

Schizoaffective disorder

Explains what schizoaffective disorder is, including its symptoms and causes. Gives advice on how you can help yourself and what types of treatment and support are available, as well as guidance for friends and family.

If you want to contact us with any feedback, email <u>contact@mind.org.uk</u>.

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What is schizoaffective disorder?

Schizoaffective disorder is a mental health problem where you experience psychosis as well as mood symptoms.

The word schizoaffective has two parts:

- 'Schizo-' refers to <u>symptoms of psychosis</u>
- '-Affective' refers to mood symptoms

Some people have suggested that schizoaffective disorder sits in the middle of a spectrum, with <u>schizophrenia</u> at one end and <u>bipolar disorder</u> at the other. This is because these diagnoses share many similar symptoms. But schizoaffective disorder is recognised as a separate diagnosis.

You might have times when you struggle to look after yourself. Or when your doctors feel that you lack insight into your behaviour and how you're feeling.

Symptoms can begin at any age, but usually start when you're a young adult. Some people only experience symptoms of schizoaffective disorder once in their life.

Schizoaffective disorder and me

"Things started having secret meanings and I was convinced I could see into the future."

Read Charlotte's story

Schizoaffective disorder and stigma

Some people may not understand or have heard of schizoaffective disorder. They may have misconceptions about you. Or a negative or inaccurate image of schizoaffective disorder.

This can feel very upsetting. Especially if the person who thinks this way is a friend, colleague, family member or healthcare professional.

Schizoaffective disorder is less well known than some other mental health problems. This may make it harder to find information or support. Or to connect

with others who have similar experiences. This may feel frustrating and lonely at times. You might want to think about the following options:

- Show people this information. It might help them understand what your diagnosis means.
- Get more involved in your treatment. You can make your voice heard. You can also take steps if you're not happy with your care. For guidance, see our pages on <u>seeking help for a mental health problem</u>.
- Know your rights. The law can help you in certain situations. For more information, see our pages on <u>legal rights</u>.
- Take action with Mind. For details of ways you can get involved in helping challenge stigma, see our page on <u>campaigning</u>.

Remember: you're not alone. You don't have to put up with people treating you badly. For more information, see our page on <u>stigma and misconceptions about</u> <u>mental health</u>.

What are the symptoms of schizoaffective disorder?

Schizoaffective disorder has two main types of symptom:

- <u>Symptoms of psychosis</u>
- <u>Mood symptoms</u>

Symptoms of psychosis

These symptoms are similar to those experienced in schizophrenia, including:

- <u>Hallucinations</u> where you may experience things that others around you don't. For example <u>hearing voices</u>, seeing visual hallucinations and other unexplained sensations.
- <u>Delusions</u> where you might hold strong beliefs that nobody else shares. For example, a fear that everyone can hear your thoughts or that you can control the weather.

You may also experience:

- Your thoughts becoming very disorientated
- Feeling confused or frightened

- Feeling disconnected from your emotions
- Difficulty concentrating
- A lack of motivation or interest in things

These feelings can be managed with the right combination of treatment, support and self-care.

For more information, see our page on <u>psychosis</u>. You could also visit <u>Intervoice</u> or <u>The Hearing Voices Network</u>.

"One of the peculiar thoughts I experienced was that I was being headhunted by a company for a job, which definitely never happened, it was just an idea in my head that I had convinced myself was true."

Mood symptoms

The mood symptoms of schizoaffective disorder are similar to those experienced in bipolar disorder. They can include both manic and depressive symptoms:

Manic symptoms - you may feel extremely excited or irritated. Or make unrealistic plans and behave in ways that might put you at risk.

Depressive symptoms - you may feel sad and low or experience sleep problems. You may also feel disconnected from others or experience suicidal feelings.

The periods of time where you experience mood symptoms are sometimes called 'episodes'. You may experience depressive episodes, manic episodes, or both. You may also experience 'mixed episodes'. This is when you have symptoms of mania and depression at the same time, or very quickly after each other.

