

understanding



schizoaffective
disorder

Understanding schizoaffective disorder

This booklet is for people who have been given a diagnosis of schizoaffective disorder, and their friends and relatives. It explains what the disorder is, and the types of treatment and support available.

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What is schizoaffective disorder?

The word schizoaffective has two parts:

- 'schizo' refers to psychotic symptoms
- 'affective' refers to mood symptoms.

You may be given a diagnosis of schizoaffective disorder if you have episodes of mental ill-health when you experience:

- psychotic symptoms, similar to schizophrenia *and*
- mood symptoms of bipolar disorder *and*
- you have both psychotic and mood symptoms at the same time or within two weeks of each other.

(For more information on these other diagnoses, see Mind's booklets *Understanding schizophrenia* and *Understanding bipolar disorder*.)

You may have periods when you struggle to look after yourself, and when your doctors consider that you lack insight into your behaviour or how you are feeling. You may be quite well between episodes.

Everyone is different, and episodes vary in length. Some people have repeated episodes, but this does not necessarily happen, and it may not be a life-time diagnosis.

Psychotic symptoms

These are experiences called hallucinations and delusions.

- **Hallucinations** – having hallucinations means experiencing things that others around you don't. These are most commonly voices which you hear either inside your head, or through your ears as if they were coming from somewhere else. You may also see visual hallucinations, or misinterpret things around you in unusual ways. You may also have unexplained touch sensations, smells and tastes. (See Mind's booklet *How to cope with hearing voices*)

- **Delusions** are strongly held beliefs that other people don't share. For example, you may feel your thoughts are being read, or you are being watched or controlled, or that you are very powerful and able to influence things that are actually outside your control.

If you experience psychotic symptoms, your thoughts may become very disorganised and you may feel very confused and frightened. Psychotic symptoms may also influence your mood, so that you feel angry and depressed, or excited and elated.

Mood symptoms

The mood symptoms of schizoaffective disorder are very like bipolar disorder (manic depression), and may be divided into 'manic type', 'depressive type' or 'mixed type' – just as bipolar disorder is.

- **Manic type** – you have episodes when your mood symptoms are mainly manic. These episodes may be mild (hypomania) or more severe. Mania can make you feel very excited and enthusiastic about life, very talkative, and you may make plans that are quite unrealistic. You may get very little sleep, and this may make the mania worse. Your own judgement and abilities may be affected so that you might be extravagant with money, and pursue risky business ventures or sexual encounters. At times your excitement can turn to anger or irritability, especially if someone contradicts or questions you. 'Manic type' may also be called 'bipolar type', especially if you have episodes of depression as well.
- **Depressive type** – you have episodes when your mood is dominated by depression and you are likely to feel sad, lonely, tired and unable to take any pleasure in life. You may want to sleep a great deal, but this may make you feel worse. If the depression gets really bad, you may feel only emptiness and despair. You may feel quite unable to relate to other people. Your thoughts may become very gloomy and you may feel suicidal.

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- **Mixed type** – this term may be used if you have episodes when you switch between mania and depression in a short time.

Cycles of mania and depression can occur at fairly regular intervals, although this varies from person to person.

How is schizoaffective disorder diagnosed?

Like most psychiatric diagnoses, there are no tests for schizoaffective disorder. A doctor will assess your symptoms, how long you have had them, and their pattern (the way the psychotic symptoms and the mood symptoms occur either together or separately during episodes).

For a diagnosis of schizoaffective disorder:

- you have to have both psychotic symptoms and mood symptoms at the same time for part of an episode
- in the same episode, you also have to have a period with only psychotic symptoms
- you also have to have the mood symptoms for a substantial part of the episode.

Symptoms usually start in early adulthood. Women are more likely to have the diagnosis than men, and are also more likely to have the depressive type.

Ruling out other conditions

The diagnosis is difficult to make and can be confused with other conditions.

Some people have psychotic symptoms during a period of severe depression, or a period of severe mania. But if you have not had the psychotic symptoms alone, without the mood symptoms, this would not count as schizoaffective disorder.

