

understanding



schizoaffective
disorder

Understanding schizoaffective disorder

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

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What is schizoaffective disorder?

You may be given a diagnosis of schizoaffective disorder if you experience:

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

The word schizoaffective has two parts:

- 'schizo-' refers to psychotic symptoms (see p.5)
- '-affective' refers to mood symptoms (see p.6).

You may have times 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.

The episodes vary in length. Some people have repeated episodes but this does not necessarily happen, and it may not be a lifetime diagnosis.

Psychotic symptoms

These are experiences called hallucinations and delusions.

Hallucinations

Having hallucinations means experiencing things that others around you don't. These may be:

- voices which you hear either inside your head or through your ears, as if they were coming from somewhere else
- seeing visual hallucinations, or feeling confused about what you see around you
- other unexplained sensations – smells, tastes and touch.

Delusions

Delusions are strongly held beliefs that other people don't share. For example, you may feel:

- that your thoughts are being read, or are being taken out of your head
- your thoughts are not your own
- you are being watched or controlled (see Mind's *Paranoia* resources)
- you are very powerful and able to influence things that are actually outside your control
- you have special insight, divine experiences or magic powers.

In general, you may feel:

- your thoughts becoming very disorganised
- very confused and frightened
- angry and depressed, or excited and elated.

Mood symptoms

The mood symptoms are very like bipolar disorder (manic depression). They may be:

- 'manic type'
- 'depressive type'
- 'mixed type'.

'Manic type' – episodes when your mood symptoms are mainly manic. These episodes may be mild (hypomania) or more severe.

You may:

- feel very excited and enthusiastic about life
- be angry or irritable, especially if someone contradicts or questions you
- be very talkative
- make plans that are quite unrealistic
- get very little sleep – this may make the mania worse
- lose judgement
- be extravagant with money
- start risky business ventures
- have risky sexual encounters.

'Manic type' may also be called 'bipolar type', especially if you have episodes of depression as well.

'Depressive type' – episodes when your mood is dominated by depression.

You may feel:

- sad, lonely, tired and unable to take any pleasure in life
- you want to sleep a great deal, but this may make you feel worse

- emptiness and despair
- unable to relate to other people
- very gloomy
- suicidal.

'Mixed type' – this term may be used if 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.

👩👧 *I have suffered with mental health issues throughout my life. 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?

There is no test for schizoaffective disorder. A doctor will make the diagnosis after assessing your symptoms, how long you have had them, and the way the psychotic and mood symptoms occur (either together or separately) during episodes.

For a diagnosis of schizoaffective disorder, in one episode you must have:

- both psychotic symptoms and mood symptoms at the same time for part of the time
- a period with only psychotic symptoms
- mood symptoms for most of the episode.

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Symptoms usually start when you are a young adult.

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.

Possible physical causes of your symptoms need to be ruled out. For example, an under- or over-active thyroid gland can cause some of the same symptoms, so 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 (or have done in the past).

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.

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. Due to this, you may be particularly vulnerable to a relapse in times of stress.
- Genetic influences. The psychotic and mood symptoms tend to run in families. You may 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 for a genetic explanation, and many people who have this diagnosis have no family history of mental health problems.

We do not know why someone might develop schizoaffective symptoms rather than schizophrenia or bipolar disorder. It may be that all of these conditions are on a spectrum of ways that individuals may be affected by life events.

What treatments are available?

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

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

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.

Talking treatments

You may be offered some form of counselling or psychotherapy. There are many different types, which each vary slightly in their approach. With all of them, the most important thing 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.
- mindfulness-based cognitive therapy (MBCT) – this is an approach to wellbeing that involves accepting life and paying attention to the present moment. It includes taking time to see what is happening

around you in a non-judgemental way, rather than going over your problems again and again. Mindfulness-based cognitive therapy is usually done in groups.

Talking treatments should be available 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 from the BABCP or BACP (see Useful Contacts on p.23). You may also be able to find a service from a local Mind.

👉👉 *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.* 👉👉

Medication

This is the treatment you are mostly likely to be offered first – especially if you are first diagnosed during a psychotic episode.

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.

👩🏻👩🏻 *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.* 👩🏻👩🏻

Physical health checks

As 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.

Arts therapies

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

Drama therapy may help you 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.

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 are going through
- how their responses may help or make matters worse for each other as well as for you
- what is helpful and unhelpful for you.

It can help you:

- understand how your experience and symptoms affect those living

with you

- treat existing problems
- work on strategies to prevent problems from coming back.

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. Further advice for friends and family members is in *How can friends and family help?* on p.20.

Where can I be treated?

You may be offered treatment for schizoaffective disorder in a number of different settings, depending on your symptoms and what is available in your area.

Health and social care

Your GP will probably refer you to your local community mental health team (CMHT). You may be seen by a variety of health professionals, including psychiatrists, mental health nurses and psychologists.

These services aim to support your recovery by treating existing problems and by working on strategies to help prevent problems from coming back.

In England you may be given a care plan under the Care Programme Approach, especially if you have been sectioned under the Mental Health Act. This means you would be allocated a named care co-ordinator, and have a written care plan which should be regularly reviewed. A similar system applies in Wales.

Hospital admission

If you become very distressed during an episode, you may be admitted to hospital. This may be:

- as a voluntary patient
- under the terms of the Mental Health Act 1983 – 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 find psychiatric wards distressing, e.g. if there's not much to do or there is little privacy.