Episodes can vary in length. Some people have repeated episodes, but this doesn't happen for everybody.

See our pages on <u>bipolar disorder</u>, <u>mania and hypomania</u> and <u>depression</u> for more information.

"On my bad days, I felt I was a pathetic coward who didn't deserve to breathe, and on my good days I believed I was a god in waiting."

Types of schizoaffective disorder

Bipolar type: You have manic episodes alongside symptoms of psychosis. You may also experience depressive episodes.

Depressive type: You only have depressive episodes alongside symptoms of psychosis.

How is schizoaffective disorder different from schizophrenia or bipolar disorder?

Schizoaffective disorder is its own diagnosis. But schizoaffective disorder, schizophrenia and bipolar disorder can involve similar symptoms and experiences.

Diagnosing schizoaffective disorder can be complex. Not all professionals agree on how best to diagnose or describe it. A diagnosis of schizoaffective disorder may be considered if you've experienced:

- Symptoms that have lasted for a month or longer
- Symptoms of psychosis and mood symptoms at the same time
- Mood symptoms for most of the time that you've felt unwell
- A period of time (usually at least 2 weeks) of symptoms of psychosis without mood symptoms
- Depressive episodes that include low mood

Schizoaffective disorder is often seen as a psychotic disorder with significant mood features, rather than a mood disorder with psychosis.

"My problems were not picked up as a teenager, which resulted in a crisis in my early 20s, involving hospital admissions and being severely mentally unwell. The diagnosis of schizoaffective disorder seemed to fit with my experience better than any other 'label' or diagnosis."

How is schizoaffective disorder diagnosed?

To make a diagnosis, a psychiatrist will assess your symptoms and ask how long you've had them. They'll consider how psychosis and mood symptoms happen for you (either together or separately) during episodes. They'll also consider how your symptoms affect your daily life or relationships.

The psychiatrist may check for any physical problems that could be causing your symptoms. <u>Recreational drugs</u> can also cause similar symptoms. So it might be useful for your psychiatrist to know if you are using any (or have done in the past).

Differences between diagnoses are subtle. You may be given different diagnoses by different psychiatrists. It may feel frustrating if your diagnosis changes.

You may feel like you've got used to one diagnosis, and now you need to get used to a new one. Or you may feel relieved and that the new diagnosis is a better fit for you. You may feel like you don't need any diagnosis at all. There's no right or wrong way to feel about this.

"At first, I was diagnosed with depression, postpartum psychosis, and then finally schizoaffective disorder. I had to do a lot of research myself to understand what I was going through better, which was difficult."

What can I do if I disagree with my diagnosis?

If your diagnosis doesn't fit with the way you feel, it's important to discuss this with a mental health professional. This is to make sure you're getting the right treatment to help you.

See our pages on <u>seeking help for a mental health problem</u> for information on how to make sure your voice is heard. And what you can do if you're not happy with your doctor.

What causes schizoaffective disorder?

Researchers don't know exactly what causes schizoaffective disorder. But it's likely to be caused by a combination of factors, such as:

- <u>Stressful or traumatic life events</u>
- <u>Childhood trauma</u>
- <u>Brain chemistry</u>
- <u>Genetics</u>

Stressful or traumatic life events

Some people find that stressful or traumatic experiences can trigger a <u>mood</u> <u>episode</u> or an episode of psychosis. Stress may also make your symptoms feel more intense or difficult to manage. You may be able to link the start of your symptoms to a very stressful period in your life, such as:

- <u>Abuse</u> or neglect
- Experiencing a traumatic loss
- Being out of work
- Being bullied or harassed, including racism
- Feeling <u>lonely</u> or isolated
- Relationship problems or break-ups
- Losing someone close to you
- Having housing problems or becoming homeless
- Having money problems

See our pages on <u>managing stress</u> for more information on the links between stress and mental health.

