

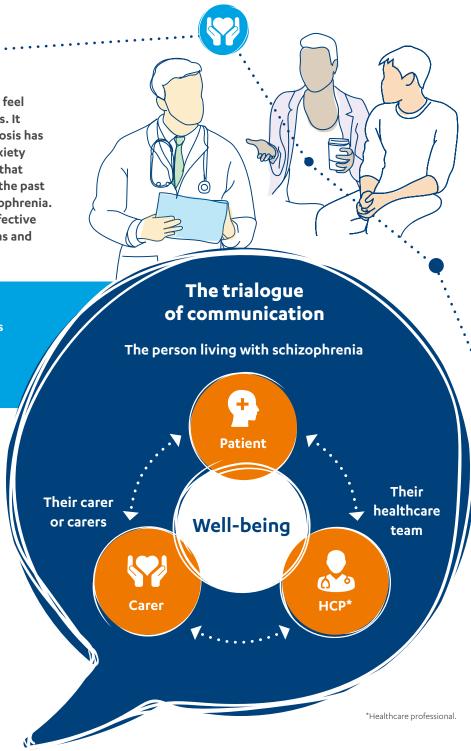
Introduction to this guide

Receiving a diagnosis of schizophrenia can feel daunting, both for you and your loved ones. It may bring on feelings of relief that a diagnosis has been made, but also shock, anger, fear, anxiety and disbelief. It is important to remember that enormous advances have been made over the past few decades in our understanding of schizophrenia. Today, with the right support, there are effective ways to help you to manage your symptoms and get back to living your life.

This guide is part of the "SmartTalk in Schizophrenia" series; each guide provides practical guidance to help you, your carer and your healthcare team make the most out of each of your consultations.

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- What to expect during discussions
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Preparing for discussions with your healthcare team

Following a diagnosis of schizophrenia, you will have regular contact with your healthcare team. Your healthcare team will be headed up by a doctor (a psychiatrist), but will likely also consist of several other members including a specialist nurse, a counsellor or a social worker.

Below are some tips to help you plan ahead and get ready for each of your discussions, so you can get the most out of each session.

Ask a family member or friend to accompany you

Having another person with you is often a good idea as they can help you to remember what was said, especially if there is a lot of information or you are feeling overwhelmed. They will also be able to offer you support if you need it.

Having a family member or other carer involved in supporting people with their treatment plan has been shown to help people with schizophrenia deal with their illness better.^{1,2}



Use the SmartTalk
Conversation Starter
document to capture
your feelings

Keep a record of how you feel

Some people find it helpful to keep a diary or to make some short notes on how they are feeling and what symptoms they have been experiencing. Even if this just covers the week before your appointment, this record will help your healthcare team see a picture of how you have been and if there is any pattern occurring. Remember to be as open and honest as possible.



Make a list of questions

It's hard to remember everything you want to ask, and the time can go quickly. Make a list of these questions in advance and have them in front of you during your discussion. It may also be a good idea to share them with your family member/friend beforehand.

What should I tell my friends about schizophrenia?

Which members of the healthcare team am I going to see regularly?

What does this word mean?

How long am I likely to be taking the treatment that you've prescribed?

What to expect during discussions

Your healthcare team will ask questions about how you've been feeling in the time since your last discussion; this may include information about school/college, work or family life, as well as your symptoms and how you've been getting on with your treatment. This will help you and your healthcare team get a clear idea of the progress you are making and also uncover any areas that need to be further addressed.



Good communication is the basis of a productive consultation. In order to have effective conversations with your doctor or other members of the healthcare team, there are a few simple things to remember:

Listen carefully: Speak up if you don't understand

Be honest and open: Try to disclose any information
the doctor or healthcare professional will want to know

Be active in discussions: Ask for more information
if there is something you want to know

sing difficult questions

Take an active part in making decisions

Although your healthcare team are experts on your condition, you are the expert on you. Evidence shows that when patients are actively involved in the choices around their care and treatment, they do better with their treatment than those who don't.^{3,4} Being involved in making decisions can help you feel more motivated to follow your care plan. If you have someone with you during discussions, they can also support you in making the right choices for you.

Decisions around what treatment to consider are important, so make sure you ask about the different options available to you. Bear in mind that treatments will likely involve a combination of pharmacological (medication) and non-pharmacological (therapy-based) treatments. There are many different types of medications and therapies for the treatment of schizophrenia.

Taking notes

It is a good idea to ask a family member, friend or carer to take notes during each discussion so you can concentrate on what is being said.

