Rethink Mental Illness.

factsheet

Anxiety disorders

This factsheet gives information on anxiety disorders. It explains the symptoms, treatments and way to manage an anxiety disorder. This factsheet is for people with anxiety disorders. And their carers, relatives and friends

Key Points.

- Anxiety can make you feel worried or scared.
- Anxiety can cause physical symptoms such as a fast heartbeat or sweating.
- It is a normal human response to be anxious in certain situations. You may have an anxiety disorder if you feel anxious all or most of the time.
- You can recover from anxiety disorders. Treatment and support are available for you.
- Your doctor can offer you treatment. What you are given will depend on your symptoms and how severe they are.

This factsheet covers:

Top

1. What are anxiety disorders?

We all have feelings of anxiety, worry and fear sometimes. These can be normal responses to certain situations. For example, you might worry about a job interview, or about paying a bill on time. These feelings can give you an awareness of risks and what you need to do in a difficult or dangerous situation. This reaction is known as 'fight or flight'.

Your brain responds to a threat or danger by releasing stress hormones such as adrenaline and cortisol. Even if the danger is not real, these hormones cause the physical symptoms of anxiety. [1] Once the threatening situation has stopped, your body will usually return to normal.

But if you have an anxiety disorder these feelings of fear and danger can be ongoing and interrupt your daily routine long after the threat has gone. [2] They can make you feel as though things are worse than they actually are.

Everyone's experience of anxiety disorders is different. Not everyone who has an anxiety disorder will experience the same symptoms.

Mental symptoms of anxiety can include:

- racing thoughts,
- uncontrollable over-thinking,
- difficulties concentrating,
- feelings of dread, panic or 'impending doom',
- feeling irritable,
- heightened alertness,
- problems with sleep,
- changes in appetite,
- wanting to escape from the situation you are in, and
- dissociation.

If you dissociate you might feel like you are not connected to your own body. Or like you are watching things happen around you, without feeling it.

Physical symptoms of anxiety can include:

- sweating,
- heavy and fast breathing,
- hot flushes or blushing,
- dry mouth,
- shaking,
- hair loss,
- fast heartbeat,
- extreme tiredness or lack of energy
- dizziness and fainting, and
- stomach aches and sickness.

Anxiety can lead to depression if left untreated.

Ali's story

Both getting to sleep and getting up in the morning is difficult for me. I have a constant sense of dread that is tough to ignore. My mind never switches off. It's exhausting. I've never got help for how I'm feeling.

Recently I became so tired. I have lost my appetite and motivation to do anything. I feel really low. Things like going to work or even doing the weekly shop have become tricky. So I decided to speak to my GP. My GP says that I am experiencing depression as well as anxiety.

My GP has talked to me about medication. And I'm now waiting for talking therapy.

I've also started using breathing techniques to help my sense of dread. And am finding the NHS Every Mind Matters website really helpful.

You can see more about breathing techniques in section 7 of this factsheet. And you can find details of the Every Mind Matters website in the further reading section at the end of this factsheet.

You can find more information about:

- Depression
- Talking therapies

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

Top

2. What are the different types of anxiety disorder?

This section provides an overview of the most common types of anxiety disorders.

- Generalised anxiety disorder (GAD)
- Panic disorder
- Social anxiety disorder
- Phobias
- Obsessive compulsive disorder (OCD)
- Skin picking
- Hair pulling
- Health anxiety
- Body dysmorphic disorder (BDD)
- Post-traumatic stress disorder (PTSD)

Generalised anxiety disorder (GAD)

GAD is common. The main symptom of GAD is over worrying about different activities and events. This may feel out of your control.[3] You feel anxious a lot of the time if you have GAD. You might feel 'on edge' and alert to your surroundings.

This can affect your day-to-day life. You might find that it affects your ability to work, travel places or leave the house. You might also get tired easily or have trouble sleeping or concentrating. You might have physical symptoms, such as muscle tension and sweating. [4].

It is common to have other conditions such as depression or other anxiety disorders if you have GAD.[5]

GAD can be difficult to diagnose because it does not have some of the unique symptoms of other anxiety disorders. Your doctor is likely to say you have GAD if you have felt anxious for most days over six months and it has had a bad impact on areas of your life.[6]

Panic disorder

You will have regular panic attacks with no particular trigger if you have panic disorder. They can happen suddenly and feel intense and frightening. You may also worry about having another panic attack.[7]

Panic disorder symptoms can include the following. [8]

- An overwhelming sense of dread or fear.
- Chest pain or a sensation that your heart is beating irregularly.
- Feeling that you might be dying or having a heart attack.
- Sweating and hot flushes or chills and shivering.
- A dry mouth, shortness of breath or choking sensation.
- Nausea, dizziness and feeling faint.
- Numbness, pins and needles or a tingling sensation in your fingers.
- A need to go to the toilet.
- A churning stomach.
- Ringing in your ears.

You may also dissociate during a panic attack. Such as feeling detached from yourself.[9]

Certain situations can cause panic attacks. For example, you may have a panic attack if you don't like small places but you have to use a lift. This doesn't mean that you have panic disorder.[10]

Social anxiety disorder

Social anxiety disorder is sometimes known as social phobia. Lots of people may worry about social situations but if you have social anxiety you will have an intense fear or dread of social or performance situations. This will happen before, during or after the event.

Some common situations where you may experience anxiety are the following.

- Speaking in public or in groups.
- Meeting new people or strangers.
- Dating.
- Eating or drinking in public.

You may be worried that you will do something or act in a way that is embarrassing.

You might feel aware of the physical signs of your anxiety. This can include sweating, a fast heartbeat, a shaky voice and blushing. You may worry that others will notice this or judge you. You might find that you try to avoid certain situations. You might realise that your fears are excessive, but you find it difficult to control them.

Your GP will ask you questions about your symptoms. And might ask you to fill out a questionnaire. This will help them find out how anxious you feel in social situations. They may refer you to a mental health specialist for a full assessment.[11]

You can ask for a telephone appointment with your GP if it would be too difficult for you to see them in person.

Phobias

A phobia is an overwhelming fear of an object, place, situation, feeling or animal.

Phobias are stronger than fears. They develop when a person has increased feelings of danger about a situation or object. Someone with a phobia may arrange their daily routine to avoid the thing that's causing them anxiety.[12]

Common examples of phobias include the following.[13]

- **Animal phobias**. Such spiders, snakes or rodents.
- **Environmental phobias**. Such as heights and germs.
- **Situational phobias**. Such as going to the dentist.
- **Body phobias**. Such as blood or being sick.
- **Sexual phobias**. Such as performance anxiety.

Agoraphobia

Agoraphobia is a fear of being in situations where escape might be difficult. Or situations where help wouldn't be available if things go wrong.[14] This could be the following.

- Leaving your home.
- Being in public spaces.
- Using public transport.
- Being in crowded spaces.

You might find that these situations make you feel distressed, panicked and anxious. You may avoid some situations altogether. This can affect day-to-day life.

Agoraphobia can make it difficult to make an appointment with your GP to talk about your symptoms. You might not feel able to leave your house or go to the GP surgery. You can arrange a telephone appointment if you have symptoms of agoraphobia.[15] A GP will decide on the best treatment options for you depending on what you tell them.

Obsessive-compulsive disorder (OCD)

You will have obsessions, compulsion or both if you have OCD.[16]

- **Obsession**. An obsession is an unwelcome thought or image that you keep thinking about and is largely out of your control. These can be difficult to ignore. These thoughts can be disturbing, which can make you feel distressed and anxious.
- **Compulsion.** A compulsion is something you think about or do repeatedly to relieve anxiety. This can be hidden or obvious. Such as saying a phrase in your head to calm yourself. Or checking that the front door is locked.

You might believe that something bad will happen if you do not do these things. You may realise that your thinking and behaviour is not logical but still find it very difficult to stop.

Speak to your GP if you think you have OCD. They should discuss treatment options with you. Or you could try to self-refer to an NHS talking treatment service.[17]

You can find more information about **'Obsessive-compulsive disorder'** at www.rethink.org. Or call our General Enquires team on 0121 522 7007 and ask them to send you a copy of our factsheet.

Skin-picking

Skin picking is medically known as dermatillomania. It is an impulse control disorder. You will regularly pick at your skin. Often you will pick healthy skin. This can cause damage to your skin, including bleeding, bruising and sometimes permanent marks. You will usually pick the skin on your face but might also pick other areas of the body. You will find it difficult to stop yourself doing it. [18]

No one knows the cause for skin-picking. It is thought that it could be a type of addiction. Or it relieves tension and stress. It is common to have OCD and dermatillomania at the same time.

Your GP may arrange for you to see a specialist mental health doctor like a psychiatrist for diagnosis.

Hair pulling

Hair pulling is medically known as trichotillomania. It is an impulse control disorder. You feel the urge to pull out your hair if you have this condition. This can be from your scalp or other places such as your arms, eyelashes, legs or pubic area. You will find it difficult to stop yourself doing this. [19]

You might experience a build-up of tension which you can relieve by pulling out the strand of hair. You might not even be aware that you're doing it.

It can be difficult to stop, which can lead to hair loss. This in turn can make you feel guilty, embarrassed and affect how you feel about yourself or how your friends and family see you.

Your doctor will look at the following to diagnose your condition. [20]

- You repeatedly pull your hair out, causing noticeable hair loss
- You feel increasing tension before you pull your hair out
- You feel relief or pleasure when you have pulled your hair out
- There are no underlying illnesses, such as a skin condition, causing you to pull your hair out
- Pulling your hair out affects your everyday life or causes you distress.

Health anxiety[21]

You may have health anxiety if you spend a lot of time worrying about if you are ill. Or worrying about getting ill. You may:

- worry that your doctor has missed something,
- check your body a lot for signs of illness,
- constantly worry about your health,
- spend a lot of time asking people if they think you are ill,
- spend a lot of time looking at health information on the internet, on the tv or in newspapers, or
- act as if you were ill.

Symptoms like headaches or a racing heartbeat can be caused by anxiety. But if you have health anxiety you may mistake these for signs of illness.

Body dysmorphic disorder (BDD)

You will have upsetting thoughts about the way you look if you have BDD. The thoughts don't go away and have a big effect on daily life.

This is not the same as being vain about your appearance. You may believe that you are ugly and that everyone sees you as ugly, even if they reassure you that this isn't true. Or you may believe that people are focused on an area of your body such as scar or birthmark. It can be very distressing and lead to depression.[22]

You may spend a large amount of time doing the following.[23]

- Staring at your face or body in the mirror.
- Comparing your features with other people's.
- Covering yourself with lots of makeup.
- Thinking about plastic surgery when you do not need it.

Speak to your GP if you think you have BDD. They should discuss treatment options with you. The GP may arrange for a team with more BDD experience to help you.[24]

Post-Traumatic Stress Disorder (PTSD)

You may have PTSD if your anxiety symptoms developed after a stressful or distressing event. Or if you have experienced trauma over a long period of time.[25]
You can find more information about '**Post-Traumatic Stress Disorder**' at www.rethink.org. Or call our General Enquiries team on 0121 522 7007 and ask them to send you a copy of our factsheet.

Top

3. What causes anxiety disorders?

We don't fully understand what causes anxiety disorders. But it is thought that the following factors can cause anxiety.[26]

Genetics. Some people seem to be born more anxious than others. You may get anxiety through your genes.
Life experience. This could be bad experiences such as being abused or losing a loved one. It could also include big changes in life such as moving home, losing your job or pregnancy.

Drugs. Caffeine in coffee and alcohol can make you feel anxious. Illegal drugs, also known as street drugs can also have an effect.

Circumstances. Sometimes you know what is causing your anxiety. When the problem goes, so does your anxiety.

Top

4. How can I get help if I think I have an anxiety disorder?

You should make an appointment to talk with your GP if you are worried about your symptoms. Or they are causing problems in your day to day life.

Your doctor will look at different things when deciding on your treatment such as the following.

- Your diagnosis and symptoms.
- What options you have tried already.
- Your goals and preferences.
- Any other conditions you have.
- Guidance from the National Institute for Health and Care Excellence (NICE).

Talking therapies

The NHS' 'Improving Access to Psychological Therapies' (IAPT) programme has made psychological therapy more available on the NHS.[27] IAPT services mainly provide support for low to moderate anxiety and depression.

The service can be run by the local NHS Trust or a non-NHS agency, like a charity who work with the local Trust.

IAPT should be available in your area. You can often self-refer or ask your GP to refer you.

To find your local the IAPT service you can search online here: www.nhs.uk/Service-Search/Psychological%20therapies%20%28IAPT%29/LocationSearch/10008

You can also ask your GP or PALS service for details of local IAPT services.

Go to www.rethink.org for information on:

- GP: What to expect from your GP
- Medication. Choice and managing problems
- Talking therapies.

Or call our General Enquiries team on 0121 522 7007 and ask them to send you a copy of our factsheet.

Top

5. How are anxiety disorders treated?

You can check what treatment and care is recommended for anxiety disorders on the National Institute for Health and Care Excellence (NICE) website.

NICE produce guidelines for how health professionals should treat certain conditions. NICE only provide guidelines for:

- Generalised anxiety disorder (GAD) and panic disorder,
- Obsessive-compulsive disorder (OCD) and body dysmorphic disorder (BDD),
- Post-traumatic stress disorder (PTSD), and
- Social anxiety disorder.

The NHS does not have to follow these recommendations. But they should have a good reason for not following them.

We have described some of the treatments for anxiety disorders below. The treatments you will be offered depend upon the type of anxiety disorder you are experiencing.

You can find more information about treatments for:

- Post-traumatic stress disorder (PTSD
- Obsessive-compulsive disorder (OCD)

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

Monitoring your symptoms

Some anxiety disorders, such as generalised anxiety disorder (GAD) may get better by itself with no treatment at all. Or after education and advice from your doctor.[28] Your doctor will monitor your symptoms to see if they improve.[29] And they will talk to you about medications that you can get without a prescription.[30] These are sometimes called over-the-counter medications.

Individual non-facilitated self help[31]

This involves working from a book or a computer program. You will be supported by a trained professional

- A written or electronic information based on cognitive behavioural therapy principles.
- Instructions to work through the material over at least 6 weeks.
- Very brief support from a therapist such as a 5-minute telephone conversation.

Individual guided self-help[32, 33]

You should:

- get written or electronic materials,
- be supported by a trained professional, who delivers the self-help programme and reviews progress and outcomes, and
- get support to use the materials, either face-to-face or over the telephone.

Psychoeducational groups[34]

Psychoeducation means that you will learn about your symptoms and how to manage them.

Your learning should:

- be based on CBT,
- get you involved,
- include presentations from a trained professional,
- include self-help manuals,
- have 1 therapist to about 12 people, and
- usually be 6 weekly sessions, each lasting 2 hours.

If these treatments do not work you should be offered cognitive behavioural therapy (CBT), applied relaxation or medication.[35]

Cognitive behavioural therapy (CBT)

CBT helps you understand the links between your thoughts, feelings and behaviour. It can help you to find ways to overcome your anxiety by challenging negative thoughts and beliefs.

Depending upon the type of anxiety disorder you have you may be offered individual or group sessions.[36, 37] If you have social anxiety disorder you should not be offered group CBT sessions.[38]

Applied Relaxation

Applied relaxation means that you will focus on relaxing your muscles in a certain way. And at a certain time. For example, learning how you can relax your muscles so that you are able to fall asleep easier.

A trained therapist will teach you different techniques to manage your situation.

Depending on the anxiety that you have, you will usually get 12–15 weekly sessions each lasting 1 hour. You will get less if you recover sooner and more if you need it.[39]

Short term psychodynamic therapy

This type of therapy focuses on the different forces in your life that are causing you problems. The aim is to look at, understand and work through these difficulties, which may have begun in childhood. Your therapist will also help you to improve your social skills.[40]

This type of therapy is specifically used for people with social anxiety disorder. You will usually have up to 25 or 30 sessions which last 50 minutes. The therapy will usually take place over a 6 to 8 month period.[41]

Exposure and response prevention (ERP)

This treatment is particularly used for people living with obsessive-compulsive disorder (OCD). Your therapist will encourage you to experience your obsessive thoughts and help you to manage them in a different way. They will build up the difficulty of each task.[42]

Eye movement desensitisation and reprocessing (EMDR)[43]

This talking therapy is used mainly for people living with post-traumatic stress disorder (PTSD).

You will make eye movements while thinking about the traumatic event. EMDR helps make your brain deal with painful memories in a different way. So, these can become less painful for you.

Medications

Selective serotonin reuptake inhibitors (SSRIs)

SSRIs are a type of antidepressant used to treat anxiety disorders. Sertraline is the most common SSRI suggested for anxiety,[44] but there are other SSRIs available.

Serotonin and noradrenaline reuptake inhibitors (SNRIs)

SNRIs are a type of antidepressant. You may be prescribed an SNRI if SSRIs did not help your anxiety.[45]

Pregabalin[46]

Pregabalin is a type of medication known as an anticonvulsant. Anticonvulsants are usually used to treat epilepsy. But pregabalin has been found to help people living with anxiety disorders.

Benzodiazepines

Doctors should only prescribe benzodiazepines if your anxiety is extreme or if you are in crisis.[47] This is because they are addictive, and they may become less effective over time.

Beta-blockers

These can help with the physical signs of anxiety. They can help to lower a fast heartbeat.[48]

Complementary therapies

Complementary therapies are treatments that are not usually part of mainstream NHS care. Some people find them useful for helping with symptoms of anxiety. Such as yoga and hypnotherapy.