Childhood trauma

Some evidence suggests that experiencing a great deal of emotional distress as a child may increase the risk of developing schizoaffective disorder. This can include experiences like:

- Sexual or physical abuse
- Neglect
- Traumatic events
- Losing someone very close to you, such as a parent or carer

Experiencing trauma and distress as a child can have a lasting effect. For example, on how you're able to regulate your emotions as an adult. See our pages on <u>trauma</u> for more information.

Brain chemistry

The way mental health problems and brain chemistry are related is still unclear and debated. The human brain is extremely complex. And the research and arguments in this area are complicated.

Schizoaffective disorder symptoms can sometimes be helped by taking certain psychiatric medications. Some of these medications are thought to act on your neurotransmitters, such as dopamine. Neurotransmitters are chemicals that communicate information throughout your brain and body. Some research suggests that schizoaffective disorder may relate to problems with how these neurotransmitters work, but no one knows for sure.

Genetics

If you experience schizoaffective disorder, you're more likely to have a family member who also experiences symptoms of schizophrenia or bipolar disorder (even if they don't have a diagnosis).

However, research into genetic causes is limited. Research hasn't found a single gene that's responsible for schizoaffective disorder. Family links are more complex.

Researchers think that environmental factors may explain why some people experience symptoms of schizoaffective disorder, <u>schizophrenia</u> and <u>bipolar</u> <u>disorder</u>. And family members can be a very influential part of your environment as you grow up.

We don't know why someone might develop schizoaffective symptoms rather than schizophrenia or bipolar disorder.

"I have a long family history of mental health problems, my Dad and his twin had a diagnosis of schizophrenia and my Mum and her Mum had a diagnosis of bipolar."

How can I help myself?

Many people who are diagnosed with schizoaffective disorder are able to live happy and fulfilling lives. Self-care can help with this.

Self-care is how you look after your daily routine and the things that affect how you're feeling. For example, exercise, relationships and diet. What helps you may be different from someone else. It's worth trying out different things until you find what works for you.

You may find that making small changes in certain areas can help prevent some problems from developing.

It can help to:

- Think about your triggers
- <u>Create a crisis plan</u>
- <u>Try peer support</u>
- <u>Try calling a helpline</u>
- <u>Try new ways of relaxing</u>
- Other activities
- Think about your diet
- <u>Try some physical activity</u>
- <u>Visit a recovery college</u>

Think about your triggers

You might find it helpful to keep track of your experiences over a period of time. You could try doing this for a few weeks at first, noting things down in a diary or on your phone. It may be helpful to track:

- Your moods and symptoms
- Everyday events
- <u>Sleep</u> quality
- Your <u>diet</u>

Doing this may help you to spot patterns in your thoughts, feelings and behaviours. It may also help you to think about situations that you find difficult, as well as those which have been helpful.

There are many online mood diaries which you may find helpful. Bipolar UK has a <u>mood scale</u>, <u>mood diary</u> and <u>mood tracker app</u>, which are free to use.

You might want to share your observations with your close family, friends or care team. It may be helpful for them to listen to you when you're having a bad day. Or to help you keep on top of your commitments and be aware of your triggers.

"Having thoughts on paper makes it easier to give them structure and find answers."

Create a crisis plan

During a crisis, you may not always be able to tell people what helps you. While you're feeling well, it may be a good idea to talk to someone you trust about what you'd like to happen if you're in a crisis.

See our page on <u>planning for a crisis</u> for more information.

Try peer support

You might find it very helpful to talk to other people who have similar experiences to you. Peer support can be a great way to do this.

Peer support can help you:

- Feel more positive about the future
- Increase your self-esteem
- Find friends
- Recognise patterns in your experiences
- Develop and discuss ways of coping
- Identify early signs of crisis

Various organisations run groups or programmes. <u>The Hearing Voices</u> <u>Network</u> hosts groups across the country for people who hear, see or sense things that others don't.

There are lots of ways to find peer support:

- See our list of <u>useful contacts</u>
- See our <u>peer support directory</u>
- Ask your local Mind about peer support
- Try an online peer support community like Mind's Side by Side

Try calling a helpline

If you need to talk to someone but don't feel ready to try peer support, there are helplines you can call when you're feeling distressed.

