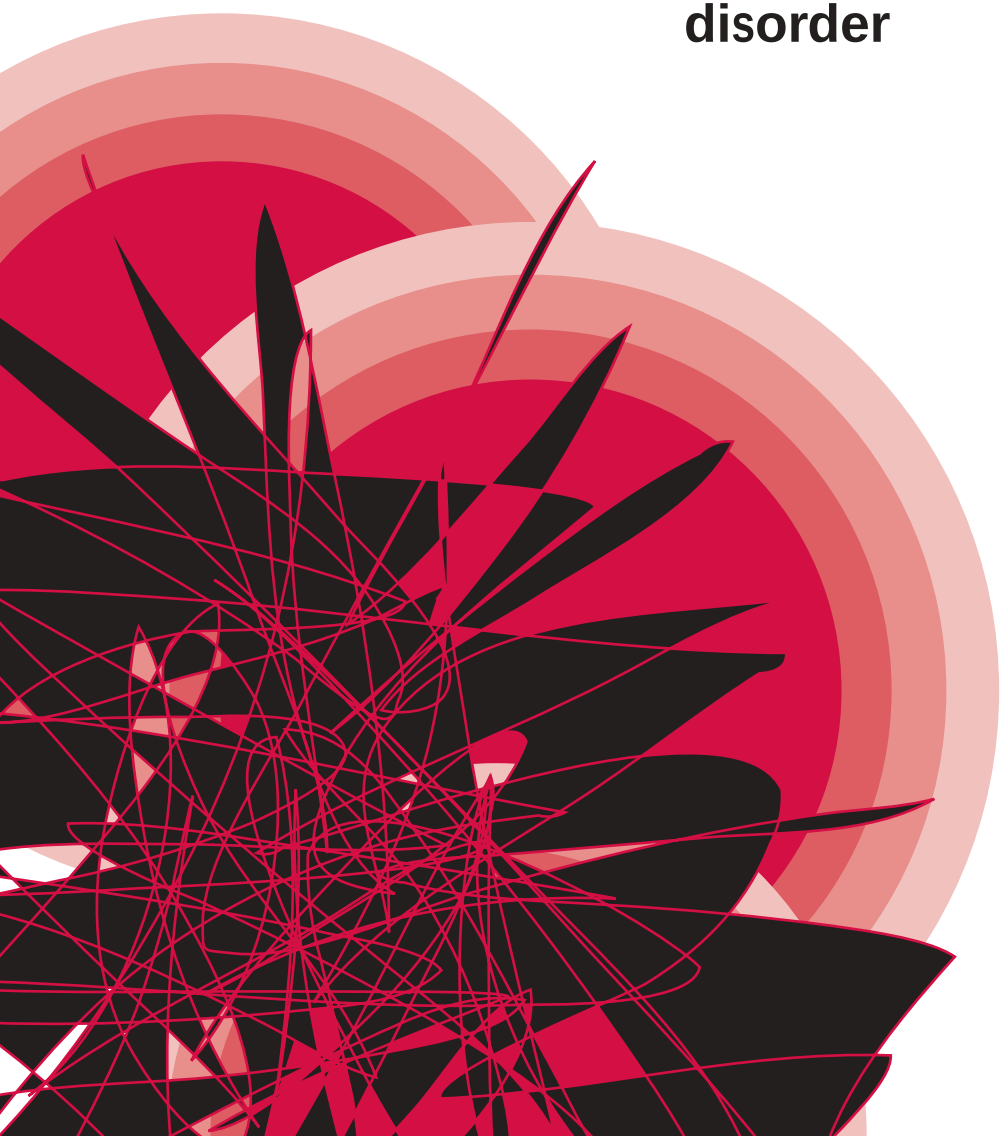
mind

For better
mental health

Understanding schizoaffective disorder



'Mild mania is known as hypomania, and usually does feel quite pleasant and can be fairly easy to live with. One has boundless energy, feels little need for sleep, is creatively inspired, talkative and is often taken to be an unusually attractive person.'

'Full-blown manic is frightening and most unpleasant … I can't hold any particular train of thought for more than a few seconds. I can't speak in complete sentences.'

