

Schizophrenia

This factsheet covers what schizophrenia is, what the symptoms are and how you can get treatment. This information is for people affected by schizophrenia in England who are 18 or over. It's also for their carers, friends and relatives and anyone interested in this subject.

Key Points.

- Schizophrenia is a mental illness that affects the way you think. It affects about 1 in every 100 people.
- Schizophrenia may develop during early adulthood. There are different types of schizophrenia.
- You may experience 'positive' and 'negative' symptoms of schizophrenia.
- Positive symptoms are when you experience things in addition to reality. For example, you might see or hear things that others don't.
 Or believe things that other people don't.
- Negative symptoms are when you lose the ability to do something. For example, losing motivation to do things or becoming withdrawn. They often last longer than positive symptoms.
- Professionals aren't sure of what causes schizophrenia. There are many different causes. The main factors that can contribute towards the development of schizophrenia are believed to be genetics and the environment.
- There are different types of treatment available for schizophrenia, such as medication and psychological treatments.

This factsheet covers:

- 1. What is schizophrenia?
- 2. What myths are there about schizophrenia?
- 3. What are the symptoms of schizophrenia and how is it diagnosed?
- 4. What are the types of schizophrenia?
- 5. <u>What causes schizophrenia?</u>
- 6. How is schizophrenia treated?
- 7. Is it possible to recover from schizophrenia?
- 8. What if I am not happy with my treatment?
- 9. What can I do to manage schizophrenia?
- 10. What risks and complications can schizophrenia cause?
- 11. What if I am a carer, friend or relative?

1. What is schizophrenia?

Schizophrenia is a mental illness which affects the way you think. The symptoms may affect how you cope with day to day life.

You could be diagnosed with schizophrenia if you experience some of the following symptoms.

- Hallucinations
- Delusions
- Disorganised thinking
- Lack of motivation
- Slow movement
- Change in sleep patterns
- Poor grooming or hygiene
- Changes in body language and emotions
- Less interest in social activities
- Low sex drive

Everyone's experience of schizophrenia is different. Not everyone with schizophrenia will experience all these symptoms.

According to the Royal College of Psychiatrists, schizophrenia affects around 1 in 100 people.¹ For some people, schizophrenia can develop during young adulthood and develop slowly. The early stage of the illness is called 'the prodromal phase'. During this phase your sleep, emotions, motivation, communication and ability to think clearly may change.²

We have created a video about 'what is schizophrenia?'. You can watch this video by clicking on the following link: www.youtube.com/watch?v=J1s4YCloCbo

What is psychosis, and how is it related to schizophrenia?

Psychosis is a medical term. If you live with psychosis you will process the world around you differently to other people. This can include how you experience, believe or view things.

Experiencing psychosis is usually part of schizophrenia. People who live with other mental health conditions can experience psychosis too.

You can find more information about '**Psychosis'** at <u>www.rethink.org</u>. Or call our General Enquiries team on 0121 522 7007 and ask them to send you a copy of our factsheet.

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2. What myths are there about schizophrenia?

There are some myths or mistaken beliefs about schizophrenia which come from the media. For example,

• 'Schizophrenia means someone has a split personality'

This is not the case. The mistake may come from the fact that the name 'schizophrenia' comes from two Greek words meaning 'split' and 'mind'.³

• 'People who live with schizophrenia are dangerous'

Those who live with schizophrenia aren't usually dangerous. People who live with schizophrenia are far more likely to be harmed by other people than harm others.⁴

There is a higher risk of violent behaviour from those who live with schizophrenia. But, as with people who don't live with schizophrenia, much of the risk is linked to the use of street drugs or alcohol.⁵

Sometimes people who live with schizophrenia commit violent crimes. The media often report them in a way which emphasises the person's mental health diagnosis. This can create fear and stigma in the general public. But it should be remembered that:

- violent crimes are also committed by people who don't live with schizophrenia,
- it's often later found that the person was failed or neglected by the mental health system, and
- the crime might have been prevented if the person had received the care and support they needed.

So, it's not right to say that schizophrenia equals dangerous.

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3. What are the symptoms of schizophrenia and how is it diagnosed?

How is schizophrenia diagnosed?

Only a psychiatrist can diagnose you with schizophrenia after a full psychiatric assessment. You may have to see the psychiatrist a few times before they diagnose you. This is because they need to see how often you are experiencing symptoms.

There are currently no blood tests or scans that can prove if you have schizophrenia. So, psychiatrists use manuals to diagnose schizophrenia and other mental illnesses.

The 2 main manuals used by medical professionals are the:

- International Classification of Diseases (ICD-11) which is produced by the World Health Organisation (WHO), or
- Diagnostic and Statistical Manual (DSM-5) which is produced by the American Psychiatric Association (APA).

The manuals explain which symptoms should be present, and for how long for you to receive a diagnosis. For example, according to the NHS you need to be hearing voices for at least 1 month before you can be diagnosed.⁶ Mental health professionals may say you have psychosis before they diagnose you with schizophrenia.

What is the future of diagnosis in schizophrenia?

There are many research studies being conducted across the world on how to better diagnose schizophrenia. For example, a recent study found through looking at images of the brain, there may be different sub-types of schizophrenia.⁷

In the future, brain scans and other tools may be used to diagnose different types of schizophrenia. This will hopefully allow people who live with schizophrenia to receive more personalised treatments. But these approaches are still being developed.

What are the symptoms of schizophrenia?