For example, <u>Samaritans</u> or <u>SANEline</u>. Talking to a trained listener could help you feel supported and make sense of what's happening for you.

Try new ways of relaxing

It may be helpful to try relaxation techniques, such as:

- Yoga, meditation or mindfulness
- Taking a shower or bath
- Try breathing in and out slowly some people find it helpful to count while doing this

• Taking a walk in nature

See our page on <u>relaxing and calming exercises</u> for more information.

Other activities

Practical activities may help to distract you. They can also help you stay connected to the present moment. Activities could include things like:

- Gardening
- Cleaning or tidying
- Cooking
- Crafts

Arts can be helpful in expressing your feelings, such as:

- Painting
- Music
- Writing

Making time in your day for other activities you enjoy, such as:

- Gaming
- Reading
- Watching films

For more ideas, see our pages on <u>arts and creative therapies</u>, <u>nature and mental</u> <u>health</u>, <u>sleep problems</u>, <u>stress</u>, <u>relaxation</u> and <u>mindfulness</u>.

Think about your diet

It can be difficult to maintain a healthy diet when we're struggling with our mental health. But eating regularly can keep your blood sugar stable and really make a difference to your mood and energy levels.

For more tips see our pages on <u>food and mood.</u>

"I put on weight since I started medication, so I have started eating really healthily. I think this has helped my depression too."

Try some physical activity

Physical activity can have a positive impact on our mood. It can be really helpful to focus on your body and physical surroundings. Moving your body may also help you to sleep better. Activities may include:

- A regular walk outdoors
- Swimming
- Yoga or meditation

Health walks are organised locally in some areas. Your GP surgery may organise a weekly walking group. Some doctors will also prescribe an exercise programme. See our pages on <u>physical activity</u> and <u>nature and mental health</u> for more information.

"Exercise is very important. If I feel I have too much energy, swimming or a fast long walk can really calm me down and help me sleep. On a low day I might not be up for a swim, but a walk into town really helps me bring my mind and body together."

Visit a recovery college

You may also find it helpful to find a recovery college. They offer courses about mental health and recovery in a supportive environment. You can find local providers on the <u>Mind Recovery Net website</u>.

What treatments are available?

Each person's experience of schizoaffective disorder will vary, as will the treatments that work best for them.

Different treatments may be helpful for symptoms of psychosis, mania or depression. If you're experiencing a combination of symptoms, you may need a combination of treatments. Or you may need different types of treatment at different times.

On this page you can find information on:

- <u>Talking therapies</u>
- <u>Arts therapies</u>
- <u>Family intervention</u>

Medication

These are taken from the <u>National Institute for Health and Care Excellence</u> (<u>NICE</u>) guidelines on the treatment of <u>schizophrenia</u>, which also covers schizoaffective disorder.

Talking therapies

You may be offered some form of counselling or psychotherapy, also known as <u>talking therapies</u>.

The main type of therapy suggested by NICE in the treatment of schizoaffective disorder is <u>cognitive behaviour therapy (CBT)</u>. CBT may help you to connect your thoughts, feelings and behaviour with your symptoms. It can also help you to develop ways of coping with difficult experiences.

Some other types of treatment may be helpful, including <u>mindfulness-based</u> <u>therapies</u> or <u>psychodynamic therapy</u>.

For more information see our pages on talking therapies.

"I have found talking therapies to be really helpful, and a way to learn how to cope with stressful events and look after myself better."

Arts therapies

Art, music, dance or drama therapies may help you to express how you are feeling, especially if it's difficult to talk about things. These kinds of therapies may help you come to terms with traumatic events that you may have experienced in the past.

You might find that arts therapies are enough to manage your symptoms on their own. Or they might work best alongside another treatment, such as medication. There is no 'right' approach. What works for you as an individual is the right approach.

For further information see our pages on arts and creative therapies.