'Imagining what they see in clouds is a common game among children. But I would take it an extra step, as the shape would take on a stark reality that didn't look like a cloud at all.'

I've been doing well mentally and emotionally for quite some time, and I credit that to my work with my therapist, not to any medicine I might take.'
Michael David Crawford

It used to be thought that schizoaffective disorder wasn't a condition in its own right, but 'the unlucky coincidence of two different diseases'. This booklet looks at the symptoms, how doctors make a diagnosis, what treatments are available and what you can do yourself.

What is schizoaffective disorder?

Many people have never heard of schizoaffective disorder. It's often confused with schizophrenia or manic depression, because the symptoms are similar to both. Even now, it's quite common for doctors to change their minds. You may have been given several different diagnoses, perhaps by different doctors.

Although schizoaffective disorder is regarded as a life-long problem for many people, it's relatively milder than either manic depression or schizophrenia and needn't stop you from carrying on an ordinary life, studying, working, forming relationships or having a family. Some people only ever have one episode, but others may have flare-ups of symptoms at intervals throughout their life, usually when they are under stress. After each relapse, most people gradually make a full recovery. Between episodes, it's quite likely that you won't have any symptoms at all, or only minor ones.

What are the symptoms?

Schizoaffective disorder affects your thinking processes and your moods. Moods can swing from deep depression to extreme elation in the course of one 'cycle' or episode of the disorder, and in this it resembles manic depression. During the same episode, you will also have schizophrenia-like symptoms, which might include seeing or hearing things that aren't apparent to anyone else (hallucinations) or believing something to be true that nobody else would believe (a delusion).

Doctors regard hallucinations and delusions as psychotic, because, in their view, the person having them is out of touch with reality. However, many mental health service users, and their supporters, would disagree with this. They suggest that Western medicine dismisses what have been common experiences throughout human history. They are experiences that continue to be an accepted part of other non-Western cultures. Critics point out that reality is subjective, and filtered through our own minds. This means that the way we perceive reality can be changed.

Depression

Depression may be the symptom you experience most. If you are depressed you will feel sad, lonely, tired and bored with life. You may want to sleep a great deal, but this may make you feel worse. If the depression gets really bad, you may not be aware of having any feelings at all, except emptiness and despair. It may seem as if there's a gap between you and other people, which is quite unbridgable. Your thoughts may become very morbid.

Mania

Depression may alternate with mania; sometimes mild (hypomania) and at other times severe. Mania can make you feel very excited and enthusiastic about life, talkative, and with your head jumping with thoughts, ideas and plans. You may get by on very little sleep (and this may make the mania worse). But you may also have a completely unfounded confidence in your own judgement and abilities, which can get you into difficulty. Characteristically, people will be extravagant with money, and pursue unwise sexual encounters and risky business ventures. At times, the good mood (euphoria) can turn to dysphoria, when you become angry and irritable, especially if someone contradicts or questions you.

The cycles of mania and depression can be at fairly regular periods, although this varies from person to person. It can range from 'rapid cycling' which means swinging between moods every day, to moods alternating every year, or so. It's possible to live without symptoms, or treatment, for years. But the symptoms can then return fiercely and suddenly, with no warning. At its extreme, full-blown mania can be a very frightening indeed for all concerned. If left untreated, the cycles can begin to happen more rapidly and more severely.

Hallucinations and delusions

Everyone has an inner voice in which they talk to themselves. It's easy to tell the difference between the inner voice in your mind, and somebody else talking to you. But hearing voices is different. This kind of hallucination sounds as if it's coming from the outside world. You have to learn how to distinguish these auditory hallucinations from someone actually talking to you. Hearing voices is regarded as a key sign of schizophrenia or schizoaffective disorder.

It's common for the voices to be harshly critical, to say that the hearer is worthless and deserves to die. Sometimes they give a running commentary on whatever is going on, or discuss the hearer, between themselves. The voices aren't always negative, however; you may find them familiar and even comforting. Hallucinations can also mean seeing something, and feeling or smelling things.