Go to www.rethink.org for information on:

- Talking therapies
- Antidepressants
- Benzodiazepines
- Complementary and alternative therapies

Or call our General Enquiries team on 0121 522 7007 and ask them to send you a copy of our factsheet.

Top

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

If you are not happy with your treatment you can:

- talk to your doctor about your treatment options,
- ask for a second opinion,
- get an advocate to help you speak to your doctor,

- contact Patient Advice and Liaison Service (PALS) and see whether they can help, or
- make a complaint.

There is more information about these options below.

Treatment options

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

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

Second opinion

A second opinion means that you would like a different doctor to give their opinion about what treatment you should have. You can also ask for a second opinion if you disagree with your diagnosis.
You don't have a right to a second opinion. But your doctor should listen to your reason for wanting a second opinion.[49]

Advocacy

An advocate is independent from the mental health service. They are free to use. They can be useful if you find it difficult to get your views heard. There are different types of advocates available. Community advocates can support you to get a health professional to listen to your concerns. And help you to get the treatment that you would like.

You can search online to search for a local advocacy service. If you can't find a service you can contact the Rethink Mental Illness Advice Service on 0300 500 927, we will look for you. But this type of service doesn't exist in all areas.

The Patient Advice and Liaison Service (PALS)

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

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

You can find out more about:

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

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

Top

7. What can I do to manage my symptoms?

You can learn to manage your symptoms by looking after yourself. Self-care is how you take care of your diet, sleep, exercise, daily routine, relationships and how you are feeling.

Lifestyle

Making small lifestyle changes can improve your wellbeing and can help your recovery.

Routine helps many people with their mental wellbeing. It will help to give a structure to your day and may give you a sense of purpose. This could be a simple routine such as eating at the same time each day, going to bed at the same time each day and buying food once per week.

Breathing exercises

Breathing exercises can help to calm you when you are feeling anxious. Or having a panic attack. You will get the most benefit if you do them regularly, as part of your daily routine.[50]

There is more information about breathing exercises in the further reading section at the end of this factsheet.

Support groups

You could join a support group. A support group is where people come together to share information, experiences and give each other support.

You might be able to find a local group by searching online. The charity Bi-polar UK have an online support group. They also have face to face support groups in some areas of the country. Their contact details are in the ‘useful contacts’ at the end of this factsheet.

Rethink Mental Illness have support groups in some areas. You can find out what is available in your area if you follow this link: www.rethink.org/about-us/our-support-groups. Or you can call the Rethink Mental Illness Advice Service on 0300 5000 927 for more information.

Recovery College

Recovery colleges are part of the NHS. They offer free courses about mental health to help you manage your symptoms. They can help you to take control of your life and become an expert in your own wellbeing and recovery. You can usually self-refer to a recovery college. But the college may inform your care team.

Unfortunately, recovery colleges are not available in all areas. To see if there is a recovery college in your area you can use a search engine such

as Google. Or contact Rethink Mental Illness Advice Service on 0300 5000 927.

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

Top

8. Information for carers, friends and relatives

If you are a carer, friend or relative of someone who hears voices, you can get support.

How can I get support?

You can do the following.

- Speak to your GP about medication and talking therapies for yourself.
- Speak to your relative's care team about a carer's assessment.
- Ask for a carer's assessment from your local social services.
- Join a carers service. They are free and available in most areas.
- Join a carers support group for emotional and practical support. Or set up your own.

What is a carer's assessment?

A carer's assessment is an assessment of the support that you need so that you can continue in your caring role.

To get a carers assessment you need to contact your local authority.

How do I get support from my peers?

You can get peer support through carer support services or carers groups. You can search for local groups in your area by using a search engine such as Google. Or you can contact the Rethink Mental Illness Advice Service and we will search for you.

How can I support the person I care for?

You can do the following.

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

What is a care plan?

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

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

Can I be involved in care planning?

As a carer you can be involved in decisions about care planning. But you don't have a legal right to this.

Your relative or friend needs to give permission for the NHS to share information about them. And their care.

You can find out more about:

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

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

Top

Further Reading

North West Boroughs Healthcare NHS Foundation Trust
This NHS website has information dedicated to different breathing techniques. These techniques can help you when you feel anxious or are having a panic attack.

Website: www.nwbh.nhs.uk/healthandwellbeing/Pages/Breathing-Techniques-.aspx

NHS – Every Mind Matters
This website has lots of useful information and practical tips on how to manage symptoms of anxiety.

Website: www.nhs.uk/oneyou/every-mind-matters/anxiety/

No Panic - Resources
The No Panic website has lots of resources to help people who are living with anxiety. This includes information on breathing techniques, relaxation techniques and advice on how to stop a panic attack.

Website: https://nopanic.org.uk/resources/

Centre for Clinical interventions
This website is provided by the department of Health in Western Australia. They have some useful information sheets and a workbook for people who are experiencing Body dysmorphic disorder (BDD).

Website: www.cci.health.wa.gov.au/Resources/For-Clinicians/Body-Dysmorphic-Disorder

Top

Useful Contacts

Anxiety UK
A user led organisation that supports anyone with anxiety, phobias, panic attacks or other anxiety disorders.

Telephone: 03444 775 774 (Monday to Friday 9.30am–5.30pm)
Text: 07537 416905
Address: Anxiety UK, Nunes House, 447 Chester Road, Manchester, M16 9HA
Email: support@anxietyuk.org.uk
Website: www.anxietyuk.org.uk

Social Anxiety UK
Offers support with social anxiety disorder. They are a web-based organisation and offer forums, a chat room and information about social anxiety.

Email: contact@social-anxiety.org.uk
Website: www.social-anxiety.org.uk

OCD-UK
Gives information, advice and support on obsessive compulsive disorder (OCD) and related disorders such as body dysmorphic disorder (BDD), skin-picking and hair pulling.

Telephone: 03332 127890 (10am – 4:45pm, Monday to Friday)
Address: OCD-UK, Harvest Barn, Chevin Green Farm, Chevin Road, Belper, Derbyshire, DE56 2UN
Email via website: www.ocduk.org
Website: www.ocduk.org

No Panic
Offers emotional support and information on anxiety disorders and medication including tranquilizers. They have a 1 to 1 mentoring scheme and a telephone recovery group available to their members.

Telephone: 0300 772 9844 (Everyday 10:00am - 10:00pm)
Address: Jubilee House, 74 High Street, Madeley, Telford, Shropshire, TF7 5AH
Email: sarah@nopanic.org.uk
Website: www.nopanic.org.uk

References

[1] Royal College of Psychiatrists. Feeling stressed. www.rcpsych.ac.uk/healthadvice/problemsdisorders/feelingstressed.aspx (accessed: 16th September 2020).
[2] Royal College of Psychiatrists. Feeling stressed. www.rcpsych.ac.uk/healthadvice/problemsdisorders/feelingstressed.aspx (Accessed: 16th September 2020).
[3] National Institute for Clinical Excellence. *Generalised anxiety disorder and panic disorder in adults: management Clinical Guidance 113.* London: National Institute for Health and Clinical Excellence; 2011. Page 5. www.nice.org.uk/guidance/cg31/resources/obsessivecompulsive-disorder-and-body-dysmorphic-disorder-treatment-pdf-975381519301 (accessed 7th October 2020). www.nice.org.uk/guidance/cg113 (accessed: 2nd October 2020).
[4] NHS. *Anxiety symptoms* www.nhs.uk/Conditions/Anxiety/Pages/Symptoms.aspx (accessed 2nd October 2020).
[5] National Institute for Clinical Excellence. *Generalised anxiety disorder and panic disorder in adults: management Clinical Guidance 113.* London: National Institute for Health and Clinical Excellence; 2011. Page 5. www.nice.org.uk/guidance/cg31/resources/obsessivecompulsive-disorder-and-body-dysmorphic-disorder-treatment-pdf-975381519301 (accessed 7th October 2020). www.nice.org.uk/guidance/cg113 (accessed: 2nd October 2020).
[6] National Institute for Clinical Excellence. *Generalised anxiety disorder and panic disorder in adults: management Clinical Guidance 113.* London: National Institute for Health and Clinical Excellence; 2011. Page 5. www.nice.org.uk/guidance/cg31/resources/obsessivecompulsive-disorder-and-body-dysmorphic-disorder-treatment-pdf-975381519301 (accessed 7th October 2020). www.nice.org.uk/guidance/cg113 (accessed: 2nd October 2020).
[7] National Institute for Clinical Excellence (2011) *Generalised anxiety disorder and panic disorder in adults: management Clinical Guidance 113.* London: National Institute for Health and Clinical Excellence; 2005. Page 5. www.nice.org.uk/guidance/cg31/resources/obsessivecompulsive-disorder-and-body-

dysmorphic-disorder-treatment-pdf-975381519301 (accessed 7th October 2020). www.nice.org.uk/guidance/cg113 (accessed: 2nd October 2020).

[8] NHS. *Panic disorder* www.nhs.uk/Conditions/Panic-disorder/Pages/Symptoms.aspx (accessed 2nd October 2020).

[9] NHS. *Panic disorder.* www.nhs.uk/Conditions/Panic-disorder/Pages/Symptoms.aspx (accessed: 2nd October 2020).

[10] National Institute for Clinical Excellence. *Generalised anxiety disorder and panic disorder in adults: management Clinical Guidance 113*. London: National Institute for Health and Clinical Excellence; 2011. Page 5. www.nice.org.uk/guidance/cg31/resources/obsessivecompulsive-disorder-and-body-dysmorphic-disorder-treatment-pdf-975381519301 (accessed 7th October 2020). www.nice.org.uk/guidance/cg113 (accessed: 2nd October 2020).

[11] NHS. *Social anxiety disorder* www.nhs.uk/conditions/social-anxiety/Pages/Social-anxiety.aspx (accessed: 2nd October 2020).

[12] NHS. Phobias. www.nhs.uk/Conditions/Phobias/Pages/Introduction.aspx (accessed: 2nd October 2020).

[13] NHS. *Phobias*. www.nhs.uk/Conditions/Phobias/Pages/Introduction.aspx (accessed: 2nd October 2020).

[14] NHS. *Agoraphobia.* www.nhs.uk/conditions/Agoraphobia/Pages/Introduction.aspx. (accessed: 2nd October 2020).

[15] NHS Choices. *Agoraphobia* www.nhs.uk/Conditions/Agoraphobia/Pages/Diagnosis.aspx (accessed: 29th June 2017)

[16] National Institute for Health and Clinical Excellence. *Obsessive compulsive disorder and body dysmorphic disorder: treatment.* London: National Institute for Health and Clinical Excellence; 2005. Page 5. www.nice.org.uk/guidance/cg31/resources/obsessivecompulsive-disorder-and-body-dysmorphic-disorder-treatment-pdf-975381519301.

[17] NHS. *Symptoms of OCD*. www.nhs.uk/Conditions/Obsessive-compulsive-disorder/Pages/Symptoms.aspx (accessed: 2nd October 2020).

[18] NHS. *Dermatillomania.* www.nhs.uk/conditions/dermatillomania/Pages/Introduction.aspx (accessed 2nd October 2020).

[19] OCD-UK. *Trichotillomania* www.ocduk.org/trichotillomania (accessed 2nd October 2020).

[20] NHS. *Trichotillomania*. www.nhs.uk/Conditions/trichotillomania/Pages/diagnosis.aspx (accessed: 2nd October 2020).

[21] NHS. *Health anxiety*. www.nhs.uk/conditions/health-anxiety/ (accessed: 7th October 2020).

[22] NHS. *Body Dysmorphic Disorder*. www.nhs.uk/Conditions/body-dysmorphia/Pages/Introduction.aspx (accessed: 2nd October 2020).

[23] NHS. *Body Dysmorphic Disorder*. www.nhs.uk/Conditions/body-dysmorphia/Pages/Introduction.aspx (accessed: 2nd October 2020).

[24] National Institute for Health and Clinical Excellence. *Obsessive compulsive disorder and body dysmorphic disorder: treatment*. Clinical Guidance 31. London: National Institute for Health and Clinical Excellence; 2005. Para 1.5

[25] NHS. *Post-traumatic stress disorder.* www.nhs.uk/conditions/post-traumatic-stress-disorder-ptsd/ (accessed 2nd October 2020).

[26] Royal College of psychiatrists. *Anxiety, Panic & Phobias*. www.rcpsych.ac.uk/mental-health/problems-disorders/anxiety-panic-and-phobias (accessed 2nd October 2020).

[27]NHS England. *Adult Improving Access to Psychological Therapies programme*. www.england.nhs.uk/mental-health/adults/iapt/ (accessed 7th October 2020).

[28] National Institute for Health and Clinical Excellence. *Generalised anxiety disorder and panic disorder in adults: management.* Clinical Guidance 113. London: National Institute for Health and Clinical Excellence; 2019. Para 1.2.9.

[29] National Institute for Health and Clinical Excellence. *Generalised anxiety disorder and panic disorder in adults: management.* Clinical Guidance 113. London: National Institute for Health and Clinical Excellence; 2019. Para 1.2.9.

[30] National Institute for Health and Clinical Excellence. *Generalised anxiety disorder and panic disorder in adults: management.* Clinical Guidance 113. London: National Institute for Health and Clinical Excellence; 2019. Para 1.2.9.

[31] National Institute for Health and Clinical Excellence. *Generalised anxiety disorder and panic disorder in adults: management.* Clinical Guidance 113. London: National Institute for Health and Clinical Excellence; 2019. Para 1.2.12.
[32] National Institute for Health and Clinical Excellence. *Generalised anxiety disorder and panic disorder in adults: management.* Clinical Guidance 113. London: National Institute for Health and Clinical Excellence; 2019. Para 1.2.13.
[33] National Institute for Health and Clinical Excellence. *Social anxiety disorder: recognition, assessment and treatment*. Clinical Guidance 159. London: National Institute for Health and Clinical Excellence; 2013. Para 1.3.15.
[34] National Institute for Health and Clinical Excellence. *Generalised anxiety disorder and panic disorder in adults: management.* Clinical Guidance 113. London: National Institute for Health and Clinical Excellence; 2019. Para 1.2.14.
[35] National Institute for Health and Clinical Excellence. *Generalised anxiety disorder and panic disorder in adults: management.* Clinical Guidance 113. London: National Institute for Health and Clinical Excellence; 2019. Para 1.2.16.
[36] National Institute for Health and Clinical Excellence. *Generalised anxiety disorder and panic disorder in adults: management.* Clinical Guidance 113. London: National Institute for Health and Clinical Excellence; 2019. Para 1.2.18.
[37] National Institute for Health and Clinical Excellence. *Social anxiety disorder: recognition, assessment and treatment*. Clinical Guidance 159. London: National Institute for Health and Clinical Excellence; 2013. Para 1.3.2.
[38] National Institute for Health and Clinical Excellence. *Social anxiety disorder: recognition, assessment and treatment*. Clinical Guidance 159. London: National Institute for Health and Clinical Excellence; 2013. Para 1.3.3.
[39] National Institute for Health and Clinical Excellence. *Generalised anxiety disorder and panic disorder in adults: management.* Clinical Guidance 113. London: National Institute for Health and Clinical Excellence; 2019. Para 1.2.19.
[40] National Institute for Health and Clinical Excellence. *Social anxiety disorder: recognition, assessment and treatment*. Clinical Guidance 159. London: National Institute for Health and Clinical Excellence; 2013. Information for the public; medical terms explained. https://www.nice.org.uk/guidance/cg159/ifp/chapter/medical-terms-explained#short-term-psychodynamic-psychotherapy-2 (accessed 7th October 2020).
[41] National Institute for Health and Clinical Excellence. *Social anxiety disorder: recognition, assessment and treatment*. Clinical Guidance 159. London: National Institute for Health and Clinical Excellence; 2013. Para 1.3.16.
[42] NHS Choices. *Obsessive compulsive disorder.* www.nhs.uk/Conditions/Obsessive-compulsive-disorder/Pages/Treatment.aspx (accessed 7th October 2020).
[43] NHS. *Types of talking therapies*. www.nhs.uk/conditions/stress-anxiety-depression/types-of-therapy/ (accessed 7th October 2020).
[44] National Institute for Health and Clinical Excellence. *Generalised anxiety disorder and panic disorder in adults: management.* Clinical Guidance 113. London: National Institute for Health and Clinical Excellence; 2019. Para 1.2.22.
[45] NHS. *Treatment: generalised anxiety disorder in adults.* www.nhs.uk/conditions/generalised-anxiety-disorder/treatment/ (accessed 7th October 2020).
[46] NHS. *Treatment: generalised anxiety disorder in adults.* www.nhs.uk/conditions/generalised-anxiety-disorder/treatment/ (accessed 7th October 2020).
[47] National Institute for Health and Clinical Excellence. *Generalised anxiety disorder and panic disorder in adults: management.* Clinical Guidance 113. London: National Institute for Health and Clinical Excellence; 2019. Para 1.2.25.
[48] NHS. *Beta blockers*. www.nhs.uk/conditions/beta-blockers/ (accessed 7th October 2020).
[49] General Medical Council. *Good Medical Practice*. Manchester: GMC; 2013. Para 16(e).
[50] NHS. *Breathing exercise for stress.* www.nhs.uk/conditions/stress-anxiety-depression/ways-relieve-stress/ (accessed 7th October 2020).

Last updated October 2020
Next update August 2023
Version 6

Rethink Mental Illness Advice Service

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

Email advice@rethink.org

Did this help?