Family intervention

This is a form of treatment that aims to provide support for the whole household. It can help your family, or the people you live with, to understand:

- What you're going through
- How their responses may help or make matters worse for you, as well as each other
- What's helpful and unhelpful for you

For example, if you're very distressed and your family members are very worried about you, they may focus too much attention on you without meaning to. This might make you feel more distressed.

Family intervention can help you:

- Understand how your experience and symptoms affect those living with you
- Manage your symptoms and think of ways to cope with problems
- Communicate your needs with the people around you

For more information, speak to your <u>community mental health team</u> or psychiatrist.

If you're a friend or family member of someone with schizoaffective disorder, see our page on <u>how friends and family can help</u>.

Medication

Depending on your symptoms and needs, you may be offered medication.

You may be prescribed:

- An <u>antipsychotic</u>, to help with symptoms of psychosis or mania
- A <u>mood stabiliser</u>, to help prevent or reduce the symptoms of mood episodes
- An <u>antidepressant</u>, to help treat depressive symptoms. If you also experience symptoms of mania, you're unlikely to be prescribed antidepressants alone. This is because there's a risk of them triggering manic episodes

Depending on your symptoms, you may only be offered one type of drug. But a combination of drugs may be offered to help with the different symptoms of

schizoaffective disorder.

Remember: always check with your doctor or pharmacist before taking any medications together. The medications could interact badly with each other.

Medication (especially antipsychotics) can have an impact on your physical health. You should receive regular check-ups from your GP on your weight, blood pressure, blood sugar levels, cholesterol and heart function.

Smoking can affect the type of side-effects you may get from medication. If you smoke, you may be offered support to stop.

See our pages on <u>things to consider before taking medication</u> and <u>your right to</u> <u>refuse medication</u> for more information. Our pages on <u>coming off medication</u> give guidance on how to come off medication safely.

For more information, see our pages on <u>medication</u>, <u>antipsychotics</u>, <u>lithium and</u> <u>other mood stabilisers</u> and <u>antidepressants</u>.

Antipsychotics

Watch Laura, Joe, Ziaul and Steve talking about their experience of taking antipsychotics in <u>this video</u> (YouTube link)

Medication can really help some of us. But it isn't right for everyone. Before deciding to take any drug, it's important that you have all the facts you need to make an informed choice. If you don't understand any aspect of a medication you're offered, don't be afraid to ask as many questions as you feel you need to.

"I think medicine can help with short term psychotic issues, but the underlying issues and depression side of things has been better dealt with through therapy and lifestyle changes."

How can friends or family help?

This section is for the friends and family of someone who has been diagnosed with schizoaffective disorder.

Support from family and friends can play an important role in helping someone recover from an episode of schizoaffective disorder. It may reduce the likelihood of them having further episodes.

It can also be stressful to care for or support somebody. You may need support for yourself.

This page will offer some suggestions on how you can help others and yourself:

- <u>Understand the diagnosis</u>
- Ask how you and others can help
- Get help in an emergency
- Get support for yourself

Understand the diagnosis

Learning more about schizoaffective disorder can help you:

- Recognise early symptoms or triggers
- Give you the confidence to discuss problems and offer help
- React calmly in difficult situations and work towards a positive outcome

If someone is experiencing symptoms of <u>psychosis</u>, such as <u>hearing voices</u>, it may be helpful if you:

- Accept that the voices are real for them, even if you can't hear them
- Focus on how they're feeling, rather than what they're experiencing
- Help them manage their symptoms. For example, you could suggest distractions

Ask how you and others can help

Ask them directly how you can be most helpful. These are some ways you could help:

- Support them to get treatment or accessing a particular service
- Keep them company if they're feeling anxious about going to something new, such as an appointment or activity
- Check in with them regularly for a chat if you're not nearby
- Support them in making decisions. Even if they ask you to act on their behalf, try to encourage them to make their own decisions
- Respect the choices they make, even if they're not what you'd choose for yourself
- Be clear about what your own limits are in terms of what you can help with
- Help them get alternative support if necessary. For example, it may be possible to find an <u>independent advocate</u> to help them

When they're feeling well, it may be helpful to discuss how you can help them in a crisis. Or if they're at the start of another episode. You might:

- Encourage them to write a crisis plan
- Discuss and look out for symptoms
- Be aware or make a note of their triggers

This can help them to avoid crises or manage them differently in future where possible.

