

# DISCOVER THE ROAD AHEAD

Support and Guidance for  
Everyone Affected by Schizophrenia

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**This handbook aims to offer support to anyone who has been affected by schizophrenia or psychosis. Whether you have the illness yourself or are caring for a family member or friend, you will find information here to help you.**

All the people involved in producing this handbook have first-hand experience of coping with schizophrenia, through caring for a family member, friend or patient. Our aim is to offer straightforward and practical advice on how to live with schizophrenia. There is no scan or quick blood test to diagnose schizophrenia. However, a better understanding of the illness and how it is treated may help you make informed decisions to ease your day-to-day living.

# Foreword

Schizophrenia is a grossly misunderstood illness. Myths and blatant untruths about the condition are regularly exchanged. As a result, people with schizophrenia are often discriminated against. This can greatly increase their sense of isolation, loneliness and fear.

Each chapter of this handbook explores a brief glimpse of how people live with schizophrenia. Every day, away from the sensationalist press articles and TV dramas, real people with schizophrenia and their families are quietly getting on with their lives, overcoming the many obstacles placed in their way.

At a time when science is breaking new ground, new treatments for schizophrenia are emerging and our understanding of the illness is ever increasing, there is every reason to be positive about the future. Nobody would pretend that living with schizophrenia is easy, but with support and understanding it should become a journey a little less difficult to travel.





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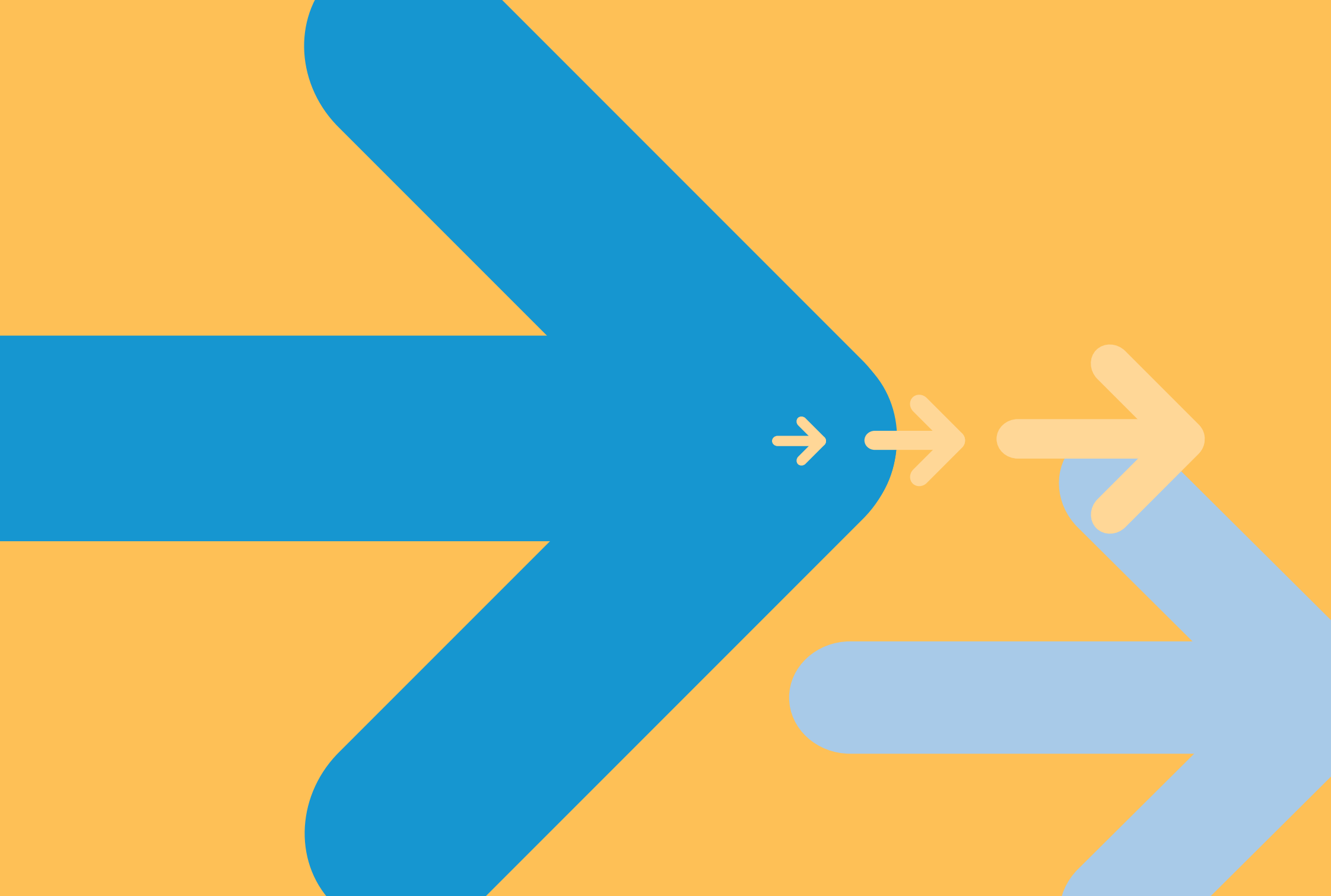
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**“I started developing symptoms of schizophrenia when I was at university studying psychology.**

I was living with people I didn't know, and I began to get very, very paranoid and suspicious of people around me. I thought my housemates were plotting against me, and I stopped leaving my room because I'd be so worried about people reading my thoughts, or people implanting thoughts in my head.

The first time I really noticed that something was wrong was when I started sensing muffled screams just at the edge of my hearing. Eventually I started hearing voices as well, and in quite a lucid moment I looked up in my psychology textbooks what hearing voices meant. It said psychosis, or schizophrenia, which was very scary for me.

My flatmates would knock on my door and say: “Emma, are you okay?” But I just ignored them. They didn't really know that it wasn't normal for me to just sit in my room and ignore people. I went to see the university psychiatrist but I wasn't able to explain all my symptoms because I got very paranoid about him. He just thought I was depressed because I'd just ended a relationship so he put me on antidepressants, which made me overdose a few days later.

When I went back home for the summer holidays my parents thought that I was being a normal hormonal teenager, being moody and not wanting to go out, not wanting to tidy my room up. But then I started behaving very oddly. I started laughing to myself a lot and talking to voices and my parents realised that I wasn't really very well.

It wasn't me that sought treatment, it was my family who said: “Emma you have a problem, we need to seek help for you”. Because I didn't acknowledge that I had a health problem, they had to actually go to the doctor and insist that the doctor get a psychiatrist to come and see me.

Although I am quite open-minded, when I was first diagnosed with schizophrenia I told my friends that I was in rehabilitation for a drugs addiction. I told myself I had a brain tumour – I didn't want to admit that I had a mental health problem”.

**Emma Harding, Senior Project Worker and Coordinator,  
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## → Where is my life going?

Whatever happened to all those things you were planning to do: the dreams, the hopes and the expectations? Was there really a time when the future didn't seem so challenging, so difficult and so bleak?

This is the harsh reality of schizophrenia. It is a condition that affects people in the prime of life. If you, or someone close to you, has schizophrenia, then your life may never be the same again.

But that does not mean your life will never be full and rewarding again. As many people who have been through this experience can tell you, it is possible to rebuild your future.

The first step in taking back control of your life is to understand more about your situation. You may already have a diagnosis, or you may be in 'limbo', somewhere between experiencing the first symptoms and receiving an explanation of the cause. In either case, you will be better prepared to face the future if you and your family and friends know more about the condition and its treatment.

# Chapter 1

## Schizophrenia: An overview



## → What is schizophrenia?

**Schizophrenia is a mental illness that affects about one in every 100 people worldwide.**

Anyone can develop it. Schizophrenia occurs in the young, the old and the middle-aged. It is seen in people from all classes and a wide range of ethnic backgrounds. It affects just as many women as men.

There is evidence that schizophrenia runs in families and there may be environmental factors that make it more likely. But the truth is that we do not really know the true cause of schizophrenia.

What we do know is that schizophrenia is a troubling condition that can significantly disrupt not only the lives of those who have it, but also the lives of family and friends. A common misconception is that it is the result of a 'split personality'. This mistake comes from the fact that the name 'schizophrenia' was derived from two Greek words meaning 'split' and 'mind'. It was intended, however, to represent that processes of thought, feeling and intention no longer interact to form a coherent whole, guiding the person's actions.

People with schizophrenia will have good days and bad days, and times when they feel low or even hopeless. But appropriate medication can help stabilise the symptoms, and understanding open communication and supportive therapy can also help people with schizophrenia go on to live productive and fulfilling lives.



Have you ever thought:  
“Where is my life going?”

## → Symptoms of schizophrenia

Having schizophrenia can feel like a roller coaster. There are many different signs and symptoms of schizophrenia and they occur in different combinations and severities according to the individual.

Although the symptoms can occur at almost any stage of life, they usually first appear during late adolescence and early adulthood. **Men tend to develop symptoms in their late teens or early 20s and women in their 20s or early 30s.** Recognising these symptoms can be particularly difficult if the illness develops during teenage years, as changes in behaviour are common at this age.

Symptoms of schizophrenia affect the way you think, feel and act. Doctors divide them into three categories:

- 'positive' symptoms – such as seeing, hearing, smelling or tasting things that aren't there and delusions, which can take many forms, eg persecutory, telepathic, grandiose, religious, sci-fi or paranormal
- 'negative' symptoms – such as low motivation or emotion and withdrawing from family and friends
- 'cognitive' symptoms – such as difficulties with attention, memory problems, being unable to concentrate

People may have different combinations of positive, negative and cognitive symptoms. The following chart describes the symptoms your doctor may refer to and explains how they may make you feel.



Having 'schizophrenia' can feel like a roller coaster

Some symptoms may make you feel 'crazy'. They are as real to the person with schizophrenia as they are unreal to their family and friends

Some symptoms may make you feel 'lazy' and result in you losing interest in people and things around you

POSITIVE SYMPTOMS	What the doctor calls it	How it may feel
	Hallucinations	<p><b>Hearing, seeing, feeling, tasting or smelling something that is not really there</b></p> <ul style="list-style-type: none"> <li>• The most common hallucination is hearing voices</li> <li>• Some people, especially in the early days, may find these voices a comfort, something that is not frightening</li> <li>• Others may have voices that may say nasty or negative things or give orders</li> </ul>
	Delusions	<p><b>Strongly believing something that cannot be true. For example:</b></p> <ul style="list-style-type: none"> <li>• thinking that you are being watched through the television</li> <li>• believing you are a famous person</li> <li>• believing the television or radio is sending you signals or messages</li> <li>• having strange or obsessive religious beliefs</li> </ul>
	Paranoid thoughts	<p><b>Extreme suspiciousness. For example:</b></p> <ul style="list-style-type: none"> <li>• feeling that other people are plotting against you, are trying to harm you or are following you</li> <li>• believing that aliens are following you</li> <li>• believing you have been 'abducted' by martians and taken to another planet</li> </ul>

NEGATIVE SYMPTOMS	What the doctor calls it	How it may feel
	Low motivation	<ul style="list-style-type: none"> <li>• You may lose interest in all aspects of your life</li> <li>• Your energy may drain away and you may find it difficult to carry out even the most basic tasks, like getting out of bed or cleaning the house</li> </ul>
	Social withdrawal	<ul style="list-style-type: none"> <li>• You may lose interest in your friends and prefer to spend most of your time on your own, experiencing often intense feelings of isolation</li> </ul>
	Lack of concentration	<ul style="list-style-type: none"> <li>• You may find it a big effort to read a book or even watch a television programme from start to finish</li> <li>• Remembering or learning new things, no matter how small, may seem impossible</li> </ul>
Poverty of speech and thought	<ul style="list-style-type: none"> <li>• You start to say something but half way through, forget whatever you were saying</li> <li>• Thinking things through may take too much effort and seem difficult to do</li> </ul>	



Some symptoms may make you feel 'hazy',  
or as if you can't think straight

COGNITIVE SYMPTOMS

What the  
doctor calls it

Problems with  
attention and  
memory

How it may feel

- You get easily distracted and may not be able to listen to music or watch TV for more than a few minutes
- You find it difficult to remember your shopping list

## → Early warning signs

The early signs of schizophrenia are often very difficult to recognise. With hindsight, many people will look back and pinpoint unusual behaviour long before a diagnosis of schizophrenia is given. But at the time nobody realised that anything was wrong. Sometimes early signs of schizophrenia can be mistaken for signs of growing up, of drug abuse or of simply being lazy, arrogant or uncooperative.

If you are worried about your behaviour or that of a member of your family, the following list of warning signs may help you decide to seek help. But remember, many adolescents or young adults experience some of these changes in behaviour or mood. Some of these can simply be signs of growing up.