Delusions are mistaken interpretations of things going on around you. You may believe that you are a famous person. Or that you have superhuman powers. You may even experience physical sensations that confirm your belief that you are in charge, or the opposite idea that you are the passive victim of evil forces.

It's quite common for people to have paranoid delusions, believing that somebody wants to hurt them, and to interpret innocent actions as threatening them. You may be convinced that somebody else is in control of your actions. You may think that other people, on the television for example, are talking about you or referring to you. Even if part of you knows this isn't true, it may not stop you having that feeling.

There is a great deal of completely inaccurate publicity about the dangers presented to the public by people who are paranoid. They should be aware that somebody in this state of mind is far more likely to hurt themselves than anybody else.

Dissociation

People sometimes report feeling as if they are a detached observer of their own life. Or they may feel that the world itself isn't real, but just a figment of their imagination. To counteract this, it may be useful to use physical sensation, such as touching textured objects, to help root you back in reality.

How is schizoaffective disorder diagnosed?

There are a number of medical conditions that cause disturbances in thought and mood (for instance a stroke, a brain injury, problems with the thyroid or adrenal glands), and a doctor needs to rule these out. The next problem is to distinguish schizoafffective disorder from either manic depression or schizophrenia. This is difficult because someone who has schizophrenia can be very depressed, and someone with manic-depression can hallucinate.

There is no test for these conditions, and your doctor will make the diagnosis on the basis of your medical and personal history, by observing your current behaviour, talking to you and giving you other psychological diagnostic tests. The diagnosis is usually based on the DSM-IV (the American Psychiatric Association's *Diagnostic and statistical manual of mental disorders*).

One of the key ways doctors distinguish schizoaffective disorder from either schizophrenia or manic depression is in the timing of the symptoms. An episode has to last for at least a month, and mood problems and thinking disorders should be happening at the same time, or within just a few days of each other. But, for at least two weeks during that month, the mood symptoms should disappear altogether, leaving only the thinking problems.

A person may have more of one type of symptom than another, so doctors may describe them as having manic type, depressive type or mixed type schizoaffective disorder.

Manic type

The mood symptoms may include:

- elation, increased self-esteem and unrealisable plans
- excitement
- irritability, with aggressive behaviour
- increased energy
- overactivity
- inability to concentrate
- uninhibited behaviour.

Thinking problems may include hallucinations or delusions, but these may not necessarily be either grandiose or paranoid. Episodes of this type usually start suddenly, and people may behave in a very disturbed way for a short time. They usually make a full recovery within a few weeks. People who have manic forms may be less vulnerable to relapse than those with depressive forms of the disorder.

Depressive type

The mood symptoms may include:

- feeling very low
- feeling slowed down
- insomnia
- no energy
- no appetite; losing weight
- loss of usual interests
- lack of concentration
- feeling guilty
- feeling hopeless
- suicidal thoughts.

Thinking problems may include hallucinations or delusions, which are likely to be grandiose or paranoid. This type is usually less dramatic and alarming than the manic type, but tends to last longer. Sometimes, people go on experiencing a few of the schizophrenic symptoms afterwards.

Mixed type

This diagnosis is made when symptoms of schizophrenia occur at exactly the same time as those of manic depression.

Confusingly, you may experience one type during one episode, but a different type during a different episode.

What causes it?

The causes are unknown, but there seem to be a number of factors that could be contributing. Stress seems to play a key role in triggering the problem, as with many types of mental distress, and you may be particularly vulnerable to a relapse in times of stress. You may well be able to identify particular events or sources, which you feel have contributed to your state of mind.

There is no doubt that there's a chemical imbalance in the brain when someone has schizoaffective disorder, but the question remains, which came first, the problems or the chemical imbalance?

Schizoaffective disorder seems to occur more often in families where other members have been diagnosed with something similar, such as schizophrenia. It suggests that people might be more prone to developing the problem because of their environment or because of something they have inherited. As a rule, the problem begins in early adulthood, and although there hasn't been much research into the problem as a whole, it may be that women are more likely to experience it than men.

What sort of help can I get?