If you have a diagnosis of schizophrenia and experience a short episode of depression, this would not mean that your diagnosis should be changed to schizoaffective disorder.

The differences are quite subtle, and you may be given different diagnoses at different times and by different psychiatrists.

In addition, physical causes of your symptoms need to be ruled out by the doctor who is diagnosing you. For example, an under- or over-active thyroid gland can cause some of the same symptoms, and your thyroid function should be checked before you are given a diagnosis. Street drugs can also cause some of the same symptoms, so your doctor will need to know if you are using any.

What causes schizoaffective disorder?

The causes of schizoaffective disorder are not known. Like other mental health problems, it may be caused by:

- **stressful life events or trauma** – this is more likely to be a cause if you experienced stressful or traumatic events when you were too young to know how to cope with them, or had not been cared for in a way that helped you to develop coping skills. Because of this, you may be particularly vulnerable to a relapse in times of stress.
- **genetic influences** – the psychotic and mood symptoms associated with schizoaffective disorder do tend to run in families. You may also be more likely to develop the symptoms if a close relative has a diagnosis of schizophrenia or bipolar disorder. However, there is not much research evidence of a genetic link to this disorder, and many people who have this diagnosis have no family history of mental health problems.

What treatments are available?

The National Institute of Health and Care Excellence (NICE) guidelines on the treatment of schizophrenia also cover schizoaffective disorder (visit nice.org.uk). They suggest that:

- you should be offered a talking treatment
- you should be offered medication, especially for your psychotic symptoms
- arts therapies should be considered
- your whole family should be offered family intervention (see p.16).

When deciding what treatment you should be offered, your doctors should discuss all the options with you, including their possible benefits and harms. Your views and preferences should always be taken into account when making decisions about your treatment.

Medication

The treatment you are mostly likely to be offered first – especially when you are first diagnosed as a result of an episode – is medication. You may be prescribed:

- **an antipsychotic**, such as olanzapine or quetiapine, to treat the psychotic symptoms
- **a mood stabiliser** such as lithium or valproate, especially if you have manic episodes rather than depression; or lamotrigine, which is licensed for depression in bipolar disorder
- **an antidepressant**, which should be used cautiously because they may cause you to have a manic episode, or to switch between mania and depression (sometimes called 'rapid cycling').

Some antipsychotics are licensed to treat mania as well as psychosis, so it may be that one drug might be adequate, depending on your symptoms. But it is quite likely that you will end up taking a combination of drugs.

See Mind's booklets, *Making sense of antipsychotics*, *Making sense of lithium and other mood stabilisers* and *Making sense of antidepressants*, for more information about these types of drugs.

Physical health checks

Because your physical health may be affected by medication, especially antipsychotics, you should receive regular check-ups from your GP on your weight, blood pressure, blood sugar levels, cholesterol and heart function.

●● *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.* ●●

Talking treatments

You may be offered some form of counselling or psychotherapy. There are many different types, which vary slightly in their approach. The most important thing with all of them is the quality of the relationship you develop with your therapist. The treatment is far more likely to be successful if you find your therapist supportive and helpful.

The main types of talking treatment suggested by NICE are:

- **cognitive behaviour therapy (CBT)** – this helps to identify and change any negative thoughts or behaviour that may be causing your difficulties. Although it's often a short-term treatment, it may last up to 12 months. For mild depression you may be offered computerised CBT, which uses a programme you can follow either by yourself or in addition to sessions with a therapist.
- **mindfulness-based cognitive therapy (MBCT)** – this is an approach to wellbeing that involves accepting life, and living and paying attention to the present moment. It includes taking time to see what is happening around you in a non-judgmental way, rather than going over your problems again and again. Mindfulness-based cognitive therapy is usually done in groups.

Talking treatments should be available for free from your GP or mental health team, and you have the right to ask for them. However, there may be a waiting list. If you wish to seek help privately, you can find details of local therapists on the BABCP or BACP websites (see 'Useful contacts' on p.20). You may also be able to find a service in a local Mind.