The symptoms of schizophrenia are commonly described as positive symptoms or negative symptoms. This doesn't mean that they are good or bad.

'Positive' symptoms are experienced in addition to reality. 'Negative' symptoms are a 'lack' of feelings or behaviours that are normally present. Both of these types of symptoms can affect your ability to function.

The negative symptoms of schizophrenia can often appear several years before somebody experiences their first episode of psychosis. ⁸

A diagnosis of schizophrenia does not mean that you will experience all types of symptoms. The way that your illness affects you will depend on the type of schizophrenia that you have. For example, not everyone with schizophrenia will experience hallucinations or delusions.

What are the 'positive symptoms' of schizophrenia?

The term 'positive symptoms' is used to describe symptoms that are experienced in addition to reality. These symptoms can also happen in other mental illnesses. They are usually called 'psychotic symptoms' or 'psychosis'.⁹

The following are some examples of positive symptoms.¹⁰

- Hallucinations
- Delusions
- Disorganised thinking

Hallucinations

These are when you see, smell, hear or feel things that other people don't.¹¹ For example:

- hearing voices,
- seeing things which other people don't see,
- feeling someone touching you who is not there, or
- smelling things which other people cannot.

Hearing voices or other sounds is the most common hallucination. ¹² Hearing voices is different for everyone. For example, voices may be:

- female or male,
- someone you know or someone you've never heard,
- sounds such as humming,
- in a different language or different accent to your own,
- whispering or shouting, or
- negative and disturbing.

You might hear voices sometimes or all of the time.

Delusions

These are beliefs that are not based on reality. Even though they feel real to you. ¹³ Other people are likely to disagree with your beliefs. A delusion is not the same as holding a religious or spiritual belief which others don't share. For example, you may believe:

- that you are being followed by secret agents or members of the public,
- that people are out to get you or trying to kill you. This can be strangers or people you know,
- that something has been planted in your brain to monitor your thoughts,
- you have special powers, are on a special mission or in some cases that you are a god, or
- your food or water is being poisoned.

You may not always find these experiences distressing, although people often do. You may be able to stay in work and function well even if you have these experiences.

Disorganised thinking¹⁴

Disorganised thinking means you might start talking quickly or slowly. Things you say might not make sense to other people. You may switch topics, or your words may become jumbled, making conversations difficult for other people to understand..

This is sometimes known as 'word salad'.

What are the 'negative symptoms' of schizophrenia?

The term 'negative symptoms' is used to describe symptoms that involve loss of ability and enjoyment in life.

The following are some examples of negative symptoms.^{15,16}

- Lack of motivation
- Losing interest in life and activities
- Problems concentrating
- Not wanting to leave your house
- Changes to your sleeping patterns
- Not wanting to have conversations with people
- Feeling uncomfortable with people
- Feeling that you haven't got anything to say
- Losing your normal thoughts and feelings
- No energy
- Poor grooming or hygiene

Cognitive Impairment

Cognitive impairment is another type of 'negative symptom'. Cognitive impairment is when you have problems with:

- remembering things,
- learning new things,
- concentrating,
- making decisions.

Negative symptoms aren't as obvious as positive symptoms. They may last longer, and stay after positive symptoms fade away. Some people with schizophrenia feel that the negative symptoms of their illness are more serious than the positive symptoms. The experience of negative symptoms varies for each person.

You can find more information about:

- Psychosis
- Hearing voices

at <u>www.rethink.org</u>. Or call our General Enquiries team on 0121 522 7007 and ask them to send you a copy of our factsheet.

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4. What are the types of schizophrenia?

There are different types of schizophrenia.¹⁷ The International Classification of Diseases (ICD-11) manual describes them as below.

Schizophrenia with paranoia¹⁸

- Common form of schizophrenia.
- Prominent hallucinations, particularly hallucinations where you hear voices or sounds.
- Prominent delusions.
- Speech and emotions may be unaffected.

Hebephrenic schizophrenia^{19,20}

- Irresponsible and unpredictable behaviour.
- Prominent disorganised thoughts.
- Problems with speech.
- Self-isolation.
- Pranks, giggling and health complaints.
- Usually diagnosed in adolescents or young adults.

Catatonic schizophrenia²¹

- Rarer than other types.
- Unusual movements, often switching between being very active and very still.
- You may not talk at all.

Simple schizophrenia²²

- Negative symptoms are prominent early and get worse quickly.
- Positive symptoms are rare.

Residual schizophrenia²³

This type of schizophrenia is diagnosed in the later stages of schizophrenia. You may be diagnosed with this if you have a history of schizophrenia but only continue to experience negative symptoms.

Schizophreniform²⁴

Schizophreniform disorder is a type of psychotic illness with symptoms similar to those of schizophrenia. But symptoms last for a short period.

Unspecified schizophrenia²⁵

Symptoms meet the general conditions for a diagnosis, but do not fit in to any of the above categories.

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5. What causes schizophrenia?

Nobody knows exactly what causes schizophrenia, it is likely to be the result of several factors. For example:²⁶

• **Stress**. Some people can develop the illness as a result of a stressful event, such as the death of a loved one or the loss of a job.

- **Genetics**. You are more likely to develop schizophrenia if you have a close relation with the illness.
- Brain damage. This is usually damage that has stopped your brain from growing normally when your mother was pregnant. Or during birth.
- **Drugs and alcohol**. Research has shown that stronger forms of cannabis increase your risk of developing schizophrenia.
- A difficult childhood. If you were deprived, or abused, as a child this can increase your risk of developing a mental illness. Including schizophrenia.