Your first contact with the medical system may be your GP, who is likely to refer you for assessment to a psychiatrist in a hospital or on a community mental health team. You should be encouraged to involve yourself, as far as possible, in decisions about your care. They should explain to you what your treatment options are, and find out what you feel would be helpful to you.

If you are not well enough to speak for yourself, which may be the case early on in your treatment, you may want to have an advocate present when you see members of the team. An advocate is someone who could represent your views, speak on your behalf, if you wish, or support you in speaking for yourself (see the *Mind guide to advocacy*, details on p. 14, and *Useful organisations,* on p. 13, for more information). You may also want to involve a friend or family in decisions.

Community care

Whether or not you have been in hospital, you should receive care from the local community mental health team and social services department, under the Care Programme Approach. This means you should have a care plan and access to a named care co-ordinator (a community psychiatric nurse, a social worker or your psychiatrist).

The care plan can vary, depending on how your needs are assessed. It may be something as simple as a statement of what medication you are taking, if any, and the date of your next appointment with the mental health team, or it may specify sessions with a psychologist, or other activities (see p. 10). The care plan should tell you what you and your doctors have agreed is appropriate, and this should be reviewed, as necessary.

Drug treatment

To begin with, you are likely to be offered psychiatric drugs. There are none specifically for schizoaffective disorder. Instead, there is a combination of drugs used for manic depression and schizophrenia.

If you are depressed, you may take SSRI antidepressants for a time. These boost the chemical messengers in the brain that are in low supply, and improve the flow of signals in the brain. They take a couple of weeks to start working, and can have side effects, which may include gastric upsets, headaches and disturbed sleep. It's worth trying a number of different ones until you find the one that suits you best.

If you are on a manic 'high' or prone to mood swings, you may be given something to stabilise this, such as lithium or valproic acid. Again, lithium usually takes several weeks to start working.

One problem with antidepressants is that they may stimulate manic episodes. It's important that your doctor monitors the effects of the antidepressants carefully, so that any modifications in dosage can be made, to cut back on them or to increase the mood stabiliser, or both.

If your psychotic symptoms are very troublesome, you may be prescribed an antipsychotic, such as risperidone or olanzapine, until the symptoms are over. Antipsychotic drugs can have unpleasant and sometimes dangerous side effects, and for this reason, many people prefer to phase these out as soon as possible.

It's very common for someone with this diagnosis to be on more than one kind of drug. Arriving at the right combination may take time, and this can be very frustrating. Feel free to discuss this with your doctor and to ask questions. (See Mind's series of booklets on treatments and drugs, details under *Further reading,* on p. 14.)

Hospital care

There may be times when you may find it very difficult to take care of yourself and need to be looked after for a while. This could happen if you become very severely depressed or manic, or if you are having a psychotic episode. It may then be necessary to go in to hospital, so that you can be stabilised with the help of medication. While you may appreciate being cared for, it may be difficult coping with the lack of privacy and with other people who are very distressed or disturbed.

Occasionally, if antidepressants aren't working, the doctors may suggest using electroconvulsive therapy (ECT). This is a controversial treatment because of the side effects it causes, including memory loss. A new technique called Transcranial Magnetic Stimulation seems to be a less damaging solution, but is not yet widely available. (See *Making sense of electroconvulsive therapy* (ECT), details, on p. 14.)

Crisis services

Some areas have developed crisis services as an alternative to hospital. They can sometimes offer accommodation but, otherwise, will provide support in your own home. Crisis services tend to rely less on drug treatments and more on talking treatments and informal support. (For more information, see p. 10, and *Further reading*, on p. 14.)

What other help can I get?

As with most mental health problems, it's a good idea to approach the problem holistically. In other words, taking into account the person as a whole, psychologically, socially and biologically. Research suggests that a person recently diagnosed with schizoaffective disorder can best be treated, and success achieved, if they have 24-hour access to counselling and other support services. This shouldn't involve too long a stay in hospital. Ideally, people should be in a residential setting, where they can have help learning the skills necessary to live an independent life. They should then be able to make a gradual transition to living alone, with help available.