Crisis services

These exist in some areas as an alternative to hospital. They may offer accommodation, or support in your own home.

Advocacy

Unfortunately while you are in a crisis medical professionals may not take seriously what you have to say. 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.

An advocate supports you to:

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

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 can offer, and learn to live successfully in a group. The length of stay is usually limited to a set period of time.

You can ask to be referred to a therapeutic community by your doctor or mental health professional.

How can I help myself?

Recognise your triggers

If you have repeated episodes, it may be helpful to keep a diary, recording:

- everyday events
- sleep
- your diet.

This may help you to:

- spot patterns
- identify 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.

There are online mood diaries which you may find helpful (see 'Useful contacts' on p.23).

👉👉 *I have had to learn ways of reducing and dealing with stress, as my symptoms are at their worst during these times.* 👉👉

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 (such as a friend, family member or work colleague) what you would like to happen if you are in a crisis.

You could also make an 'advance decision', explaining what you would like to happen if you become unable 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 decisions are legally binding. See Mind's online *Advance decisions* resource for further details.

Share your experience

You might find it very helpful to talk to other people who have the same diagnosis or a related one (such as schizophrenia, psychosis or bipolar disorder). Various organisations run self-help groups which encourage you to share your experiences and help you come to terms with them.

Self-help groups 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
- take active steps to manage your situation.

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

For organisations that can put you in touch with self-help groups, see 'Useful contacts' on p.23.

Peer support groups also enable you to get in touch with others with similar experiences, to support and learn from each other. See Mind's online *Peer Support* resources for further details.

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 such as:

- yoga, meditation or mindfulness
- a spiritual practice
- massage, aromatherapy or reflexology (these may not suit you if you are uncomfortable with being touched).

Practical activities such as:

- gardening
- cooking
- crafts – making things may help you stay connected to reality in a purposeful way.

Arts activities can be helpful in expressing your feelings:

- painting
- music
- writing.

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

For more ideas, see Mind's online resources *How to cope with sleep problems*, *How to manage stress* and *Relaxation*.

Think about your diet

Try to eat regularly to keep your blood sugar stable – this can make a lot of difference to your mood and energy levels.

Try keeping a food diary to see if there are any foods which you are sensitive to.

For more tips, see Mind's online resource *Food and mood*.

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

Try some physical activity

Many people find that physical activity can help them, such as:

- a regular walk in the open air
- sports activities
- swimming.

These may also improve your sleep.

In some areas, health walks are organised locally, and some doctors will prescribe an exercise programme. (See Mind's online resources *Physical activity, sport and exercise* and *Ecotherapy*).

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.



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

Recovery approach

As you focus on the positive, you may find the Recovery approach helpful. This means:

- living the very best life you can, with the life experiences you have had and the consequences of them, even if these include 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
- maintaining hope.

Support in this may be available from Recovery and Wellbeing centres or Recovery Colleges, if you have any in your area.

 *I have learnt to understand myself better, I have graduated university, and I now work with others with mental health difficulties to help them move forward in their life.* 

How can friends or family 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:

- accept that the voices are real for them, even if you can't hear them
- focus on how they are feeling, rather than what they are experiencing.

These suggestions may also help:

Ask how you and others can help

Ask your friend or relative how you can be most helpful. Practical things you can do might include:



- support them to get treatment
- help them to access a particular service
- keep them company if they are going to something new, such as a treatment or activity, and are feeling anxious about it
- encourage them to look after themselves if they are neglecting their general wellbeing or appearance
- phone them regularly for a chat if you are not nearby
- support them in making 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'

- respect the choices they make, even if they would not be what you would choose for yourself
- be clear about what you feel you can and can't help with
- help them get alternative support if necessary – it may be possible to find an independent advocate to help them.

When your friend or relative is 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
- look out for symptoms
- look out for triggers.

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

 *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 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's online *Mental Health Act* resource for further details.

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. See 'Useful Contacts' on p.23.

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 national and local voluntary organisations provide help and information for carers on these topics.

Useful contacts

Mind

Mind Infoline: 0300 123 3393
(Monday to Friday, 9am to 6pm)
email: info@mind.org.uk
text: 86463
web: mind.org.uk
Details of local Minds, other local services and Mind's Legal Line. Language Line is available for languages other than English.

Bipolar UK

tel: 020 7931 6480
web: bipolaruk.org.uk
Information and support for people affected by bipolar disorder.

British Association for Behavioural and Cognitive Psychotherapies (BABCP)

web: babcp.com
Details of accredited therapists.

British Association for Counselling and Psychotherapy (BACP)

web: 01455 883300
itsgoodtotalk.org.uk
Details of local practitioners.

Carers UK

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

Elefriends

web: elefriends.org.uk
A supportive online community where you can talk openly about your mental health.

Hearing Voices Network

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

Intervoice

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

Mood Diaries

medhelp.org/land/mood-tracker
moodscope.com
moodchart.org
moodpanda.com

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 including 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

To buy copies of Mind's information booklets, visit mind.org.uk/shop or phone 0844 448 4448 or email publications@mind.org.uk

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tel: 020 8519 2122
fax: 020 8522 1725
web: mind.org.uk

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.

Mind Infoline: 0300 123 3393

info@mind.org.uk

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