You may begin to believe that you are being watched through the television

# → Early warning signs of schizophrenia

## → Changes in mood such as:

moodiness, depression, inability to cry, excessive crying, laughing for no particular reason or inability to laugh

## → Sensory changes such as:

hearing voices, unusual sensitivity to noise or light

## → Changes in activity such as:

becoming extremely active or inactive, sleeping excessively or hardly at all

## → Changes in social behaviour such as:

avoiding social situations, dropping out of activities, refusing to go out, allowing relationships to deteriorate, saying irrational or inappropriate things, using peculiar words or making meaningless statements

## → Changes in relations with family such as:

constantly arguing, never phoning home, phoning home at strange times of the night

## → Changes at school or work such as:

problems in concentrating, declining academic performance

## → Changes in behaviour such as:

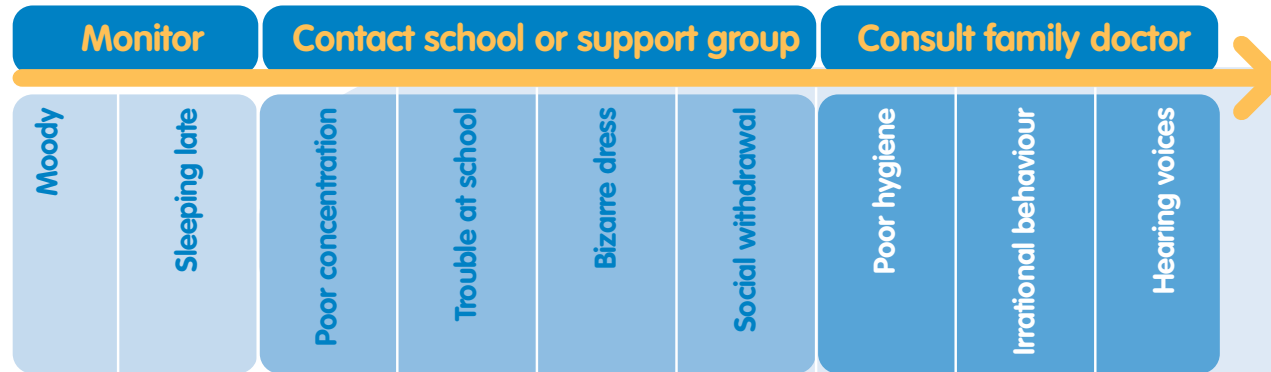
strange postures, prolonged staring, extreme religious beliefs, using illegal drugs

## → Changes in appearance such as:

wearing bizarre clothes, poor personal hygiene

## → When to seek help

Because many of the early signs of schizophrenia commonly occur ordinarily in young adults, it can be difficult to know when to seek help. If you are worried about yourself or someone you care for, it is best to rely on your instincts. If you feel something is seriously wrong then it is better to seek specialist help sooner, rather than later. This chart offers a guide to the most appropriate response.



## → Who to approach for help

If you are worried that you, a friend or a member of your family might be showing early signs of schizophrenia you need to seek specialist help. A diagnosis of schizophrenia can only be made by a psychiatrist. But because there are many other conditions that can cause symptoms similar to schizophrenia, your first step should be consulting your doctor. He or she will decide whether it is necessary to contact a specialist.

## → Waiting for a diagnosis

One of the worst times for those with early symptoms of schizophrenia is what's often called the 'limbo' period between developing symptoms and receiving the diagnosis. Unfortunately, there is no scan or blood test that can be used to diagnose schizophrenia. A psychiatrist will need to observe the person's behaviour over several weeks and conduct interviews with both the person with symptoms and, if possible, members of the immediate family.

'Shopping' for a new doctor will not make the diagnosis go away

### → How long will it take?

In some countries receiving an official diagnosis from a psychiatrist can take as little as six weeks from the start of seeking help. In others, however, it may take as long as 18 months or more. Many people spend this time 'doctor shopping', searching for an explanation and sometimes refusing to believe the diagnosis of schizophrenia. Once the diagnosis has been made it is important to accept it and start to plan how you and everyone affected are going to manage from now on.



## Tá Seán 16 bliana déag d'aois agus tá cónaí air lena thuismitheoirí agus lena dheirfiúr óg i Rath Éanaigh, bruachbhaile lastuaidh de Bhaile Átha Cliath.

Bhaineadh Seán taitneamh as a bheith ar scoil nuair a bhí sé óg. B'fhurasta dó cairdeas a dhéanamh le daoine agus bhíodh caighdeán a chuid obair ranga ar aon chaighdeán leis an leath ab fhearr sa rang i gcónaí. Tá cúrsaí sa bhaile agus ar scoil ag éirí níos deacra agus níos deacra do Shean le bliain anuas nó mar sin. Dála a lán déagóirí eile, b'íomaí giúmar a thagadh air agus d'éirigh sé cúlánta. Chaitheadh sé formhór a chuid ama ina sheomra codlata. Is ar éigin a labhraíodh sé lena dheirfiúr ar chor ar bith agus ba le focail singile agus gnúsacht a dhéanadh sé comhrá lena thuismitheoirí.

"Sin mar a bhíonn déagóirí," arsa a mháthair agus bhí sí ag tnúth go gcuirfeadh sé an chéim sin de.

Chuaigh sé ní ba dheacra agus ní ba dheacra ar Shean éirí ar maidin. Bhíodh sé déanach ar scoil go minic agus bhíodh sé i dtrioblóid lena mhúinteoirí dá bharr. Shíl sé nach raibh sé seo ceart ná cóir. Ní air féin a bhí an milleán go raibh sé déanach. Cén fáth a raibh na múinteoirí anuas air?

"Níor thaitin mé riamh leo. Níl siad ach ag iarraidh leithscéal a fháil le bata is bóthar a thabhairt dom amach as an scoil," ar seisean leis féin.

Chun an fhírinne a dhéanamh, nuair a rinne sé machnamh ar an scéal thuig sé nárbh iad na múinteoirí amháin ag bhí ag iarraidh fáil réidh leis. Thug sé faoi deara go raibh a lán dá chairde ag iarraidh é a sheachaint. Stopaidís an comhrá a luaithe is a thagadh sé ar an láthair, agus bhí sé cinnte go raibh siad ag cogarnach is ag cúlchaint faoi.

Níorbh fhéidir le Seán a thuiscint cad a bhí déanta aige a thuilleadh a leithéid d'íde. Chuir sé imní agus mearbhall air agus chreid sé nach raibh éinne ann óna bhféadfadh sé cabhair a iarraidh. Chaitheadh sé ní ba mhó ama fós ina aonar. Thosaigh sé ag múitseáil ón scoil agus chaitheadh sé an lá ag taisteal ar fud na cathrach ar an DART.

Bhíodh faifíos air agus é ar an DART, áfach. Dhéanadh sé a dhícheall gan cur isteach ar éinne. Choinníodh sé a cheann cromtha síos agus sheachnaíodh sé féachaint sna súile ar éinne, ach in ainneoin sin is uile, d'airíodh sé go raibh paisinéirí ag breathnú air, is ag magadh faoi is ag caint faoi nuair a shiúladh sé tharstu.

De réir a chéile d'airigh Seán go raibh sé ina aonar go hiomlán. Cá bhféadfadh sé cabhair a iarraidh má bhí na strainséirí nach raibh aithne dá laghad aige orthu i mbun comhcheilge ina choinne?

Ansin, lá amháin chonaic Seán fógra ar an DART ag insint go raibh líne chabhrach ann a thabharfadh tacaíocht mhothúchánach do dhaoine a d'airigh go raibh siad aonaránach nó nach raibh dóchas dá laghad acu. Ní raibh a fhios ag Seán an chaoi ina gcuirfeadh líne chabhrach cosc le daoine a bheith ag caint faoi, ach ar a laghad b'fhéidir go gcabhródh sé leis dul i ngleic leis an scanradh a bhíodh air. Dhiaíligh se an uimhir go neirbhíseach.

Bean chneasta a labhair leis. D'éist sí lena scéal agus ba chosúil gur chreid sí é. Bhí comhairle fhónta aici dó. Mhol sí dó labhairt le duine éigin a d'fhéadfadh muinín a chur ann agus mhol sí dó cuairt a thabhairt ar dhochtúir.

Rinne Seán a smaointe. B'fhéidir go n-aireodh sé ní b'fhearr dá labhródh sé lena mháthair, agus bíodh is nár airigh sé tinn, b'fhéidir go gcabhródh an dochtúir leis gan a bheith chomh tuirseach i rith an lae.

## → Fact and fiction

Most people have heard of schizophrenia, often when it is sensationalised in the media, but few people know what the term really means. This is understandable. Despite being common, schizophrenia is often wrongly portrayed in newspapers and on television. This can make schizophrenia seem more frightening than it really is. The reality is that schizophrenia is a treatable condition that only rarely causes people to become aggressive or dangerous.

### Ten things you should know about schizophrenia

- 1 Schizophrenia can be treated. One in four people with schizophrenia completely recover within five years. For most others, symptoms can be decreased and well-being improved at different levels.
- 2 People with schizophrenia can achieve great things. Look at Nobel Prize winner and economist John Nash, jazz trumpeter Tom Harrell, Fleetwood Mac guitarist Peter Green. (Ref: <http://www.schizophrenia.com>)
- 3 People with schizophrenia do NOT have a 'split personality'. Although they may behave unusually at times, they do not suddenly change into a different person.
- 4 Lots of people, whatever their illness, forget to take their prescribed medication. However, the consequences of forgetting schizophrenia medication can lead to a relapse, or recurrence of symptoms.

# Chapter 2

## Schizophrenia explained



- 5** It is rare for people with schizophrenia to be violent or dangerous.
- 6** Schizophrenia is NOT caused by bad parents. People with schizophrenia have good parents, bad parents or completely indifferent parents. Just like everyone else.
- 7** People with schizophrenia are NOT lazy. Lack of energy is a symptom of the illness. It can be treated in day hospitals, at drop-in centres or even by going back to work.
- 8** Caring for someone with schizophrenia can be rewarding. Difficult, certainly. Exhausting, at times. Frustrating, almost always. But helping someone rebuild their life, whether as a family member, health professional or friend, can bring immense personal satisfaction.
- 9** What people with schizophrenia see or hear seems absolutely real to them – no matter how unbelievable or unrealistic others may find it.
- 10** Relapse can make it difficult for people with schizophrenia to return to their previous level of well-being. This means it is VITAL to continue taking medication and attending therapy sessions, even when the symptoms seem to be under control.

## → Why me?

It's a question that most people affected by schizophrenia ask at some stage. "What have I done to deserve this?" The answer is "nothing at all". Nobody is to blame for schizophrenia. Not you nor anybody else.

Schizophrenia is an illness of the most complicated organ in the body – the brain. There are many chemical messengers (neurotransmitters) that pass messages around the brain.

Although we don't fully understand why the brain malfunctions in people with schizophrenia, we do know that certain parts of the brain of people with schizophrenia produce excessive quantities of a chemical messenger (neurotransmitter) called dopamine, while other parts of their brain may have too little dopamine.



'Dopamine'  
stands accused  
in schizophrenia

Dopamine plays an important role in the way we feel pleasure and experience different moods. Too much dopamine may throw these feelings and senses off balance. It may cause people to experience feelings of paranoia, have delusions or hear voices. These are called 'positive symptoms'. Too little dopamine may cause apathy, feelings of loneliness and lack of motivation. These are called 'negative symptoms'.

The reasons why dopamine levels become unbalanced are not fully understood. In truth, the onset of the schizophrenia is probably due to a combination of factors.

**These factors include:**

- Family history – there is a slightly higher than average chance of developing schizophrenia if a close family member has the illness. However, even if both parents have schizophrenia there is still a 60 percent chance their children will not.
- Growing up in the inner city.
- Abusing drugs such as cannabis and amphetamines.
  - Being exposed to stressful events.
  - Infectious disease during pregnancy.



## How will schizophrenia affect my life?

**This depends on how quickly you get help. Many people with schizophrenia live full and productive lives. With regular medication and the support of family, friends and healthcare professionals, many people are able to manage their symptoms and regain an acceptable level of stability in their lives.**

Untreated, however, schizophrenia can do more and more damage. If symptoms are severe, carrying out basic everyday tasks may be problematic. You may find it difficult to look after yourself, or forget to eat properly or brush your teeth or wash regularly. You may find yourself drinking more alcohol, smoking or taking drugs. As a result your physical health may also begin to suffer.

Symptoms such as hearing voices or seeing things that are not really there can be very confusing and make it hard to concentrate on important things like your job or studies. Learning new tasks or remembering things can also become increasingly difficult.

Schizophrenia is likely to affect your relationships with other people. You may begin to feel that people close to you no longer like you or are plotting against you. It can become difficult to trust even close members of your family. Strangers may seem scary or threatening.