We'd love to know if this information helped you.

Drop us a line at: feedback@rethink.org

or write to us at Rethink Mental Illness:
RAIS
PO Box 17106
Birmingham B9 9LL

or call us on 0808 801 0525

We're open 9:30am to 4pm
Monday to Friday (excluding bank holidays)

Rethink Mental Illness.

Leading the way to a better quality of life for everyone affected by severe mental illness.

For further information
on Rethink Mental Illness
Phone 0121 522 7007
Email info@rethink.org

facebook.com/rethinkcharity
twitter.com/rethink_
www.rethink.org

Need more help?

Go to **www.rethink.org** for information on symptoms, treatments, money and benefits and your rights.

Don't have access to the web?

Call us on 0121 522 7007. We are open Monday to Friday, 9am to 5pm, and we will send you the information you need in the post.

Need to talk to an adviser?

If you need practical advice, call us on 0808 801 0525 between 9:30am to 4pm, Monday to Friday. Our specialist advisers can help you with queries like how to apply for benefits, get access to care or make a complaint.

Can you help us to keep going?

We can only help people because of donations from people like you. If you can donate please go to **www.rethink.org/donate** or call 0121 522 7007 to make a gift. We are very grateful for all our donors' generous support.

factsheet

Bipolar disorder

This factsheet explains the symptoms of bipolar disorder, treatments and ways to manage the condition. This factsheet is for people with bipolar disorder. And their carers, relatives and friends.

Key Points.

- Bipolar disorder, also known as bipolar affective disorder, is a mood disorder. It used to be called manic depression.
- Bipolar disorder can cause your mood to swing from an extreme high to an extreme low.
- Manic symptoms can include increased energy, excitement, impulsive behaviour, and agitation.
- Depressive symptoms can include lack of energy, feeling worthless, low self-esteem and suicidal thoughts.
- You can also have psychotic symptoms. Psychotic symptoms can mean that you see and hear things that feel real, but they don't exist.
- There are different types of bipolar disorder.
- We don't know what causes bipolar. But it is thought to be a combination of genetic and environmental causes
- Bipolar disorder is treated with medication or talking therapies.

This factsheet covers:

Top

1. What is bipolar disorder?

Bipolar disorder can be a life-long mental health problem that mainly affects your mood. It affects how you feel, and your mood can change massively. You can experience episodes of:

- mania, and
- depression**.**

You may feel well between these times. When your mood changes, you might see changes in your energy levels or how you act.

Symptoms of bipolar disorder can be severe. They can affect areas of your life, such as work, school and relationships.

You usually develop bipolar disorder before you are 20. It can develop in later life, but it rarely develops after the age of 40.[1]

You could have symptoms of bipolar disorder for some time before a doctor diagnoses you. A doctor might say you have something else such as depression before you get a bipolar disorder diagnosis.[2] This is because diagnosing mental illnesses can be sometimes difficult for doctors. They usually can't do things like blood tests and scans to help them.

Bipolar disorder used to be called manic depression.

Top

2. What are the symptoms of bipolar disorder?

Bipolar disorder symptoms can make it difficult to deal with day-to-day life. It can have a bad effect on your relationships and work. The different types of symptoms are described below.

Mania[3]

Symptoms of mania can include:

- feeling happy or excited, even if things aren't going well for you,
- being full of new and exciting ideas,
- moving quickly from one idea to another,
- racing thoughts,
- talking very quickly,
- hearing voices that other people can't hear,
- being more irritable than normal,
- feeling much better about yourself than usual,
- being easily distracted and struggle to focus on one topic,
- not being able to sleep, or feel that you don't want to sleep,
- thinking you can do much more than you actually can,
- make unusual, or big decisions without thinking them through, and

- doing things you normally wouldn't do which can cause problems. Such as:
    - spending a lot of money,
    - having casual sex with different people,
    - using drugs or alcohol,
    - gambling, or
    - making unwise decisions.

Hypomania

Hypomania is like mania but you will have milder symptoms.

Depression[4]

Symptoms of depression can include:

- low mood,
- having less energy and feeling tired,
- feeling hopeless or negative,
- feeling guilty, worthless or helpless,
- being less interested in things you normally like doing,
- difficulty concentrating, remembering or making decisions,
- feeling restless or irritable,
- sleeping too much or not being able to sleep,
- eating less or over eating,
- losing or gaining weight, when you don't mean to, and
- thoughts of death or suicide, or suicide attempts.

Psychosis[5]

Sometimes you can have psychotic symptoms during a severe episode of mania or depression. Symptoms of psychosis can be:

- hallucinations. This means that you may hear, see, or feel things that are not there, and
- delusions. This means you may believe things that aren't true. Other people will usually find your beliefs unusual.

Psychotic symptoms in bipolar disorder can reflect your mood. For example, if you have a manic episode you may believe that you have special powers or are being monitored by the government. If you have depressive episode, you may feel very guilty about something you think you have done. You may feel that you are worse than anybody else or feel that you don't exist.

You can find more information about:

- Depression
- Psychosis

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

Top

3. What are the different types of bipolar disorder?

There are different types of bipolar disorder.

What is bipolar disorder I disorder?

A diagnosis of bipolar I disorder means you will have had at least 1 episode of mania that lasts longer than 1 week.[6] You may also have periods of depression.[7] Manic episodes will generally last 3-6 months if left untreated. Depressive episodes will generally last 6-12 months without treatment.[8]

What is bipolar II disorder?

A diagnosis of bipolar II disorder means it is common to have symptoms of depression. You will have had at least 1 period of major depression.[9] And at least 1 period of hypomania instead of mania.[10]

What is bipolar I or II disorder with mixed features?

You will experience symptoms of mania or hypomania and depression at the same time.[11] You may hear this being called 'mixed bipolar state'. You may feel very sad and hopeless at the same time as feeling restlessness and being overactive.

What is bipolar I or II disorder with rapid cycling?

Rapid cycling means you have had 4 or more depressive, manic or hypomanic episodes in a 12-month period.[12]

What is bipolar I or II with seasonal pattern?

Seasonal pattern means that either your depression, mania or hypomania is regularly affected in the same way by the seasons. For example, you may find that each winter you have a depressive episode, but your mania doesn't regularly follow a pattern. [13]

There can be some similarities between bipolar I or II with seasonal pattern and another conditional called seasonal affective disorder.[14]

What is cyclothymia?

A diagnosis of cyclothymic disorder means you will have experienced regular episodes of hypomania and depression for at least 2 years.[15] You won't be diagnosed with bipolar because your symptoms will be milder. But they can last longer. Cyclothymia can develop into bipolar disorder.

Top

4. What causes bipolar disorder?

The cause of bipolar disorder isn't clear. Research suggests that a combination of different things can make it more likely that you will develop bipolar disorder.

Genetic factors

There is a 13% chance you will develop bipolar disorder if someone in your immediate family, like a parent, brother or sister has bipolar disorder.

This risk is higher if both of your parents have the condition or if your twin has the condition.[16]

Researchers haven't found the exact genes that cause bipolar disorder. But different genes have been linked to the development of bipolar disorder.[17]

Brain chemical imbalance

Different chemicals in your brain affect your mood and behaviour. Too much or too little of these chemicals could lead to you developing mania or depression.[18]

Environmental factors

Stressful life events can trigger symptoms of bipolar disorder. Such as childhood abuse or the loss of a loved one. They can increase your chances of developing depressive episodes.[19]

You can find more information about **'Does mental illness run in families?'** at www.rethink.org. Or call our General Enquiries team on 0121 522 7007 and ask them to send you a copy of our factsheet.

Top

5. How do I get help if I think I have bipolar disorder?

The usual first step to getting help is to speak to your GP.

It can help to keep a record of your moods. This can help you and your GP to understand your mood swings.[20] Bipolar UK have a mood diary and a mood scale on their website. You can find their details in the Useful contacts section at the end of this factsheet.

Your GP can't diagnose bipolar disorder. Only a psychiatrist can make a formal diagnosis. Your GP may arrange an appointment with a psychiatrist if you have:

- depression, and
- ever felt very excited or not in control of your mood or behaviour for at least 4 days in a row.[21]

They might refer you to a psychiatrist at your local NHS community mental health team (CMHT).

Your GP should make an urgent referral to the CMHT if they think that you might have mania or severe depression. Or there is a chance that you are a danger to yourself or someone else.[22]

Your GP should refer you to your local NHS early intervention team if you have an episode of psychosis and it's your first one.[23]

Bipolar disorder can be difficult to diagnose because it affects everyone differently. Also, the symptoms of bipolar disorder can be experienced by people who have other mental illness diagnoses.[24] It can take a long time to get a diagnosis of bipolar disorder.

You can find more information about:

- NHS mental health teams (MHTs)

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

Top

6. What is the treatment for mania, hypomania and depression?

You can check what treatment and care is recommended for bipolar disorders on the National Institute for Health and Care Excellence (NICE) website.

NICE produce guidelines for how health professionals should treat certain conditions. You can download these from their website at: www.nice.org.uk.

The NHS doesn't have to follow these recommendations. But they should have a good reason for not following them**.**

What medications are recommended?

Mood stabilisers are usually used to manage mania, hypomania and depressive symptoms.

The mood stabilisers we talk about in this factsheet are:[25,26]

- Lithium
- Certain antipsychotic medication
- Certain anticonvulsive medication
- Certain benzodiazepine medication

Mania and hypomania

You should be offered a mood stabiliser to help manage your mania or hypomania.[27] Your doctor may refer to your medication as 'antimanic' medication.[28]

If you are taking antidepressants your doctor may advise you to withdraw from taking them.[29]

You will usually be offered an antipsychotic first. The common antipsychotics used for the treatment of bipolar disorder are:[30]

- Haloperidol
- Olanzapine
- Quetiapine
- Risperidone

If the first antipsychotic you are given doesn't work, then you should be offered a different antipsychotic medication from the list above.[31]

If a different antipsychotic doesn't work, then you may be offered lithium to take alongside it.[32] If the lithium doesn't work you may be offered sodium valproate to take with an antipsychotic.[33] Sodium valproate is an anticonvulsive medication.

Sodium Valproate shouldn't be given to girls or young women who might want to get pregnant.[34]

Your doctor should think about giving you benzodiazepine medication short term.[35]

Your doctor will suggest different dosages and combinations to you depending on what works best for you. Your personal preferences should be listened to.

<u>Depression</u>

Your doctor should offer you medication to treat depressive symptoms. You may be offered the following medication:[36]

- Fluoxetine with Olanzapine
- Quetiapine
- Olanzapine or
- Lamotrigine

Fluoxetine is an antidepressant. Lamotrigine is an anticonvulsant medication.

Your doctor can prescribe the above medication alongside: [37],[38]

- Lithium, and
- Sodium valproate.

If you would like to take medication, doctors will use different dosages and combinations depending on what works best for you. Your personal preferences should be listened to.

You can find more information about:

- Mood stabilisers
- Antipsychotics
- Antidepressants

- Benzodiazepines
- Medication – choice and managing problems

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

What psychological treatments are recommended?

If you have an episode of depression you should be offered medication and a high intensity talking therapy, such as:[39]

- cognitive behavioural therapy (CBT), or
- interpersonal therapy.

What is cognitive behavioural therapy (CBT)?

CBT is a talking therapy that can help you manage your problems by changing the way you think and behave.[40]

What is interpersonal therapy?

Interpersonal therapy is a talking therapy that focuses on you and your relationships with other people.[41]

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

Top

7. What are the long-term treatments for bipolar disorder?

Bipolar disorder is a life-long and often recurring illness. You may need long term support to help manage your condition.[42]

What medication options are there?

Your doctor will look at what medication worked for you during episodes of mania or depression. They should ask you whether you want to continue this treatment or if you want to change to lithium.[43]

Lithium usually works better than other types of medication for long-term treatment.[44] Your doctor should give you information about how to take lithium safely. If lithium doesn't work well enough or causes you problems, you may be offered:[45]

- Valproate,
- Olanzapine, or
- Quetiapine.

Your doctor should monitor your health. Physical health checks should be done at least once a year. These checks will include: [46]

- measuring your weight,
- blood and urine tests,
- checking your liver and heart, and
- checking your pulse and blood pressure.

What psychological treatments are recommended?[47]

You should be offered a psychological therapy that is specially designed for bipolar disorder. You could have individual or group therapy.

The aim of your therapy is to stop you from becoming unwell again. This is known as 'relapse.' Your therapy should help you to:[48]

- understand your condition,
- think about the effect that your thoughts and behaviour have on your mood,
- monitor your mood, thoughts and behaviour,
- think about risk and distress,
- make plans to stay well,
- make plans to follow if you start to become unwell,
- be aware of how you communicate, and
- manage difficulties you may have in day to day life.

If you live with your family or are in close contact with them, you should also be offered 'family intervention.'

Family intervention is where you and your family work with mental health professionals to help to manage relationships. This should be offered to people who you live with or who you are in close contact with.

The support that you and your family are given will depend on what problems there are and what preferences you all have. This could be group family sessions or individual sessions. Your family should get support for 3 months to 1 year and should have at least 10 planned sessions.[49]

Is there any other support?

Your mental health team should give you advice about exercise and healthy eating.[50]

If you want to return to work, you should be offered support with that including training. You should get this support if your care is managed by your GP or by your community mental health team.[51]

You might not be able to work or to find any. Your healthcare professionals should think about other activities that could help you back to employment in the future.[52]

Your healthcare team should help you to make a recovery plan. The plan should help you to identify early warning signs and triggers that may make

you unwell again and ways of coping. Your plan should also have people to call if you become very distressed.[53]

You should be encouraged to make an 'advance statement.'[54] This is an instruction to health professionals about what you would like to happen with your care if you ever lack mental capacity to make your own decisions.[55]

What is the Care Programme Approach?

You may be assessed under the Care Programme Approach (CPA) if you have complex needs or you are vulnerable.[56]

CPA is a package of care that is used by secondary mental health services. You will have a care plan and someone to coordinate your care. All care plans should include a crisis plan.[57]

CPA aims to support your mental health recovery by helping you to understand your:

- strengths,
- goals,
- support needs, and
- difficulties.

CPA should be available if you have a wide range of needs from different services or you are thought to be a high risk.[58] Both you and your GP should be given a copy of your care plan.[59]

Your carers can be involved in your care plan and given a copy if you give your consent for this to happen.

You can find more information about:

- Care Programme Approach
- Planning your care. Advance statements and advance decisions
- Mood stabilisers
- Antipsychotics
- Antidepressants
- Medication. Choice and managing problems
- Talking therapies

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

Top

8. What if I'm not happy with my treatment?

If you aren't happy with your treatment you can:

- talk to your doctor about your treatment options,
- ask for a second opinion,

- get an advocate to help you speak to your doctor,
- contact Patient Advice and Liaison Service (PALS), or
- make a complaint.

There is more information about these options below.

How can I speak to my doctor about my treatment options?

You can speak to your doctor about your treatment. Explain why you aren't happy with it. You could ask what other treatments you could try.

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

What's a second opinion?

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

You don't have a right to a second opinion. But your doctor should listen to your reason for wanting a second opinion.[60]

What is advocacy?

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

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

You can search online to search for a local advocacy service.

What is the Patient Advice and Liaison Service (PALS)?

PALS is part of the NHS. They give information and support to patients and a good place to start if you're not happy with any aspect of the NHS.

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

How can I complain?

You can complain about your treatment or any other aspect of the NHS verbally or in writing. See our information on 'Complaining about the NHS or social services' for more information.

You can find out more about:

- Medication. Choice and managing problems

- Second opinions
- Advocacy
- Complaining about the NHS or social services

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

Top

9. What can I do to manage my symptoms?

You can learn to manage your symptoms by looking after yourself. Self-care is how you take care of your diet, sleep, exercise, daily routine, relationships and how you are feeling.

What lifestyle changes can I make?

Making small lifestyle changes can improve your wellbeing and can help your recovery.

Routine helps many people with their mental wellbeing. It will help to give a structure to your day and may give you a sense of purpose. This could be a simple routine such as eating at the same time each day, going to bed at the same time each day and buying food once per week.

Your healthcare professionals should offer you a combined healthy eating, exercise and sleep programme. [61]

You can find more information about wellbeing any physical health at: www.rethink.org/advice-and-information/living-with-mental-illness/wellbeing-physical-health/.

What are support groups?

You could join a support group. A support group is where people come together to share information, experiences and give each other support.

You might be able to find a local group by searching online. The charity Bi-polar UK have an online support group. They also have face to face support groups in some areas of the country. Their contact details are in the Useful contacts at the end of this factsheet.

Rethink Mental Illness have support groups in some areas. You can find out what is available in your area if you follow this link: www.rethink.org/about-us/our-support-groups. Or you can contact our General Enquiries team on 0121 522 7007 or info@rethink.org for more information.

What are recovery colleges?

Recovery colleges are part of the NHS. They offer free courses about mental health to help you manage your symptoms. They can help you to take control of your life and become an expert in your own wellbeing and

recovery.[62] You can usually self-refer to a recovery college. But the college may inform your care team.

Unfortunately, recovery colleges aren't available in all areas. To see if there is a recovery college in your area you can use a search engine such as Google.

What is a Wellness Recovery Action Plan (WRAP)?

