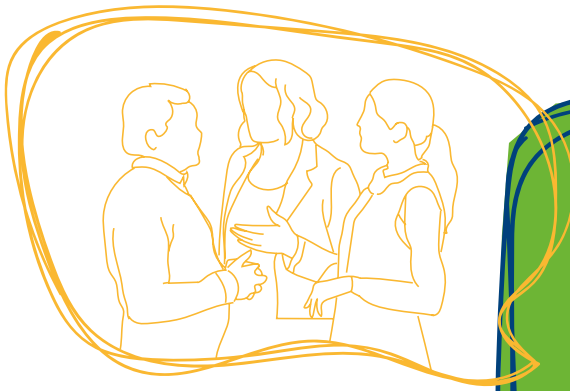


SmartTalk in **Schizophrenia**

for carers



Helping to make every appointment count

Janssen Neuroscience
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Introduction to this guide

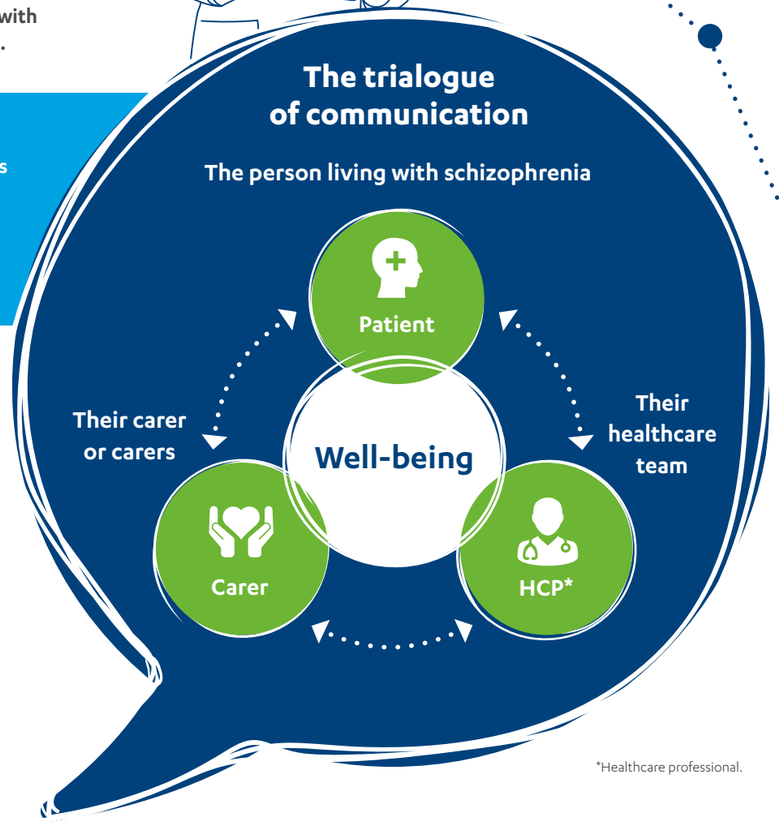
A diagnosis of schizophrenia can feel daunting for the person receiving the diagnosis, but also for their family, friends and loved ones around them. It may bring on feelings of relief that a diagnosis has been made, but also shock, anger, fear, anxiety and disbelief. It is important to remember that enormous advances have been made over the past decades in our understanding of schizophrenia. Today, with the right support, there are a number of effective ways to manage the symptoms of schizophrenia, helping the person living with schizophrenia to get back to living their life.



This guide is part of the "SmartTalk in Schizophrenia" series; each guide provides practical guidance to help you as a carer, the person you care for and their healthcare team to make the most out of each consultation.

Contents

- Your role as a carer
- Preparing for discussions with the healthcare team
  - Sample questions to ask
- What to expect during discussions
- Emergency contact information
- After your appointment
- Sources for more information
- Notes



*Healthcare professional.