For more information about the different types of talking treatments and how to access them, see *Making sense of talking treatments*.

Arts therapies

Art and music therapies may help you to express how you are feeling, especially if you are having difficulty talking about this.

Drama therapy may help you to come to terms with traumatic events that you may have experienced in the past and which may contribute to your psychotic experiences.

Some people have been able to make a complete recovery through such therapies. (See Mind's online booklet *Making sense of arts therapies*.)

Family intervention

Family intervention aims to provide support for the whole household. It can help your family or the people you live with understand what you are going through, and to identify what is helpful and unhelpful for you.

It also explores how your experience and symptoms affect those living with you, and the ways that their responses may help or make matters worse for each other as well as for you. For example, if you are unwell and your family members are very worried about you, they may unintentionally focus too much attention on you, making you feel more distressed.

Community care

Everyone who has been referred to psychiatric services in England should have their needs assessed through the Care Programme Approach. These services aim to support your recovery by treating existing problems, and by working on strategies to help prevent problems from coming back.

You may be referred to the service by your GP or by a community mental health team if you have been in contact with services before. You may be seen by a variety of health professionals, including psychiatrists, mental health nurses and psychologists.

You should be allocated a named care coordinator, and have a written care plan, which should be regularly reviewed.

A similar system applies in Wales. For more information, see Mind's online booklet *The Mind guide to community-based mental health and social care*.

Hospital admission

If you become very distressed during an episode, you may be admitted to hospital. This may be as a voluntary patient, or under the terms of the Mental Health Act 1983 – often known as being 'sectioned'. If you are admitted to hospital, this gives medical staff a chance to assess your needs and decide how to help.

In-patient care can be helpful and supportive, giving you help from a team of experienced mental health professionals, as well as the chance to meet other patients with similar problems and circumstances. However, some people can find a psychiatric ward distressing, if there's not much to do or there is little privacy.

For more information about sectioning, see *Mind rights guide 1: civil admission to hospital*.

Crisis services

Crisis services exist in some areas as an alternative to hospital. They may offer accommodation, or support in your own home. For more information on crisis services, contact the Mind Infoline or see *The Mind guide to crisis services* on Mind's website.

What other support can I get?

Advocacy

Advocacy is a process of supporting and enabling people to:

- express their views and concerns
- access information and services
- defend and promote their rights and responsibilities
- explore choices and options.

Medical professionals in contact with you while you are in a crisis may not take what you have to say seriously. It can be very helpful to have the services of an advocate to help put forward your views, and to negotiate treatment and care that you can accept. For more information, see *The Mind guide to advocacy*.

Therapeutic communities

Therapeutic communities provide a supportive, live-in environment for people with mental health problems. They usually hold regular meetings with all residents. You may benefit from the insights that others with similar problems may offer, and learn to live successfully in a group. The length of stay is usually limited to a set period of time.

●● *I was part of the community for 18 months which was both unbelievably helpful, and incredibly hard work. The support I received from other patients was amazing and has provided me with wonderful friendships.* ●●

How can I help myself ?

Share your experience

Talking to other people who have the same or a similar diagnosis (such as schizophrenia or psychosis) can help you to feel more positive about the future, increase your self-esteem and help you to find companionship. Various organisations run self-help groups, which encourage members to share their experiences and help them to come to terms with them.

Self-help groups can help you:

- recognise underlying patterns in your experiences
- develop and discuss strategies
- identify early signs of crisis
- take active steps to manage your situation.

Self-help groups can be particularly helpful with coping with hallucinations such as voices.

For organisations that can put you in touch with self-help groups, see 'Useful contacts' on p.20.

Try new ways of relaxing

Sleep is important, but you may find it very difficult to settle to sleep during an episode. You may be disturbed by voices, or upsetting thoughts, or you may feel too wound up to sleep, especially during a manic episode. If you are depressed you may sleep too much and end up feeling sluggish.