Learning to spot early signs of mania or depression is important in self-management. The idea of the WRAP is to help you stay well and achieve what you would like to. The WRAP looks at areas like how you are affected by your illness and what you could do to manage them. There are guides that can help with this. You can ask your healthcare professional to make one with you or ask them for a template of one.[63]

There is more information about the WRAP in the further reading section at the end of this factsheet.

Rethink Mental Illness has created a guide called '**Staying well with bipolar**'. This is a guide based on information from people who have or support someone with bipolar disorder. You can download it here www.rethink.org/living-with-mental-illness/staying-well-with-bipolar.

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

Top

10. What risks and complications can bipolar disorder cause?

There can be complications and risks for people who live with bipolar disorder. But these risks can be lessened with the right support and treatment.

What about suicide and self-harm?

You might have an illness where you experience psychosis, such as schizophrenia or bipolar disorder. Your risk of suicide is estimated to be between 5% and 6% higher than the general population.[64]

You are more likely to try to take your own life if you have a history of attempted suicide and depression.[65] It is important that you get the right treatment for your symptoms of depression and have an up to date crisis plan.

There is also research that suggests you are 30% - 40% more likely to self-harm if you live with bipolar disorder.[66]

What about financial risk?

If you have mania or hypomania you may struggle to manage your finances. You may spend lots of money without thinking about the effect that it may have on your life.[67]

You could make a ‘Lasting Power of Attorney.’ This is a legal process. This means that you pick someone that you trust to manage your finances if you lack mental capacity to manage them by yourself.[68]

You can work with your carer and mental health team. You can form an action plan. This can say what they can do if you have a period of mania or hypomania and you start to make poor financial decisions.

What about physical health risk?

People with bipolar disorder have a higher rate of physical illnesses such as diabetes and heart disease. You should have a physical health check at least once every year to help manage these risks.[69]

What about alcohol and drugs risk?

Just over 30% of people with bipolar disorder misuse drugs or alcohol.[70] Drinking alcohol, smoking or taking other drugs while taking medication could stop your medication working properly and make your symptoms worse.[71]

If you want advice or help with alcohol or drug use contact your GP.

What about driving risk?

You must tell the Drivers and Vehicle Licensing Agency (DVLA) that you have bipolar disorder. [72] You must stop driving if you have an episode of severe depression, hypomania, mania or psychosis.[73]

You can find out more about:

- Suicidal thoughts – how to cope
- Self-harm
- Mental capacity and mental illness
- Cannabis and mental health
- Drugs, alcohol and mental health
- Driving and mental illness

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

Top

11. Information for family, carers and friends

How can I get support?

You can speak to your GP. You should be given your own assessment through NHS mental health services to work out what effect your caring role is having on your health. And what support you need. Such as practical support and emergency support.[74]

These are some other options for you:

- Join a carers service
- Join a carers support group
- Ask your local authority for a carer's assessment
- Read about the condition
- Apply for welfare benefits for carers

Rethink Mental Illness run carers' support groups in some areas. You can also search for groups on the Carers Trust website:

- **Rethink Mental Illness**: www.rethink.org/about-us/our-support-groups
- **Carers Trust:** https://carers.org/search/network-partners;

How can I support the person I care for?

You might find it easier to support someone with bipolar disorder if you understand their symptoms, treatment and self-management skills.

You should be aware of what you can do if you are worried about their mental state. It can be helpful to know contact information for their mental health team or GP.

You could find out from your relative if they have a crisis plan. You could help your relative to make a crisis plan if they don't have one.

As a carer you should be involved in decisions about care planning. But you don't have a legal right to this. The medical team should encourage the person that you care for to allow information to be shared with you.[75]

You can find out more information about:

- Supporting someone with a mental illness
- Carers assessment – Under the Care Act 2014
- Benefits for carers
- Getting help in a crisis
- Money matters. Options for dealing with someone else's money and benefits
- Suicidal thoughts - How to support someone
- Responding to unusual behaviour
- Confidentiality and information sharing - For carers, friends and family

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

Top

Further Reading

Wellness Recovery Action Plan (WRAP) Plus. Formerly living without Depression and Manic Depression - Mary Ellen Copeland, PhD.

The Wellness Recovery Action Plan® or WRAP® is a self-designed wellness process. You can use a WRAP to get well, stay well and make your life your own. It was developed in 1997 by a group of people who were searching for ways to overcome their own mental health issues and move on to fulfilling their life dreams and goals.

Website: http://www.mentalhealthrecovery.com

Useful Contacts

Bipolar UK
This is a user led charity working to enable people affected by bipolar disorder to take control of their lives. You can email or leave a voicemail to arrange a call back with a staff member.

Telephone: 0333 323 3880
Address: Bipolar UK, 11 Belgrave Road, London, SW1V 1RB
Email: info@bipolaruk.org.uk
Website: www.bipolaruk.org.uk

The Hearing Voices Network
This service gives support and understanding for those who hear voices or experience other types of hallucination.

Address: c/o Sheffield Hearing Voices Network, Limbrick Day Service, Limbrick Road, Sheffield, S6 2PE
Email: nhvn@hotmail.co.uk
Website: www.hearing-voices.org

References

[1] NHS Choices. Bipolar Disorder www.nhs.uk/conditions/bipolar-disorder (accessed 7th January 2021).
[2] NHS Choices. Bipolar Disorder www.nhs.uk/conditions/bipolar-disorder (accessed7th January 2021).
[3] Royal College of Psychiatrists – *Bipolar.* www.rcpsych.ac.uk/mentalhealthinfo/problems/bipolardisorder/bipolardisorder.aspx (accessed 7th January 2021).
[4] Royal College of Psychiatrists – *Bipolar.* www.rcpsych.ac.uk/mentalhealthinfo/problems/bipolardisorder/bipolardisorder.aspx (accessed7th January 2021).
[5] Royal College of Psychiatrists – *Bipolar.* www.rcpsych.ac.uk/mentalhealthinfo/problems/bipolardisorder/bipolardisorder.aspx (accessed7th January 20201).
[6] Royal College of Psychiatrists – *Bipolar.* www.rcpsych.ac.uk/mentalhealthinfo/problems/bipolardisorder/bipolardisorder.aspx (accessed7th January 2021).

[7] Royal College of Psychiatrists – *Bipolar.* www.rcpsych.ac.uk/mentalhealthinfo/problems/bipolardisorder/bipolardisorder.aspx (accessed 4th January 2021).
[8] Royal College of Psychiatrists – *Bipolar.* www.rcpsych.ac.uk/mentalhealthinfo/problems/bipolardisorder/bipolardisorder.aspx (accessed7th January 2021).
[9] Royal College of Psychiatrists – *Bipolar.* www.rcpsych.ac.uk/mentalhealthinfo/problems/bipolardisorder/bipolardisorder.aspx (accessed7th January 2021).
[10] America Psychiatric Association. *Desk Reference to the Diagnostic Criteria from DSM-5*. Arlington: America Psychiatric Association; 2013. Page 74.
[11] America Psychiatric Association. *Desk Reference to the Diagnostic Criteria from DSM-5*. Arlington: America Psychiatric Association; 2013. Page 84-85.
[12] Royal College of Psychiatrists – *Bipolar.* www.rcpsych.ac.uk/mentalhealthinfo/problems/bipolardisorder/bipolardisorder.aspx (Accessed7th January 2021).
[13] America Psychiatric Association. *Desk Reference to the Diagnostic Criteria from DSM-5*. Arlington: America Psychiatric Association; 2013. Page 90.
[14] Rohan et al. Is seasonal affective disorder a bipolar variant? *US National Library of Medicine.* 2010. 9(2): 42–54. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2874241/ (accessed 03.06.21)
[15] America Psychiatric Association. *Desk Reference to the Diagnostic Criteria from DSM-5*. Arlington: America Psychiatric Association; 2013. Page 76.
[16] The Centre for Genetics Education, 2012. *Mental Illness – Schizophrenia and Bipolar disorder.* https://www.genetics.edu.au/publications-and-resources/facts-sheets/fact-sheet-59-mental-illness-disorders/view (Accessed 7th January 2021).
[17] The Centre for Genetics Education, 2012. *Mental illness and inherited predisposition- schizophrenia and bipolar disorder.* www.genetics.edu.au/genetics/Genetic-conditions-support-groups/FS58KBS.pdf (accessed7th January 2021).
[18] NHS Choices. *Bipolar disorder – causes*. www.nhs.uk/Conditions/Bipolar-disorder/Pages/Causes.aspx (accessed7th January 2021).
[19] The Centre for Genetics Education, 2012. *Mental Illness – Schizophrenia and Bipolar disorder.* www.genetics.edu.au/publications-and-resources/facts-sheets/fact-sheet-59-mental-illness-disorders/view (Accessed 7th January 2021).
[20] Bipolar UK. *Could mood swings mean bipolar?* www.bipolaruk.org/Handlers/Download.ashx?IDMF=d7773246-c042-4ef5-99c8-4157c3e26186 (accessed 7th January 2021).
[21] National Institute for Health and Clinical Excellence. Bipolar disorder: assessment and management. Clinical Guidance 185. London: National Institute for health and Clinical Excellence; 2014. Para 1.2.1.
[22] National Institute for Health and Clinical Excellence. Bipolar disorder: assessment and management. Clinical Guidance 185. London: National Institute for health and Clinical Excellence; 2014. Para 1.2.2.
[23] National Institute for Health and Clinical Excellence. Bipolar disorder: assessment and management. Clinical Guidance 185. London: National Institute for health and Clinical Excellence; 2014. Para 1.3.1.
[24] National Collaborating Centre for Mental Health. *Bipolar disorder. The NICE guideline on the assessment and management of bipolar disorder in adults, children and young people in primary and secondary care.* Pages 37-39. www.nice.org.uk/guidance/cg185/evidence/full-guideline-pdf-4840895629 (accessed 7th January 2021)

[25]Royal College of Psychiatry. B*ipolar disorder*. www.rcpsych.ac.uk/mental-health/problems-disorders/bipolar-disorder (accessed 7th January 2021).
[26] Webmd. *Benzodiazepines for Bipolar Disorder.* www.webmd.com/bipolar-disorder/guide/bipolar-benzodiazepines (accessed 7th January 2021).
[27] National Institute for Health and Clinical Excellence. Bipolar disorder: assessment and management. Clinical Guidance 185. London: National Institute for health and Clinical Excellence; 2014. Para 1.5.3.
[28] British National Formulary. *Mania and hypomania.*https://bnf.nice.org.uk/treatment-summary/mania-and-hypomania.html (Accessed 7th January 2021).
[29] National Institute for Health and Clinical Excellence. Bipolar disorder: assessment and management. Clinical Guidance 185. London: National Institute for health and Clinical Excellence; 2014.Para 1.5.2.
[30] National Institute for Health and Clinical Excellence. Bipolar disorder: assessment and management. Clinical Guidance 185. London: National Institute for health and Clinical Excellence; 2014.Para 1.5.3.
[31] National Institute for Health and Clinical Excellence. Bipolar disorder: assessment and management. Clinical Guidance 185. London: National Institute for health and Clinical Excellence; 2014.Para 1.5.4.
[32] National Institute for Health and Clinical Excellence. Bipolar disorder: assessment and management. Clinical Guidance 185. London: National Institute for health and Clinical Excellence; 2014. Para 1.5.5.
[33] National Institute for Health and Clinical Excellence. Bipolar disorder: assessment and management. Clinical Guidance 185. London: National Institute for health and Clinical Excellence; 2014.Para 1.5.5.
[34] National Institute for Health and Clinical Excellence. Bipolar disorder: assessment and management. Clinical Guidance 185. London: National Institute for health and Clinical Excellence; 2014.Para 1.11.10
[35]Webmd. *Benzodiazepines for Bipolar Disorder.* www.webmd.com/bipolar-disorder/guide/bipolar-benzodiazepines (accessed 7th January 2021).
[36] National Institute for Health and Clinical Excellence. Bipolar disorder: assessment and management. Clinical Guidance 185. London: National Institute for health and Clinical Excellence; 2014.Para 1.6.3.
[37] National Institute for Health and Clinical Excellence. Bipolar disorder: assessment and management. Clinical Guidance 185. London: National Institute for health and Clinical Excellence; 2014. Para 1.6.4.
[38] National Institute for Health and Clinical Excellence. Bipolar disorder: assessment and management. Clinical Guidance 185. London: National Institute for health and Clinical Excellence; 2014.Para 1.6.5.
[39] National Institute for Health and Clinical Excellence. Bipolar disorder: assessment and management. Clinical Guidance 185. London: National Institute for health and Clinical Excellence; 2014. Para 1.6.1.
[40] Royal College of Psychiatry. *Psychotherapies.* https://www.rcpsych.ac.uk/healthadvice/treatmentsandwellbeing/psychotherapies.aspx (accessed 7th January 2021).
[41] As note 39.
[42] National Institute for Health and Clinical Excellence. Bipolar disorder: assessment and management. Clinical Guidance 185. London: National Institute for health and Clinical Excellence; 2014.Para 1.7.1.
[43] National Institute for Health and Clinical Excellence. Bipolar disorder: assessment and management. Clinical Guidance 185. London: National Institute for health and Clinical Excellence; 2014.Para 1.7.5.
[44] National Institute for Health and Clinical Excellence. Bipolar disorder: assessment and management. Clinical Guidance 185. London: National Institute for health and Clinical Excellence; 2014. Para 1.7.5.

[45] National Institute for Health and Clinical Excellence. Bipolar disorder: assessment and management. Clinical Guidance 185. London: National Institute for health and Clinical Excellence; 2014. Para 1.7.6.
[46] National Institute for Health and Clinical Excellence. Bipolar disorder: assessment and management. Clinical Guidance 185. London: National Institute for health and Clinical Excellence; 2014. Para 1.2.10 – 1.2.12.
[47] National Institute for Health and Clinical Excellence. Bipolar disorder: assessment and management. Clinical Guidance 185. London: National Institute for health and Clinical Excellence; 2014. Para 1.6.1
[48] National Institute for Health and Clinical Excellence. Bipolar disorder: assessment and management. Clinical Guidance 185. London: National Institute for health and Clinical Excellence; 2014.Para 1.7.4.
[49] National Institute for Health and Clinical Excellence. *Psychosis and schizophrenia in adults: prevention and management.* Clinical Guidance 178. London: National Institute for Health and Clinical Excellence; 2014. para 1.3.7.2.
[50] National Institute for Health and Clinical Excellence. Bipolar disorder: assessment and management. Clinical Guidance 185. London: National Institute for health and Clinical Excellence; 2014. Para 1.8.2.
[51] National Institute for Health and Clinical Excellence. Bipolar disorder: assessment and management. Clinical Guidance 185. London: National Institute for health and Clinical Excellence; 2014.Para 1.9.6.
[52] National Institute for Health and Clinical Excellence. Bipolar disorder: assessment and management. Clinical Guidance 185. London: National Institute for health and Clinical Excellence; 2014.Para 1.9.6.
[53] National Institute for Health and Clinical Excellence. Bipolar disorder: assessment and management. Clinical Guidance 185. London: National Institute for health and Clinical Excellence; 2014. Para 1.4.1.
[54] National Institute for Health and Clinical Excellence. Bipolar disorder: assessment and management. Clinical Guidance 185. London: National Institute for health and Clinical Excellence; 2014.Para 1.1.10.
[55] NHS England. *Advance statements.*www.nhs.uk/conditions/end-of-life-care/advance-statement/ (accessed 11th January 2021).
[56] National Institute for Health and Clinical Excellence. Bipolar disorder: assessment and management. Clinical Guidance 185. London: National Institute for health and Clinical Excellence; 2014.Para 1.3.4.
[57] Tees, Esk and Wear Valleys NHS Foundation trust. *The care programme approach and standard care*. www.tewv.nhs.uk/content/uploads/2018/09/CPA-The-Care-Programme-Approach-and-Standard-Care.pdf Page 11 (accessed 11th January 2021).
[58] Tees, Esk and Wear Valleys NHS Foundation trust. *The care programme approach and standard care*. www.tewv.nhs.uk/content/uploads/2018/09/CPA-The-Care-Programme-Approach-and-Standard-Care.pdf. Pages 5-12 (accessed 11th January 2021).
[59] National Institute for Health and Clinical Excellence. Bipolar disorder: assessment and management. Clinical Guidance 185. London: National Institute for health and Clinical Excellence; 2014. Para 1.3.4.
[60] General Medical Council. *Good Medical Practice*. Manchester: GMC; 2013. Para 16(e).
[61] National Institute for Health and Clinical Excellence. Bipolar disorder: assessment and management. Clinical Guidance 185. London: National Institute for health and Clinical Excellence; 2014.Para 1.8.2.
[62] Priory. *What is a recovery college?* www.priorygroup.com/recovery-colleges/what-is-a-recovery-college (accessed 11th January 2021).
[63] Mental health recovery. *WRAP is.* https://mentalhealthrecovery.com/wrap-is/ (accessed 11th January 2021).

[64] Nordentoft M, Madsen T, & Fedyszyn I. 2015. Suicidal behavior and mortality in first-episode psychosis. *Journal of Nervous and Mental Disease* 203. Page 387-92.

65 Nordentoft M, Madsen T, & Fedyszyn I. 2015. Suicidal behavior and mortality in first-episode psychosis. *Journal of Nervous and Mental Disease* 203.Page 387-92.

[66] Anderson Ian M, Haddad Peter M, Scott Jan. Bipolar Disorder. *British Medical Journal* 2012 345. www.bmj.com/bmj/section-pdf/187715?path=/bmj/346/7889/Clinical_Review.full.pdf (accessed 7th January 2021).

