**

- Delusions or deluded thinking means strongly believing in something that cannot be true.
- This can be things like thinking that you are being watched, believing that you are a famous person, or believing that the television or radio is sending you signals.

- **Paranoid thoughts**

- Paranoia is extreme distrust, or believing the worst.
- Examples include feeling that other people are plotting against you or are trying to harm you.

Negative symptoms

This term describes a lack of feelings or behaviours that are usually present. Negative symptoms can include low motivation or mood, or withdrawing from family and friends.

- **Low motivation**
 - This can be losing interest in any or all aspects of life.
 - A lack of energy can mean that you find it difficult to do simple things, such as getting out of bed.
- **Lack of emotion**
 - This lack of feeling can be shown by a lack of expression, a flat tone of voice or a lack of eye contact.
- **Social withdrawal**
 - This is not wanting to socialize with family or friends, preferring to spend most of your time alone.

Cognitive symptoms

This term is used to refer to changes in mental capacity, such as difficulties concentrating or remembering things.

- **Disorganized thoughts and speech**
 - Fragmented thinking can come across in the way you speak and is characteristic of schizophrenia.
 - Examples include responding to questions with an unrelated answer, and saying illogical things.
- **Lack of concentration or attention**
 - A lack of concentration or attention can mean that tasks like reading a book or watching a television programme become very difficult and frustrating.
 - Thought processes can be slowed, which can make interacting with others difficult.
- **Memory problems**
 - Remembering events or information, or learning new things, may become challenging.

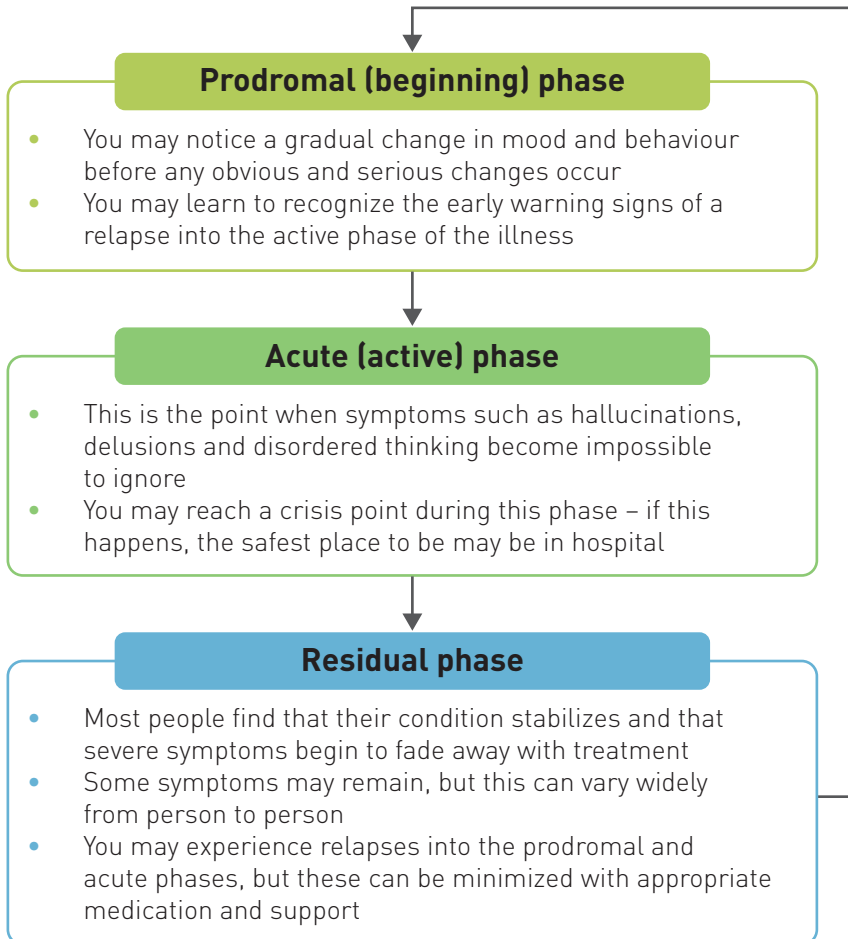
A personal perspective on the symptoms of schizophrenia

"I have felt for a long time, from the beginning of this, that I am in a different dimension. My feelings and thoughts are not natural. They are a stranger's, they are not mine. I have felt that I am special; that I have discovered the truth, the authority in the background. I have felt that I am a messenger between the universe and the earth. I am in a special position; I am the chosen one. I have felt that everybody wants to hide something from me. They don't want me to know the truth. I have felt that everybody is playing a role. And everybody is talking about me, and they can hear my thoughts. For a long time I was afraid to go out in the streets. I didn't have control of reality. My thinking was not normal. I was watching the 'signs' that 'they' were trying to send and show me. I made connections between my feelings and thoughts and the outside world. It was scary. I could express these things only after the bad period: in that state, I could not. It was a changed state of mind. I had no private life. I thought that the people wanted to communicate with me about something without speaking."