It may be helpful to learn relaxation techniques, yoga or meditation, to help calm your thoughts. Some people find developing a spiritual practice very helpful. For some people, massage, aromatherapy or reflexology can be a benefit, but it may not suit you if you are uncomfortable with being touched.

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Doing practical things, like gardening, cooking, or making things may also be relaxing, and, may help you stay connected to reality in a purposeful way. You may find painting, music, writing or other forms of creative arts helpful in expressing your feelings.

You may also find it relaxing to maintain a structured daily routine for yourself.

For more ideas, see Mind's booklets *How to cope with sleep problems* and *How to manage stress*, and the leaflet *Mind tips for better mental health: relaxation*.

Try some physical activity

Many people find that physical activity can help them. It doesn't have to be very strenuous or sporty – though you may enjoy those types of activities – but simply having a regular walk in the fresh air, especially in the park or in the country, can be both calming and uplifting. It may also improve your sleep. In some areas, health walks are organised locally, and some doctors will prescribe an exercise programme. (See *Mind tips for better mental health: physical activity* and *Making sense of ecotherapy*.)

●● *Exercise is very important. If I feel I have too much energy, swimming or a fast and 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.* ●●

Think about your diet

It is also important to pay attention to your diet. Try to eat regularly to keep your blood sugar as stable as possible. This can make a lot of difference to your mood and energy levels. It may be helpful to keep a food diary to see if there are any foods which you are sensitive to. (See the Mind *Food and mood* poster.)

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

Recognise your triggers

If you have repeated episodes, it may be helpful to keep a diary, recording everyday events, your mood, your diet and sleep. There are also online mood diaries which you may find helpful (see 'Useful contacts' on p.20). Diaries may help you spot patterns and so identify triggers, situations or even particular foods or drinks to avoid and those which have been helpful. You might want to share these things with your close family or friends so they can help.

👤👤 *...[being more aware] has enabled me to become a much better judge of certain triggers, and defining a crisis point at which I should consider going back on medication – rather than over-thinking and worrying all the time.* 👤👤

Create a crisis plan

During a crisis, you may not be able to tell people what helps you. So while you are well, it may be a good idea to discuss with someone you trust what you would like to happen, or not to happen, when you are in a crisis.

You can also make an 'advance statement'. This includes any statement that you make while you are well, explaining what you would like to happen if you are in crisis and become unable ('lose capacity') to make decisions about your treatment or domestic arrangements. If someone else needs to decide things in your best interests, your advance statement should always be taken into account. Some parts of advance statements are legally binding. (For more information, see Mind's online booklet the *Mind guide to crisis services*, and *Mind's Briefing 4: Healthcare and welfare/personal care decisions under the Mental Capacity Act 2005*.)

Focus on the positive

Having a diagnosis of schizoaffective disorder does not have to dominate your life. It does not have to be life-long, and you may not necessarily have repeated episodes.

The Recovery approach in mental health means:

- living the very best life you can, with the life experiences you have had, and the consequences of them, even if these are long-term or recurrent mental health problems
- building your resilience and wellbeing, and focusing on the things you can do, rather than those you may no longer be able to do
- making our own choices, and being your own person
- very importantly, maintaining hope.

As you learn to manage your symptoms, recognising what is helpful as well as things which might trigger a relapse, you can focus on the things you do well, and that you enjoy and find fulfilling.

👉👉 *Once I accepted that I had an illness, I was able to focus on developing coping strategies. I now control it rather than the other way around. Knowledge and understanding are power.* 👉👉

What can friends or family do to help?

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

As a friend or family member, you can be very important in helping someone recover from an episode of schizoaffective disorder, and reducing the likelihood of them having further episodes.

Most people want to feel cared about, not to feel alone, and to have someone they can discuss their feelings and options with.

If someone is experiencing psychotic symptoms, such as hearing voices, it can be very helpful if you acknowledge their reality for them, even though you don't share the experiences. It may also be helpful if you can focus on how they are feeling, rather than what they are experiencing.