Lack of energy and motivation may leave you feeling like there is no point in getting out of bed. All you want to do is stay indoors and shut the rest of the world out. The less you go out, the more isolated you become and the more difficult it becomes to break out of this vicious circle.

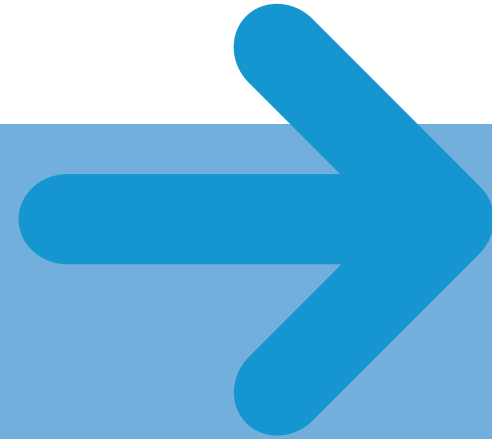
All of these symptoms may make you feel very low and depressed. At times you may even feel that you are stuck in a hopeless situation with no way out. This is not unusual and it is important to ensure that you do all you can to lift your mood, and talk to someone you trust about your feelings. Chapter 3 contains more advice on how to combat negative feelings.



## How will the illness progress?

The way in which schizophrenia progresses can vary considerably between individuals. However, there are three distinct phases:

- Prodromal phase – before your illness begins in earnest, you may notice a gradual change in your mood and behaviour. You may begin to withdraw from social contact, start acting strangely, feel tired and listless and begin to neglect your appearance and personal hygiene. Your world may seem to be changing. You may feel neither happy nor particularly sad, just emotionally flat. Many people with schizophrenia learn to recognise these early symptoms as a warning that they may be about to relapse into the active phase of their disease. A review of your treatment at this early stage can prevent that damaging relapse happening.
- Acute or active phase – this is the point where your illness becomes impossible to ignore. But part of the illness may be a lack of understanding that you are ill. Symptoms such as delusions, hallucinations and muddled thinking become prominent and you may reach a crisis point. During a crisis, hospital may be the safest place to be. Here your condition will be assessed and you will receive effective treatment.
- Residual phase – as the treatment takes effect most people find that their condition stabilises and the acute symptoms begin to disappear. Some symptoms (lack of energy, social withdrawal etc) may remain for a varying time period – for some they may disappear quite quickly, for others they may not disappear. This phase can last many years, often interrupted by relapses into the acute phase. With regular medication and support, however, many people can keep these relapses to a minimum.





## What are my chances of getting better?

You are bound to be concerned about the future.

The overall outlook for people with schizophrenia is as follows:

- Approximately one in four people recover completely within five years and need no further treatment. For most others, symptoms can be decreased and well-being improved at different levels.
- About one in every two people goes for long periods of symptom-free remission, interspersed with occasional relapses during which some symptoms return. The severity and frequency of these relapses varies greatly and often depends on the quality of the care and support the person receives. After a first psychotic episode up to three-quarters of people who stop taking their medication relapse within one year. **This figure drops to less than half in people who continue to take their medication.**
- About 10 percent of people will continue to have persistent problems. Treatment may help reduce some symptoms and make life easier. However, the illness is likely to remain for the rest of their lives.

Which of these categories you fall into is impossible to predict. It may depend on many things including the severity of your illness, your personal circumstances and how well you follow your doctor's instructions about medication.

## → The need to go to hospital

The majority of people with schizophrenia receive most of their treatment close to home from a team of doctors, nurses, social workers, occupational therapists, psychologists and other community-based support services. There are, however, times when you may need to go to hospital. You will probably receive your initial diagnosis from a psychiatrist in hospital. You may also attend regular check-ups to ensure that your treatment is working and not causing any unacceptable side effects. If you become very ill hospital may be the safest place to be. You may need to be admitted for anything from several days to some weeks and in some cases a few months, so that you can receive 24-hour care. You will probably stay in the psychiatric ward.

It is best if you can make the decision to enter hospital yourself. If, however, you become too ill to make this decision, you may be asked to undergo 'compulsory admission'. This does not mean you lose your rights to decide about your future. A key worker will be assigned to you when you arrive at the hospital. He or she will explain what rights you have under your country's mental health legislation. If you find it difficult to understand these rights, ask for written information.

## → How can I understand my treatment?

Your doctor will try to explain your symptoms in a simple, easy to understand way. However, there are many technical terms you may hear that will be unfamiliar to you. The glossary in Chapter 9 will help you understand these terms. Don't be afraid to ask questions or write things down. If it is all too complicated to understand, ask the doctor to simplify it. Ask if there is any written information that you can take away.

## → Importance of self-management

Most people with schizophrenia may not recognise when they are becoming unwell, however, some people do learn to pick up on early warning signs. Therefore, it is usually the carer or close family members who can help identify warning signs such as loss of interest, problems with concentration, not being able to keep on top of day-to-day life which may occur in the run up to a patient becoming unwell again.

Being aware of changes in your mood and behaviour can help you manage your illness and help you deal with an impending crisis. You may need extra support from your psychiatric healthcare team, or your psychiatrist may need to review your medication. Planning what you need to do in advance of a relapse can make sure you get extra help quickly and efficiently.

Family members can also react to the warning signs by making sure that they are especially careful to avoid criticism or hostility during your vulnerable period and that they are available to offer extra support if needed (see Chapter 8).



## There was a time when Patrick actually enjoyed hearing the voices.

Of course, they were worrying to begin with. He couldn't understand where they came from or why they were talking to him. Several times he had to go and check he hadn't left the radio on.

But as time passed the voices became more familiar and he began to get used to them. After all, he had been feeling pretty lonely since moving to Dublin to continue his studies. And while the voices might be a bit confusing, at least they were company.

For some reason, Patrick had found it hard to make friends with his new fellow students. He'd never had a problem socialising when he was growing up back home. But now, talking to people seemed to take more and more effort and after a while he simply couldn't be bothered. He even stopped going to the cafeteria with the other students for lunch. He just didn't seem hungry any more.

After lectures he would go back to his room and bury himself in his studies. If the voices came, he would sit back and listen to what they had to say. But recently the voices had turned nasty. Before, they used to say such complimentary things. How he was destined for glory. How God had chosen him to save mankind. How only **he** could expose the terrorist cell that had infiltrated the student flats.

What they were saying now was dark and frightening. The terrorists were on to him. They were in league with the secret police. And they were watching him through the CCTV in the street.

Then one night the voices woke him, shouting out a warning. The terrorists were coming. They would be here any minute. He had to escape. Patrick screamed out into the night for help. He could hear his neighbours shouting, sirens in the street, then a banging on his front door.

A few hours later Patrick's parents arrived. The doctor, who had come to Patrick's flat with the police, had called them and told them what had happened. He explained that Patrick had experienced an "acute psychotic episode" and would need hospital treatment immediately.

## → Dealing with **the diagnosis**

If you or someone close to you has just been diagnosed with schizophrenia it is only natural to feel a strong sense of disbelief and denial. You may be confused about what having schizophrenia really means. You and your family may also be reluctant to believe the diagnosis and may go in search of a second or third opinion. All of these reactions are normal and understandable.

# Chapter 3

## The diagnosis is real

After you've got over the initial reaction, however, it is time to begin to plan how you are going to manage your new situation. For, although a diagnosis of schizophrenia can feel shocking, there is a benefit to knowing it. Now you know what is wrong, you are in a much better position to try to make improvements.

## → Making sense of the diagnosis

At such a worrying time it is bound to be difficult to take in all the information you will be given about your condition and its treatment. If you feel that things are happening too fast, there are a number of things you can do to try and make sense of the situation.

- Don't be afraid to ask if there is something you don't understand
- Write down all the questions you want to ask, to help you remember
- Take a pad and pencil to write down important information
- Go with a friend or relative. They may remember details you don't
- Ask for information leaflets
- Ask if there are any support groups that may be able to help you
- Ask if there are any family support groups

## → Learning to cope

If you receive a diagnosis of schizophrenia it will be useful to learn some 'coping strategies'. The following strategies may help you avoid some of the triggers of schizophrenia symptoms and prepare you for any crises that may occur.

## → Learning to reduce stress

One of the most common triggers for schizophrenia symptoms is stress. Unfortunately, because having schizophrenia is extremely stressful in itself, stress is almost impossible to avoid. Nevertheless, it is important to realise that stress is not unique to people with schizophrenia. Nearly everybody gets stressed at some point. Some people just manage to deal with it better than others.

The following strategies may help you either reduce the stress in your life or cope with it better.

- Learn what happens to you during stressful situations, using the table shown in this section. This may help you recognise the warning signs.
- Write a list of situations that make you feel stressed. What can you do to avoid them? If you can't avoid them, is there any way you can make them less stressful?
- If you feel a situation is becoming stressful (a crowded street or shop for instance), withdraw gradually. Trying to escape suddenly can make you feel even more stressed.
- Avoid alcohol, illicit drugs and caffeine (in tea, coffee and cola). These may relax you at the time but cause 'rebound' anxiety later on.

## Talking to someone you trust can help

- Learn to relax
  - see the strategies below or ask your doctor, nurse or occupational therapist about relaxation training.

### For instance:

- listening to music
  - taking a bath
    - going for a walk
    - reading
    - surfing the internet
    - going to the cinema or watching TV with a friend
  - playing sport
  - swimming
  - meditation
- yoga



- Find someone to talk to. You are not alone. If you have a problem, share it with someone you trust.
- Simplify your life – don't take on too many tasks, try to do just one thing at a time.
- Make a schedule for each day and stick to it.
- If a conflict with someone is causing you stress, try talking to a person who is completely external to the situation to see if they can help sort it out with an objective view of the circumstances.

## What happens at times of stress?

### In our mind

We think about problems over and over again

We become worried about being worried  
(circular thinking)

We become confused

We feel afraid, even when there is no danger

The world around us feels out of control

We feel like something terrible is going to  
happen at any moment

### To our body

Hands tremble and feel sweaty

Dry mouth and throat

Thumping heart

Tightness in the chest

Headache and tension in the neck muscles

Muscle stiffness

Tingling fingers, or 'pins and needles'

Difficulty breathing

Dizziness, often caused by breathing too fast

## → Learning to **beat low mood**

Around one third of people with schizophrenia also experience low mood or depression. Perhaps this is understandable given the difficulties they face. However, this does not mean you simply have to put up with feeling this way. There are many things that may help improve your mood and combat the feelings of depression:

- Ask your doctor or pharmacist for help – you may be suffering from a depressive illness that may require medication
- Get some rest – some symptoms of depression may be associated with fatigue.  
A good night's sleep can make you feel a lot better
- Get out of the house – isolation and boredom will only make you feel worse.  
Leaving the house, even if only to go and buy a newspaper, can reduce these negative feelings
- Visit a friend or relative – human contact is a great way to raise your spirits
- Take some exercise – this will relieve tension, reduce stress and improve your mood
- Do something you enjoy – when you are depressed it is easy to forget that there are things you still find pleasurable.  
Read a book, watch a film, walk in the park or visit friends. Anything that takes your mind off your problems will help
- Learn to relax (see the strategies in the next section) – ask your doctor, nurse or occupational therapist about relaxation training
- Learn to deal with stress – see the strategies in the previous section
- Phone a helpline – if you feel you have no one to talk to, a helpline can be a great source of practical advice and support



## Learning to **relax**

### → **Regulate your breathing**

Simply slowing down your breathing can help you cope with anxiety and reduce stressful feelings. Whenever you feel particularly anxious or stressed, breathe in deeply through your nose, count to seven then let the air out gradually and count to 11. Now start to breathe in a six-second cycle: In for three seconds, out for three seconds. At the end of each minute, hold your breath again for 10 seconds.

### → **Construct a relaxation zone**

Choose a quiet, warm room in a place where you feel comfortable and safe. Place a mattress or comfortable rug on the floor. Dim the lights. Light a scented candle and play some music or a relaxation tape (you can buy these). The music you choose should be soft and gentle. Avoid songs with lyrics that might distract you. Now lie down and begin some relaxation exercises.

### → **Learn some relaxation exercises**

For instance, when lying down concentrate on gradually relaxing all your muscles. Begin at your fingers and toes and slowly release the tension, moving along your arms and legs then body and finishing with your neck and head.