If there is something you don't understand during the conversation, ask the healthcare team member to repeat it or explain it more simply.

Addressing difficult questions

Don't be afraid to share information that seems embarrassing or to ask potentially tricky questions. These may include questions about your sex life, drug or alcohol use or your close relationships. Your healthcare team will have heard similar questions many times before and can help quide you through any problems you are facing.

Emergency contact information

Discuss what to do if you need immediate, urgent help. Find out if there is a contact number that you can call and make a note of it below. Make sure you share this number with your family members/carer.



Tel:



Shared decision-making helps patients do better on their treatment

After your appointment

Take time to think about and reflect on your consultation. Run through the notes with your carer directly after your discussion so that you are both clear on what was said and if there are any immediate things that need to be done, like making appointments with other members of the healthcare team.

Learning more about schizophrenia

During discussions with your healthcare team, it is likely that you will talk about schizophrenia in depth. This is often referred to as psychoeducation. Psychoeducation involves teaching you, your family, friends and carer all about your condition and how to cope with it in different ways.

This includes learning more about why you feel the way you do and how your treatments work – but it should also include learning how to develop communication, problem solving and stress management skills.⁵

The more you can learn about your condition, the more you can do to help yourself. For example, there are well-documented "triggers" that can cause someone with schizophrenia to relapse and undo good progress they have been making. These may be stress-related, or brought on by certain situations.

Your healthcare team may provide you with resources to take home, or refer you to another specialist to learn more. Be sure to ask about this if you feel like you aren't being given this information.

Do you know what triggers can cause a relapse in your condition?

Connect with other families affected by schizophrenia

If you feel isolated or just want someone else to talk to, it can be helpful to connect with other patients and families to exchange experiences and advice.

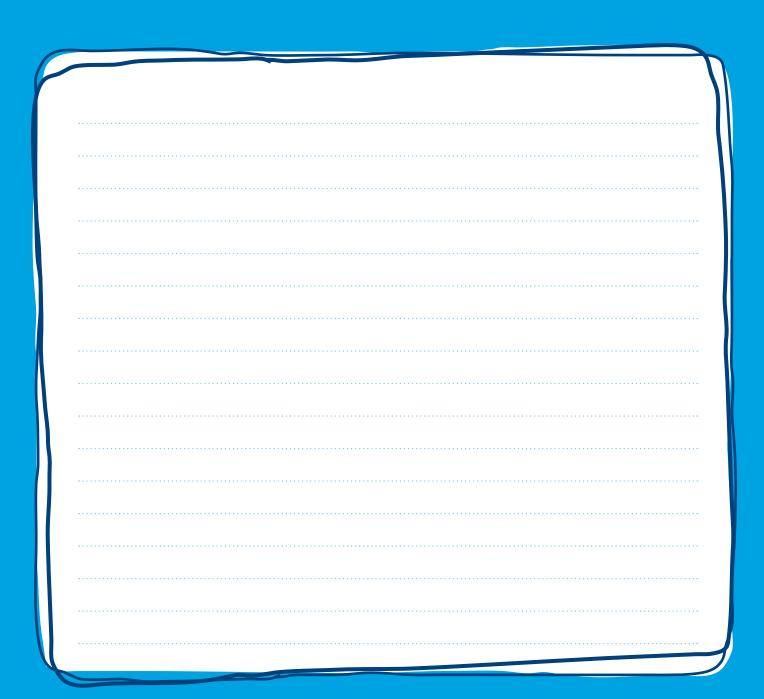


Rethink mental illness (UK) – www.rethink.org/advice-information
GAMIAN – www.gamian.eu/publications

Local Support Groups

UK – https://www.rethink.org/help-in-your-area/ **Europe** – http://eufami.org/members/members-per-country





References

- 1. Olfson, et al. Predicting medication noncompliance after hospital discharge among patients with schizophrenia. Psychiatr Serv 2000;51(2):216-22.
- 2. O'Donnell, et al. Compliance therapy: a randomised controlled trial in schizophrenia. BMJ 2003;327:834.
- 3. Greene and Hibbard. Why does patient activation matter? An examination of the relationships between patient activation and health-related outcomes. J Gen Intern Med 2012;27:520-26.
- 4. Alegria, et al. Evaluation of a patient activation and empowerment intervention in mental health care. Med Care 2008;46(3):247-56.
- 5. Motlova, et al. Psychoeducation as an opportunity for patients, psychiatrists, and psychiatric educators: why do we ignore it? Academ Psychiatry 2017;41(4):447-51.







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Signatory Approvals		
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