Your role as a carer

Providing support and care to someone living with schizophrenia can be challenging, but also extremely rewarding.

Having a family member or other carer involved in supporting people with schizophrenia can help them deal with their illness better.[1,2] Your support can help the person you care for feel less isolated and more connected, manage their treatment plan and generally make their condition more manageable.

It is useful to sit down with the person you care for to discuss and decide what role and responsibilities they would like you to take on, and what they feel more comfortable handling themselves. This is an opportunity to both decide how involved you should be; for example, whether they want you to help them decide on medication and other therapies, such as talking therapies, or provide them with everyday support. Remember that you can revisit this discussion and make any changes at any point in time.



Preparing for discussions with the healthcare team

Following a diagnosis of schizophrenia, the person that you care for will have regular contact with their healthcare team. Their 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.

Make some notes or keep a feelings and behaviours record for the person you care for

As a carer, you have a unique perspective and may notice behaviours or changes in behaviours in the person you care for between visits. Try to encourage them to write down how they feel day-to-day, or offer to do this together. Even if this just covers the week before the appointment, this record will help the healthcare team see a picture of how they have been and if any pattern is occurring.

Make a list of questions

It's hard to remember everything you want to ask, and the time can go quickly. If appropriate 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 your list with the person you care for beforehand.

Use the **SmartTalk Conversation Starter** document to capture behaviours

What to expect during discussions

The healthcare team will want to know how things have been going since the last discussion. As a carer, your insight is extremely useful and you are well placed to notice changes in the behaviour of the person you care for, changes in family dynamics, changes in symptoms/side effects and whether they have been taking their medication as prescribed.

Rules of good communication

Good communication is the basis of a productive consultation. In order to have effective conversations with the 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 team would find useful to know***

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

Take an active part in making decisions

Evidence supports that when patients and carers are actively involved in the choices around their care and treatment, they do better with their treatment than those that are more passive.[3,4] Making decisions together with the healthcare team can help you and the person you care for feel more motivated and confident.

Decisions around treatment options are important; make sure you ask lots of questions so that the right choice can be made. 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

If you are able, it is a good idea to offer to take notes during each discussion so the person you care for can concentrate on what's 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

Sometimes there are questions that may be difficult for the person you care for to raise during a consultation, such as questions around sex life or drug/alcohol use. Try to encourage them to be open with the healthcare team and respect that they may want time alone with them if they prefer to discuss something sensitive.

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 other members of your family/close friends.

Tel:

After your appointment

Ask what you can do at home to continue to support the person you care for. Run through your notes directly after each 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 the healthcare team, it is likely that you will talk about schizophrenia in depth. This is often referred to as psychoeducation. Psychoeducation involves teaching you and the person you care for all about your condition and how to cope with it in different ways.

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

The more you can learn about schizophrenia, the more you can do to help.[6] For example, there are well-documented "triggers" that can cause someone to relapse and undo good progress they have been making. These may be stress-related, or brought on by certain situations. Find out what these are, recognise the symptoms and try to work out what their triggers might be, so you can try to avoid these situations.

The 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 for the person you care for?

Connect with other families affected by schizophrenia

People with schizophrenia and their families often report feelings of isolation and being misunderstood. Some find it helpful to connect with other patients and families to exchange experiences and advice.



Sources for more information

SANE (UK) – www.sane.org.uk/resources
Rethink mental illness (UK) – www.rethink.org/advice-and-information/
GAMIAN – www.gamian.eu/publications

For carers specifically:

EUFAMI – www.eufami.org/members/

- **Schizophrenia carer playbook** – www.eufami.org/wp-content/uploads/2019/02/schizophrenia_carer_playbook.pdf

Local Support Groups

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

Notes 

References

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5. Motlova, *et al.* Psychoeducation as an opportunity for patients, psychiatrists, and psychiatric educators: Why do we ignore it? *Academ Psychiatr* 2017;41(4):447–51.
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Signatory Approvals	
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