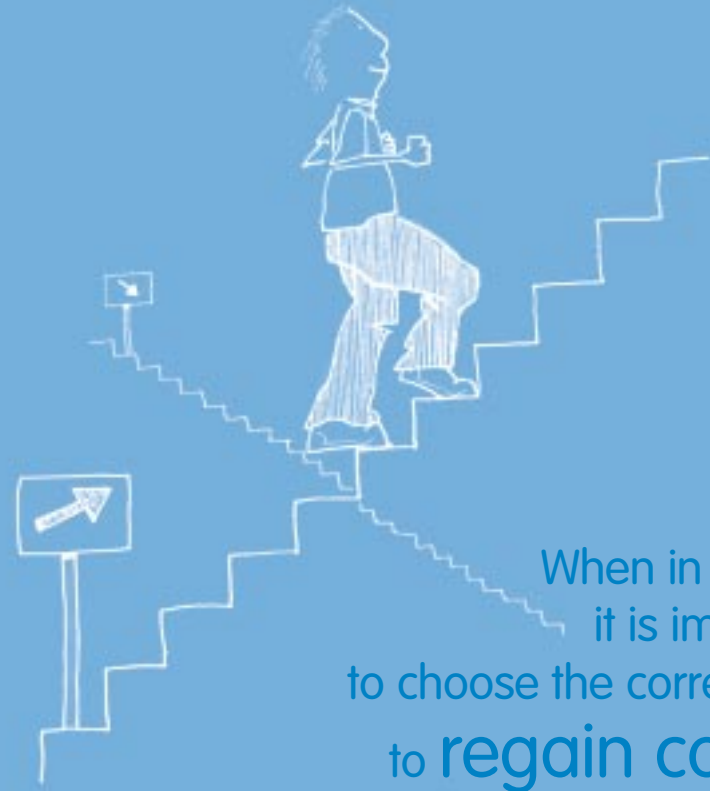
### → **Ask an expert**

Occupational therapists will be able to offer specialist advice on relaxation techniques. Or ask your doctor about relaxation training.

## → Learning to **regain control**

There a number of things you can do to start regaining control of your life. For example:

- It's really important to try to avoid recreational drugs – cannabis and other drugs can make the symptoms of schizophrenia worse, trigger a psychotic episode and bring on depression
- Drink sensibly – alcohol may make you feel relaxed at the time, but it can cause 'rebound' tension in the hours and days that follow. Drinking too much may make you feel depressed and make your problems much worse
- Ask your doctor for advice on making your lifestyle healthier. Cutting down on smoking, eating healthier food and taking more exercise will all improve your physical health. This, in turn, can help your mental well-being
- Deal with depression – if you are feeling low, seek help. Talk to your doctor or other health professional. Seek advice from the experts.



When in a crisis,  
it is important  
to choose the correct path  
to **regain control**

## → Learning to **combat negative thoughts**

Sometimes you may feel that everything is getting you down and that life is all too much to cope with. Thinking about suicide is quite common among people with schizophrenia. It is important to remember that **you will not always feel this way**, and there are a number of things you can do to try to suppress these thoughts.

- Try to talk to someone you trust. Expressing your feelings can make them seem less overwhelming and may help to change your mood. If you have thought about suicide, don't be afraid of telling someone. Talking about suicide won't make it more likely to happen
  - Try to change your immediate surroundings. If you are in your room, go outside for a walk, visit a friend or relative or simply move to another room
    - Make a list of all the positive things about yourself, your friends and the people you care about. Use this list to fight the suicidal thoughts
      - Agree with members of your family that you will call them if you are ever feeling suicidal
        - Call the doctor or hospital if you feel overwhelmed by suicidal thoughts

## → Alcohol and illicit drugs **are not the answer**

**Many people with schizophrenia turn to alcohol and/or illicit drugs to try to relieve symptoms or to help them cope with feelings of fear, isolation or depression. The use of cannabis, amphetamines and other substances like cocaine is especially common among young people with schizophrenia.**

Although some people claim that using illicit drugs gives them temporary relief or restores normality in their behaviour or blunts symptoms, in the long term they may actually be making their schizophrenia symptoms worse. There is plenty of evidence to show that these substances worsen the psychotic symptoms of the illness – paranoia, hallucinations and delusions. They can also ‘trigger’ a psychotic episode of schizophrenia, even in those who have never had an episode before, but who may be at high risk of developing schizophrenia – for instance, people who have close family members with schizophrenia.

If you ‘treat’ your schizophrenia symptoms with substances such as cannabis you also delay getting an appropriate prescription for antipsychotic medication. The longer the delay in getting medication and other therapies, the longer the schizophrenia episodes will last. This will reduce your chances of improving your life and control over your condition.

## → How can **families help?**

- In the active phase of schizophrenia, the person affected may be too overwhelmed to sort out even minor problems. Taking on some of their responsibilities may help ease the stress in the short term. However, guard against taking over their life. This may create dependency and cause more problems later on.
- People with schizophrenia may use words that sound like nonsense to others. If you cannot understand, try to communicate in other ways. Doing things together like listening to music, painting, watching TV or simply sitting quietly can allow you to show your interest and concern without necessarily using words.
- Never talk as if the person with schizophrenia is not there. People with schizophrenia are usually aware of what is going on around them.

- Look after yourself – you will be no use to your family member if you allow yourself to become emotionally exhausted and physically ill yourself. Protect against this by:
  - Keeping your own support network of friends and colleagues
    - Avoiding becoming isolated
    - Recognising signs of stress in yourself
      - Identifying the various situations that your family finds most stressful to cope with
      - Keeping up your interests outside the family
        - Seeking professional support
        - Taking a little time each day just for you
- Be prepared for a relapse or crisis – the best way to handle a crisis, or possibly avoid one, is to know what to do before it happens.
- Prepare for recovery – as your family member’s condition improves, you may need to make some decisions about living arrangements. Some people return home, some go to group homes and others find rooms and apartments of their own. Each family must make its own decision. Your social worker will be able to offer advice on what kind of accommodation is available and what could be most helpful during different stages of recovery.
- Be prepared for your family member to experience a relapse or crisis.



**Anna has become increasingly worried about her 22-year-old daughter, Mary, who lives with her in an apartment in Cork.**

Although Mary has never been a particularly outgoing person, she has always taken great pride in her appearance. Not recently, however. Her hair doesn't seem to have been washed for weeks, she has stopped wearing make-up and her clothes look like she has been sleeping in them.

At first, Anna assumed that Mary must have had a row with one of her friends. After all she hadn't been out with them for a while and seemed to prefer staying in her room, sleeping all day and listening to music most of the night.

But when Anna tried to talk about it, Mary became very upset, screaming and shouting wildly:  
"Shut-up, shut-up. Why is everyone always telling me what to do? Why can't you all just leave me alone? I can't hear myself think with all your nagging."



Now the music from Mary's room is getting louder and louder. When Anna asks her to turn it down, Mary screams at her: "Get out. Of course the music's loud. It has to be to drown out all your chatter."

A little later Anna finds her daughter banging her fists hard against her head. Something clearly needs to be done, so Anna makes an appointment with the family doctor.

When Mary sees the doctor, however, she seems much better. She is rational and in control and answers the doctor's questions clearly and calmly. The doctor prescribes some antidepressants and asks Mary to come back in six weeks' time.

Six weeks later, Mary has not taken a single tablet. Her strange behaviour has continued and now she is refusing to go back to the doctor.

In the end Anna decides to visit the doctor alone. To help her explain the problems, she writes down a list of all the unusual things Mary has done, her strange sleeping patterns, and her

aggressive outbursts. The doctor agrees to make a home visit later in the week.

After seeing Mary the second time, the doctor decides to refer her to a psychiatrist.


"You must think it's something to worry about then?" asks Anna. The doctor explains that Mary's behaviour could be due to a number of causes. It might be a physical or a mental illness, he says. The doctor gives Anna some leaflets on mental illness. "The psychiatrist will be able to make a proper diagnosis."

Over the next six months Anna and Mary visit the hospital several times to see the psychiatrist and other members of the psychiatric team. After a series of detailed interviews, with both mother and daughter covering all aspects of Mary's life, the psychiatrist finally makes her diagnosis.

"Mary, we would like to inform you that you have schizophrenia," she says.

## → Is there a cure?

Although as many as three in four people with schizophrenia improve significantly or recover fully, there is no known cure for the illness. The only way to control symptoms is with antipsychotic medication, combined with other non-medicine supportive therapies.



The evolution  
of treatment  
from asylums to  
talking therapies

# Chapter 4

## Treatment explained

The treatment of schizophrenia has come a long way over the past 100 years (see table). Once considered a mysterious condition to be treated with a range of bizarre and brutal therapies, schizophrenia is now regarded as a treatable mental illness. Treatment is now centred on the person rather than the illness and usually consists of a combination of medications called antipsychotics, and non-drug therapy.



## History of Schizophrenia Treatment

### Before medication (1911 – 1950s)

With no effective medicines available, doctors in the early 20th century used a crude form of electroshock therapy to treat patients with schizophrenia. This caused excessive fever and epileptic seizures, which appeared to decrease psychotic symptoms. Insulin therapy was also used to sedate patients and reduce the number of functioning brain cells.

Surgery was also sometimes used to remove the part of the brain that processes emotions. Known as lobotomy, this procedure helped control aggressive behaviour but left patients subdued and lacking emotion.

### The first antipsychotics – The typicals (1950s –1960s)

The first antipsychotics became available in the 1950s. Throughout the 1960s more sophisticated antipsychotic drugs such as haloperidol and fluphenazine were introduced. Known as **typical** antipsychotics, these medications became the treatment of choice for the next 30 years. Typical antipsychotics continue to be used as a treatment option.

However, although effective against the positive symptoms of schizophrenia, typical antipsychotics have a number of side effects and only a limited effect against the negative or cognitive symptoms of schizophrenia.



## History of Schizophrenia Treatment

### The atypicals (1990s)

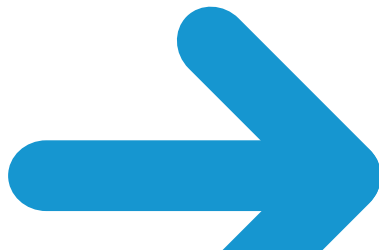
In 1990 a new class of medications, known as atypical antipsychotics, was introduced. These new agents are effective in controlling the symptoms of schizophrenia and are less likely to cause some of the side effects experienced with previous medications. In addition, these agents were effective against positive, negative and cognitive symptoms.

There are now a number of different atypicals available. Each has its own advantages and disadvantages, allowing treatment to be tailored to the needs of individual patients.

Most official guidelines now recommend that atypical antipsychotics should be the first choice treatment for schizophrenia instead of the older, typical antipsychotics. However, there are some people with schizophrenia who are being treated and doing well on typical drugs.

### Latest advances

Our understanding of schizophrenia is improving all the time. And as we gain a greater insight into what causes schizophrenia symptoms, so new treatments continue to emerge.





# Antipsychotic medication

Antipsychotic medication is the most effective way to control the many symptoms (eg hallucinations, delusions and thinking problems) associated with schizophrenia. There is a wide variety of these medications available and you may need to try several before finding the one that is best for you.



## Typical antipsychotics

Typical antipsychotics have been around since the 1950s. They work by blocking dopamine receptors in the brain.



### Main benefits

- Effective at controlling hallucinations, delusions and paranoid thoughts

### Main drawbacks

- Little effect on the negative symptoms of schizophrenia such as low motivation, emotional flatness and social withdrawal. Potential to experience quite a few uncomfortable side effects including uncontrollable movements such as tremors and shaking, dry mouth and extreme tiredness. Because of these side effects, typical antipsychotics are no longer considered the first choice medication for schizophrenia in most countries. However, many people take typical antipsychotics without any problems and it is important, therefore, that if you have been using typical antipsychotics without problems, there is probably no need whatsoever for you to change your treatment

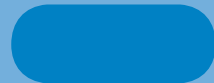
# → Atypical antipsychotics

Most of these medications became available for clinical use in the 1990s. They are believed to work somewhat differently in the brain compared with the typical antipsychotics.