[67] Money and mental health. *Bipolar disorder and financial difficulties: some preliminary findings.* www.moneyandmentalhealth.org/bipolar-financial-difficulties-research-findings/ (accessed 14th January 2021).

[68] Gov. *Lasting power of attorney: acting as an attorney.* www.gov.uk/lasting-power-attorney-duties (Accessed 14th January 2021).

[69] National Institute for Health and Clinical Excellence. Bipolar disorder: assessment and management. Clinical Guidance 185. London: National Institute for health and Clinical Excellence; 2014.Para 1.2.12.

[70] Cassidy F, Ahearn EP, Carroll BJ. Substance abuse in bipolar disorder. *Bipolar Disorders*. An international journal of psychiatry and neurosciences 2001;3 (4). www.onlinelibrary.wiley.com/doi/pdf/10.1034/j.1399-5618.2001.30403.x (accessed 7th January 2021)

[71] National Institute for Health and Clinical Excellence. Bipolar disorder: assessment and management. Clinical Guidance 185. London: National Institute for health and Clinical Excellence; 2014. Para 1.10.2 .

[72] Government. *Psychiatric disorders: assessing fitness to drive.* https://www.gov.uk/bipolar-disorder-and-driving (accessed7th January 2021).

[73] Government. *Psychiatric disorders: assessing fitness to drive* https://www.gov.uk/guidance/psychiatric-disorders-assessing-fitness-to-drive#hypomania-or-mania (accessed 7th January 2021).

[74] National Institute for Health and Clinical Excellence. Bipolar disorder: assessment and management. Clinical Guidance 185. London: National Institute for health and Clinical Excellence; 2014. Para 1.1.12.

[75] National Institute for Health and Clinical Excellence. Bipolar disorder: assessment and management. Clinical Guidance 185. London: National Institute for health and Clinical Excellence; 2014.Para 1.1.15.

Last updated March 2021
Next update March 2024
Version 10

This factsheet is available in large print.

Rethink Mental Illness Advice Service

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

Email advice@rethink.org

Did this help?

We'd love to know if this information helped you.

Drop us a line at: feedback@rethink.org

or write to us at Rethink Mental Illness:
RAIS
PO Box 17106
Birmingham B9 9LL

or call us on 0808 801 0525

We're open 9:30am to 4pm
Monday to Friday (excluding bank holidays)

Rethink Mental Illness.

Leading the way to a better quality of life for everyone affected by severe mental illness.

For further information
on Rethink Mental Illness
Phone 0121 522 7007
Email info@rethink.org

facebook.com/rethinkcharity
twitter.com/rethink_
www.rethink.org

Need more help?

Go to **www.rethink.org** for information on symptoms, treatments, money and benefits and your rights.

Don't have access to the web?

Call us on 0121 522 7007. We are open Monday to Friday, 9am to 5pm, and we will send you the information you need in the post.

Need to talk to an adviser?

If you need practical advice, call us on 0808 801 0525 between 9:30am to 4pm, Monday to Friday. Our specialist advisers can help you with queries like how to apply for benefits, get access to care or make a complaint.

Can you help us to keep going?

We can only help people because of donations from people like you. If you can donate please go to **www.rethink.org/donate** or call 0121 522 7007 to make a gift. We are very grateful for all our donors' generous support.

Rethink Mental Illness.

factsheet

Depression

This factsheet might be useful to you if you have depression or if you think you might have depression. It explains the causes, symptoms and treatments of depression. It may also help you if you're a carer, friend or relative of someone with depression.

Key Points.

- Some signs of depression are feeling low, feeling bad about yourself and not wanting to do things.
- Depression affects different people in different ways.
- If you think you might have depression you can speak to your GP.
- Depression may be treated with medication and talking treatments. Self-help techniques, peer support groups and coping strategies can also help.
- Different things can lead to depression. Your upbringing, stressful events and your lifestyle might all have an effect.
- If you feel low, getting enough sleep and eating healthy foods might help. It might also help to keep active, even if you don't feel like it.

Top

This factsheet covers:

Top

1. What is depression?

Everyone has ups and downs. Sometimes you might feel a bit low, for lots of different reasons. People may say that they are feeling depressed when they are feeling down, but this does not always mean that they have depression.

Depression is a long lasting low mood disorder.[1] It affects your ability to do everyday things, feel pleasure or take interest in activities.

Depression is:[2]

- a mental illness that is recognised around the world,
- common - it affects about one in ten of us,
- something that anyone can get, and
- treatable.

Depression is not:

- something you can 'snap out of',
- a sign of weakness,
- something that everyone experiences, or
- something that lasts forever as one episode.

Doctors might describe depression as 'mild', 'moderate' or 'severe'. Your doctor may offer you different treatments depending on how they describe it.[3]

How common is depression?

Depression can affect people of any age, including children. It is one of the most common mental illnesses. The number of people who have

depression may be higher than this because not everyone with depression goes to their GP.

Top

2. What are the symptoms of depression and how is it diagnosed?

The NHS recommends that you should see your GP if you experience the symptoms of depression for most of the day and every day for over 2 weeks.[4]

Doctors make decisions about diagnosis based on guidelines. One guideline used by NHS doctors is the International Classification of Diseases (ICD-10).

When you see a doctor they will look for the symptoms that are set out in the ICD-10 guidance. You do not have to have all of these to be diagnosed with depression. You might have just a few of them.

The symptoms of depression are:[5]

- low mood, feeling sad, irritable or angry,
- having less energy to do certain things,
- losing interest or enjoyment in activities you used to enjoy,
- loss of concentration,
- becoming tired more easily,
- disturbed sleep and losing your appetite,
- feeling less good about yourself (loss of self-confidence), or
- feeling guilty or worthless.

You may also find that with low mood you:

- feel less pleasure from things,
- feel more agitated,
- lose interest in sex,
- find your thoughts and movements slow down, and
- have thoughts of self-harm or suicide.

Your doctor should also ask about any possible causes of depression. They may also do some tests to check if you have any physical problems which might cause symptoms of depression such as an underactive thyroid.[6]

Top

3. What are the different types of depression?

You might have heard a number of terms used to describe depression. In this section, we explain what some of these terms mean.

Clinical depression

Clinical depression is a common term, but it is not a formal diagnosis. People sometimes say ‘clinical diagnosis’ to just mean they have been diagnosed by a doctor.

Depressive episode[7]

Your doctor might say that you are going through a 'depressive episode'. This is the formal name that doctors give depression when they make a diagnosis. They may say that you are going through a 'mild', 'moderate' or 'severe' episode.

Recurrent depressive disorder[8]

If you have had repeated episodes of depression, your doctor might say that you have recurrent depressive disorder. They may say that your current episode is 'mild', 'moderate' or 'severe'.

Reactive depression

If your doctor thinks that your episode of depression was caused by particular stressful events in your life, they may say that it is reactive.[9] For example, divorce, job or money worries. This is sometimes separated from an adjustment disorder, where you may struggle with some symptoms of depression because of adapting to a major change in your life. Such as separation from people, retirement or migrating to a new area.[10]

Severe depressive episode with psychotic symptoms[11]

If you are going through a severe episode of depression, you may get hallucinations or delusions. A hallucination means you might hear, see, smell, taste or feel things that aren’t real. A delusion means that you might believe things that don’t match reality. These symptoms are called psychosis.

Dysthymia[12]

Your doctor might diagnose you with dysthymia if you have felt low for several years, but the symptoms are not severe enough, or the episodes are not long enough for a doctor to diagnose recurrent depressive disorder.

Cyclothymia[13]

Your doctor might diagnose cyclothymia if you struggle with persistently unstable moods. You might have several periods of depression and periods of mild elation. These periods of depression or elation are not severe enough or long enough to diagnose recurrent depression or bipolar disorder. Cyclothymia is more commonly associated with bipolar disorder than depression.

Post-natal depression

Post-natal depression refers to episodes of depression after childbirth.[14] It is a common illness which affects more than 1 in 10 women within 1 year

of having a baby. You may get symptoms that are similar to those in other types of depression.[15]

Seasonal affective disorder (SAD)

This type of depression affects you at the same time of year, usually in the winter.[16,17] The symptoms are similar to depression, but some people find they sleep more rather than less, and crave carbohydrates like chocolate, cakes and bread.[18]

Manic depression[19]

Manic depression is the old name for bipolar disorder. It is a different illness to depression. People with this illness have highs (mania) and lows (depression).

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

Top

4. What causes depression?

There is no single cause of depression. Different things may cause depression for different people. This section looks at some of the things that might cause depression, or depressive symptoms.

Genetic factors

Some studies suggest that your genetics can play a part in developing depression. For example, one study found that particular genes may play a key role in developing recurrent depression.[20] However, studies into the genetics of depression are at an early stage.[21]

Your background and current situation

Researchers have also looked at whether having parents or other family members with depression can increase your chances of developing the condition. For example, some studies have looked into the effects having a mother with postpartum depression can have on children as they grow up.[22]

Stressful events, such as problems at home or work, a relationship ending or financial issues may also make it more likely you will get depression.[23]

Hormones and chemicals

Changes in your hormones and chemicals in your body may cause depressive symptoms.

For example, at some point many women might find their mood is affected in the weeks before their period, called pre-menstrual syndrome (PMS). Some women may struggle with premenstrual dysphoric disorder (PMDD) which has a lot of psychological symptoms similar to depression.[24]

Having problems with your thyroid or having low levels of Vitamin B12 may also be linked to feeling symptoms of depression.[25,26]

Lifestyle factors

Some studies have shown that not exercising, being under or overweight and having fewer social relationships can increase the risk of experiencing depressive symptoms.[27,28]

Drugs and alcohol

Both legal and illegal drugs might affect your mental health. If you take prescribed medications, it is important to make sure you take them in the way your doctor suggests.

Some people will drink alcohol because it feels like it can relieve anxiety or depression. However, the evidence suggests that if you drink regularly or misuse alcohol you are at a greater risk of developing depression.[29,30]

You can find more information about **'Drugs, alcohol and mental health'** at www.rethink.org. Or call our General Enquiries team on 0121 522 7007 and ask them to send you a copy of our factsheet.

Other illnesses

Depression can come with other mental or physical health conditions such as such as diabetes or cancer. These conditions can make you feel low or may be a trigger for depression.[31]

Some people with brain injuries and dementia may also have changes in their moods.[32,33]

You can find more information on looking after your physical health in our **'Good health guide'** at www.rethink.org. Or call our General Enquiries team on 0121 522 7007 and ask them to send you a copy of our factsheet.

Top

5. How is depression treated?

The first step to getting treatment is to see your GP. If your GP thinks you have depression, they will talk to you about the treatments they can offer.

Talking therapies

Talking therapy is available on the NHS, from private healthcare providers and sometimes from charities. You will meet a trained therapist for a fixed number of sessions. Sometimes this will be with a group of people with depression.

There are different types of talking therapy that you might be offered. These include:[34,35]

- cognitive-behavioural therapy,
- psychodynamic therapy,

- problem-solving therapy,
- interpersonal therapy,
- behaviour activation,
- group therapy,
- relationship counselling,
- bereavement counselling,
- mindfulness based therapy, and
- counselling.

The type of therapy you are offered will depend on the cause of your symptoms and their severity. Therapies may also have different levels based on how long or intense the treatment is.

Ask your GP about therapy if you think it might help. Not all of these therapies will be available in your area. Some areas offer a self-referral option for NHS talking therapies. Please refer to your local Improving Access to Psychological Therapies (IAPT) service to find out about this option.

You may also be able to access therapy privately or through your employer in an Employee Assistance Programme.

When you finish treatment, your doctor may suggest Mindfulness Based CBT (MCBT) which can be helpful if your depression comes back. MCBT combines mindfulness techniques like breathing exercises and meditation with CBT.[36] The National Institute of Health and Care Excellence (NICE), recommend individual CBT or MCBT for people who struggle with their depression coming back, or relapsing.[37]

Computerised cognitive behavioural therapy (cCBT)

Computerised cognitive behavioural therapy (cCBT) is one way of treating mild to moderate depression.[38] You learn CBT techniques online using a computer. You will go through the same type of session as you would if you were with a therapist. It can be helpful after you have finished talking therapies to stop your symptoms coming back.

'Beating the Blues' is one of the cCBT programmes you can get. They are free but you need to talk to your GP about it.[39]

Antidepressants

Your doctor might offer you an antidepressant.[40] You may need to try different types before you find one that works for you. If you do not want to take antidepressants, tell your doctor and you can discuss other options.

Antidepressants can have side effects and can affect other medicines you are taking. Your doctor will check if you have physical health conditions or if you take other medication.

It is important to talk to your doctor before you stop taking medication, because stopping suddenly can cause problems.

Exercise Therapy[41]

Regular exercise can help with your mood if you struggle with depression. Some GP surgeries will put you in touch with local exercise schemes. This is sometimes called ‘exercise on prescription’ and can give you access to free or reduced cost programmes.

Brain stimulation

Electroconvulsive therapy (ECT)

Electroconvulsive therapy (ECT) is a procedure sometimes used to treat severe depression. In this treatment, an electrical current is briefly passed through your brain while you are under general anaesthetic. This means you are not awake during the procedure.[42] You should only have ECT if you have severe depression, it is life-threatening and treatment is needed as soon as possible. Or you may be given ECT if no other treatments have worked.[43]

Transcranial direct current stimulation (tDCS)

This treatment involves using a small battery-operated machine to pass a low current through your brain to stimulate activity. You are awake during the procedure, with daily sessions for several weeks.[44] NICE state that there is not a lot of good evidence for how tDCS works for depression, but there are no major safety concerns.[45]

Repetitive transcranial magnetic stimulation (rTMS)

TMS uses electromagnetic coils to deliver pulses of magnetic energy to specific parts of your brain. This stimulates the brain and may help to reduce depression and anxiety. You are awake during the procedure and can leave hospital the same day.[46] If this is offered, you may have daily sessions for several weeks. NICE have examined rTMS and found that it is safe and effective enough to be offered on the NHS.[47]

Complementary or Alternative Therapies

Complementary therapies are treatments which are not part of mainstream medical care. They can include aromatherapy, herbal remedies, acupuncture, massage, meditation and yoga. These treatments may help improve your emotional wellbeing and may help with side effects.

You can find more information about:

- Antidepressants
- Talking Therapies
- Electroconvulsive Therapy (ECT)
- Complementary and alternative treatments

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

Top

6. What treatment should I be offered?

The National Institute of Health and Care Excellence (NICE) writes guidance on what treatment doctors should offer you. But your doctor does not have to give you these treatments and the treatments may not be available in your area.

Different treatments may be available in your area. Your doctor might think these suit your symptoms more than the recommended treatments.

NICE recommend that depression is treated in different steps depending on how severe the condition is for you. The steps are as follows.[48]

Step 1: Everyone who may have depression

Your doctor should offer you:

- an assessment of your symptoms,
- support, such as contact in appointments or by telephone,
- information on how to deal with your symptoms,
- monitoring of your symptoms and follow-up, and
- referral for further assessment and treatment if needed.

Step 2: Mild to moderate depression

Your doctor may offer you:

- low-intensity interventions, such as self-help guided by the doctor or computerised cognitive behavioural therapy (cCBT),
- physical activity programmes,
- group cognitive behavioural therapy (CBT),
- medication if you have a history of moderate or severe depression, or you have had symptoms for a long time, and
- referral for further assessment and treatment if needed.

Step 3: Moderate to severe depression, or mild to moderate depression when other treatments haven't worked

Your doctor may suggest:

- medication,
- higher intensity therapy such as individual CBT or behavioural activation,
- combined treatments of both medication and therapies,
- support from different teams if you need it, and
- referral for further assessment and treatment if needed.

Step 4: Severe and complex depression or if your life is at risk

Your doctor may suggest:

- medication,
- high-intensity talking therapy,

- electroconvulsive therapy (ECT),
- crisis services,
- combinations of different treatments,
- support from different teams if you need it, and
- hospital treatment in emergencies.

Top

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

If you are not happy with your treatment you can:

- talk to your doctor to see if they can suggest changes,
- get an advocate to help you speak your doctor,
- ask for a second opinion if you feel it would help,
- contact Patient Advice and Liaison Service (PALS) and see whether they can help, or
- make a complaint.

There is more information about these options below.

Advocacy

An advocate is someone separate from mental health services but who understands the system and your rights. They can come to a meeting with you to help you get what you are entitled to.

You can search online to see if there are any local advocacy services in your area or Rethink Mental Illness Advice Service could search for you.

Second opinion

Talk to your doctor about your treatment to see if you can resolve the problem with them first. If you don't agree with their decisions about diagnosis or treatment, you could ask for a second opinion. You are not legally entitled to a second opinion, but your doctor might agree to it if it would help with treatment options.

'PALS'

The Patient Advice and Liaison Service (PALS) at your NHS trust can help to resolve problems or issues you have with an NHS service. You can find your local PALS' details at http://www.nhs.uk/Service-Search/Patient-advice-and-liaison-services-(PALS)/LocationSearch/363.

Complaints

It is best to try and solve the problem with the team or doctor first. If this does not help you can make a formal complaint. If you are unhappy with their response to your complaint, then you may be able t take this up to the Parliamentary and Health Service Ombudsman.

You can get an Independent Health Complaints Advocate (IHCA) to help you make a complaint against an NHS service.