There is research to suggest that may be an association between menopause and schizophrenia. This may be due to the hormonal changes during this stage of life for women.²⁷

You can find more information about:

- Does mental illness run in families?
- Drugs, alcohol and mental health
- Cannabis and mental health

at <u>www.rethink.org</u>. Or call our General Enquiries team on 0121 522 7007 and ask them to send you a copy of our factsheet.

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6. How is schizophrenia treated?

There are different types of treatment available. Medical professionals should work with you to find the right treatment for you. The National Institute for Health and Care Excellence (NICE) recommends that you should be offered a combination of medication and talking therapies.²⁸

People who live with schizophrenia can respond to treatment differently. For many treatment helps to reduce symptoms to help make daily life easier. You may find that you need to continue with treatment to keep well.

For every 5 people with schizophrenia:29

- 1 will get better within 5 years of their first obvious symptoms.
- 3 will get better but will have times when they get worse again.
- 1 will have troublesome symptoms for long periods of time.

What medication should I be offered?

Your doctor may offer you medication known as an 'antipsychotic'. These reduce the symptoms of schizophrenia, but don't cure the illness. Your healthcare professionals should work with you to help choose a medication. If you want, your carer can also help you make the decision. Doctors should explain the benefits and side effects of each drug.

In the past, some antipsychotics had negative side effects. Some people find that the side effects of newer antipsychotic drugs are easier to manage.

If you have been on an antipsychotic for a few weeks and the side effects are too difficult to cope with, you should ask your doctor about trying a different one. NICE state that people who have not responded to at least 2 other antipsychotic drugs should be offered clozapine.³⁰

Antipsychotic medication can come as tablets, a syrup or as an injection. The injections are called a depot. You may find a depot useful if you struggle to remember to take your medication, or might take too much.³¹ Your doctor should take your views into account when prescribing you medication.

Your medication should be reviewed at least once a year.³²

What type of psychosocial treatment will I be offered?

Your doctor should offer you psychosocial treatments. These treatments help you to look at how your thoughts and behaviour are influenced by the people and society you live in. This can include the following.

Cognitive behavioural therapy for psychosis (CBTp)

NICE says the NHS should offer cognitive behavioural therapy for psychosis (CBTp) to all adults with psychosis or schizophrenia.³³ CBTp does not get rid of your symptoms. CBTp can help you to manage your feelings and symptoms better.

Family intervention

NICE recommend family members of people with psychosis and schizophrenia should be offered family intervention.³⁴ This can help to improve how you feel about family relationships. This can help reduce any problems in the family caused by your symptoms.

Family intervention is where you and your family work with mental health professionals to help to manage relationships.

It should be offered to people who you live with or who you are in close contact with. The support that you and your family are given will depend on what problems there are and what preferences you all have. This could be group family sessions or individual sessions.

Your family should get support for 3 months to 1 year and should have at least 10 planned sessions.³⁵

Family intervention could be to,36

- learn more about your symptoms, and
- improve communication among family members.

Family intervention could help you and your family to:

- learn more about your symptoms,
- understand what is happening to you,
- improve communication with each other,
- know how to support each other,
- think positively,
- become more independent,
- be able to solve problems with each other,
- know how to manage a crisis, and
- improve mental wellbeing.

Psychoeducation

This involves learning about your illness, your treatment and how to spot early signs of becoming unwell again. It can prevent you having a relapse. Psychoeducation may also be helpful for anyone who is supporting you, such as family, a partner or a trusted colleague.

Arts therapies

This can help to reduce the negative symptoms of the illness.³⁷ It can help you to express yourself more creatively.

NHS Early intervention teams

Early intervention teams are specialist NHS services which provide treatment and support for people when they first experience psychosis and schizophrenia. They are usually made up of psychiatrists, psychologists, mental health nurses, social workers and support workers.

Your doctor should refer you to an early intervention team when they diagnose you with a first episode of psychosis. NICE suggests that you should start treatment within 2 weeks of referral.³⁸ Early intervention services operate differently across the country. If there is not a service in your area, then you should have access to a crisis or home treatment team.

You can find more information about:

- Antipsychotics
- Talking treatments
- NHS Mental Health Teams (MHTs)
- Medication choice and managing problems

at <u>www.rethink.org</u>. Or call our General Enquiries team on 0121 522 7007 and ask them to send you a copy of our factsheet.

7. Is it possible to recover from schizophrenia?

Many people who live with schizophrenia have recovery journeys that lead them to live meaningful lives.

Recovery can be thought of in terms of:

- clinical recovery, and
- personal recovery.

What is clinical recovery?

Your doctor might have talked to you about 'recovery'. Some doctors and health professionals think of recovery as:

- no longer having mental illness symptoms, or
- where your symptoms are controlled by treatment to such a degree that they are not significantly a problem.

Sometimes this is called 'clinical recovery'.

Everyone's experience of clinical recovery is different.

- Some people completely recover from schizophrenia and go on to be symptom free.
- Some who live with schizophrenia can improve a great deal with ongoing treatment.
- Some improve with treatment but need ongoing support from mental health and social services.

What is personal recovery?

Dealing with symptoms is important to a lot of people. But some people think that recovery is wider than this. We call this 'personal recovery.'

Personal recovery means that you can live a meaningful life.

What you think of as being a meaningful life might be different to how other people see it. You can think about what you would like to do to live a meaningful life and work towards that goal.