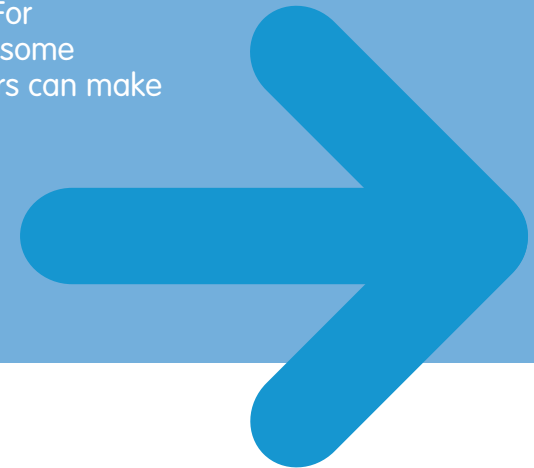
## **Main benefits**

- Effective at controlling the positive, negative and cognitive symptoms of schizophrenia. Low incidence of movement side effects compared to older typicals



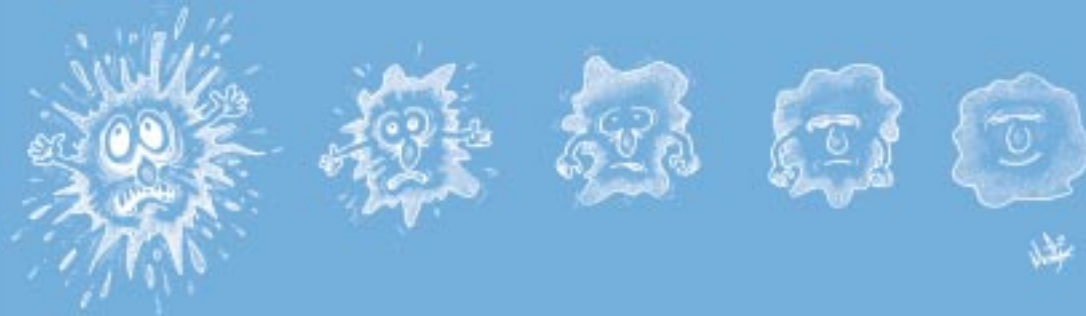
## **Main drawbacks**

- Different atypicals have different side effects. For example, weight gain can be a problem with some atypicals, some can cause sedation and others can make people feel more energised





All medications that have proven to be effective against schizophrenic symptoms act by influencing dopamine pathways in the brain



Balancing dopamine is believed to help to reduce some symptoms

## → Tailoring treatment

With a variety of so many medications for schizophrenia to choose from, your psychiatrist should be able to find one that suits you. This choice will depend on a number of things – how well the medicine controls your symptoms, whether you suffer any unacceptable side effects and how you feel about your own treatment. It is most important that you let your psychiatrist know what you most want from your treatment. If there is a particular symptom that troubles you or a side effect that you are most keen to avoid, let your doctors know. They may be able to tailor your treatment accordingly.



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There is no 'one size fits all'  
when it comes to medication

## → Switching treatment

Any change to your treatment can be confusing. You may have to take your new medicine at different times of the day, it may cause different side effects or it may affect your symptoms in a different way. It is therefore important that you ask for information on your new treatment before you take it. You should also make sure your family know that you are changing to a different medication and that both you and they know who to contact if you have any problems.

## → Types of medication

What the doctor calls it

Type of medicine

### TABLET

Oral  
Oral dispersable tablet (ODT)

Tablet that you swallow, usually with liquid  
Tablet that dissolves in your mouth

### LIQUID

Oral solution (OS)

Liquid

### INJECTION INTO A MUSCLE – INTRA-MUSCULAR INJECTION (IM)

Short-acting injection  
Long-acting injection (depot)

The effect lasts for 12-24 hours. Used for acute treatment  
The effect lasts for 2-4 weeks



## Side effects – what to expect

With the diverse choice of antipsychotic medications on offer, it is no longer reasonable to expect people with schizophrenia to put up with deeply unpleasant side effects. If you feel you are suffering unacceptable side effects you should tell your doctor or psychiatric nurse immediately. Many side effects can be reduced or sometimes eliminated simply by changing the dose or even the medication you use. Others can be controlled by use of other additional medications or by altering your diet or lifestyle. You should also let your doctor know if you have suffered any side effects to any medication in the past. This may affect the type of antipsychotic drug he or she chooses to give you.

## → Taking your medication

Antipsychotic medication is designed not only to help make you better but also to keep you well. This means that you need to keep taking the medication, even after you start to feel better. One of the most common reasons for people relapsing after a successful treatment is that they stop taking their medication correctly.

**you need to keep taking the medication,  
even after you start to feel better**

**Some common reasons for not taking antipsychotic medication correctly:**

- The person does not realise or accept that he or she is ill – this is where the encouragement of friends and family can play an essential role in ensuring that the medication is taken according to the doctor's instructions
- The side effects are unacceptable – if this is the case, talk to your psychiatric nurse or psychiatrist. It may be possible to alter the dose of your medication or switch to a new one
- The medication schedule is too complicated – again talk to a mental health professional. They may be able to simplify your schedule or suggest a medication that is simpler to take. In some cases the doctor may recommend the use of a 'depot' injection. This is given once every two or three weeks and means it is not necessary to remember to take the medication every day

## → Questions to ask **about your medication**

When discussing your medication with your doctor or nurse there may be questions you want to ask.  
**Here are some suggestions:**

- **How will this drug help me?**
- **Which of my symptoms will it help me with?**
- **What are the risks of this drug?**
- **Who should I talk to if I think I am having side effects?**
- **How long will it take to see some benefit?**
- **Can I get hooked on it?**



Do you know everything you want to know about your medicine?

## → Treatment diary

You may have to try several different antipsychotic medications before you find the one that is right for you. You can help your doctor decide which drug suits you best by writing down what you like and what you don't like about each medication you try.

Medicine	Dates used	Good points	Bad points

## → Non-medication **treatments**

**Other therapies are usually used in combination with antipsychotic medication. The aims are to reduce the symptoms of schizophrenia, prevent relapse, help you stay on your medication and help you rebuild your life.**

Your doctor will be able to tell you about the range and the types of therapies available in your area.

**These treatments are sometimes referred to as 'psychosocial therapies' and include:**

### Cognitive behaviour therapy

This is a relatively short-term psychological therapy used to treat a wide range of mental health problems. In schizophrenia, it is thought to be most useful in helping to reduce delusional beliefs and to combat depression.

The ultimate goal of cognitive behaviour therapy is to change any unhealthy patterns you may have developed in your thinking or behaviour. This will, in turn, help change the way you feel.

Most cognitive behaviour therapists are psychologists, although doctors, nurses, counsellors and social workers can also use the technique. The therapy is usually given in a structured form. You and your therapist will agree a number of goals and set certain tasks for you to carry out in between sessions.



# Non-medication treatments

## Psychotherapy

A psychotherapist will encourage you to explore your most difficult and painful emotions and experiences. This may include general feelings of anxiety and depression or specific traumatic events that have happened in your past.

Although there are many different types of psychotherapy, the common goal of each is to help you become more self-sufficient and able to make rational, informed decisions about your life. Your therapist will help you solve current problems and teach you skills to help you cope with difficulties that may arise in the future.

**Although psychotherapy cannot cure schizophrenia it may help you cope with specific symptoms, such as:**

- anxiety
- panic attacks
- phobias
- emotional problems
- stress
- insomnia
- depression
- relationship problems
- psychological sexual problems

The treatment may also help you come to terms with the fact that you have schizophrenia and to comply better with your treatment.

Psychotherapy may be provided for individuals or children, and within couples, families or groups.



# Non-medication treatments

## Family therapy

Research has shown that family interventions can delay or even prevent relapse in people with schizophrenia who have significant family contact.

Family therapy should involve as many family members as possible and aims to reduce some of the stress and extreme emotions of family life that can make schizophrenia symptoms worse.

The treatment consists of educating family members about schizophrenia, offering behavioural and problem-solving advice, providing family support and teaching crisis management techniques.

The therapy can be offered to single families or conducted in larger groups. It may or may not include the person with schizophrenia, depending on which phase of the illness he or she is in at the time.

## Counselling

Trained counsellors can help you talk about your thoughts and feelings, without fear of being judged or criticised. This may help you talk your problems through and determine solutions.

### **There are two basic approaches to counselling:**

- The existential approach, which will encourage you to explore the meaning and value of your life and learn how to be true to your own ideals, priorities and values.
- The person-centred approach, which views you as the best authority on what is happening to you. This approach aims to help you create the conditions that will allow you to fulfil your own potential for growth.



## Choosing a therapist

With so many different non-medication therapies to choose from, it can be difficult to decide which is the best for you. Many people find it is easier to make this choice based on the therapist rather than the therapy they are offering. For instance, you might want to see a therapist from a background or culture similar to your own. You might prefer a female therapist or, alternatively, a male therapist.

Indeed, research has shown that how you get on with the individual therapist is more important than the type of therapy you get. If you and the therapist can work well together, trust and respect each other, it is more likely that the treatment will work.

Your doctor should take your preferences and feelings about the therapist into account when recommending a non-medication treatment. You may also get good advice from voluntary organisations and support groups.

## → Questions to ask **your therapist**

- What kind of therapy do you offer and what is it trying to achieve?
- How long do the sessions last?
- How often are they held?
- How many sessions am I likely to need?
- How long before I should expect to feel some benefit from therapy?
- Can I contact you between sessions if I need to?
- What training have you had and how many years have you been practising?
- Do you belong to a professional organisation?
- Have you had experience of working with people with schizophrenia?



**Mark was first diagnosed with schizophrenia seven years ago and has been on medication ever since. The treatment has proved highly effective at controlling his symptoms and he has been able to continue working as a teacher at a school in Tralee.**

However, Mark has undergone several changes to his medication over the years.

Initially, he was prescribed a typical antipsychotic, which he took twice a day. This seemed to control his symptoms but caused some side effects. Mark's energy levels dropped alarmingly and he found it increasingly difficult to last the whole school day without falling asleep. He also found that his hands would often shake uncontrollably, which could make it difficult to write on the blackboard. But the side effect that distressed Mark the most was a spasm affecting his mouth and tongue. At one point Mark became so concerned because his students were mocking his slurred speech that he started to refuse his medication. He became irritable, easily distracted and forgetful.

Fortunately, Mark's partner recognised these as early signs of a relapse and persuaded him to revisit his psychiatrist and have his treatment programme reviewed. The psychiatrist decided to change Mark's medication to one of the newer 'atypical' antipsychotics.

Mark's condition soon began to improve. His signs of relapse disappeared and so did the unpleasant side effects of his previous medication.

No longer held back by his tremor and slurred speech, Mark began to feel less self-conscious in front of his classes and he approached his teaching with a renewed vigour. Over the next few months, however, Mark began to feel self-conscious about something else entirely. He appeared to be putting on weight.

Mark decided to take more exercise and to go on a low-fat diet. But although Mark's weight gain slowed a little, there was no denying the fact that he was still getting heavier.

Finally, Mark decided to seek help from his family doctor, who informed him that weight gain was, indeed, a known side effect of Mark's atypical antipsychotic.

Mark returned to his psychiatrist for another review of his medication. This time another atypical antipsychotic was prescribed. Over the next few months Mark's weight began to fall. Furthermore, Mark has also managed to stick to the low-fat diet and exercise programme. He says he feels the fittest he has ever been.

## → Reaching out for support

Nobody could pretend that living with schizophrenia is easy. But you don't need to struggle alone. There is a big support network out there made up of dedicated professionals, committed volunteers and people who simply love you and care for you very much. Making full use of these people's support will help you along the road to recovery.



# Chapter 5

## Help is at hand

There is a big support network  
of people who care for you



### **The family doctor**

When you first become ill, the family doctor is probably the first medical professional you will see. Although unlikely to be a specialist in mental illness, he or she will be able to check for any other causes of your symptoms and will know where to refer you for specialist care. The family doctor will also be able to help you with any other health problems you may have.



### **The psychiatrist**

The psychiatrist is a specialist in mental health. He or she will make your diagnosis and discuss what treatment you should have. If you have any questions or concerns about your condition, its treatment or any side effects you may be having, you should ask to speak to the psychiatrist.



### **The psychiatric nurse**

The psychiatric nurse is probably the mental health professional you will see most. He or she will be responsible for making sure you receive your medication and encouraging you to take it, for assessing your response to treatment and for monitoring any side effects.



### **The social worker**

The social worker will help you reintegrate yourself back into life. This may be by putting you in touch with other support agencies, helping you sort out your housing or benefit needs or ensuring that you receive the services you are entitled to.



### **The occupational therapist**

Occupational therapists can help you get back to work, either in your old job or, if that is not possible, by finding new employment. The occupational therapist will help you identify the key skills you already have and gain the additional skills you may need.



### **The pharmacist**

A pharmacist can help you with any questions you may have about your medication. So, if you are worried about side effects or whether your treatment is properly controlling your symptoms, the pharmacist can give you expert advice that is easy to understand. If you need medication for any other condition, the pharmacist will be able to advise you on which medicines are compatible with your antipsychotics.



### **The psychologist**

A psychologist is trained in the study of human behaviour and experience. When involved in the area of mental health, the psychologist usually works as a clinical, community or counselling psychologist and, unless also medically qualified, does not prescribe medication.



### **Support groups**

Patient organisations, mental health charities and support groups are an invaluable source of information and support. Often run by people who have direct personal experiences of situations similar to your own, they can help guide you through the difficult journey towards recovery.



### **Telephone helplines**

If you don't want to talk about your problems with someone face to face, a telephone helpline is a good place to begin looking for advice, information and support.



### **Sports clubs/Hobby groups**

Just because you have schizophrenia doesn't mean you shouldn't have other interests. Indeed, keeping active and meeting other people who share your interests can help improve your mood and keep you interested in life.