You can find more information about:

- Advocacy
- Second opinions
- Complaints

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

Top

8. What self-care and management skills can I try?

You can learn to manage your symptoms by looking after yourself. Self-care is how you take care of your diet, exercise, daily routine, relationships and how you are feeling. You will learn how to notice when you are becoming unwell and know what your triggers are.

Your diet

Our diet affects our physical health. Depending on what you eat you could develop problems like obesity, heart disease and diabetes. In the same way, the things we eat may affect our moods and mental health.[49]

Some people deal with their depression by eating high-fat and high-sugar foods. Also, seasonal affective disorder (SAD) can make you crave sugary carbohydrates like cakes and biscuits.[50]

To manage your diet you can:[51]

- eat regular meals
- don't skip meals,
- eat a healthy balance of fat and reduce the amount of trans-fat you eat,
- eat fruit, vegetables and wholegrains,
- eat oily fish such as salmon, mackerel, herring or trout,
- drink 6-8 glasses of water per day,
- limit your caffeine in drinks such as tea, coffee or fizzy drinks, and
- limit the amount of alcohol you drink.

The UK Chief Medical Officer recommends that to keep the risks from alcohol low, men and women should not regularly drink more than 14 units of alcohol a week.[52]

If you have depression, making these changes may not have an instant impact on your mood. However, they can be important for long-term recovery.

Exercise

Exercising regularly can help your mood.[53] You can exercise any way you like, so long as it safely increases your heart rate and makes you breathe

faster. Exercise can also help if you have problems sleeping.[54] Getting proper sleep may be important for your mental health.

How much you can do depends on your age, physical health and fitness. If you do not exercise already, start with small amounts and fit this into your daily routine. You can then slowly increase the amount you do. This approach may help with your motivation.

There are programmes like the NHS's Couch to 5KM where they gradually help you go from doing no exercise to walking or jogging for 5 kilometres.[55] Some other ideas are listed below.

- **Going for a walk:** You could get a pedometer or an app that counts your steps. Slowly challenge yourself to walk more steps and reach a goal.
- **Cycling:** Make sure you wear a helmet and high visibility vests or chest strap. Stick to quiet roads if you aren't confident on a bike.
- **Gardening:** There may be a local NHS or charitable gardening scheme in your area. Ask your GP, volunteering services or social services.

  You can check your area on 'The Conversation Volunteers' website to see if there are any projects in your area. Their details are in Useful Contacts at the end of this factsheet.
- **Jogging:** Try jogging around the block to start with. Then slowly increase the amount of time you jog for, or the distance you go.
- **Playing a sport:** Try speaking to friends or family to see if they will join you in a sport. Or join a local club. You could also look at individual sports.
- **Gym:** As well as indoor gyms, there are free 'green gyms' all across the country. See 'The Conversation Volunteers' website for more details in the Useful Contacts section.
- **Housework:** Doing housework in an active way can be good exercise.

Some mental health medication can cause problems with weight gain. Exercise could also help you manage this. To help, you could look at the NHS 12-week diet and exercise plan which you can find here: https://www.nhs.uk/live-well/healthy-weight/start-the-nhs-weight-loss-plan/

You should speak to your doctor if you have any concerns about gaining weight due to medication. You should also speak to your doctor if you have any concerns before starting to exercise.

Top

9. What risks and complications can depression cause?

Having depression can cause other problems. It can affect your mental health as well as your physical health, and it may affect other areas of your life too. For example, depression may cause:[56]

- disturbed sleep,
- aches and pains,
- low sex drive,
- difficulties with work and your hobbies,
- difficulties keeping contact with friends and families, or
- suicidal thoughts.

Some people might also drink more alcohol to try and relieve depression. However, as we said in Section 4, this can actually make depression worse.[57]

If you have any of these problems, speak to your GP.

Top

10. Information for family, carers and friends

You can get support if you are a carer, friend or family member of someone living with depression.

You could get in touch with carer support groups or sibling support groups. You can search for local groups in your area online or ask your GP.

You can ask your local authority for a carer's assessment if you need more practical support to help care for someone.

As a carer you should be involved in decisions about care planning. There are rules about information sharing and confidentiality which may make it difficult for you to get all the information you need in some circumstances.

You can find out more information about:

- Carer's assessments
- Caring for yourself
- Confidentiality and information sharing
- Benefits for carers

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

Supporting the person you care for

You might find it easier to support someone with depression if you understand their symptoms, treatment and self management skills. You can use this to support them to get help and stay well.

Below are some initial suggestions for providing practical day to day support to someone with depression.[58]

- Offer them emotional support by being a good listener, reminding them that treatment is available and reassuring them. Remember that depression is an illness and people cannot “snap out of it”.
- Encourage them to get some exercise and eat healthily. You could invite them out on walks, or help them do things they used to enjoy.
- Keep a note of changes in their medication, or their condition. This can help the person you care for in appointments.
- Help them to stay away from alcohol and other unhealthy things.
- Take them seriously if they are feeling very unwell and are thinking about hurting themselves. Encourage them to get professional help.

You could also try and find out about self-help or support groups in their area. Your local IAPT service may be a good place to start.

Think about what you can do if you are worried about someone’s mental state or risk of self harm. It will help to keep details of their mental health team and discuss a crisis plan with them.

You can find out more information about:

- Supporting someone with a mental illness
- Getting help in a crisis
- Suicidal thoughts – how to support someone
- Responding to unusual behaviour

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

Top

Useful Contacts

Mood Swings Network
This service provides a range of services for people affected by a mood disorder such as depression, including their family and friends.

Telephone: 0161 832 3736 (10am - 4pm, Monday to Friday)
Email: info@moodswings.org.uk
Website: www.moodswings.org.uk

The Conservation Volunteers
This organisation helps people to get involved in local conservation projects and has Green Gyms.

Website: www.tcv.org.uk

Do-it
This is an organisation that supports people to get into volunteering across the country.

Website: www.do-it.org/

Pandas Foundation
This organisation provides advice and support for people struggling with pre- and post-natal depression.

Telephone: 0843 28 98 401
Email: info@pandasfoundation.org.uk
Website: www.pandasfoundation.org.uk

Cruse Bereavement Care
This organisation provides support for people struggling with bereavement. They offer support by telephone and in local centres across the country.

Telephone: 0808 808 1677
Website: www.cruse.org.uk

Further Reading

You can find more information about:

- Bipolar Disorder
- Psychosis
- Drugs, Alcohol and Mental Health
- Antidepressants
- Talking Therapies
- Electroconvulsive Therapy (ECT)
- Complementary Therapies
- Advocacy
- Second opinion
- Medication – Choice and managing problems
- Complaints

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

Counselling Directory
This website has lots of information about depression and other self-help resources.

Website: www.counselling-directory.org.uk/depression.html

Northumberland, Tyne and Wear NHS Foundation Trust
This NHS trust has produced a self-help guide for Depression and Low mood.

Website: https://web.ntw.nhs.uk/selfhelp/

Overcoming
This website has information on self help guides you can buy for a range of different conditions. They are not free resources but can read reviews of different books here. You may be able to get some of the books cheaper if you buy them second hand.

Website: www.overcoming.co.uk

Online cognitive behavioural therapy (CBT) resources
This website is from the NHS. It has a selection of different resources that can help with depression.

Website: www.nhs.uk/conditions/stress-anxiety-depression/pages/low-mood-stress-anxiety.aspx

Top

References

[1] NHS Choices. *Clinical Depression- Symptoms.* www.nhs.uk/conditions/clinical-depression/symptoms/ (accessed 9 July 2018).
[2] NHS Choices. *Clinical Depression- Overview.* https://www.nhs.uk/conditions/clinical-depression/ (accessed 10 July 2018).
[3] As note 2.
[4] NHS Choices. *Clinical Depression- Diagnosis*. www.nhs.uk/conditions/clinical-depression/diagnosis/ (accessed 9 July 2018).
[5] World Health Organisation. *International Classification of Diseases (ICD) – 10. Depressive episode.* F32.0-F32.9. http://apps.who.int/classifications/icd10/browse/2010/en (accessed 13 July 2018).
[6] As note 4.
[7] As note 5, at para F32.
[8] As note 5, at para F33.
[9] As note 5, at para F32.

[10] As note 5, at para F43.2.
[11] As note 5, at para F32.3.
[12] As note 5, at para F34.1.
[13] As note 5, at para F34.0
[14] As note 5, at para F53.
[15] NHS Choices. *Postnatal depression- overview.* https://www.nhs.uk/conditions/post-natal-depression/ (accessed 13 July 2018).
[16] As note 5, at para F33.
[17] NHS Choices. *Seasonal affective disorder (SAD)- Overview.* https://www.nhs.uk/conditions/seasonal-affective-disorder-sad/ (accessed 13 July 2018).
[18] As note 17.
[19] As note 5, at para F31.
[20] Breen G, Webb BT, Butler AW, van den Oord EJ, Tozzi F, Craddock N, Gill M, Korszun A, Maier W, Middleton L, Mors O, Owen MJ, Cohen-Woods S, Perry J, Galwey NW, Upmanyu R, Craig I, Lewis CM, Ng M, Brewster S, Preisig M, Rietschel M, Jones L, Knight J, Rice J, Muglia P, Farmer AE, McGuffin P. A genome-wide significant linkage for severe depression on chromosome 3: the depression network study. *American Journal of Psychiatry* 2011; 168(8): 840-847. https://doi.org/10.1176/appi.ajp.2011.10091342 (accessed 16 July 2018).
[21] Genetics Home Reference. *Depression.* https://ghr.nlm.nih.gov/condition/depression (accessed 16 July 2018).
[22] Bernard-Bonnin AC, Canadian Paediatric Society, Mental Health and Developmental Disabilities Committee. Maternal depression and child development. *Paediatrics & Child Health* 2004; 9(8): 575–583. https://doi.org/10.1093/pch/9.8.575 (accessed 16 July 2018).
[23] Kendler KS, Karkowski LM, Prescott CA. Causal relationship between stressful life events and the onset of major depression. *American Journal of Psychiatry* 1999; 155(6): 837-841. https://doi.org/10.1176/ajp.156.6.837 (accessed 16 July 2018).
[24] NHS Choices. *Premenstrual Syndrome.* www.nhs.uk/Conditions/Premenstrual-syndrome/Pages/Symptoms.aspx (accessed 16 July 2018).
[25] NHS Choices. *Underactive thyroid (hypothyroidism).* www.nhs.uk/Conditions/Thyroid-under-active/Pages/Symptoms.aspx (accessed 16 July 2018).
[26] NHS Choices. *Vitamin B12 or folate deficiency anaemia.* www.nhs.uk/Conditions/Anaemia-vitamin-B12-and-folate-deficiency/Pages/Symptoms.aspx (accessed 16 July 2018).
[27] Molarius A, Berglund K, Eriksson C, Eriksson HG, Linden-Bostrom M, Nordstrom E, Persson C, Sahlqvist L, Starrin B, Ydreborg B. Mental health symptoms in relation to socio-economic conditions and lifestyle factors- a population-based study in Sweden. *BMC Public Health* 2009; 9(302): 1-9. https://bmcpublichealth.biomedcentral.com/articles/10.1186/1471-2458-9-302 (accessed 13 July 2018).
[28] Luppino FS, de Wit LM, Bouvy PF, Stijnen T, Cuijpers P, Penninx BW, Zitman FG. Overweight, obesity, and depression: a systematic review and meta-analysis of longitudinal studies. *Archive of Genetic Psychiatry* 2010;

67(3): 220-229. doi:10.1001/archgenpsychiatry.2010.2 (accessed 13 July 2018).
[29] Royal College of Psychiatrists. *Alcohol and depression.* https://www.rcpsych.ac.uk/healthadvice/problemsdisorders/alcoholdepression.aspx (accessed 16 July 2018).
[30] Boden JM, Fergusson DM. Alcohol and depression. *Addiction* 2011; 106(5): 906-914. https://onlinelibrary.wiley.com/doi/full/10.1111/j.1360-0443.2010.03351.x (accessed 16 July 2018).
[31] U.S. Department of Health and Human Services, National Institute of Mental Health. *Depression (NIH Publication No. 15-3561).* Bethesda, Maryland: U.S Government Printing Office; 2015. Page 4.
[32] NHS Choices. *Severe head injury-Complications.* https://www.nhs.uk/conditions/severe-head-injury/complications/ (accessed 16 July 2018).
[33] NHS Choices. *Dementia Guide- Mood and dementia.* https://www.nhs.uk/conditions/dementia/living-well-with-dementia/#mood-and-dementia (accessed 16 July 2018).
[34] NHS Choices. *Talking therapies explained.* https://www.nhs.uk/conditions/stress-anxiety-depression/types-of-therapy/ (accessed 16 July 2018).
[35] Royal College of Psychiatrists. *Depression.* https://www.rcpsych.ac.uk/healthadvice/problemsanddisorders/depression.aspx (accessed 16 July 2018).
[36] As note 34.
[37] National Institute for Health and Care Excellence. Depression in adults: recognition and management. Clinical Guidance 90. London: National Institute for Health and Care Excellence; 2009. Para 1.9.1.8.
[38] As note 37, at para 1.4.2.1.
[39] NHS Choices. *Cognitive behavioural therapy (CBT)- Computerised CBT.* https://www.nhs.uk/conditions/cognitive-behavioural-therapy-cbt/how-it-works/#computerised-cbt (accessed 16 July 2018).
[40] As note 37, at para 1.5.1.1.
[41] NHS Choices. *Exercise for depression.* https://www.nhs.uk/conditions/stress-anxiety-depression/exercise-for-depression/ (accessed 16 July 2018).
[42] NHS Choices. *Clinical Depression-Treatment.* https://www.nhs.uk/conditions/clinical-depression/treatment/ (accessed 16 July 2018).
[43] As note 37, at para 1.10.4.
[44] As note 42.
[45] National Institute for Health and Care Excellence. *Transcranial direct current stimulation (tDCS) for depression.* Interventional Procedures Guidance 530. London: National Institute for Health and Care Excellence; 2015. Para 1.1.
[46] As note 42.
[47] National Institute for Health and Care Excellence. *Repetitive transcranial magnetic stimulation for depression*. Interventional Procedure Guidance 542. London: National Institute for Health and Care Excellence; 2015. Para 1.1.
[48] As note 37, at para 1.2-1.6.

[49] Mental Health Foundation. *Feeding Minds.* London: Mental Health Foundation; 2006. Page 6.
[50] As note 17.
[51] British Dietetic Association. *Depression and diet.* https://www.bda.uk.com/foodfacts/Diet_Depression.pdf (accessed 16 July 2018).
[52] Drinkaware. *Alcohol limits and unit guidelines.* https://www.drinkaware.co.uk/alcohol-facts/alcoholic-drinks-units/alcohol-limits-unit-guidelines/ (accessed 16 July 2018).
[53] Mental Health Foundation. *How to look after your mental health using exercise*. https://www.mentalhealth.org.uk/publications/how-to-using-exercise (accessed 16 July 2018).
[54] Passos GS, Poyares, D, Santana MG, D'Aurea CV, Youngstedt SD, Tufik S, de Mello MT. Effects of moderate aerobic exercise training on chronic primary insomnia. *Sleep Medicine* 2011:12(10); 1018-1027. https://doi.org/10.1016/j.sleep.2011.02.007 (accessed 16 July 2018).
[55] NHC Choices. *Couch to 5K: week by week.* https://www.nhs.uk/live-well/exercise/couch-to-5k-week-by-week/ (accessed 16 July 2018).
[56] As note 1.
[57] As note 29.
[58] Royal College of Psychiatrists. *Depression. Working in partnership with psychiatrists and carers.* https://www.rcpsych.ac.uk/healthadvice/informationforcarers/depressionchecklist.aspx (accessed 16 July 2018).

Last updated July 2019
Next update July 2022
Version: 10

This factsheet is available in large print.

Health & care information you can trust

The Information Standard Certified Member

Rethink Mental Illness Advice Service

Phone 0300 5000 927
Monday to Friday, 9:30am to 4pm (excluding bank holidays)

Email advice@rethink.org

Did this help?

We'd love to know if this information helped you.

Drop us a line at: feedback@rethink.org

or write to us at Rethink Mental Illness:
RAIS
PO Box 17106
Birmingham B9 9LL

or call us on 0300 5000 927.

We're open 9:30am to 4pm
Monday to Friday (excluding bank holidays)

Rethink Mental Illness.

Leading the way to a better quality of life for everyone affected by severe mental illness.

For further information
on Rethink Mental Illness
Phone 0121 522 7007
Email info@rethink.org

facebook.com/rethinkcharity
twitter.com/rethink_
www.rethink.org

Need more help?

Go to **www.rethink.org** for information on symptoms, treatments, money and benefits and your rights.

Don't have access to the web?

Call us on 0121 522 7007. We are open Monday to Friday, 9am to 5pm, and we will send you the information you need in the post.

Need to talk to an adviser?

If you need practical advice, call us on 0300 5000 927 between 9:30am to 4pm, Monday to Friday. Our specialist advisers can help you with queries like how to apply for benefits, get access to care or make a complaint.

Can you help us to keep going?

We can only help people because of donations from people like you. If you can donate please go to **www.rethink.org/donate** or call 0121 522 7007 to make a gift. We are very grateful for all our donors' generous support.

FundRaising Standards Board

INVESTORS IN PEOPLE | Gold

Rethink Mental Illness is a partner in: time to change let's end mental health discrimination

factsheet

Dissociation and dissociative disorders

This factsheet gives information about dissociation and dissociative disorders. It explains the different dissociative disorders, their symptoms and treatments. This factsheet is for anyone with dissociation and dissociative disorder and their carers, friends or relatives.