– István

How will the illness progress?

Once the signs of schizophrenia begin to show, you may notice that patterns in your condition emerge. Having a different range of symptoms at different times is to be expected; there are distinct 'phases' of schizophrenia, which can occur in cycles.



Other explanations for schizophrenia-like symptoms

- **Substance abuse**
 - Using illegal drugs may cause symptoms of psychosis including hallucinations or changes in personality.
- **Combining medications**
 - Taking medications that interact with each other may lead to hallucinations.
- **Bipolar disorder**
 - In some instances, such as during severe manic episodes, people with bipolar disorder may experience hallucinations and delusions.
- **Depression**
 - Changes in mood, personality and energy may be signs of depression. In severe cases of depression, known as psychotic depression, people may experience delusions.



Chapter 4

Dealing with the diagnosis: what now?

Who should I tell about my illness?

Who you decide to tell about your illness is completely up to you. Perhaps a useful comparison is to the situation of having a physical illness – if you had a physical illness that significantly affected your life, who would you tell? The answer to this question may give you an idea of who you should tell about having schizophrenia.

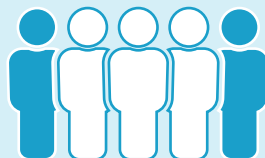
It is often a good idea to explain your condition to the people with whom you have the closest relationships; for example, those you live with and those you work closely with. It may not be necessary to tell people who you do not have strong bonds with. Ultimately, everyone's situation is different, and only you will know what is best for your own situation.

Will I get better?

**1 in 5 people will
recover completely
within 5 years**



**3 in 5 people will
improve, but may still
experience symptoms
occasionally**



**1 in 5 people will
continue to have
troublesome
symptoms**



There is a common misconception that people with schizophrenia have no chance of recovery. This is not true: the symptoms of schizophrenia can improve with appropriate treatment, and some people recover completely.³

Recovery is a process that involves learning to manage your symptoms, developing support systems and working towards your goals. Appropriate ways to manage your condition with medication and therapy are outlined in the next part of this guide.

³Schizophrenia treatment and recovery: getting the help and support you need. 2016. Available from: <http://www.helpguide.org/articles/schizophrenia/schizophrenia-treatment-and-recovery.htm> (Accessed February 2016).

Management

Chapter 5

Finding the right management strategy

"Mental illness is not a choice, but recovery is."

– **Unknown**

The aims of treatment are to relieve symptoms, prevent psychotic episodes and enable the person with schizophrenia to progress along the road to recovery. A treatment plan that combines medication with psychotherapy, often referred to as 'talking therapy', and peer-to-peer contact is often the most effective approach, but everyone is different and it is important to find the right combination of therapies for you.