Below are some ways you can think of recovery.

- Taking steps to get closer to where you would like to be. For example, you may want a better social life.
- Building hope for the future. You could change your goals, skills, roles or outlook.

Recovery is an ongoing process. It is normal to have difficulties or setbacks along the way. You could describe yourself as 'recovered' at any stage if you feel things are better than they were before.

What can help me recover?

You may want to think about the following questions.

- What do I want to have done by this time next year?
- How can I do it?
- Do I need support to do it?
- Who can support me?

The following things can be important in recovery.

- **Hope**. You might find it helpful to read stories from people about their recovery or to join a support group.
- Acceptance. It can be helpful to accept your illness but also to focus on the things you can do. It helps to have realistic goals.
- **Control**. It might help you be more in control of things in your life, like treatment or support options.
- **Stability**. Having a stable housing and financial situation can play a big part in recovery you might need to get help with these things.
- Relationships. Contact with people can help you to stay well.
- **Treatment**. The right treatment can help to start and maintain recovery.
- Lifestyle. Things like sleep, exercise, diet and routine can be important. And making changes to
- **Being active**. New activities can help you to learn new skills and meet new people. This might include working, studying, volunteering or doing things like gardening or joining a club.

You can find out more information about '**Recovery'** at <u>www.rethink.org</u>. Or call our General Enquiries team on 0121 522 7007 and ask them to send you a copy.

Sometimes it can be helpful to hear other people's recovery stories.

Sarah's story

What it took for me to recover from schizophrenia was having people who believed in me and who did not give up on me.

Their belief and love for me encouraged me to believe in myself, so I could have the patience to heal slowly over several years, with the help of steady, continued medical treatment.

Their love and confidence in me gave me a reason and the strength to try and endure the emotional pain and social stigma of having schizophrenia.

8. What if I am not happy with my treatment?

If you are not happy with your treatment you can:

- talk to your doctor about your treatment options,
- ask for a second opinion,
- get an advocate to help you speak to your doctor,
- contact Patient Advice and Liaison Service (PALS) and see whether they can help, or
- make a complaint.

There is more information about these options below.

Treatment options

You should first speak to your doctor about your treatment. Explain why you are not happy with it. You could ask what other treatments you could try.

Tell your doctor if there is a type of treatment that you would like to try. Doctors should listen to your preference. If you are not given this treatment, ask your doctor to explain why it is not suitable for you.

Second opinion

A second opinion means that you would like a different doctor to give their opinion about what treatment you should have. You can also ask for a second opinion if you disagree with your diagnosis.

You don't have a right to a second opinion. But your doctor should listen to your reason for wanting a second opinion.³⁹

Advocacy

An advocate is independent from the mental health service. They are free to use. They can be useful if you find it difficult to get your views heard.

There are different types of advocates available. Community advocates can support you to get a health professional to listen to your concerns. And help you to get the treatment that you would like.

You can search online to search for a local advocacy service. If you can't find a service, you can call our advice service on 0808 801 0525. We will look for you. But this type of service doesn't exist in all areas.

The Patient Advice and Liaison Service (PALS)

PALS is part of the NHS. They give information and support to patients.

You can find your local PALS' details through this website link: <u>www.nhs.uk/Service-Search/Patient-advice-and-liaison-services-</u> (PALS)/LocationSearch/363.

Complaints

If you can't sort your problem, you can make a complaint. This is where your concerns are investigated in further detail.

You can ask a member of your health team to explain how to make a complaint

You can ask an advocate to help you make a complaint. Advocates that do this are called Independent Health Complaints Advocates. They are free to use and don't work for the NHS.

You can find out more about:

- Medication Choice and managing problems
- Second opinions
- Advocacy
- Complaining about the NHS or social services

at <u>www.rethink.org</u>. Or call our General Enquiries team on 0121 522 7007 and ask them to send you a copy of our factsheet.

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9. What can I do to manage schizophrenia?

People deal with their experience in different ways. You might need to try different things before finding something that works.

Support groups

You could join a support group. A support group is where people come together to share information, experiences and give each other support. Hearing about the experiences of others can help you feel understood. This may help you feel less alone and boost your self-confidence.

You might be able to find a local group by searching online. Rethink Mental Illness have support groups in some areas. You can find out what is available in your area, or get help to set up your own support group if you follow this link:

www.rethink.org/about-us/our-support-groups.

Or you can call our advice service on 0808 801 0525 for more information.

Recovery College

Recovery colleges are part of the NHS. They offer free courses about mental health to help you manage your experiences. They can help you to take control of your life and become an expert in your own wellbeing and recovery. You can usually self-refer to a recovery college. But the college may tell your care team. Unfortunately, recovery colleges are not available in all areas. To see if there is a recovery college in your area you can use a search engine such as Google. Or you can call our advice service on 0808 801 0525 for more information.

Peer support through the NHS

Your doctor may offer you peer support. Peer support is when you work with someone who has lived experience of psychosis. And who are now in recovery.⁴⁰ They should be able to offer advice and support with: ⁴¹

- side effects,
- recognising and coping with symptoms,
- what to do in a crisis,
- meeting other people who can support you, and recovery.

Self-management techniques

Managing your condition on your own is called self-help. Health professionals may offer you help to manage your condition on your own. They may call this a self-management programme.

You can try some of the suggestions below to manage or cope with upsetting experiences.