Key Points.

- If you dissociate you might have symptoms such as not feeling connected to your own body or developing different identities.
- Dissociative disorder is a mental illness that affects the way you think. You may have the symptoms of dissociation, without having a dissociative disorder. You may have the symptoms of dissociation as part of another mental illness.
- There are lots of different causes of dissociative disorders.
- You may get talking therapies for dissociative disorders.
- You may be given medication that may help with symptoms of dissociation and dissociative disorder.

This factsheet covers:

Top

1. What is dissociation?

Many people will experience dissociation at some point in their lives. Lots of different things can cause you to dissociate. For example, you might dissociate when you are very stressed, or after something traumatic has happened to you. You might also have symptoms of dissociation as part of another mental illness like anxiety.[1]

Some of the symptoms of dissociation include the following.[2]

- You may forget about certain time periods, events and personal information.
- Feeling disconnected from your own body.
- Feeling disconnected from the world around you.
- You might not have a sense of who you are.
- You may have clear multiple identities.
- You may feel little or no physical pain.

You might have these symptoms for as long as the event that triggered them, or for a short time afterwards. This is called an episode.

For some people these symptoms can last for much longer. If you have a dissociative disorder you might experience these symptoms for long episodes or even constantly.[3]

Top

2. What are the different types of dissociative disorder?

There are different types of dissociative disorder.[4] There is more information on each of these below.

It‘s important to remember that you could have the symptoms of dissociation without a dissociative disorder. There is also a lot of disagreement among professionals over dissociative disorders.

What is dissociative amnesia?

If you have dissociative amnesia you might not remember things that have happened to you. This may relate to a stressful or traumatic event,[5] but doesn’t have to.

In severe cases you might struggle to remember:[6]

- who you are,
- what happened to you, or
- how you felt at the time of the trauma.

This isn't the same as simply forgetting something. It is a memory 'lapse'. This means you can't access the memory at that time, but they are also not permanently lost.[7]

With dissociative amnesia you might still engage with other people, such as holding conversations.[8] You might also still remember other things and live a normal life. But you might also have flashbacks, unpleasant thoughts or nightmares about the things you struggle to remember.[9]

You may have dissociative amnesia with dissociative fugue. This is where someone with dissociative amnesia travels or wanders somewhere else, related to the things they can't remember. You may or may not have travelled on purpose.[10]

What is dissociative identity disorder (DID)?

Dissociative identity disorder (DID) is sometimes called 'Multiple Personality Disorder.[11] But we have called it DID in this factsheet.

If you have DID you might seem to have 2 or more different identities, called 'alternate identities.[12] These identities might take control at different times.

You might find that your behaviour changes depending on which identity has control. You might also have some difficulty remembering things that have happened as you switch between identities.[13] Some people with DID are aware of their different identities, while others are not.[14]

There is a lot of disagreement between researchers over the notion of DID.

We think of someone with DID as having different identities. But some researchers think that that these are actually different parts of one identity which aren't working together properly.

They suggest that DID is caused by experiencing severe trauma over a long time in childhood. By experiencing trauma in childhood, you take on different identities and behaviours to protect yourself. As you grow up these behaviours become more fully formed until it looks like you have different identities. When in fact the different parts of your identity don't work together properly. [15]

What is other specified dissociative disorder?[16]

With this diagnosis you might regularly have the symptoms of dissociation but not fit into any of the types.

A psychiatrist uses this diagnosis when they think the reason you dissociate is important.

The reasons they give include the following.

- You dissociate regularly and have done for a long time. You might dissociate in separate, regular episodes. Between these episodes you might not notice any changes.
- You have dissociation from coercion. This means someone else forced or persuaded you. For example, if you were brainwashed, or imprisoned for a long time.
- Your dissociation is acute. This means that your episode is short but severe. It might be because of one or more stressful events.
- You are in a dissociative trance. This means you have very little awareness of things happening around you. Or you might not respond to things and people around you because of trauma.

What is unspecified dissociative disorder?[17]

This diagnosis is used where you dissociate but do not fit into a specific dissociative disorder.

Psychiatrists also use this diagnosis when they choose not to specify the reasons why you do not fit into a specific disorder.

Or if they don't have enough information for a specific diagnosis. For example, after a first assessment in accident and emergency.

What are dissociative seizures?[18]

Dissociative seizures are hard to get diagnosed. They are regularly wrongly diagnosed as epilepsy.

Dissociative disorders can also be known as non-epileptic attack disorder (NEAD).

It can be hard to tell the difference between a dissociative and epileptic seizure. An EEG can read epileptic seizures but can't read dissociative seizures. An EEG is a test that detects electrical activity in your brain using small, metal discs attached to your scalp.

Dissociative seizures happen for psychological reasons not physical reasons.

What is depersonalisation/ derealisation disorder (DPDR)?

The feelings of depersonalisation and derealisation can be a symptom of other conditions. It has also been found among people with frontal lobe epilepsy[19] and migraines.[20]

But it can also be a disorder by itself. This means it is a 'primary disorder'. There is some disagreement among professionals whether DPDR should be listed with the other dissociative disorders at all.

DPDR has some differences to other dissociative disorders. In DPDR you might not question your identity or have different identities at all. You may still be able to tell the difference between things around you.[21] And there may be no symptoms of amnesia. Instead, with DPDR you might feel emotionally numb and questions what it feels like to live. We have explained this in more detail below.

You might have these feelings constantly rather than in episodes. It doesn't have to have been caused by a traumatic or stressful event.

Many people think that this disorder might be more common than previously thought.[22] This might be because of:[23]

- a lack of information about it,
- patients who didn't report their symptoms, and
- doctors who don't know enough about it, meaning they under-report the condition.

With DPDR you might have symptoms of depersonalisation or derealisation or both.

Depersonalisation

With depersonalisation you might feel 'cut off' from yourself and your body, or like you are living in a dream. You may feel emotionally numb to memories and the things happening around you.[24] It may feel like you are watching yourself live.[25]

The experience of depersonalisation can be very difficult to put into words. You might say things like 'I feel like I don't exist anymore' or 'It's as if I'm watching my life from behind glass'.

Derealisation

If you have derealisation you might feel cut off from the world around you. You might feel that things around you don't feel real. Or they might seem foggy or lifeless.[26]

Jane's story

Jane started feeling the symptoms of depersonalisation after smoking cannabis. She felt like her eyes were fixed on parts of the room and that she was not connected to everything around her. She felt as if she was a spectator in her own life for many months, rather than actually living 'in the moment'. It took Jane a long time to be diagnosed. To recover, she was helped to distract herself from the DPDR symptoms for long stretches with engaging activities. This then expanded into periods of time when she felt connected to the things around her again. Cognitive-behavioural therapy and mindfulness taught her to manage her anxiety and the distressing symptoms of DPDR.

Top

3. What causes dissociation?

There are different things that can cause you to dissociate. For example:[27]

- traumatic events,
- difficult problems that cause stress, and
- difficult relationships.

Other researchers have suggested that the use of cannabis may sometimes be a cause of depersonalisation/ derealisation disorder (DPDR).[28]

Top

4. How are dissociation and dissociative disorders treated?

Dissociation can be treated in lots of different ways. The type of treatment you get might depend on which type of disorder you have.

Can medications help?

At the moment, there are no medications for dissociative disorders themselves[29], although you may take medication for some symptoms.

If you have episodes of dissociation you might also have a condition such as depression or anxiety. Some medications could help with this. For example, antidepressants could be used for depressive symptoms and benzodiazepines for anxiety.[30]

Benzodiazepines can be addictive and should be prescribed for a short period only.[31] Benzodiazepines can make Dissociation worse.[32]

You can find more information on:

- Antidepressants
- Benzodiazepines

at www.rethink.org. Or call our General Enquiries Team on 0121 522 7007 and ask them to send you a copy of our factsheets.

What psychosocial treatments can help?

Talking therapies are usually recommended for dissociation. There are lots of different types of talking therapy. Different ones might be used for different dissociative disorders.

What is psychodynamic psychotherapy?

If you have DID, then your doctors may think about long-term relationally psychotherapy.[33] This is a type of therapy where you talk about your relationships and thoughts. You might talk about your past. Your therapist can link the ways you think and act with things that have happened to you.[34]

For DID, psychotherapy might be needed for a long time, with at least 1 session every week.[35] This will depend on individual's situations and on their ability and level to function, resources, support and motivation.[36]

What is eye movement desensitisation and reprocessing (EMDR)?

DID may also be helped by eye-movement desensitisation and reprocessing (EMDR). In EMDR you make side-to-side eye movements while talking about the trauma that happened. [37]

Doctors must be careful when using EMDR because it could make your DID worse if not done properly. But EMDR can have benefits when it is used along with other treatment. The type of EMDR used for DID is slightly different to other conditions. So, it is important that your doctor knows about your DID before you start EMDR.[38]

What is cognitive behavioural therapy (CBT)?

Cognitive behavioural therapy (CBT) is another type of talking therapy. You will talk about the way your thoughts and feelings affect you. And how your behaviours may make this worse. You focus less on the past and try to change the way you think and behave.[39]

Parts of CBT are recommended to treat DID, by helping you to change your thoughts and behaviours that come from the trauma.[40]

A CBT approach has also been suggested for long-lasting DPDR. If you have DPDR you might often worry about your symptoms and think you have a serious mental illness or that something is wrong with your brain.[41] CBT may help to change this way of thinking. By reducing your anxiety and depression that comes with this worrying, it may also reduce your symptoms of DPDR.[42]

You can find more information about **'Talking therapies'** at www.rethink.org. Or call our General Enquiries Team on 0121 522 7007 and ask them to send you a copy of our factsheet.

Top

5. What treatment should I be offered?

In the UK, the National Institute of Health and Care Excellence (NICE) publish guidelines on physical and mental health conditions. These guidelines are a standard for NHS treatment. At the time of writing, there are no NICE guidelines on dissociation or dissociative disorders.

But this doesn't mean you shouldn't be offered treatment. If you think you are having any of these symptoms, then explain this to your GP. They may refer you to a psychiatrist.

You can find more about '**GPs - What to expect from your doctor' at** www.rethink.org. Or call our General Enquiries Team on 0121 522 7007 and ask them to send you a copy of our factsheet.

Top

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

If you aren't happy with your treatment you can:

- ask for a second opinion,
- ask an advocate to help you speak to your doctor,
- contact the Patient Advice and Liaison Service (PALS), or
- make a complaint.

There is more information about these options below:

How do I ask for a second opinion?

If you aren't happy with your diagnosis or treatment, speak to your doctor. If they don't offer you any other treatment options, you can ask for a second opinion. This is where another doctor will assess you and suggest diagnoses or treatment. You don't have a legal right to a second opinion, but your doctor might agree to one. [43]

What is advocacy?

An advocate can help you understand your rights to treatment from the NHS. They can also help you be fully involved in decisions about your care. An advocate is separate from the NHS.

You can search online to see if there are any local advocacy services in your area. Or the Rethink Mental Illness Advice Service could search for you. You can find their details at the end of this factsheet.

What is the Patient Advice and Liaison Service (PALS)?

The Patient Advice and Liaison Service (PALS) at your NHS trust can try and help you with any problems or issues you have. You can find your local PALS' details at: www.nhs.uk/Service-Search/Patient-advice-and-liaison-services-(PALS)/LocationSearch/363.

How can I make a complaint?

If you aren't happy with the way you have been treated, you can make a complaint. You have to make a complaint about the NHS within 12 months of what you want to complain about.

You can find more information about:

- Second Opinions
- Advocacy
- Complaints about the NHS or Social services

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

Top

7. What are self-care and management skills?

You can learn to manage your symptoms by looking after yourself at home. You will learn how to notice when you are becoming unwell and know what your triggers are.

Not all of the techniques here will work for everyone. It is important to try something that you enjoy and that you can commit to and that works for you.

Keeping a diary

You might find it helpful to keep a diary. You could write about how you felt over the day. Or you could write down goals that you want to achieve. You could use it as part of cognitive behavioural therapy (CBT).

Keeping a diary isn't for everyone. If you have depersonalisation/ derealisation disorder (DPDR) you might already spend a lot of time thinking about how other people see you. A diary may make you feel worse if it forces you to think about yourself. A diary can still help but talk to your GP or a counsellor first.

Grounding techniques[44]

These techniques can be helpful for people who have been through trauma or who regularly dissociate. They can help to 'ground' you in the here and now. This may help when experiencing flashbacks.

Grounding works best when it is practiced regularly. Try practicing these things every day. There are different types of grounding techniques.

Using your surroundings

To use your surroundings, look around yourself. Focus on all the details of everything that is around you. Try describing this to yourself either out loud or silently in your head. Use all of your senses.

Using words

You could try positive words or phrases about yourself. For example, 'I am strong' or 'I will succeed'. Write down a few things that are meaningful and positive for you. You could carry these around with you. Try reading them to yourself or aloud if your symptoms are bad.

Using images

This is similar to using your surroundings. Try thinking of a place that you feel peaceful and safe. This can be a real or imaginary place. If it is a real

place, choose somewhere that is positive with no traumatic memories. Shut your eyes and imagine that place. Focus on all of the details and all of your senses.

Using posture

Try moving into a posture that makes you feel strong. This could be standing up with your shoulders back or relaxing your shoulders. Try different postures until you find one that works for you.

Using objects

Try choosing an object that is personal to you. You should try and pick something that only has positive memories attached to it. Carry it around with you and use it to remind yourself of who you are and where you are.

Relaxation

There are lots of different ways to relax. The important thing is to find something you enjoy doing. For example, cooking, reading or gardening. You might find that meditation or mindfulness helps.

Some relaxation techniques such as meditation and mindfulness may make some people feel worse. For example, if you have DPDR you might struggle with meditation.[45] If this is the case, try and find something else that works for you. If you have CBT, you could tell the therapist. They could help you find something that works.

Exercise and diet

There are no specific exercises that can definitely help. But you could try jogging, swimming or just trying to walk more and something that suits your ability. Trying to eat more fresh fruits and vegetables can help. You could also try to reduce the amount of fat, salt and sugar you eat. Reducing the amount of caffeine, you drink can be helpful.

Sleep

If you don’t sleep enough your symptoms might feel worse. It can take a few weeks for you to get into better sleep habits. Here are some tips for helping you sleep.

- Sleep when you feel sleepy.
- Keep your bedroom as a place for only sleeping.
- If you are lying awake in bed for a long period, get up and move around for a while.
- Avoid taking naps during the day.
- Try not to have caffeine for a few hours before you go to bed.
- Make sure you get up at the same time every day. This can help you get into a regular routine.

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

Top

8. What risks and complications can dissociation cause?

Some people with a dissociative disorder may also have another mental health condition, such as anxiety or depression.[46] This is called a 'co-morbid' condition. In some cases, this can make your dissociative disorder harder in day to day life. However, all these conditions are manageable and treatable.

You can find more information on:

- Depression
- Anxiety Disorders

at www.rethink.org. Or call our General Enquiries Team on 0121 522 7007 and ask them to send you a copy of our factsheets.

Top

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

What support can I get?

If you are a carer, friend or family member of someone living with a dissociative disorder you can get support.

You can get peer support through carer support groups. You can search for local groups in your area on the following websites:

- **Rethink Mental Illness:** www.rethink.org
- **Carers: Carers UK:** www.carersuk.org
- **Carers Trust:** www.carers.org

If you need more practical support, you can ask your local authority for a carer's assessment. You might be able to get support from your local authority.

As a carer you should be involved in decisions about your relative's care planning. But you can only be involved if your relative agrees to this. If they don't agree, their healthcare professionals can't share information about them with you.

You can find out more information about:

- Carer's assessment and support planning
- Confidentiality and information sharing – For carers, friends and relatives
- Benefits for carers

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

How can I supporting the person I care for?

You might find it easier to support someone with a dissociative disorder if you understand their symptoms, treatments and self-care options. You can use this to support and encourage them to get help and stay well.

You should also be aware of what you can do if you are worried about their mental state. Keep the details of their mental health team or GP handy and discuss a crisis plan with them.

You can find out more information about:

- Supporting someone with a mental illness
- Getting help in a crisis
- Suicidal thoughts - How to support someone
- Responding to unusual behavior

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

Top

Further Reading

Caroline Spring
Online training on dissociation and Dissociative Identity Disorder, webinars and literature.

Phone: 01480 878687
Email: info@carolynspring.com
Website: www.carolynspring.com/

Useful Contacts

Clinic for Dissociative Studies
This organisation has lots of information on dissociative disorders on their website. They also provide care and treatment for dissociative disorders. They can accept referrals from the NHS. They offer general information about dissociative disorders but do not run a helpline.

Telephone: 020 7794 1655
Address: 35 Tottenham Lane, London, United Kingdom, N8 9BD
Email: info@clinicds.com
Website: www.clinicds.co.uk

South London and Maudsley Trauma and Dissocation Service
A specialist outpatient assessment, consultation and treatment service. It's for adults who are experiencing psychological difficulties following trauma and/or dissociative disorders. The only NHS specialist service offering treatment for people presenting with complex post-traumatic stress disorder (PTSD) and severe dissociative disorders. Referrals are accepted from GPs and senior clinicians. All referrals have to be approved and funded by the local clinical commissioning group (CCG).