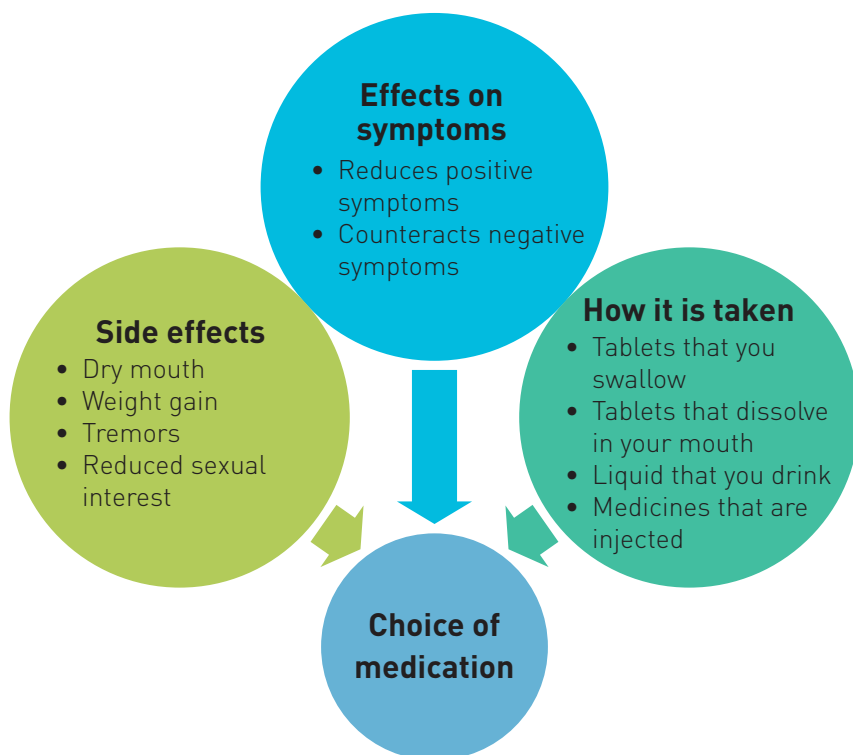


Medication

"I think that medication keeps me going, and it has played a crucial role until now. My goal is to reduce my medication little by little. I try to be quite educated – I read a lot about it and I discuss it with my doctor."

– **Monika**

There are many different medication options for schizophrenia and it is important to find the right one for you. The medication your psychiatrist recommends will depend on a number of things, including how you feel about your treatment, how well the medicine controls your symptoms and whether you suffer any unacceptable unwanted effects.



Different medications reduce some symptoms of schizophrenia more than others, so you will need to decide which symptoms you most want to control. Like many medicines, those used to treat schizophrenia can also have side effects. Different medications will have different side effects from each other, and the effects of one medication may change over time. Your psychiatrist will monitor your progress once you have begun treatment, and may suggest options for reducing side effects such as adjusting the dose or switching to a different medication. Another consideration is that medications can be taken in different ways; for example, medicines can be taken daily as tablets or liquids, or injected every few weeks.

With so many options and factors to consider, it is important that you discuss what you most want from your treatment with your psychiatrist as early on in the process as possible; for example, you may have a specific aim for your treatment, or there may be a specific symptom or side effect that you want to avoid. Finding a psychiatrist with whom you 'click' can make talking about your condition easier, and this can help to ensure that you make decisions about goals for your treatment together.

"I think that medications have different effects on people with mental illness. For me, six or seven kinds of antipsychotics were tried over 10 years. Finding the right medication was a turning point in my life. My basic antipsychotic was an injection, which was given every second week for 5 years, and I took antidepressants too. In 2011, I felt that there was no more improvement with this medication and, after discussion with my doctor, I changed to pills. Since then we have achieved a big improvement in my health. I am still taking the pills with an antidepressant. We have reduced the amount of medication since 2011. This has to be done little by little."

– István

Sticking with your medication

Once you start receiving medication, it can be tempting to think that your lack of symptoms means that you don't need the medication any more. If you start skipping doses, however, it is likely that your symptoms will return; up to 80% of people who stop taking their medication relapse within 1 year.⁴ In some instances, suddenly stopping your medication can be harmful. Therefore you should always talk with your psychiatrist before making any decisions about your treatment. Above all, if you decide to stop taking your medication, it is important that you tell someone.

"Medication is important because it protects me from having a psychotic episode. I take my pills every night – if I don't take them I know that there's a possibility of a psychotic episode."

– Ronan

Coming off medication

There may be some special situations when it might be necessary to stop taking your medication; for example, during pregnancy or while breastfeeding. In these cases, the benefits to you of the medication will be assessed against its risks to the baby. You may be advised to discontinue your medication long enough before you become pregnant for the medicine to be cleared from your system; however, this will depend entirely on your individual situation, so it is crucial that you discuss with your psychiatrist any plans you have for starting or expanding your family.

⁴Schizophrenia treatment and management: approach considerations. 2015. Available from: <http://emedicine.medscape.com/article/288259-treatment> (Accessed February 2016).

Psychotherapy

There are many different types of psychotherapy but the common goals that they all share include:

- solving problems that you are currently having
- teaching you skills to overcome problems in the future
- helping you to become self-sufficient.

Psychotherapy usually involves sitting down with a therapist, either one to one or in a group, and engaging in open dialogue about your condition. Discussions of how to cope with your illness may include how to manage your mood and how to respond positively to whatever triggers your symptoms.

A psychotherapist may sometimes encourage you to explore difficult and painful emotions and experiences, such as feelings of anxiety and depression, or specific traumatic events. For this and other reasons, it is important to find a therapist who you feel at ease with, to maximize the potential benefits. Indeed, if you and your therapist trust and respect each other, the treatment is more likely to work.