### **Citizens' advice agencies**

You may be entitled to benefits to help with your housing and welfare costs. Expert advisers can help you work out what you are entitled to and how to claim it.



### **The internet**

Learning how to use the internet can open up a vast library of information on schizophrenia and related conditions. Email and chatrooms can also put you in touch with people who may have experiences similar to your own.

Ask your key support worker for advice on good internet resources.



### **Family and friends**

When going through the trauma of mental illness it is often easy to lose sight of the fact that there are people who still love you and care for you. As a result many people with schizophrenia feel isolated and alone. That is why there really is no substitute for the support offered by family and friends. Family and friends can offer both emotional support and practical help in dealing with the illness.





**Liam knows he isn't the only 15-year-old in Galway from a one-parent family. It's just that in his family, it's sometimes difficult to know who the parent is, him or his father.**

Liam's father, Joseph, has schizophrenia. In the past, this has made it very difficult for Liam. Often he has had to care for himself, buy his own groceries and cook his own food. Sometimes, he has witnessed his father's psychotic episodes, which have been upsetting and frightening. More often, he has spent hours trying to persuade his father to get out of bed.

It's a difficult life. Too difficult for Liam's mum and sister, who left home last year when things got too much. Since then, Liam has had to cope on his own.

Recently, however, he has been getting a lot more help. His father has started attending a local hospital day centre, where he receives support from a team of doctors, psychiatric nurses, social workers and occupational therapists. This means Liam can go to school without worrying what his father might be doing back home.

It also means that his father, Joseph, has begun taking his medication regularly. He already feels a lot better and is able to help out around the house a little more.

Every other week a psychiatric nurse visits Joseph at their home to see how he is doing and to see if Liam needs any more support. A social worker also visits occasionally.

Sometimes Liam visits the centre with his father. Last time he went they acted out a role play where Liam played the part of the patient and Joseph played the doctor. Later they discussed how patients could talk to their family and friends about their illness. It was fun playing games with his father again. But it also made Liam think. It had never really occurred to him before how hard things must be for his father.

Joseph has also enrolled in a social and personal skills programme set up by the centre's psychiatrist. In time this will help Joseph regain some of the social skills he has lost during his illness. Liam hopes it will give his father the confidence to go out a little more. They used to go and watch football together. It would be nice to see another game.

→ Always two steps forward,  
**sometimes one step back**

Recovering from schizophrenia is a difficult road to follow. Just when you think you are getting somewhere, another setback appears on the horizon. This can be terribly dispiriting, but learning to accept the disappointments is all part of the process.

# Chapter 6

## The good days and the bad days

Often, it is difficult to deal with problems when they arise. You may become upset and find it hard to think clearly and calmly. One way around this is to keep a diary of all the difficulties you face. You can then come back to them when you are feeling stronger and more able to think of a solution. Use the diary for your meetings with your health professional. You can go through it together and try to find solutions.

## → Regaining **your** confidence

When you start to recover there still may be times when you feel low and lack confidence. You may have feelings of shyness and be reluctant to interact with people the way you used to. It will not always be easy, but building new social relationships is an important step on the road to recovery.

### The following things may help:

- Make a list of the things you enjoy doing with other people, and try to slowly reintegrate these activities into your life.
- Make a list of the things you like about yourself and that other people like about you, like a good sense of humour, generosity, your artistic ability or computer skills.
- Slowly but surely socialise with people you care for and trust while you build your confidence.



**Keeping active**  
and interacting with others may  
help boost your confidence

## → Importance of physical health

When you have a mental illness such as schizophrenia, it is sometimes easy to let your physical health slip as well. Unhealthy habits can leave you feeling unfit and physically unwell. This can, in turn, affect your mental health and lead to a downward spiral of mental and physical deterioration.

Your doctor will be able to advise you on how to make your lifestyle healthier. Some general tips are:

- Don't put off seeing your doctor if you feel unwell.
- Try to cut down or give up smoking.
- Drink alcohol in moderation.
- If you are overweight try to lose small amounts of weight steadily, and consistently, over a long period of time.
- Take more exercise. If you hate exercising, think why that is. If it's because you find it lonely, join a class. If you feel self-conscious with others, do something alone, like walking, running or swimming at quiet times in the pool.
- Try to avoid eating cakes, crisps, chips and biscuits.
- Eat two portions of fish a week, with one portion of oil-rich fish (mackerel, sardines or herring).
- Cut back on butter, margarine and other spreads, or choose low-fat alternatives.
- Eat plenty of fresh fruit and vegetables. Steam the vegetables instead of boiling them.
- Use skimmed or semi-skimmed milk.
- Pasta, rice or potatoes should take up about a third of the room on your plate.
- Avoid adding salt to your meals.
- Drink plenty of fluids – aim for eight to 10 glasses of water, fruit juice or semi-skimmed milk each day.

# → Personal relationships

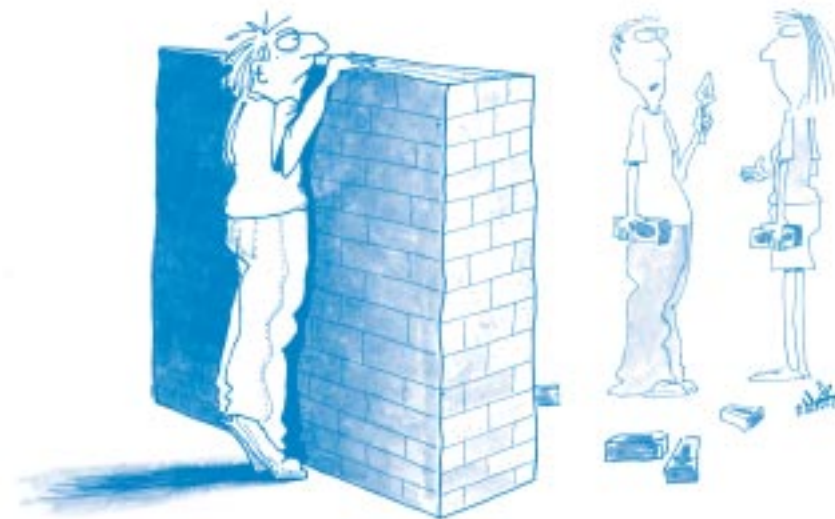
Most people find relationships difficult even at the best of times. When you have a mental illness, interacting with almost anybody can sometimes feel impossible. There are no easy answers to relationship problems. However, there are some practical steps you can take to make things easier.

- Try not to worry – schizophrenia can make you oversensitive to the things people say or do. Don't waste time worrying whether someone is 'going off' you or wondering why they didn't phone you back.
- Talk to your partner – if you have a partner it is likely that he or she will be worried about what effect your illness may have on your relationship. Your treatment may be affecting your sex life, for instance. Talk about these fears together and seek your doctor's advice if there is a problem you both feel needs to be addressed.
- Deal with conflicts – if you have an argument, don't brood over it. When you have calmed down, try to see the other person's point of view. If the two of you can't sort the problem out, consider bringing in a third person to mediate.
- Keep your family in the loop – even if you no longer live with your family, they will still care about how you are getting on. Let them know what you are doing, how your treatment is going and what you are planning for the future.
- Make acquaintances – passing the time of day with neighbours or shop assistants can be a good way of holding stress-free conversations.
- Prepare for conversations – it's hard to get chatting with someone if you can't think of what to say next. Try to have some answers ready for common questions such as **"What do you do?"**



## → Coping with stigma and discrimination

One of the challenges in recovering from schizophrenia is dealing with the reactions of other people. There is a huge amount of ignorance about mental illness in general and schizophrenia in particular. Myths about the disease can lead people to believe that people with schizophrenia are dangerous, wild and unpredictable. This can create a vicious cycle of alienation and discrimination for those who have schizophrenia and often for the members of their families. Stigma can become the main cause for social isolation, inability to find work, alcohol or drug abuse, homelessness and excessive institutionalisation, all of which decrease the chance of recovery.



Sometimes you may feel there is a wall between you and others

**Because stigma occurs in other people's minds it can be difficult to combat. However, there are some things you can do:**

- Learn as much as you can about schizophrenia, so you can correct ignorant views with solid facts
- Try to educate those around you about schizophrenia
- If an ignorant view in a TV programme or newspaper article offends you, write and complain
- Fight discrimination. Contact your union if you endure prejudice at work. Complain to management if you are discriminated against as a customer or service user



**Tuigean Siobhán anois nach mbeidh a saol mar a bhí arís go deo.**

**Tá an bhreiteacht a bhí uirthi faoi smacht anois. Tógann sí a cuid íocshláinte go rialta agus tá sé cúpla mí anois ó d'airigh sí aon chomhartha den scitsifréine uirthi.**

In ainneoin sin is uile tá Siobhán den bharúil go bhfuil an saol mórthimpeall uirthi éirithe níos uaigní agus níos naimhdí.

Tá cúiseanna maithe leis seo. Nuair a bhí Siobhán tinn chuir a breiteacht scanradh agus buairt uirthi féin agus na daoine a bhí timpeall uirthi. Tá a fhios aici gur mhaslaigh sí is gur thug sí drochíde dona lán dá dlúthchairde. Ní féidir léi an milleán a chur orthu anois óir is mian leo fanacht amach uaithi.

Airíonn sí doicheall a comhghleacaithe san ollmhargadh ina mbíonn sí ag obair. Tá cuid acu tar éis diúltú oibriú in éineacht léi. Deir siad gur duine dainséarach í agus go bhfuil sí glan as a ciall. Rinne Siobhán iarracht a mhíniú go bhfuil a breiteacht faoi smacht anois, agus fiú nuair a bhí sí tinn, nach ndearna sí dochar d'éinne ach amháin di féin. Níor chreid siad í i ndáiríre. Tá na nuachtáin léite acu agus is ionann scitsifréine dar leo agus fir ghealtacha ag leadradh rompu le tuanna, agus ionsaithe fíochmhara randamacha á ndéanamh ar dhaoine.

Ní féidir lena muintir mórán tacaíochta a thabhairt di. Ba bheag cairdeas a bhí eatarthu riamh, agus is ar éigin ar labhair sí lena tuismitheoirí ó ghlan sí amach as an gceantar tuaithe deich mbliana ó shin agus le triall ar Bhaile Átha Cliath. Is lú fós an ceangal atá eatarthu anois de thoradh na breiteachta.

Tá tuar amháin dóchais ann, áfach. Mura mian lena seanchairde a bheith muinteartha léi, tá Siobhán féin ag bualadh le daoine eile anois, agus is féidir léi tosú arís as an nua leo. Níl sé ach cúpla seachtain ó dhiailigh sí uimhir theileafóin eagraíocht tacaíochta anseo in Éirinn.

Bhí comhairle mhaith acu maidir le deileáil le naimhdeas na ndaoine san ollmhargadh. Mhol siad di iarraidh ar a teiripeoir saothair labhairt lena comhghleacaithe faoi na rudaí a bhí ina gcúis bhuairimh agus imní dóibh. B'fhéidir go gcuirfeadh sé sin ar a suaimhneas iad faoina bheith ag obair léi feasta.

Chabhraigh an eagraíocht le Siobhán dul i dteagmháil le daoine a d'fhulaing mar a d'fhulaing sí féin. Socraíodh go mbuailfeadh sí leis na daoine sin. B'ait léi bualadh leo. B'íomaí cúlra a bhí acu agus bhí Siobhán cúthaileach neirbhíseach ar dtús, ach i gceann tamaill thosaíodar go léir ag caint is ag gairí is ag insint faoi na rudaí a tharla dóibh.

Den chéad uair le míonna d'airigh Siobhán go raibh sí ag baint taitnimh as an saol.

## → Slowly does it

Once you have begun to recover from schizophrenia you will, no doubt, want to regain your previous lifestyle as quickly as possible. But remember it is very important not to rush these things. The road to recovery is a long one and it is best travelled in short steps rather than giant leaps. Above all make sure you progress at a pace you are comfortable with. There are bound to be those

around you who are encouraging you and willing you to become your old self again.

Accept this encouragement, but don't let anyone push you into doing something before you feel ready.

Small steps will help you get back on the road to recovery

# Chapter 7

## Getting back on the road



## Plan your day

When you are well there are many things you do each day without even thinking about it. But when you are recovering from schizophrenia it is easy to let whole days slip by without achieving anything. Sometimes it can help to plan the whole day in advance. For example:

### AM

- Wake up
- Eat breakfast
- Shower and brush teeth
- Walk to shops. Buy food, newspaper, get video, birthday card for Mum
- Relax. Read newspaper
- Cycle to day centre

### PM

- Back home. Prepare lunch. Eat lunch
- Appointment with community psychiatric nurse
- Write letter to friend
- Clean bathroom
- Prepare dinner. Eat dinner
- Watch video
- Relax. Listen to music
- Brush teeth. Go to bed





## Keep a calendar

It is easy to forget things like appointments, social events and the birthdays of your family and friends. By keeping a calendar you can make sure you are always aware of what is coming up.