Skills training

Skills training can teach you to improve your handling of social situations, as well as personal care, how to manage your money, shopping, cooking, and job-hunting. You may also find ways of dealing with some of the symptoms, if they recur, other than medication. For example, many people find alternative ways of coping with voices (see *Further reading*, on p.14.).

Talking treatments

Giving someone medicine offers them relief from their symptoms, but doesn't necessarily improve their outlook. A talking treatment, such as individual psychotherapy, allows you to discuss relationship issues, and to understand the background to your problems. It can help you develop the insight you need to take control of your life. Achieving real change is a lengthy process, and it's often painful. You may be able to access this kind of help through your GP practice. If not, there are organisations whose members may offer a sliding scale of fees (see *Useful organisations*, on p. 12). You should try to work with someone who is experienced in these problems. It might be best to start looking when you're feeling emotionally stable.

Studies have suggested that cognitive behaviour therapy, which is a patient-led approach, is very effective. Together, patient and psychologist explore the disorder, establish and work on your goals and develop ways of managing everyday problems.

Group therapy is sometimes an option, but it's more likely to be successful in an inpatient rather than an outpatient setting. Under other circumstances, you may find it too challenging, socially. (For more information about talking treatments, see *Further reading,* on p. 14.)

What can I do to help myself?

There is great benefit in feeling that you are beginning to take control of your problem, rather than having the problem (or the professionals) taking control of you.

Support groups

Getting together with people who share your problem, or who have some inkling of what the experience is like, can bring comfort, an outlet and information. Support groups specifically for people diagnosed with schizoaffective disorder are very hard to find in the UK. An alternative is to find a more general mental health user group, such as a local Mind association. If you are hearing voices, consider contacting the Hearing Voices Network, who may have a group in your area. (See *Useful organisations*, on p. 13, for more information.)

Complementary therapies

You may also find complementary therapies helpful in dealing with the stress of everyday life and helping you unwind. Yoga, aromatherapy and massage could all be worth trying. (See *Further reading*, on p. 14, for more information.)

Eat a balanced diet

What and when you eat can influence the way you feel. Varying blood sugar levels may have a major effect on your mood, and it's worth being aware of your diet.

Working life

If you are working, your employer should be prepared to make changes to your working arrangements, if that would help you. This could mean adjusting your hours, organising work around your strengths and weaknesses, or providing a quiet room where employees can relax properly and unwind.

Being prepared

Accepting that you may have a long-term condition could be the first step towards ensuring that problems are kept to a minimum. Planning your life with this in mind doesn't mean letting it dominate. On the contrary, it reduces the chances of disruption.

- Try to work out, and stick to, a regular daily routine. Avoid making too many changes in your life. Take one at a time.
- Make your home environment as tranquil as possible.
- It's crucial to identify what causes you stress, so that you can avoid it or develop strategies for tackling it.
- Look after yourself by taking regular exercise, which has very positive effects if you suffer from depression. Get plenty of rest. Avoid alcohol or street drugs.
- Be prepared to get feedback on your feelings or fears from someone you trust, so that you can check whether or not they are based on reality.
- Identify someone you can talk to, such as a friend, family member or therapist, if you feel the pressure building up.
- Develop a list of warning signs of a relapse.
- Keep a crisis card or an advance directive listing what you would like to happen in a crisis. This could include who you want told, what you will find helpful, details of any medication you are currently taking, any that have helped in the past, and any you would prefer to avoid.
- If you have a relapse, accept that there will be setbacks, but that you will get past them.

What can friends and relatives do to help?

It can be upsetting if someone you care about is deeply depressed, or experiencing psychotic symptoms. It will be helpful if you can acknowledge that the experience is real for them, and sympathise with their anxiety and distress.

One of the most useful ways of helping is to encourage them to look after their mental and physical health. Practical help might include going with them to appointments, as well as social occasions, if they find it helpful.