Cognitive behavioural therapy

The specific goal of cognitive behavioural therapy is to change unhealthy patterns you may have developed in your thinking or behaviour. A structured approach of identifying goals and setting small tasks for you to practise between sessions is used to address specific problems. This approach is also used to teach you the techniques to manage problems that may arise in the future.

Group therapy

Group therapy describes any psychotherapy in a social setting. Although group therapy does not necessarily mean talking in a group of people with schizophrenia, it can have a number of advantages over other psychotherapies. You may feel more at ease sharing your thoughts with others who have experienced similar things, as well as a reduced level of fear of being discredited and a greater level of trust.

Family-focused therapy

This type of psychotherapy recognizes that schizophrenia can affect whole families, not just the person with the condition. The specific aims of family-focused therapy are to aid communication between family members and to build a supportive environment for the person with schizophrenia.

Other psychotherapies

There are many other types of psychotherapy; for example, hypnotherapy, psychoanalysis, and expressive therapies such as art and music therapy. Some of these are likely to be more useful to you than others and, importantly, some may interfere with the management strategy you and your healthcare team have agreed on. Therefore, you should talk to your psychiatrists and psychotherapists about any new approach you may want to try.

Some questions to consider asking your therapist

- What kind of therapy do you offer?
- Do you belong to a professional organization?
- Do you have experience of working with people with schizophrenia?
- How long do the sessions last?
- How often are they held?
- How many sessions am I likely to need?
- Can I contact you between sessions if I need to?
- What sort of results can I expect?
- How long before I should expect to feel some benefit from therapy?
- What does the therapy cost?

Psychoeducation

Psychoeducation is based on the idea that the more you and your family and caregivers know about your condition, the better you will be able to manage it together. It involves a trained therapist delivering a clearly defined programme that has been designed to educate participants about mental illness. A course of psychoeducation may include a series of sessions over months or years, and can be aimed specifically at caregivers and family members, at people with schizophrenia, or a combination of both.

Because the therapy involves taking in a lot of information, going to sessions when your condition is most stable is likely to be most effective. Many people find that they benefit not only from the information they receive during psychoeducation but also from the learning process itself. Psychoeducation should be used in combination with psychotherapy and medication, and can help you develop coping strategies that use your own knowledge of your illness. Furthermore, it can be a great help to family members and caregivers, as a better understanding of the condition can help them to recognize and meet the needs of the person with schizophrenia.

Support groups

Living with schizophrenia can be isolating at times. Joining a support group can be a good way to socialize and share experiences with others who know what it is like to live with the condition.

Many support groups have been set up by people with schizophrenia, and include people who are successfully managing their condition and moving on with their lives. Different groups specialize in different types of support, and can operate at local, national and international levels.

One benefit of joining a support group is that it can be much easier to talk about your problems and feelings with people who know what you are going through than with, for example, a family member or therapist. People with schizophrenia are experts in their own

condition, and so they may be able to give helpful advice based on their experiences. Sharing stories and finding common ground can also create a bond of friendship. Further information about support groups is given in Chapter 9 of this booklet.

Reluctance to seek help

There may be times when a family member or friend thinks that you should seek medical help, but you believe that you are well and feel reluctant to do so. Talking to someone who has been in a similar position may be useful, as they may help to ease your fears.

As a family member or friend, it can be extremely difficult to broach this subject, and the way that you react can be important in determining the outcome for the person with schizophrenia. First, it is a good idea to discuss the situation together as early as possible, or at a time when the person with schizophrenia feels well; the more time that passes, the more likely it is that a crisis point will be reached. A support group for family members and caregivers may be able to provide valuable advice. Secondly, try speaking to someone who can give you the perspective of a person with schizophrenia. If possible, try to arrange for a doctor to visit the person with schizophrenia at home. This may be particularly useful as it can allow all members of the household to be involved.

If, as a person with schizophrenia, you do not accept help, it is important for you to know that there is a legal process that can lead to your compulsory admission to hospital and treatment if there is a risk of harm to you or others. This would be a very distressing course of action for all involved and so family members and caregivers should see this option as a last resort. Further information on compulsory hospital admission and treatment will be available from your local support group, citizen's rights organization or the healthcare service in your country.