If you try to accept every invitation you receive (even if you don't particularly want to go at the time), you will always have something to look forward to.

## → Day-by-day diary

As you make progress it can be useful for your doctors to know exactly how you are doing, what is working and what problems still remain. It can therefore be a good idea to chart your progress in a day-to-day diary. For example:

Day	How do I feel?	Medication taken	Any side effects	Today's highlight	Any problems
Monday	Well	Yes	No	Got out of bed early and had a bath	No
Tuesday	OK	Yes	A little drowsy	Didn't hear any voices	Didn't leave my room
Wednesday	Not too bad, but feel a bit down about weight	No	Have put on 0.5 kg!!	Cognitive therapy session. Went really well	Should have taken my pills – will do it tomorrow
Thursday	A little low	Yes	Drowsy	No highlight today	Expected a visit from Mike. Didn't show up
Friday	Low again, a little bit anxious	Yes	None	Speaking to Mike	Spoke to Mike. He apologised
Saturday	OK	Yes	None	Watching football on TV. We won!	No
Sunday	OK	Yes	None	Went out for a walk	No



**When Michael thinks back, he can't believe the pace at which he used to live his life.**

**As a successful lawyer in a busy Limerick practice he would regularly work a 14-hour day and spend most of the evening socialising with clients. Weekends would be spent visiting friends and hosting dinner parties with his wife. Michael was ambitious and hard-working. He was relaxed in the company of others and known for his sharp mind and easy sense of humour.**

But all that came to an abrupt halt when Michael suffered his first psychotic episode.

It took six months of doctors' appointments, psychiatric assessments, visits from the psychiatric nurse and regular medication before he felt able to start seeing other people again. If it hadn't been for the support of his wife, Michael isn't sure he would have recovered at all.

Now he is feeling much stronger. His medication seems to be working and Michael feels ready to face the world once again. He knows, however, that he must take things slowly this time. A few weeks ago, he tried visiting the theatre with his wife and a couple of friends. But while he enjoyed the production, he found socialising in the bar afterwards extremely difficult. He became anxious and felt increasingly out of control.

Since then he has taken things one step at a time. His wife suggested they visited some of the places they used to go when they were younger. They took his emergency contact numbers with them just in case, but everything went well and they enjoyed themselves. Just the two of them, reliving happy memories.

More recently Michael has felt able to meet members of his family and friends. He now feels comfortable in groups of three or four people and as he relaxes he has felt some of his social skills beginning to return. He has even made one or two jokes.

Michael knows the next step will be to start meeting people on his own, without the supporting presence of his wife. It's a daunting prospect, but Michael feels he will be ready soon.



## → Don't become **the patient**

A diagnosis of schizophrenia can be traumatic, not only for the person who has developed the illness, but also for the whole family.

When a member of your family is diagnosed with schizophrenia you can suddenly find yourself thrown into a strange and unfamiliar world. You may find yourself acting as a 'buffer zone' between the good times and the bad. When things are going well, the person affected may be able to cope on his or her own. When a crisis arises they may be admitted to hospital. For the times in between, you may have to offer considerable support.

# Chapter 8

## Helping someone with schizophrenia

You may be torn between feelings of concern for your loved one, confusion over what the future may bring and anger at the sudden demands being put on you. If you are not careful, these conflicting emotions can tear your family apart.

Schizophrenia creates a ripple effect  
touching many people





**There are a number of things you can do, both to help your loved one through their illness and to help you and other family members cope. For example:**

- Learn as much as you can about schizophrenia
- Find out what support services and contact groups are available in your area
- Join a carers/family network to share experiences and offer mutual support
- Ask your doctor if there is any written advice available for carers and family members
- Recognise the warning signs of schizophrenia and know who to contact if you think your loved one is beginning to relapse
- Learn how to cope with a crisis
- Make sure you involve your loved one in making any decisions about their care
- If your friend or family member does not realise they are ill, go to see the doctor yourself and discuss your concerns
- Don't hide away and hope it will just disappear

- Talk to others in the same situation
- Try to encourage your loved one to take his or her medication. If they do not want to, try to understand their reasons and discuss ways to solve them
- Try to help other friends and family members understand the illness and stay in touch
- Do not neglect other family members. Often brothers and sisters of people with schizophrenia feel they are not getting their fair share of attention. This can breed resentment and jealousy
- Contact a support group. Sharing your experiences with others in a similar position can be a great help

- **Don't be a martyr! You deserve to have a life as well. Make sure you take enough time for yourself to do things you want to do. If you are feeling overwhelmed, ask your mental health team if there are any respite services available**



## The search for information

**It can be very difficult to remain involved in the care of someone with schizophrenia if you do not know everything that is going on. Unfortunately, family members often find themselves fighting for information about their loved one's care. You may be denied this information because the person with schizophrenia does not believe he or she is ill, does not want you to know he or she is ill or has turned against the family and is deliberately keeping you out of the information loop.**

Because health professionals have a duty to respect the confidentiality of their patients, there may be little you can do to remain informed about the care of someone who is determined to shut you out. This can lead to difficult situations. For instance, your family member may suddenly turn up on your doorstep having been discharged from hospital without you knowing.

You should therefore try to make it clear both to your family member and his or her key workers that the medical decisions being taken are important to you as well as the patient.

## → Relapse – recognise the warning signs and symptoms

Experiencing a relapse of schizophrenia symptoms is distressing for everyone. The best prevention is ensuring the person affected takes their medication as instructed. However, it is worth being sensitive to the day-to-day changes in your loved one's behaviour so you can be prepared to deal with a possible relapse. Learn to recognise the particular signs and symptoms that signal an impending crisis so you can be prepared to give extra support and care. These signals will probably be the ones that first prompted you to get help for your loved one.

Each person is different, but some of the common warning signs are:

- Moodiness, depression, extreme anxiety, excessive crying, laughing for no reason
- Hearing voices, unusual sensitivity to noise or light
- Losing sense of humour
- Becoming extremely active or inactive, sleeping excessively or hardly at all
- Avoiding social situations, dropping out of activities, refusing to go out, allowing relationships to deteriorate
- Saying irrational or inappropriate things, using peculiar words or making meaningless statements
- Strange postures, prolonged staring
- Wearing bizarre clothes, poor personal hygiene

It is important to remember that the best way to prevent relapse is for the person affected to take medication as instructed. If they refuse, try to work out the reasons why. If they feel the treatment isn't working or that side effects are an issue, you may want to investigate alternative medications.

## → Keep a diary

If you are looking after someone with schizophrenia it can also be very useful to keep a diary. This can help you identify patterns of behaviour that might indicate that treatment is going well, not going so well or has been missed altogether. It may also help you to predict the onset of relapses.



## → Coping with a crisis

If someone close to you has already had one psychotic episode, it is a good idea to learn how to react if it happens again. The table offers a few tips:



# Coping with a crisis

→ Avoid threats and ultimatums

→ Remember you can always walk away

→ Try not to shout

→ Avoid criticisms

→ Don't try to deceive

→ Avoid arguments with other family members over what to do

→ Don't stand if the person is seated

→ Avoid direct continuous eye contact or touching

→ Comply with requests that are reasonable

→ Don't block the doorway or lock exit doors

→ Speak in a normal tone

→ Prepare a list of phone numbers for:

- the family doctor

- the psychiatrist

- the key worker

- an emergency centre for psychiatric admissions

- the police

→ Make sure you know which hospital to go to in case of an emergency

→ Find out who you can phone for support at any time of the day or night

→ Decide who will take care of other children (if there are any)

## Advance directive

**One way of ensuring that you respect your loved one's wishes is to help them prepare an 'advance directive'. This is a statement that sets out how they would like their care to proceed should they become too ill to make the decisions themselves.**

**This may include:**

- The name and contact details of a family member or friend who is to be given authority to act as an advocate on the individual's behalf
- A list of the areas in which the advocate may make decisions. For example:
  - medication
  - other treatment
  - finance
  - housing
- A list of specific medications the individual would prefer to avoid

Copies of the advance directive should be stored with the individual's medical notes, at their home and with a family member. You might also suggest your loved one carries a copy in his or her wallet in case of emergency.



**There were times when Helen wished that she was the one who was sick. Maybe then she could lie around watching TV all day. Maybe then she wouldn't have to rush home from work to care for her sister Alice. Maybe then her parents would pay her a little more attention.**

Helen knew it wasn't right to feel this way. It wasn't Alice's fault she had schizophrenia, and Helen felt guilty for resenting all the attention that her sister was getting.

It was just that things were so much easier before Alice got ill. Back then Helen would go swimming every day after work. She would see her friends at the weekend and often just drop everything and go away for a few days. Best of all, every now and again she would meet up with Alice and the two sisters would travel up to Dublin to go shopping in Grafton Street.

But when Alice started getting ill she didn't want to go shopping any more. In fact she didn't seem to want to do anything any more.

"You're so boring and weird these days," Helen shouted at her. "It's no wonder you haven't got any friends." Helen feels guilty about that too.

Now, of course, Helen knows a lot more about schizophrenia. She knows that Alice is trying really hard to get better and she knows that she will need all the support she can get.

So, Helen is trying not to criticise her sister quite so much. She is learning to offer gentle, positive encouragement as she helps with simple daily tasks like getting dressed in the morning or taking a shower. Already Alice seems to be taking more care with her appearance.

Helen also helps Alice deal with the team of doctors and nurses who have been managing her care. She accompanies her to doctor's appointments and makes sure that all the relevant information (such as family history) is taken into account. She notes down when Alice's medication should be taken and what side effects to look out for. And she has made sure she recognises the signs of relapse and knows what to do about it.

Slowly Alice is becoming more independent and Helen is proud of the important part she knows she has played in her sister's recovery. But there is something the community psychiatric nurse said on his last visit that has been playing on her mind. "Make sure you have a life too," he said.

It sounds like good advice. Tonight Alice will cook her own food and Helen is going swimming with friends after work.



**“The thing that turned everything around for me was finding the right medication. That was important because that really acted as a gateway to lots of other services that I’ve been able to access. If I hadn’t had the medication I wouldn’t have been well enough to make use of the groups and activities available at the day hospital or the therapy that I was receiving. I wouldn’t have been able to recognise the care and support my family have given me.**

Lots of other things really helped, like having supportive friends as well as family, having a secure place to live, having enough money to survive, and obviously having a really good psychiatrist has been really important – being able to be treated by somebody that I trust.

I ended up taking a year out of university but luckily was invited to re-sit the exams that I had failed. This was probably one of the biggest turning points in my life – when I turned the exam paper over and realised that I was actually going to get back to university. It was a really big achievement for me.

I did lose lots of friends during my illness, but I also found out who my real friends are. I’ve had difficulties with relationships and it has also been quite hard for me to get a job. I’ve had to battle with the stigmatisation that employers usually have towards people who have mental health problems, particularly schizophrenia, because it has very bad press.

At the moment I’m senior project worker at the User Employment Programme (UEP) at Springfield Hospital and have recently also been offered the role of Coordinator of the UEP team. I support people with mental health problems to work within our trust: I support them to get the job in the first place but also to carry on keeping the job once it has been secured. I’ll give them support and advice throughout their work and career if they so choose. I’ve also just finished a master’s in occupational psychology.

Schizophrenia is misunderstood by society at large, but hopefully people will get more accurate information through the media, through school and education, so hopefully things will start to turn around soon.”

***Emma Harding, Senior Project Worker and Coordinator, User Employment Programme, Springfield Hospital, UK***



# Chapter 9

Useful information

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# Glossary

## Glossary A-D

### Acute schizophrenia

This describes an episode of schizophrenia when symptoms are at their most severe.

### Adherence

Taking medication according to the treatment dosage and schedule instructed by your doctor. This is also sometimes referred to as compliance.

### Affective flattening

'Affect' is a medical term for emotion. Affective flattening is when emotions are blunted or limited. This is a 'negative' symptom of schizophrenia.

### Akathisia

Pacing and a total inability to sit still. If forced to sit still the person experiences extreme anxiety and agitation.

### Alogia

An inability to speak. Alogia is a 'negative' symptom of schizophrenia.

### Anhedonia

The inability to enjoy activities that previously gave pleasure.

### Antipsychotic

The general name for prescription medications used to treat schizophrenia. These are normally divided into 'typical' and 'atypical' medications.

### Atypical

A type of antipsychotic used to treat schizophrenia. Most atypicals were introduced in the 1990s and have fewer side effects than typical antipsychotics. They are generally considered the first choice of treatment for schizophrenia.