Ask how you and others can help

Ask your friend or relative if they would like practical support, and how you can be most helpful. This might include:

- support to get treatment
- help to access particular services
- company if they are going to something new, such as a treatment or activity, and are feeling anxious about it
- encouraging them to look after themselves if they are going through a tough time and neglecting their general wellbeing or appearance
- a regular phone call for a chat if you are not nearby
- support with decisions – even if they have asked you to act on their behalf, it's important to encourage them to make their own decisions, consult them and avoid taking over
- respecting the choices they make, even if they would not be what you would choose for yourself
- being clear about what you feel you can and can't help with, and helping them get alternative support if necessary. It may be possible to find an independent advocate to help them (see the *Mind guide to advocacy*).

When they are feeling well it can be helpful to discuss with them how you can help if a crisis occurs, or if they are at the start of another episode.

You might encourage them to write a crisis plan (see p.15). You may also be able to help them to look out for symptoms, and things that may seem to trigger an episode. This can help them to avoid them or manage them differently in the future where possible.

●● ...[my fiancée] isn't afraid to talk to me if she thinks I am getting worse and this has helped me notice changes ●● myself.

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 assessment for them. The Nearest Relative, as defined under the Mental Health Act, can request that the person at risk be given a mental health assessment by an Approved Mental Health Professional. This assessment involves considering treatment options and deciding whether or not the person should be admitted to hospital under the Mental Health Act. (See *Mind rights guide1: civil admission to hospital* and Mind's web page *Nearest relatives under the Mental Health Act*, for more information.)

Get support for yourself

It can be very upsetting when someone you are close to experiences a psychotic episode with severe depression or mania. You may find it helpful to get support in coping with your own feelings, or to talk to people who have similar experiences. This may be available at a local Mind or Rethink, or other carers' group.

Carers are also entitled to have their own needs for practical and emotional support assessed by social services as part of a carer's assessment. A number of voluntary organisations provide help and information for carers around these topics. (See 'Useful contacts' and Mind's booklet *How to cope as a carer*.)

Useful contacts

Mind

Mind Infoline: 0300 123 3393
(Monday to Friday 9am to 6pm)
email: info@mind.org.uk
web: mind.org.uk
Details of local Minds and other local services, and Mind's Legal Advice Line. Language Line is available for talking in a language other than English.

British Association for Behavioural and Cognitive Psychotherapies (BABCP)

tel: 0161 705 4304
web: babcp.com
Can provide details of accredited therapists.

British Association for Counselling and Psychotherapy (BACP)

tel: 01455 883 300
web: itsgoodtotalk.org.uk
For details of local practitioners.

Carers UK

advice line: 0808 808 7777
web: carersuk.org
Independent information and support for carers.

Hearing Voices Network

helpline: 0114 271 8210
web: hearing-voices.org
Local support groups and information for people who hear voices.

Intervoice

web: intervoiceonline.org
Support for people who hear voices.

Mood Diaries

web: medhelp.org/land/mood-tracker
web: moodscope.com
web: moodchart.org
web: moodpanda.com
There are lots of templates, websites and phone applications to help you keep track of your moods. Mind does not endorse any particular one.

Rethink Mental Illness

advice line: 0300 5000 927
web: rethink.org
Support and information about mental health problems, including schizoaffective disorder.

Royal College of Psychiatrists

web: rcpsych.ac.uk
Mental health information includes a video about someone whose mother has schizoaffective disorder.

Further information

Mind offers a range of mental health information on:

- diagnoses
- treatments
- practical help for wellbeing
- mental health legislation
- where to get help

To read or print Mind's information booklets for free, visit mind.org.uk or contact Mind infoline on 0300 123 3393 or at info@mind.org.uk

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Mind

We're Mind, the mental health charity for England and Wales. We believe no one should have to face a mental health problem alone. We're here for you. Today. Now. We're on your doorstep, on the end of a phone or online. Whether you're stressed, depressed or in crisis. We'll listen, give you advice, support and fight your corner. And we'll push for a better deal and respect for everyone experiencing a mental health problem.

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