Chapter 6

Personal relationships

Home life

Schizophrenia is not easy to live with. It can put strain on your relationships with people in your family or those you share a home with. During relapses in your illness, you may not realize the demands that are being made of people around you; when you emerge into recovery, you may find yourself feeling rather lonely. Likewise, it can be difficult to live with a person with schizophrenia. Nevertheless, there are some practical steps you can take together to make things easier.

Family planning

If you are planning a family, there are a number of issues that you need to discuss with your partner early on, such as the risk of your child developing schizophrenia, how you will manage having a child, and, if you are a woman, the possibility that you will relapse after giving birth or during the pregnancy. There will be decisions that are not easy to make, but information from your healthcare team can aid in difficult discussions.

As mentioned in Chapter 5, some medications used to treat schizophrenia may not be suitable for use during pregnancy. Therefore, you should discuss your options with your doctor before trying to conceive a child.

If you are a person with schizophrenia	If you are a family member of a person with schizophrenia
Learn more about schizophrenia	
Explain it to your friends and family	Try to be understanding of your family member's behaviour
Be honest	
For example, about your plans for the future	For example, about your fears and your hopes
Agree on boundaries	
Tell people close to you what you want them to do and, importantly, what you <i>don't</i> want them to do	Respect your family member's wishes as far as possible
Build trust	
Trust that your family want what is best for you	Show the person that you have their best interests at heart
Don't be ashamed	
You are not to blame for your illness and it is nothing to be ashamed of	There is nothing shameful about caring for someone with schizophrenia
Learn from others	
Support groups will have members who have been in similar situations and can help	Support groups will have members who have been in similar situations and can help

Working relationships

Many people with schizophrenia are able to continue working once their condition is under control. Others decide to adjust their work commitments to suit their condition. This can include changing to a less stressful role, reducing their number of working hours or taking up a job share. Some employers are more flexible than others in their attitudes towards allowing people to change their work contracts; however, national and international laws are in place to protect against discrimination in the workplace. If you need to find out more about your rights, there are a number of sources of help and guidance available to you, including the human resources department of your company, citizen's rights organizations and schizophrenia support groups.

A personal perspective on working as a person with schizophrenia

"I'm a mechanical engineer by first degree, and I also studied business administration. I design machine parts for a big company in Israel. I do have good colleagues at work, and I appreciate them very much. I consider it a good place to work. My colleagues at work notice when I'm getting better. They don't bother me too much, and they don't ask difficult questions – they let me continue with my day without sticking their noses in things that are a bit delicate."

– Ronan

Social life

It can be difficult to maintain a social life if you have schizophrenia. As mentioned earlier in this guide, schizophrenia can lead to symptoms including being less able to socialize and a lack of emotion, so you may lose touch with people you were friends with. As you start to recover, however, you may find yourself wanting to go out and socialize more.

Support groups can be a good way to meet and socialize with other people with schizophrenia, but it is important not to surround yourself completely with others who have the condition. Meeting and socializing with people without the illness can help you to see a world outside of schizophrenia. Psychotherapy can help you to regain your confidence and overcome the social barriers associated with mental illness, to enable you to have a normal social life.

Caring for someone with schizophrenia can also affect your social life; it is important to recognize this and to take steps to make sure your own needs are met. Sharing responsibilities with other family members and/or caregivers can be a good way to allow you to have some time to yourself, to socialize and to do other things that you enjoy.

General health

Many people with schizophrenia struggle with their physical health as well as their mental health. They have a high risk of heart disease and obesity, which means that people with schizophrenia have a shorter life expectancy than the general population.⁵

One reason for this could be that the symptoms of schizophrenia make it difficult to maintain a healthy lifestyle; some unhealthy behaviours, such as eating unhealthy foods, drinking alcohol, taking illegal drugs and smoking, are common in people with schizophrenia. Furthermore, some of the medications used to treat people with schizophrenia can have a negative effect on general health; for example, weight gain is a common side effect of many medicines for the condition.

Whether or not you choose to adjust your lifestyle is up to you, but there are several ways in which looking after your general health can help in the overall management of your condition.

Diet

Some treatments for schizophrenia can increase the risk of weight gain and obesity. Sticking to a healthy diet is a good way to minimize this risk. Your doctor will monitor your weight and, if weight gain becomes a problem, it may be worth discussing different medication options.