### Avolition

Inability to start or finish basic tasks. A 'negative' symptom of schizophrenia.

### Blunting of affect

Lack of emotion. The voice may become monotonous and the expression on the face may not change.

### Catatonia or catatonic behaviour

An extreme lack of reaction to the surrounding environment. The person may become rigid or seemingly 'paralysed' or appear to be in a trance.

### Chronic schizophrenia

Schizophrenia is referred to as chronic when the symptoms persist long-term.

### Cognition

Functions of the brain involved in thinking, remembering and processing information.

### Delusion

A fixed belief that has no basis in reality and is not affected by rational argument or evidence to the contrary. People experiencing delusions are often convinced they are a famous person, are being persecuted or are capable of extraordinary accomplishments. The delusions often have a link to God or religion.

### Depot injection

This is an injection given once every two or three weeks and means that it is not necessary to take the antipsychotic medication every day.

# Glossary D-N

## **Dopamine**

A neurotransmitter in the brain that plays a role in the way we feel pleasure and emotion. Many of the symptoms of schizophrenia are believed to be caused by an increase of dopamine in certain parts of the brain and low levels in other parts. Most antipsychotics work by either blocking or stabilising dopamine levels in the brain.

## **Extrapyramidal symptoms**

Movement disorders such as uncontrollable tremor, shaking, restlessness and facial movements. Extrapyramidal symptoms (referred to as EPS) are usually a side effect associated with the older, typical antipsychotic medications.

## **Generic name**

The molecular name of the medicine is referred to as the generic name. It indicates the chemical make-up of the medication. The manufacturer of the medication markets the medicine under a particular name called the brand name. The brand name will almost always be different from the generic name.

## **Genetics**

The science that studies the principles and mechanisms of heredity, particularly the way traits are passed from parents to their children. Genetics may play a role in the development of schizophrenia. Research to study the association of schizophrenia with genetics is ongoing.

## **Insight**

This refers to a person's awareness of the presence and meaning of symptoms and their role in producing illness. Although insight alone may not 'cure' illness, emotional acceptance of one's illness often helps people manage and reduce the impact of their symptoms.

## **Long-acting (depot) injection**

This type of injection slowly releases the medication into the muscle. It is usually used for people who have difficulty taking medication as prescribed, or refuse medication. Injections may be given every 2-4 weeks, usually in hospital.

## **Maintenance dosage**

A dosage of medication that, taken at regular intervals, helps to control symptoms.

## **Metabolism**

The physical and chemical processes of changes in the body tissue that allow nutrients, such as from food, to be absorbed into the blood after digestion. The process involves the passage of food from the gut to the excretory organs such as the kidneys and digestive system. Metabolic disorders that can often affect people with schizophrenia include diabetes and high cholesterol.

## **Multiple personality**

A rare disorder in which a person displays two or more distinct and separate personalities, often of different ages and genders. This disorder is quite separate and different from schizophrenia, but is often wrongly assumed to be similar.

## **Negative symptoms**

A group of schizophrenia symptoms such as low motivation, lack of concentration and withdrawal from family and friends. These symptoms are sometimes considered harder to treat than positive symptoms, and are often responsible for much of the loneliness and isolation that people with schizophrenia feel. Some of the negative symptoms are believed to be linked to low levels of dopamine in certain parts of the brain.

# Glossary N-P

## Neuroleptics

An old term for 'Antipsychotics' that is still frequently used (see Antipsychotics).

## Occupational therapy

Therapy that involves building skills and expressing feelings through a variety of creative tasks such as handicrafts (pottery, painting, carpentry) or role playing, music or poetry reading. Occupational therapy can also be used to help people build practical skills that can help them move into employment.

## Out-patient

An individual who comes to the hospital to receive medical care such as receiving medication or therapy. An out-patient does not need to be admitted in the hospital.

## Positive symptoms

A group of symptoms including hallucinations (seeing, hearing, tasting or smelling things that aren't there), delusions (believing things that cannot possibly be true) and paranoia (extreme suspiciousness). These symptoms can be extremely disturbing to the person experiencing them, but tend to respond well to antipsychotic medication.

## Psychiatric nurse

A nurse with specialised training and experience in dealing with psychiatric and mental health.

## Psychiatrist

A medical doctor who specialises in psychiatry. Psychiatrists are trained in medicine, receive specialised training in mental illness, and are qualified to prescribe medication for schizophrenia. Compare with Psychologist.

## Psychiatry

The medical science that deals with the origin, diagnosis, prevention and treatment of mental and emotional disorders.

## Psychoanalysis

A talking therapy introduced by Dr Sigmund Freud, which involves the analysis of dreams, childhood experiences, etc to overcome present problems. It is founded on the belief that an individual's problems are mainly caused by unconscious drives and negative early childhood experiences.

## Psychologist

A person who holds a degree in psychology. Psychologists involved with patient care are called clinical psychologists. They may provide psychotherapy but are not authorised to prescribe medication. Compare with Psychiatrist.

## Psychology

The science and study of the mental processes and behaviour of people.

## Psychosis

A major mental health disorder in which a person's ability to think, respond emotionally, remember, communicate, interpret reality and behave appropriately interferes with their ability to cope with the ordinary demands of life.

## Psychosomatic illness

Physical symptoms that may be caused by stress or other mental, non-physical factors.

## Psychotherapy

The treatment of mental and emotional problems through discussions between a patient and therapist. Supportive therapy and family therapy are types of psychotherapy.

## Glossary R-V

### **Receptor**

Special places on nerve endings capable of responding to a chemical or physical stimulus from within the body or in the environment. Some medicines are known to increase sensitivity in one or several receptor types. Others can block or stimulate specific receptors.

### **Rehabilitation**

Rehabilitation programs are designed to help people return to their previous level of functioning after a disabling illness, injury, addiction or prison sentence. The aim is to teach skills that will allow the person to live independently.

### **Remission**

The reduction of symptoms. In schizophrenia this means the partial or complete decline in 'positive' and 'negative' symptoms.

### **Schizophrenia**

A mental illness that affects one in 100 people worldwide. It is characterised by 'positive' symptoms such as delusions and hallucinations, 'negative' symptoms such as lack of motivation and withdrawal from family and friends, and 'cognitive' symptoms such as muddled thinking. Schizophrenia is treated with antipsychotic medication and other supportive therapies.

### **Self-help group**

A group of people who meet to improve their situation through discussion and special activities. Unlike group psychotherapy, they are not usually led by a therapist.

### **Sheltered employment**

A type of employment or vocational programme that mimics a real work situation. Often, contracts are received from local businesses and individuals are trained and supervised to do the work. Job types vary, depending on the contract and local arrangements, but often include factory work or clerical work. Although the main aim is to teach basic work skills, individuals often receive some modest payment for their work.

### **Short-acting injection**

An injection of antipsychotic medication often used during an emergency situation, such as an acute episode, when symptoms need to be controlled quickly. The effect usually wears off in 12-24 hours.

### **Social worker**

A person with specialised training to help individuals with their social adjustment. In schizophrenia, this may involve counselling of individuals and their

families in dealing with various social or emotional issues that are a result of the illness.

### **Split personality**

See Multiple personality

### **Stigma**

In the context of mental illness, stigma refers to society's negative assessment of people with a mental health problem in general, often reflected in the public's negative treatment of such people.

### **Typical antipsychotics**

The first antipsychotic medications, introduced in the 1950s. Although effective against the positive symptoms of schizophrenia, typical antipsychotics tend to cause troublesome movement disorders such as tremor and shaking. They also have a number of side effects and only limited effect against the negative symptoms of schizophrenia. In addition, they have no effect on cognitive symptoms.

### **Vocational counselling**

Counselling that helps a person search and train for a job.

## → Sources of information

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- Treating and Managing Schizophrenia (Core Interventions): Understanding NICE guidance – Information for People with Schizophrenia, Their Advocates and Carers, and the Public. National Institute for Clinical Excellence. 2002.
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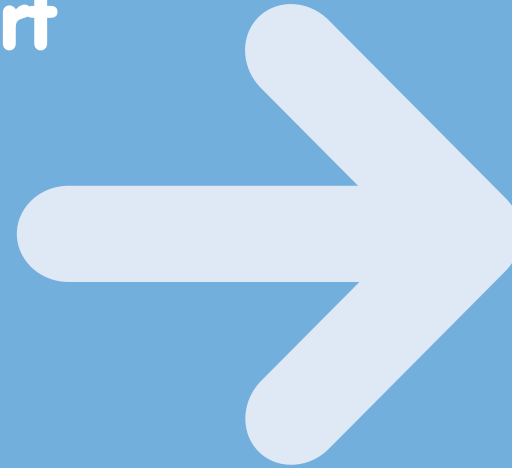
# → Noticeable side effects of antipsychotic medication\*

How it makes you feel	What the doctor calls it
→ Uncontrollable trembling	Extrapyramidal symptom (EPS): Tremor
→ Stiff muscles	Extrapyramidal symptom (EPS): Dystonia
→ Abnormal body movements	Extrapyramidal symptom (EPS): Dyskinesia
→ Inner restlessness with anxiety	Extrapyramidal symptom (EPS): Akathisia
→ Feeling alert	Activation, Non-sedating
→ Low glucose level, weakness	Diabetes or impaired glucose tolerance
→ Unnatural heart rate	QTc disturbances
→ Twitching of tongue, face and jaw	Tardive dyskinesia
→ Dry mouth, constipation, blurred vision, difficulty urinating	Anticholinergic side effects
→ Feeling drowsy or sleepy	Somnolence
→ Leaking breasts, irregular periods, erectile dysfunction, infertility	Prolactin elevation
→ Weight gain	Excessive weight gain

\* The incidence of side effects can vary for different medications



# Online information and support



## International:

[www.eufami.org](http://www.eufami.org)  
[www.gamian.org](http://www.gamian.org)  
[www.mentalhealtheuropa.org](http://www.mentalhealtheuropa.org)  
[www.wfmh.org](http://www.wfmh.org)

## Germany:

[www.psychiatrie-aktuell.de/disease/detail.jhtml?itemname=schizophrenia](http://www.psychiatrie-aktuell.de/disease/detail.jhtml?itemname=schizophrenia)  
[www.kompetenznetz-schizophrenie.de/](http://www.kompetenznetz-schizophrenie.de/)

## Ireland:

[www.aware.ie](http://www.aware.ie)  
[www.grow.ie](http://www.grow.ie)  
[www.mentalhealthireland.ie](http://www.mentalhealthireland.ie)  
[www.sirl.ie](http://www.sirl.ie)

## Information Helplines Ireland:

Aware: 1890 303 302  
Grow: 021 4277 520  
Samaritans: 1850 60 90 90  
SIRL: 1890 621 631

## UK:

[www.rethink.org](http://www.rethink.org)  
[www.sane.org.uk](http://www.sane.org.uk)  
[www.mind.org.uk/](http://www.mind.org.uk/)  
[www.mentality.org.uk/](http://www.mentality.org.uk/)  
[www.eufami.org](http://www.eufami.org)  
[www.mentalwellness.com](http://www.mentalwellness.com)  
[www.samaritans.org](http://www.samaritans.org)

## USA & Canada:

[www.nimh.nih.gov/publicat/index.cfm](http://www.nimh.nih.gov/publicat/index.cfm)  
[www.schizophrenia.com/](http://www.schizophrenia.com/)  
[www.schizophrenia.ca/](http://www.schizophrenia.ca/)  
[www.mentalhealth.com/dis/p20-ps01.html](http://www.mentalhealth.com/dis/p20-ps01.html)

## Schizophrenia web community

[www.groups.msn.com/SchizophreniaWebCommunity/\\_homepage.msnw?pgmarket=en-us](http://www.groups.msn.com/SchizophreniaWebCommunity/_homepage.msnw?pgmarket=en-us)

## Schizophrenia family handbook

[www.mentalhealth.com/book/p40-sc01.html](http://www.mentalhealth.com/book/p40-sc01.html)

## Basic facts about schizophrenia

[www.mentalhealth.com/book/p40-sc02.html](http://www.mentalhealth.com/book/p40-sc02.html)

## Pharmacotherapy of schizophrenia

[www.mhc.com/Algorithms/Schizophrenia/](http://www.mhc.com/Algorithms/Schizophrenia/)

## Recent research

[www.mentalhealth.com/dis-rs/frs-ps01.html](http://www.mentalhealth.com/dis-rs/frs-ps01.html)

## Personal experience about schizophrenia

[www.chovil.com/](http://www.chovil.com/)

## World fellowship for schizophrenia and allied disorders

[www.world-schizophrenia.org/](http://www.world-schizophrenia.org/)

## Reference Manual for Families and Caregivers

[www.schizophrenia.ca/refmanualindesign.html](http://www.schizophrenia.ca/refmanualindesign.html)