For further information see our pages on <u>supporting someone to seek</u> <u>help</u>, <u>advocacy</u> and <u>planning for a crisis</u>.

"My fiancée isn't afraid to talk to me if she thinks I am getting worse. This has helped me notice changes myself."

Get help in an emergency

If you think your friend or family member may be at risk of hurting themselves or others, it may be necessary to consider a Mental Health Act assessment for them.

The <u>nearest relative</u>, as defined under <u>the Mental Health Act</u>, can request that the person at risk be given a mental health assessment by an <u>approved mental</u> <u>health professional</u>. This assessment involves considering treatment options. This may include deciding if the person should be admitted to hospital under the Mental Health Act.

For further information see our pages on <u>the Mental Health Act</u>, <u>crisis</u> <u>services</u>, <u>sectioning</u>, and the <u>nearest relative</u>.

Get support for yourself

It can be very upsetting when someone you're close to is struggling with their mental health.

You may find it helpful to get support in coping with your own feelings, either through <u>talking therapy</u> or <u>peer support</u>, where you can talk to other people who have similar experiences. This support may be available at a <u>local Mind</u> or other carers' groups, such as <u>Carers UK</u>.

Carers are also entitled to have their own needs for practical and emotional support assessed by social services. This is called a carer's assessment. A number of national and local voluntary organisations provide <u>help and information for</u> <u>carers</u> on these topics.

For further information, see our pages on <u>how to cope when supporting someone</u> <u>else</u>, <u>managing stress</u> and <u>maintaining your wellbeing</u>.

Useful contacts

Mind's services

- <u>Mind's helplines</u> provide information and support by phone and email.
- <u>Local Minds</u> offer face-to-face services across England and Wales. These services include talking therapies, peer support and advocacy.
- <u>Side by Side</u> is Mind's support online community for anyone experiencing a mental health problem.

Other organisations

Bipolar UK

bipolaruk.org

Information and support for people affected by bipolar disorder, hypomania and mania. Offers a telephone peer support line, and an online peer support community.

British Association for Behavioural and Cognitive Psychotherapies (BABCP) babcp.com

Information about cognitive behavioural therapy and related treatments, including details of accredited therapists.

British Association for Counselling and Psychotherapy (BACP)

<u>bacp.co.uk</u> Professional body for talking therapy and counselling. Provides information and a list of accredited therapists.

Carers UK

<u>0808 808 7777</u> <u>029 2081 1370</u> (Carers Wales) <u>advice@carersuk.org</u> <u>carersuk.org</u> Advice and support for anyone who provides care.

Hearing Voices Network

<u>hearing-voices.org</u> Information and support for people who hear voices or have other unshared perceptions, including local support groups.

Intervoice intervoiceonline.org International network for people who hear voices.

Mood Diaries <u>medhelp.org/land/mood-tracker</u> <u>moodscope.com</u> <u>moodpanda.com</u> Some examples of mood diaries – many more are available. Mind doesn't endorse any particular one.

National Institute for Health and Care Excellence (NICE)

<u>nice.org.uk</u> Produces guidelines on best practice in healthcare. © Mind 2022

Samaritans

<u>116 123</u> (freephone) jo@samaritans.org Freepost SAMARITANS LETTERS samaritans.org

Samaritans are open 24/7 for anyone who needs to talk. You can <u>visit some Samaritans</u> <u>branches in person</u>. Samaritans also have a Welsh Language Line on <u>0808 164</u> <u>0123</u> (7pm–11pm every day).

Sane

<u>sane.org.uk</u>

Offers emotional support and information for anyone affected by mental health problems.

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