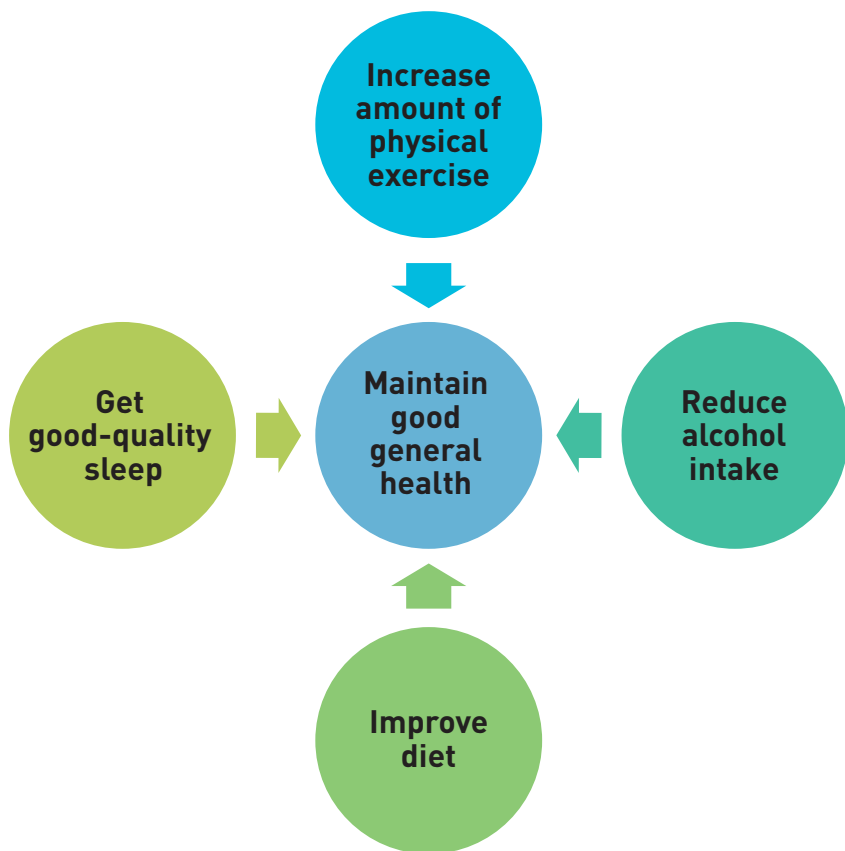
Alcohol

Drinking to excess should be avoided, not only to improve your general health but also because there is a strong association between schizophrenia and alcoholism, which means that the risk of becoming addicted to alcohol is greater if you have schizophrenia. Therefore, it is a good idea to moderate your drinking as much as possible.

⁵Cardiovascular disease and diabetes in people with severe mental illness: causes, consequences and pragmatic management. 2011. Available from: http://www.rcpsych.ac.uk/pdf/PCCJ_Holt_FINALONLINE_JAN%5B1%5D.pdf [Accessed February 2016].

Physical exercise

There are several reasons to incorporate a physical exercise regimen into your lifestyle. First, getting a good amount of exercise will help you to control your weight in combination with a healthy diet. Secondly, exercise can put you in a better frame of mind, as hormones released during exercise are associated with improved mood. Exercise can also improve the way you sleep.



Sleep

People with schizophrenia tend to have disrupted sleep patterns: you may find yourself sleeping more or less than most people, or at different times of the day. This can lead to excessive tiredness, known as fatigue. A change in sleep patterns can be the first sign of a psychotic episode, and therefore can be taken as a warning sign.

Maintaining a regular routine can help you to get your sleep patterns back to normal. This can include having a bedtime routine, going to bed at the same time and waking up at the same time. Relaxation techniques, such as meditation, can help to reduce stress; this is important because stress can stop you sleeping peacefully.

Caffeine should be avoided, especially in the evening, as it can disrupt your sleep.

Personal hygiene

Schizophrenia can change the way that you care for yourself: poor personal hygiene is common among people with the condition. This aspect of the illness may arise from symptoms such as a lack of motivation or delusions. Dental problems in particular can develop due to dry mouth caused by medication, or if you forget to take care of your teeth. Therefore, it is important to tell your dentist what medication you are taking and to follow their advice on oral health.

Making a checklist of daily tasks, such as brushing your teeth, showering and getting dressed, can help you to avoid self-neglect. Doing these tasks at the same time each day can help to establish a daily routine.