References

Michael David Crawford
(www.geometricvisions.com/madness/schizoaffective-dissorder/someone.html)
The Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) (The American Psychiatric Association)
The ICD-10 Classification of Mental and Behavioural Disorders (The World Health Organisation)
Oxford Textbook of Psychiatry 3rd edition (1996)
PsychNet-UK Web Directory
(www.psychnet-uk.com/dsm_iv/schizoaffective_disorder.htm)

Useful organisations

Hearing Voices Network
91 Oldham Street, Manchester M4 1LW
helpline. 0161 834 3033, web: www.hearing-voices.org
User network and local support group for people who hear voices

Rethink Severe Mental Illness (NSF)
28 Castle Street, Kingston-upon-Thames, Surrey KT1 1SS
advice line: 020 8974 6814, web: www.rethink.org.
For everyone affected by severe mental illness

The Manic Depression Fellowship (MDF)
Castle Works, 21 St Georges Road, London SE1 6ES
tel. 020 7793 2600, web: www.mdf.org.uk
Works to enable people affected by manic depression to take control of their lives

The Food and Mood Project
PO Box 2737, Lewes BN7 2GN
email: info@foodandmood.org web: www.foodandmood.org
Information about the effects of what you eat

Institute for Optimum Nutrition Information Service
Blades Court, Deodar Road, London SW15 2NU
tel. 020 8877 9993, web: www.ion.ac.uk
Aims to protect and preserve people's health through nutrition

Further reading

- ☐ *Accepting voices* eds. M. Romme, S. Escher (Mind 1993) £13.99
- ☐ *A can of madness* J. Pegler (Chipmunka Publishing 2002) £9.99
- ☐ *Coping with bipolar disorder: a guide to living with manic depression* S. Jones, P. Hayward, D. Lam (Oneworld 2002) £10.99
- ☐ *Coping with depression* and elation Dr P. McKeon (Sheldon Press 1997) £6.99
- ☐ *The day the voices stopped* K. Steele, C. Berman (Basic Books 2002) £11.50
- ☐ *How to cope as a carer* (Mind 2003) £1
- ☐ *How to improve your mental wellbeing* (Mind 2002) £1
- ☐ *How to increase your self-esteem* (Mind 2003) £1
- ☐ *How to look after yourself* (Mind 2002) £1
- ☐ *How to rebuild your life after breakdown* (Mind 2000) £1
- ☐ *How to recognise the early signs of mental distress* (Mind 2002) £1
- ☐ *Living with mental illness: a book for relatives and friends* E. Kuipers, P. Bebbington (Souvenir Press 1997) £9.99
- ☐ *Living with schizophrenia: a holistic approach to understanding, preventing and recovering from negative symptoms* J. Watkins (Hill of Content 1996) £9.99
- ☐ *Making sense of antidepressants* (Mind 2002) £3.50
- ☐ *Making sense of antipsychotics* (minor tranquillisers) (Mind 2003) £3.50
- ☐ *Making sense of cognitive behaviour therapy* (Mind 2001) £3.50
- ☐ *Making sense of electroconvulsive therapy* (ECT) (Mind 2003) £3.50
- ☐ *Making sense of lithium* (Mind 2003) £3.50
- ☐ *Making sense of minor tranquillisers* (Mind 2003) £3.50
- ☐ *Making sense of sleeping pills* (Mind 2000) £3.50
- ☐ *The Mental health act 1983: an outline guide* (Mind 2002) £1
- ☐ *The Mind guide to advocacy* (Mind 2000) £1
- ☐ *The Mind guide to food and mood* (Mind 2000) £1
- ☐ *The Mind guide to managing stress* (Mind 2003) £1
- ☐ *The Mind guide to physical activity* (Mind 2001) £1
- ☐ *The Mind guide to relaxation* (Mind 2001) £1
- ☐ *The Mind guide to surviving working life* (Mind 2003) £1
- ☐ *Mind rights guide 1: civil admission to hospital* (Mind 2003) £1
- ☐ *Understanding depression* (Mind 2003) £1
- ☐ *Understanding mental illness* (Mind 2003) £1
- ☐ *Understanding talking treatments* (Mind 2002) £1

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Mind (National Association for Mental Health)
15-19 Broadway
London E15 4BQ
tel: 020 8519 2122
fax: 020 8522 1725
web: www.mind.org.uk

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