- Speak to a supportive, friend, family member or someone else who has schizophrenia or has experienced psychosis.
- Try relaxation techniques, mindfulness and breathing exercises.
- Do things that you find relaxing such as having a bath
- Try a complementary therapy such as meditation, massage, reflexology or aromatherapy.
- Stick to a sleep pattern, eat well and look after yourself.
- Set small goals such as going out for a small amount of time every day. Reward yourself when you achieve a goal.
- Do regular exercise such as walking, swimming, yoga or cycling.

Taking control of the voices

If you hear voices, you could:

- talk back to them,
- distract yourself, or
- keep a diary.

You can find out more about:

- Recovery
- Hearing voices
- Psychosis
- Complementary and alternative treatments

at <u>www.rethink.org</u>. Or call our General Enquiries team on 0121 522 7007 and ask them to send you a copy of our factsheet.

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10. What risks and complications can schizophrenia cause?

Physical health

Research suggests that people with serious mental illness (SMI), such as schizophrenia, have a shorter life expectancy. People with mental illness may die 15 to 20 years earlier than the general population.^{42,43} This may because people who live with SMI are at higher risk of having a range of health issues. Such as being overweight, having heart disease, smoking and diabetes.^{44,45}

Because of these issues, NICE recommends that when you start taking antipsychotic medication, your doctor should do a full range of physical health checks. This should include weight, blood pressure and other blood tests. These checks should be repeated regularly. ⁴⁶

Mental health professionals are responsible for doing these checks for the first year of treatment. Responsibility may then pass to your GP. Your doctor or mental health team should offer you a programme which combines healthy eating and physical health checks. You should be supported by a healthcare professional to help stop smoking.

Suicide

The risk of suicide is increased for people with schizophrenia. Research indicates that around 5–13% of people who live with with schizophrenia die by suicide.⁴⁷

Research has found that the increased risk is not usually because of positive symptoms. The risk of suicide is associated more to affective symptoms, such as low mood.⁴⁸

Key risk factors for suicide include: 49

- previous suicide attempts,
- feelings of hopelessness,
- depressive symptoms,
- family history of psychiatric illness,
- physical health issues associated to schizophrenia,
- not using treatment,
- younger age,
- alcohol and drug use,
- family history of depression,
- family history of suicide, and
- not using treatment.

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11. What if I am a carer, friend or relative?

It can be distressing if you are a carer, friend or relative of someone who has schizophrenia. You can get support.

How can I get support for myself?

You can do the following.

- Speak to your GP about medication and talking therapies for yourself.
- Speak to your relative's care team about family intervention. For more information about family intervention see <u>section 5</u> of this factsheet.
- Speak to your relative's care team about a carer's assessment.
- Ask for a carers assessment.
- Join a carers service. They are free and available in most areas.
- Join a carers support group for emotional and practical support. Or set up your own.

What is a carers assessment?

NICE guidelines state that you should be given your own assessment through the community mental health team (CMHT) to work out what effect your caring role is having on your health. And what support you need. Such as practical support and emergency support.⁵⁰

The CMHT should tell you about your right to have a carers assessment through your local authority. To get a carer's assessment you need to contact your local authority.

How do I get support from my peers?

You can get peer support through carer support services or carers groups. You can search for local groups in your area by using a search engine such as Google. Or you can call our advice service on 0808 801 0525. They will search for you.

How can I support the person I care for?

You can do the following.

- Read information about schizophrenia, hearing voices or psychosis.
- Ask the person you support to tell you what their symptoms are and if they have any self-management techniques that you could help them with.
- Encourage them to see a GP if you are worried about their mental health.
- Ask to see a copy of their care plan. They should have a care plan if they are supported by a care coordinator.
- Help them to manage their finances.

What is a care plan?

The care plan is a written document that says what care your relative or friend will get and who is responsible for it.

A care plan should always include a crisis plan. A crisis plan will have information about who to contact if they become unwell. You should be given information about what to do in a crisis. ⁵¹ You can use this information to support and encourage them to stay well and get help if needed.

Can I be involved in care planning?

As a carer you should be involved in decisions about care planning. But you don't have a legal right to this. The healthcare team should encourage the person that you care for to allow information to be shared with you.⁵²

What can I do if my friend or family member is in crisis?

If you think your friend or relative is experiencing psychotic symptoms you may want them to see a doctor. This can be difficult if they do not believe they are unwell. This is called 'lacking insight'.

If you think that your friend or family member is a risk of harm to themselves or others you can:

- call their GP and tell them,
- call 999 and ask for an ambulance,
- take them to A&E, or
- use your nearest relative (NR) rights to ask for a Mental Health Act assessment.

Your nearest relative is a legal term under the Mental Health Act. It is different to 'next of kin.' Your nearest relative has certain rights.

What is a Mental Health Act Assessment?

A Mental Health Act assessment is an assessment to see if someone needs to go to hospital to be treated against their will.

How do I ask for a Mental Health Act assessment?

If you are concerned that your friend or family member is a risk to themselves or other people you could try and get a Mental Health Act assessment by contacting an Approved Mental Health Professional (AMHP).

An AMHP works for social services but can often be found through the community mental health team (CMHT) or mental health crisis team. It is best if the request comes from your friend or family member's nearest relative.

The only way to give someone treatment who doesn't want it is through the Mental Health Act. Your friend or family member will only be detained under the Mental Health Act if they are assessed as a high risk to themselves or other people.

There is no definition for what high risk means. It could include:

- not being aware of hazards because of delusional thoughts or confusion,
- refusing to eat for fear that food is contaminated, or
- threatening to harm others due to delusions or severe paranoia.