Sexual health

Healthy sexual relationships are important and you should not ignore this part of your life. Schizophrenia itself and some medications for schizophrenia can lead to reduced sexual desire. On the other hand, you may experience unusual or strong sexual feelings. Increased sexual behaviour and strange thoughts of a sexual nature are likely to be related to the changes in the mind that occur as part of the

condition. As schizophrenia usually first becomes apparent during a person's late teens and early twenties, when libido is typically high, it is not surprising that changes in sexual thoughts often occur at this time.

If you have a tendency to take part in high-risk sexual behaviour, your risk of getting a sexually transmitted disease, such as HIV, is high. Therefore, it is important to understand the risks and to seek advice for maintaining good sexual health from your doctor.



Moving on

Chapter 7

Living with schizophrenia

“I want a good relationship with my wife, with my children, with my family and with my colleagues at work. I don’t want to have another psychotic episode, but, if it happens, I know I can manage and people around me know how to deal with it.”

– **Ronan**

As you begin to recover from your illness, it is likely that you will want to start regaining control of your life. This can include learning how to avoid triggering a relapse, and developing coping strategies for when times get tough.

Warning signs of a relapse

- Moodiness, aggression or depression
- Excessive crying or laughing
- Hallucinations or talking to oneself
- Changes in activity or sleep patterns
- Changes in behaviour
- Being asocial
- Making meaningless statements
- Strange postures or prolonged staring
- Changes in appearance or poor personal hygiene

There are several things that are thought to increase a person’s chances of relapsing into the acute phase of schizophrenia, such as high stress levels, stressful life events and the use of illegal drugs.

Avoiding stress

Stress is a common trigger for schizophrenia and, unfortunately, it is extremely difficult to avoid stress completely because having schizophrenia can be extremely stressful in itself. Nevertheless, it is possible to manage your stress levels and to reduce the impact that stress has on your life.



Illegal drugs

It is common, especially for young people, to turn to drugs such as cannabis or amphetamines to try and block out the symptoms of schizophrenia. You may think that illegal drugs will help to numb feelings of depression or anxiety but, although some drugs may give temporary relief, in the long term they may actually make symptoms of schizophrenia worse or cause a relapse. Some illegal drugs can increase symptoms such as paranoia, hallucinations and delusions.

As the effects of illegal drugs may worsen the symptoms of schizophrenia, it can be difficult for your doctors to be sure that the medication you are receiving is working properly if you are taking other drugs at the same time. More importantly, mixing drugs can be highly dangerous to your health.

Depression and suicidality

About one in three people with schizophrenia will experience low mood or depression at some point. Tragically, suicide rates are higher in people with schizophrenia than in the general population. Therefore, it is of the utmost importance that you recognize the warning signs of suicidality and learn ways in which to combat negative thoughts.

Signs of suicidality

- Feeling like a burden to family and friends
- Feeling hopeless or helpless, as if there is no solution to the problem at hand
- Talking about wanting to die
- Reckless or dangerous behaviour
- No longer fearing death
- Drinking excessively or abusing drugs
- Asocial behaviour
- Writing a suicide note

Although at the time it may seem like you will feel this way forever, there are several things that you can do to beat depression, and it is crucial that you talk to someone about your feelings.

Ways to improve your mood

- **Talk to your psychiatrist:** you may be suffering from a depressive illness that is treatable.
- **Get some rest:** a good night's sleep can make you feel a lot better and your outlook may be different in the morning.
- **Get a change of scenery:** you may associate one particular place with being depressed, so leaving this place can reduce these feelings.
- **Visit friends or family:** isolation and boredom can worsen negative feelings, so socializing with others is a good way to prevent this.
- **Do something you enjoy:** don't forget that there are things that make you happy.
- **Learn to relax:** ask your doctor or therapist about relaxation therapies, such as meditation.
- **Talk to someone:** sharing your problems with others, whoever they may be, can be a weight off your mind.
- **Phone a helpline:** helplines can be useful when you need to talk but feel you have no one to talk to. If you feel you are close to a crisis, it is of the utmost importance that you tell someone – people who work for helplines can give you the practical advice and support you need.



Chapter 8

Advocacy

Advance directive

One way of making sure that the decisions made in your life are your own, even during times of crisis, is to have a plan of how you would like to be treated if you do lose control of your behaviour. You can record any wishes you might have in an 'advance directive', such as the one included in the back of this guide.

The advance directive may include the name and contact details of a family member or caregiver who is to be given authority to act as an advocate on your behalf, as well as information relating to your preferences on medication, finance and housing.

Legal and financial issues

Advice on your legal rights can be obtained from your healthcare team, citizen's rights organizations and support groups. There are two reasons why it may be a good idea to investigate your rights. First, if your condition places limitations on your ability to work, you may be entitled to financial benefits. Secondly, it is a good idea to know your legal rights if abnormal behaviour during psychotic episodes leads to dealings with the police and legal system.



Chapter 9

Further information

Networking and other sources of information

International organizations

EUFAMI

European Federation of Associations of Families of People with Mental Illness

The European representative organization for family support associations across Europe. EUFAMI promotes the interests and wellbeing of families and caregivers affected by severe mental illness.

<http://www.eufami.org/>

GAMIAN-Europe

Global Alliance of Mental Illness Advocacy Networks-Europe

A patient-driven, pan-European organization that represents the interests of people affected by mental illness and advocates for their rights.

<http://www.gamian.eu/>

ISF

International Schizophrenia Foundation

A non-profit organization with international affiliates dedicated to raising the levels of diagnosis, treatment and prevention of the schizophrenias and allied disorders.

<http://www.orthomed.org/isf/isf.html>

WFMH

World Federation for Mental Health

An international organization for the promotion of mental health.

<http://wfmh.com/>

Patient groups, support groups and other useful websites

Intervoice

The International Hearing Voices Network

A network of people who hear voices, see visions or have other unusual perceptions.

<http://www.intervoiceonline.org/>

Mind

A charity that provides advice and support to empower anyone experiencing a mental health problem.

<http://www.mind.org.uk/information-support/types-of-mental-health-problems/schizophrenia/>

Rethink Mental Illness

A charity working to help everyone affected by severe mental illness to recover a better quality of life.

<https://www.rethink.org/diagnosis-treatment/conditions/schizophrenia>

Further reading

Anoiksis. *Psychosis? Me?* Anoiksis, 2014. Available from:

<http://www.psychosegevoelig.nl/english/> [Accessed September 2016].

Key contacts

In case of emergency, please contact:	
Key contact 1	Key contact 2
Name.....	Name.....
Address.....	Address.....
.....
.....
Telephone.....	Telephone.....
Mobile.....	Mobile.....
Doctor	Preferred hospital
Name.....	Name.....
Address.....	Address.....
.....
.....
Telephone.....	Telephone.....
Mobile.....	Mobile.....

Crisis card

My name is Please call me
I have schizophrenia. This means that there may be occasions when I do not have full control over my behaviour. On such occasions, please approach me in a calm manner. Speak clearly and explain everything that is going to happen. If I don't understand, please explain again. Please contact my named Confidant as soon as possible. **Thank you.**

Personal details

Name.....
Address.....
.....
.....
Telephone.....
Mobile.....

Please contact my Confidant

Name.....
Address.....
.....
.....
Telephone.....
Mobile.....

Doctor

Name.....
Address.....
.....
.....
Telephone.....
Mobile.....

Preferred hospital

Name.....
Address.....
.....
.....
Contact name.....
Telephone.....

Blood group.....
Medication.....
Health insurance.....
Other details.....

Advance directive

In the event of a crisis, I understand that I may not have complete control over my own behaviour.

Under these circumstances, I authorize
to act as my advocate.

..... has my permission to:
.....
.....
.....

If I am hospitalized, please inform:

Name.....
Address.....
.....
Telephone.....
Mobile.....

My preferred medical treatment is:

.....
.....
.....

I do not wish to be treated with:

.....
.....
.....

I have the following allergies:

.....
.....
.....

Glossary

Term	Meaning
Advance directive	A plan that sets out how you would like to proceed in the event of a crisis or emergency
Antipsychotics	A class of medication used to manage psychosis
Bipolar disorder	A mental health condition characterized by cycles of depression and elation or mania
Depression	Feelings of intense unhappiness or pessimism; can include loss of energy, loss of appetite and disrupted sleep
Diagnosis	The identification of an illness based on examination of the symptoms
Doctor	A medical professional with wide-ranging medical knowledge who can refer people to a mental health specialist
Prodromal phase	The beginning phase in which warning signs may occur
Psychiatrist	A medical professional who specializes in mental health conditions and is able to prescribe medication
Psychologist	A medical professional who specializes in the mind and behaviour, but is not able to prescribe medication
Psychosis	A state of mind in which you lose touch with reality
Relapse	Reappearance of symptoms after a period without symptoms
Remission	A period in which symptoms are reduced or are absent altogether
Side effects	Unwanted effects caused by a medication
Stigma	Feeling of disapproval held by society that is often deemed unfair