Think about the following questions:

- Who is in danger of being harmed?
- What evidence do you have of this? Have they done it before?
- How has their behaviour changed?
- When did their behaviour change?
- Are they aggressive? If so, how?
- Have they tried to harm themselves or other people? If so, how and when did it happen?
- Have they stopped eating, drinking or bathing?
- Have you got any evidence to show the changes in their behaviour?

Because of the stress involved in detaining someone it is usually the best option if your friend or family member can be encouraged to get the help for themselves, such as though their GP. There is no extra care available whilst detained, compared to in the community.

You can find out more about:

- Supporting someone with a mental illness
- Getting help in a crisis
- Suicidal thoughts. How to support someone
- Responding to unusual thoughts and behaviours
- Carers assessment
- Confidentiality and information sharing. For carers, friends and family
- Money matters: dealing with someone else's finances
- Worried about someone's mental health
- Benefits for carers
- Stress
- Nearest Relative
- Mental Health Act

at <u>www.rethink.org</u>. Or call our General Enquiries team on 0121 522 7007 and ask them to send you a copy of our factsheet.

Further Reading

At Rethink Mental Illness, we have done some reports into severe mental illness. You can read more about this here: <u>www.rethink.org/aboutus/who-we-are/the-schizophrenia-commission</u>

Eleanor Longden – The voices in my head

This video tells Eleanor's story about the voices she hears. She talks about her journey back to better mental health. And she makes the case that by learning to listen to her voices she was able to survive.

Website: <u>www.ted.com/talks/eleanor_longden_the_voices_in_my_head</u> The BBC – Why do people hear voices in their heads?

This BBC radio programme looks at what causes people to hear voices. You can listen to it online or download it.

Website: www.bbc.co.uk/programmes/w3csvtc3

Understanding Voices

A website produced by Durham University together with mental health professionals, voice-hearers and their families. The website aims to make it easier for people to find information about different approaches to voicehearing. And ways of supporting those who are struggling with the voices they hear.

Website: https://understandingvoices.com/

Me and My Mind

A website produced by the South London and Maudsley (SLaM) NHS Foundation Trust. The service is for young people in the SLaM area. But there is lots of useful information on the website and resources you can download.

Website: www.meandmymind.nhs.uk/

Avatar Therapy

Researchers have been looking into how computer-based treatment may help with hearing voices. ^{53,54} This treatment is known as avatar therapy. Avatar therapy is not available on the NHS at the moment. In this therapy you create a computer-generated face with a voice which is like a voice you hear. This is called an 'avatar'. You work with a therapist to talk to the avatar and gain more control over the voice you hear. Results show that this therapy is helpful for some people. But there is more research taking place.

Avatar Therapy UCL webpage: www.phon.ucl.ac.uk/project/avtherapy/

Caring for someone with psychosis or schizophrenia

This is a free, online course provided by Kings College in London. It is aimed at people who care for people who have psychosis or schizophrenia.

Website: www.futurelearn.com/courses/caring-psychosis-schizophrenia

The Royal College of Psychiatrists

Their website has reliable information about different mental illnesses.

Telephone: 020 7235 2351

Email through online form: www.rcpsych.ac.uk/about-us/contact-us Website: www.rcpsych.ac.uk/about-us/contact-us

The Hearing Voices Network (HVN)

HVN are a charity. They give information, support and understanding to people who hear voices and those who support them. They also support people who have visual hallucinations and people who have tactile sensations. They have a list of self-help groups across the country.

Email: <u>info@hearing-voices.org</u> Website: <u>www.hearing-voices.org</u>

Intervoice

Intervoice are a charity. They encourage people all over the world to share ideas through their online community. You can also find information about hearing voices through their articles and resources.

Email: <u>info@intervoiceonline.org</u> Website: <u>www.intervoiceonline.org</u>

Headway

Help people with a brain injury and their families.

Telephone: 0808 800 2244

Address: Headway - the brain injury association, Bradbury House, 190 Bagnall Road, Old Basford, Nottingham, NG6 8SF E-mail: <u>helpline@headway.org.uk</u> Website: <u>www.headway.org.uk</u>

¹ Royal College of Psychiatrists. Schizophrenia

www.rcpsych.ac.uk/healthadvice/parentsandyouthinfo/parentscarers/schizophrenia.aspx (accessed 14th December 2020).

Useful Contacts

References

² Larson et al. *Early signs, diagnosis and therapeutics of the prodromal phase of schizophrenia and related psychotic disorders.* 2010; 10(8): 1347–1359. DOI: 10.1586/ern.10.93

³ Psychology Today. A brief history of schizophrenia.

www.psychologytoday.com/gb/blog/hide-and-seek/201209/brief-history-schizophrenia (accessed 16th December 2020).

⁴ Royal College of Psychiatrists. Schizophrenia

www.rcpsych.ac.uk/healthadvice/parentsandyouthinfo/parentscarers/schizophrenia.aspx (accessed 9th February 2021).

⁵ Royal College of Psychiatrists. Schizophrenia

www.rcpsych.ac.uk/healthadvice/parentsandyouthinfo/parentscarers/schizophrenia.aspx (accessed 9th February 2021).

⁶ NHS Choices. Schizophrenia –

diagnosis.<u>www.nhs.uk/conditions/schizophrenia/diagnosis/</u> . (accessed 14th December 2020).

⁷ Chand, G. B., Dwyer, D. B., Erus, G., Sotiras, A., Varol, E., Srinivasan, D., ... & Kahn, R. S. (2020). Two distinct neuroanatomical subtypes of schizophrenia revealed using machine learning. *Brain*, *143*(3), 1027-1038.

⁸ NHS Choices. Schizophrenia – symptoms.

www.nhs.uk/conditions/schizophrenia/symptoms/ (accessed 17th December 2020). ⁹ Royal College of Psychiatrists. *Schizophrenia: What is schizophrenia?*

www.rcpsych.ac.uk/mental-health/problems-disorders/schizophrenia (accessed 17th January 2021).

¹⁰ NHS Choices. Schizophrenia – symptoms.

www.nhs.uk/conditions/schizophrenia/symptoms/ (accessed 14th December 2020). ¹¹ NHS. *Hallucinations and hearing voices* www.nhs.uk/conditions/hallucinations/ (accessed 28th January 2021)

¹² NHS. Hallucinations and hearing voices https://www.nhs.uk/conditions/hallucinations/ (accessed 28th January 2021)

¹³ NHS. *Symptoms. psychosis* <u>www.nhs.uk/conditions/psychosis/symptoms/</u> (accessed 2nd February 2021)

¹⁴ NHS Choices. *Schizophrenia* – *symptoms*.

www.nhs.uk/conditions/schizophrenia/symptoms/ (accessed 17th January 2021). ¹⁵ NHS. *Schizophrenia: symptoms*. www.nhs.uk/conditions/schizophrenia/symptoms/ (accessed 17th January 2021).

¹⁶ Royal College of Psychiatrists. *Schizophrenia: What are the symptoms of schizophrenia*? <u>www.rcpsych.ac.uk/mental-health/problems-disorders/schizophrenia</u> (accessed 17th January 2021).

¹⁷ World Health Organization (1994) *The ICD-11 Classification of Mental and Behavioural Disorders Clinical descriptions and diagnostic guidelines* Schizophrenia 6A20 <u>https://icd.who.int/browse11/l-</u>

<u>m/en#/http%3a%2f%2fid.who.int%2ficd%2fentity%2f1683919430</u> (accessed 16th June 2022)

¹⁸ World Health Organization (1994) *The ICD-11 Classification of Mental and Behavioural Disorders Clinical descriptions and diagnostic guidelines* Schizophrenia 6A20 *https://icd.who.int/browse11/l-*

<u>m/en#/http%3a%2f%2fid.who.int%2ficd%2fentity%2f1683919430</u> (accessed 16th June 2022)

¹⁹ Britannica. *Hebephrenic Schizophrenia*. <u>www.britannica.com/science/hebephrenic-schizophrenia</u> (accessed 28th June 2022)

²⁰ Mental Health Reference. *Hebephrenic Schizophrenia Diagnostic Criteria.*

https://mhreference.org/schizophrenic/schizophrenia-icd/hebephrenic/ (accessed 2nd February 2021).

²¹ World Health Organization (1994) *The ICD-10 Classification of Mental and Behavioural Disorders Clinical descriptions and diagnostic guidelines F20.2* http://apps.who.int/classifications/icd10/browse/2016/en#/F20.2

²² World Health Organization (1994) *The ICD-11 Classification of Mental and Behavioural Disorders Clinical descriptions and diagnostic guidelines* Schizophrenia 6A20 *https://icd.who.int/browse11/l-*

<u>m/en#/http%3a%2f%2fid.who.int%2ficd%2fentity%2f1683919430</u> (accessed 16th June 2022)

²³ American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders Fifth edition*. DSM-5. Washington DC: American Psychiatric Publishing; 2013.
 Page 97

²⁴ American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders Fifth edition*. DSM-5. Washington DC: American Psychiatric Publishing; 2013. Page 89.

²⁶ Royal College of Psychiatrists. Schizophrenia: What causes schizophrenia? <u>www.rcpsych.ac.uk/mental-health/problems-disorders/schizophrenia</u> (accessed 17th January 2021).

²⁷ González-Rodríguez, A., & Seeman, M. V. (2018). Pharmacotherapy for schizophrenia in postmenopausal women. *Expert Opinion on Pharmacotherapy*, *19*(8), 809-821.
 ²⁸ National Institute of Health and Care Excellence. *Psychosis and schizophrenia in adults: preventionand management*. Clinical Guidance178. London: National Institute for Health and Clinical Excellence; 2014 para 1.3.4.2.

²⁹ Royal College of Psychiatrists. Schizophrenia.

http://www.rcpsych.ac.uk/healthadvice/problemsdisorders/schizophrenia.aspx

³⁰ National Institute of Health and Care Excellence. *Psychosis and schizophrenia in adults: preventionand management*.Clinical Guidance178. London: National Institute for Health and Clinical Excellence; 2014 para 1.5.7.2.

³¹ Royal College of Psychiatrists. *Antipsychotics*.

http://www.rcpsych.ac.uk/healthadvice/treatmentswellbeing/antipsychoticmedication.aspx (accessed 27th January 2021).

³² National Institute of Health and Care Excellence. *Psychosis and schizophrenia in adults: preventionand management*.Clinical Guidance178. London: National Institute for Health and Clinical Excellence; 2014 para 1.5.1.3.

³³ National Institute of Health and Care Excellence. *Psychosis and schizophrenia in adults quality standard [QS80]*. London: National Institute for Health and Clinical Excellence; 2015 Statement 2.

³⁴ National Institute of Health and Care Excellence. *Psychosis and schizophrenia in adults: preventionand management*.Clinical Guidance178. London: National Institute for Health and Clinical Excellence; 2014 para 1.5.4.2.

³⁵ National Institute of Health and Care Excellence. *Psychosis and schizophrenia in adults: preventionand management*.Clinical Guidance178. London: National Institute for Health and Clinical Excellence; 2014 para 1.3.7.2.

³⁶ National Institute of Health and Care Excellence. *Psychosis and schizophrenia in adults: preventionand management*.Clinical Guidance178. London: National Institute for Health and Clinical Excellence; 2014, para 1.3.7.2.

³⁷ National Institute of Health and Care Excellence. *Psychosis and schizophrenia in adults: preventionand management*.Clinical Guidance178. London: National Institute for Health and Clinical Excellence; 2014. 1.4.4.3

³⁸ National Institute of Health and Care Excellence. *Psychosis and schizophrenia in adults quality standard [QS80]*. London: National Institute for Health and Clinical Excellence; 2015 Statement 1.

³⁹ General Medical Council. *Good Medical Practice*. Manchester: GMC; 2013. Para 16(e).
 ⁴⁰ National Institute for Health and Clinical Excellence. Psychosis and

schizophrenia in adults: prevention and management. Clinical Guidance

178. London: National Institute for Health and Clinical Excellence; 2014.Para 1.1.6.1. ⁴¹ National Institute for Health and Clinical Excellence. Psychosis and schizophrenia in adults: prevention and management. Clinical Guidance

 178. London: National Institute for Health and Clinical Excellence; 2014.. Para 1.1.6.3.
 ⁴² Chang et al. Life Expectancy at Birth for People with Serious Mental Illness and Other Major Disorders from a Secondary Mental Health Care Case Register in London. PLoS

ONE 6(5): e19590. <u>doi:10.1371/journal.pone.0019590</u> (Accessed: 16 December 2020) ⁴³ Rethink Mental Illness. *The Schizophrenia Commission Progress Report 2017.*

Available at: <u>https://www.rethink.org/aboutus/who-we-are/the-schizophrenia-commission/</u> (accessed 2nd February 2021)

⁴⁴ Chang et al. Life Expectancy at Birth for People with Serious Mental Illness and Other Major Disorders from a Secondary Mental Health Care Case Register in London. PLoS ONE 6(5): e19590. <u>doi:10.1371/journal.pone.0019590</u> (Accessed: 16 December 2020)

⁴⁵ Disability Rights Commission. *Equal Treatment: Closing the Gap, London, Disability Rights Commission*. s2006. Page 37 (Accessed 16th December 2020)

⁴⁶ National Institute of Health and Care Excellence. *Psychosis and schizophrenia in adults: preventionand management*.Clinical Guidance178. London: National Institute for Health and Clinical Excellence; 2014para, 1.3.6

⁴⁷ Pompili, M., Amador, X. F., Girardi, P., Harkavy-Friedman, J., Harrow, M., Kaplan, K., ... & Montross, L. P. (2007). Suicide risk in schizophrenia: learning from the past to change the future. *Annals of general psychiatry*, *6*(1), 1-22. See Abstract
⁴⁸ Hawton, K., Sutton, L., Haw, C., Sinclair, J. and Deeks, J.D. Schizophrenia and suicide: systematic review of risk factors. *British Journal of Psychiatry* 2005;187: 9-20 DOI: 10.1192/bjp.187.1.9

⁴⁹ Cassidy, R. M., Yang, F., Kapczinski, F., & Passos, I. C. (2018). Risk factors for suicidality in patients with schizophrenia: a systematic review, meta-analysis, and meta-regression of 96 studies. *Schizophrenia bulletin*, *44*(4), 787-797.

⁵⁰ National Institute for Health and Clinical Excellence. *Psychosis and schizophrenia in adults: prevention and management.* Clinical Guidance 178. London: National Institute for Health and Clinical Excellence; 2014. Para 1.1.5.1.

⁵¹ National Institute for Health and Clinical Excellence. *Psychosis and schizophrenia in adults: prevention and management.* Clinical Guidance
 178. London: National Institute for Health and Clinical Excellence; 2014.Para 1.1.5.3.
 ⁵² National Institute for Health and Clinical Excellence. *Psychosis and schizophrenia in adults: prevention and management.* Clinical Guidance
 178. London: National Institute for Health and Clinical Excellence; 2014.Para 1.1.5.3.
 ⁵² National Institute for Health and Clinical Excellence. *Psychosis and schizophrenia in adults: prevention and management.* Clinical Guidance
 178. London: National Institute for Health and Clinical Excellence; 2014.Para 1.1.5.4.
 ⁵³ Leff, J et al. *Computer-assisted therapy for medication-resistant auditory hallucinations:*

proof-of-concept study. The British Journal of Psychiatry. Jun 2013; 202(6): pp 428-433. ⁵⁴ NHS Choices. Avatars may help control 'voices' in schizophrenia

www.nhs.uk/news/2013/05May/Pages/Avatars-may-help-control-voices-inschizophrenia.aspx (accessed January 2019) © Rethink Mental Illness 2014 Last updated December 2020 Next update April 2023 Version number 10.1

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Rethink Mental Illness Advice Service

Phone 0808 801 0525 Monday to Friday, 9:30am to 4pm (excluding bank holidays)

Email advice@rethink.org

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