Phone: 020 3228 2969
Email: TDS@slam.nhs.uk
Website: www.slam.nhs.uk/national-services/adult-services/trauma-and-dissociation-service/

References

[1] Very Well Mind. *Dissociation as a symptom of Anxiety.* www.verywellmind.com/dissociation-anxiety-4692760 (accessed 15th October 2020).
[2] NHS. *Dissociative disorders.* https://www.nhs.uk/conditions/dissociative-disorders/ (available 15th October 2020)
[3] World Health Organisation. *International Statistical Classification of Diseases and Related Health Problems 10th Revision* http://apps.who.int/classifications/icd10/browse/2016/enat para F44.
[4] American Psychiatric Association. *Desk Reference to the Diagnostic Criteria from DSM-5.* Washington DC: American Psychiatric Association; 2013. Page291-298.
[5] American Psychiatric Association. *Desk Reference to the Diagnostic Criteria from DSM-5.* Washington DC: American Psychiatric Association; 2013. page 298.
[6] American Psychiatric Association. *Desk Reference to the Diagnostic Criteria from DSM-5.* Washington DC: American Psychiatric Association; 2013. page 298.
[7] American Psychiatric Association. *Desk Reference to the Diagnostic Criteria from DSM-5.* Washington DC: American Psychiatric Association; 2013. page 298.
[8] Loewenstein RJ. Dissociative Amnesia and Dissociative Fugue. In: Michelson LK, Ray WJ (eds.) *Handbook of Dissociation*. Springer US: 1996. p 307-336.
[9] Loewenstein RJ. Dissociative Amnesia and Dissociative Fugue. In: Michelson LK, Ray WJ (eds.) *Handbook of Dissociation*. Springer US: 1996. As note 9, at page 310. (Lowenstein, 1991b).
[10] WebMD. *Mental Health and Dissociative fugue.* www.webmd.com/mental-health/dissociative-fugue#1 (accessed 16th October 2020)

[11] World Health Organisation. *International Statistical Classification of Diseases and Related Health Problems 10th Revision* http://apps.who.int/classifications/icd10/browse/2016/enat para F44.8.
[12] International Society for the Study of Trauma and Dissociation. *Dissociation FAQs.*https://www.isst-d.org/resources/dissociation-faqs/(accessed 16th October 2020).
[13] American Psychiatric Association. *Desk Reference to the Diagnostic Criteria from DSM-5.* Washington DC: American Psychiatric Association; 2013. page 293.
[14] NHS. *Dissociative disorders.* www.nhs.uk/conditions/dissociative-disorders/ (accessed 19th October 2020)
[15] Psychology today. *Dissociative Identity Disorder (Multiple personality disorder).* www.psychologytoday.com/gb/conditions/dissociative-identity-disorder-multiple-personality-disorder (accessed 23rd October 2020).
[16] American Psychiatric Association. *Desk Reference to the Diagnostic Criteria from DSM-5.* Washington DC: American Psychiatric Association; 2013. page 306.
[17] American Psychiatric Association. *Desk Reference to the Diagnostic Criteria from DSM-5.* Washington DC: American Psychiatric Association; 2013. page 308.
[18] Epilepsy Action. *Dissociative seizures.* www.epilepsy.org.uk/info/diagnosis/dissociative-seizures-non-epileptic-attack-disorder-nead#diagnosed. (accessed 12th October 2020)
[19] NIH. *Depersonalization – and derealisation-like phenomena of epileptic origin.* www.ncbi.nlm.nih.gov/pmc/articles/PMC6764488/ (accessed 23rd October 2020)
[20] ResearchGate. *Prolonged depersonalization/derealization-like symptom after migraine headache: A case report.* www.researchgate.net/publication/261771335_Prolonged_depersonalizationderealization-like_symptom_after_migraine_headache_A_case_report (Accessed 22nd February 2021).
[21] American Psychiatric Association. *Desk Reference to the Diagnostic Criteria from DSM-5.* Washington DC: American Psychiatric Association; 2013. page 291.
[22] Simeon D, Gross S, Guralnik O, Stein DJ, Schmeidler J, Hollander E. Feeling Unreal: 30 Cases of DSM-III-R Depersonalization Disorder. *American Journal Of Psychiatry* 1997; 154(8): 1107-1113. http://ajp.psychiatryonline.org/doi/pdf/10.1176/ajp.154.8.1107 (accessed 17th February 2021).
[23] Simeon D, Gross S, Guralnik O, Stein DJ, Schmeidler J, Hollander E. Feeling Unreal: 30 Cases of DSM-III-R Depersonalization Disorder. *American Journal Of Psychiatry* 1997; 154(8): 1107-1113. http://ajp.psychiatryonline.org/doi/pdf/10.1176/ajp.154.8.1107 (accessed 17th February 2021). page 1107.
[24] American Psychiatric Association. *Desk Reference to the Diagnostic Criteria from DSM-5.* Washington DC: American Psychiatric Association; 2013. page 302.
[25] American Psychiatric Association. *Desk Reference to the Diagnostic Criteria from DSM-5.* Washington DC: American Psychiatric Association; 2013. page 302.
[26] American Psychiatric Association. *Desk Reference to the Diagnostic Criteria from DSM-5.* Washington DC: American Psychiatric Association; 2013. page 302.
[27] World Health Organisation. *International Statistical Classification of Diseases and Related Health Problems 10th Revision* http://apps.who.int/classifications/icd10/browse/2016/en at para F44.
[28] Simeon D. Depersonalisation Disorder. A Contemporary Overview. *CNS Drugs* 2004; 18(6): 343-354. http://link.springer.com/article/10.2165/00023210-200418060-00002 (accessed 17th February 2021).
[29] NHS. *Dissociative disorders.* https://www.nhs.uk/conditions/dissociative-disorders/ (accessed 23rd October 2020)
[30] NHS. *Dissociative disorder.* www.nhs.uk/conditions/dissociative-disorders/ (accessed 24th December 2020).
[31] Frank. *Benzodiazepines.* www.talktofrank.com/drug/benzodiazepines?a=Benzodiazepines#addiction (accessed 23rd March 2021).
[32] The Recovery Village. *Treatment for Dissociative Disorders.* www.therecoveryvillage.com/mental-health/dissociative-disorders/treatment/ (Accessed 23rd March 2021).
[33] Patient. *A brief guide to working with dissociative identity disorder.* https://patient.info/doctor/a-brief-guide-to-working-with-dissociative-identity-disorder#nav-5 (Accessed 24th December 2020).

[34] Patient. *A brief guide to working with dissociative identity disorder.* https://patient.info/doctor/a-brief-guide-to-working-with-dissociative-identity-disorder#nav-5 (Accessed 24th December 2020).
[35] Patient. *A brief guide to working with dissociative identity disorder.* https://patient.info/doctor/a-brief-guide-to-working-with-dissociative-identity-disorder#nav-5 (Accessed 24th December 2020).
[36] Patient. *A brief guide to working with dissociative identity disorder.* https://patient.info/doctor/a-brief-guide-to-working-with-dissociative-identity-disorder#nav-5 (Accessed 24th December 2020).
[37] NHS Tee, Esk and Wear Valleys. *What is Eye Movement Desensitisation Reprocessing (EMDR)?* www.tewv.nhs.uk/services/what-is-eye-movement-desensitisation-reprocessing-emdr/ (accessed 24th December 2020)
[38] Patient. *A brief guide to working with dissociative identity disorder.* https://patient.info/doctor/a-brief-guide-to-working-with-dissociative-identity-disorder#nav-5 (Accessed 24th December 2020).
[39] NHS. *Cognitive Behavioural Therapy.* www.nhs.uk/conditions/cognitive-behavioural-therapy-cbt/ (Accessed 24th December 2020)
[40] International Society for the Study of Trauma and Dissociation. Guidelines for Treating Dissociative Identity Disorder in Adults, Third Revision. *Journal of Trauma & Dissociation* 2011; 12(2): 115-187. www.isst-d.org/wp-content/uploads/2019/02/GUIDELINES_REVISED2011.pdf(accessed 18th February 2021). page 146.
[41] Hunter ECM, Phillips ML, Chalder T, Sierra M, David AS. DP disorder: a cognitive-behavioural conceptualisation. *Behaviour Research and Therapy* 2003; 41(12): 1451-1467. www.researchgate.net/publication/9036919_Depersonalisation_disorder_A_cognitive-behavioural_conceptualisation (accessed 24th December 2020).
[42] Hunter ECM, Baker D, Phillips ML, Sierra M, David AS. Cognitive-behaviour therapy for depersonalisation disorder: an open study. *Behaviour Research and Therapy* 2005; 43(9): 1121-1130. https://dx.doi.org/10.1016/j.brat.2004.08.003 (accessed 24th December2020).
[43] General Medical Council. *Good Medical Practice*. Manchester: GMC; 2013 (updated April, 2014). Para 16(e).
[44] Healthline. *30 Grounding Techniques to Quiet distressing thoughts.* www.healthline.com/health/grounding-techniques (Accessed 18th February 2021)
[45] Depersonalization Recovery. *Mindfulness meditation and Depersonalization disorder.* http://depersonalizationrecovery.com/articles/mindfulness-meditation-and-depersonalization-disorder/. (Accessed 18th February 2021).
[46] Baker D, Hunter E, Lawrence E, Medford N, Patel M, Senior C, Sierra M, Lambert MV, Phillips M, David AS. Depersonalisation disorder: clinical features in 204 cases. *British Journal of Psychiatry* 2003; 182(5): 428-433. http://bjp.rcpsych.org/content/182/5/428 (accessed 24th December 2020).

Last updated: December 2020

Next update: December 2023

Version: 2

This factsheet is available in large print.

Rethink Mental Illness Advice Service

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

Email advice@rethink.org

Did this help?

We'd love to know if this information helped you.

Drop us a line at: feedback@rethink.org

or write to us at Rethink Mental Illness:
RAIS
PO Box 17106
Birmingham B9 9LL

or call us on 0808 801 0525

We're open 9:30am to 4pm
Monday to Friday (excluding bank holidays)

Rethink Mental Illness.

Leading the way to a better quality of life for everyone affected by severe mental illness.

For further information
on Rethink Mental Illness
Phone 0121 522 7007
Email info@rethink.org

facebook.com/rethinkcharity

twitter.com/rethink_

www.rethink.org

Need more help?

Go to **www.rethink.org** for information on symptoms, treatments, money and benefits and your rights.

Don't have access to the web?

Call us on 0121 522 7007. We are open Monday to Friday, 9am to 5pm, and we will send you the information you need in the post.

Need to talk to an adviser?

If you need practical advice, call us on 0808 801 0525 between 9:30am to 4pm, Monday to Friday. Our specialist advisers can help you with queries like how to apply for benefits, get access to care or make a complaint.

Can you help us to keep going?

We can only help people because of donations from people like you. If you can donate please go to **www.rethink.org/donate** or call 0121 522 7007 to make a gift. We are very grateful for all our donors' generous support.

factsheet

Eating Disorders

This factsheet covers different eating disorders and symptoms. As well as treatment options. You might find it useful if you have an eating disorder. Or you care for someone who does.

Key Points.

- You will use food to try to manage your feelings if you have an eating disorder.
- There are different types of eating disorders.
- You will have an unhealthy relationship with food and weight. You may eat too little or too much food.
- Eating disorders often start during your teenage years or early adulthood. You may develop them as an adult.
- Eating disorders can lead to serious physical health problems.
- Treatments for eating disorders can be medication, talking therapies and family therapy.

This fact sheet covers:

Top

1. What are eating disorders?

An eating disorder is a mental illness. You will use food to try to manage your feelings. If you have an eating disorder you will have an unhealthy relationship with food. This may be eating too much or too little food. Or eating a lot of food in one sitting. You may become obsessed with food and your eating patterns if you have an eating disorder.

Anyone can develop an eating disorder. It doesn't matter what your age, gender, cultural or racial background is.

Top

2. What are the different types of eating disorders?

There are many different eating disorders. This factsheet covers Anorexia Nervosa, Bulimia Nervosa, Binge Eating Disorder and 'Other Specified Feeding and Eating Disorders'.

Anorexia Nervosa

You will try to keep your weight as low as possible if you have anorexia. You may think you are overweight even if others say you are dangerously thin. You may fear gaining weight and dismiss ideas to encourage you to eat more.

Behavioural symptoms[1]	**Physical signs**[2]
• Strict dieting. Such as counting the calories in food excessively, avoiding food you think is fattening and eat only low-calorie food. • Being secretive. Such as hiding food, lying about what you have eaten and avoiding eating with other people. • Cut food into tiny pieces to make it less obvious that you have eaten little. • Take appetite suppressants such as diet pills. • Over exercising and get upset if something stops you from exercising. • Becoming socially isolated. • Making self-sick. This is known as purging.	• Feel weak and have less muscle strength. • Difficulty concentrating. • Dizzy spells. • Constipation, bloating and stomach pain. • Grow soft, fine hair on your body and face. Hair falling out. • Feeling cold. Swollen feet, hands or face. Low blood pressure. • Setting high standards and being a perfectionist. • Sleeping problems. • Getting irritable and moody. • In girls and women periods can stop, become irregular or do not start. • Loss of interest in sex.

Bulimia Nervosa

You will have an unhealthy eating cycle if you have bulimia. You will eat a lot of food and then do something to yourself to stop weight gain. You may make yourself vomit, take laxatives or over exercise.

The eating is called ‘binging’ and what you do after is called ‘purging’.[3] You will usually have an average body weight. This may mean other people do not notice you are having these problems.[4]

Behavioural symptoms[5,6]	**Physical signs**[7]
• Eating large amounts of food. This is known as bingeing. • Feel guilty or ashamed after bingeing and purging. • Spending a lot of time thinking about food. • Not able to control your eating. • Have a distorted view of your body shape or weight. • Have mood swings. • Secretive about your bingeing and purging. • Feel anxious and tense. • Can be associated with depression, low self-esteem, alcohol misuse and self-harm. • Disappearing soon after eating.	• Calluses on the back of your hand. These are caused by forcing yourself to be sick. • Stomach pain, bloating and constipation. • Gastric problems. • Being tired and not having energy. • In girls and women - periods stop or are not regular. • Frequent weight changes. • Hands and feet swelling. • Damage to teeth.

Binge eating disorder (BED)

You will eat a lot of food in a short period of time on a regular basis if you have BED. As with bulimia, you won’t feel in control of your eating. It is likely to cause you distress. You may feel disconnected and struggle to remember what you have eaten.[8]

Behavioural symptoms[9]	Physical signs[10]
• Eat faster than normal during a binge. • Eat when you're not hungry and until you feel uncomfortably full. • Eat alone or secretly. • Have feelings of guilt, shame or disgust after binge eating. • Low self-esteem and depression and anxiety.	• Overweight for your age and height. • Tiredness and difficulty sleeping. • Constipation and bloating.

Other eating disorders and eating problems

Other Specified Feeding and Eating Disorder (OSFED)

OSFED means you have symptoms of an eating disorder. But you don't have all the typical symptoms of anorexia, bulimia or BED. You could have a mixture of symptoms from different eating disorders. This does not mean that your illness is less serious.[11] It used to be known as Eating Disorder Not Otherwise Specified (EDNOS).

Orthorexia nervosa[12]

Orthorexia is not a recognised clinical diagnosis. But many people struggle with the symptoms. Orthorexia is when you pay too much attention to eating food that you feel is healthy and pure. It may begin as a healthy diet but becomes rigorous and obsessive. You may become socially isolated because you plan your life around food.

Pica[13]

You eat non-food objects if you have Pica. Such as chalk, paint, stones and clothing. There is no nutritional benefit in these items. Some objects will pass through your body without harm. However, pica can be very dangerous. It can lead to health concerns such as dental and stomach problems.

We still don't understand what causes pica. There is a link to a lack of certain minerals such as iron. Some researchers believe it is a coping mechanism for some people.

Rumination disorder or 'chew and spit'[14]

You will chew and spit out food without swallowing it if you have rumination disorder. You may do this over and over again. This can affect anyone.

Selective Eating Disorder (SED)[15]

You will only eat certain foods and may refuse to try other foods if you have SED. This is common in young children. But the problem can continue into adulthood.

Diabulimia[16]

Diabulimia only effects people with type 1 diabetes. You will reduce or stop taking your insulin to try to lose weight. If you have type 1 diabetes you need your insulin to live.

Diabulimia is not a recognised medical term but it is what people call it.

Top

3. How are eating disorders diagnosed?

Doctors use guidelines for diagnosing different mental health conditions, such as eating disorders. When deciding on a diagnosis doctors will look at these guidelines. They will look at what symptoms you have had. And how long you have had these for. The main guidelines are:

- International Classification of Diseases (ICD-10), produced by the World Health Organisation (WHO), and
- Diagnostic and Statistical Manual (DSM-5), produced by the American Psychiatric Association.

A health professional will assess you to work out if they think you have an eating disorder. As part of the assessment they will:[17]

- ask about your feelings, thoughts and behaviours,
- see if there has been any rapid weight loss,
- check if your body mass index (BMI) is too high or too low,
- ask you about any diets that you are on,
- listen to the concerns that your family or carers have about your eating behaviour, and
- think about different reasons for your symptoms.

Top

4. What causes eating disorders?

We do not know exactly why someone develops an eating disorder. Some people believe that eating disorders develop because of social pressures to be thin.[18] Social pressures could be social media and fashion magazines. Others believe it is a way to feel in control.

Most specialists believe that eating disorders develop because of a mix of psychological, environmental and genetic factors. [19,20,21]

Psychological factors could be:

- being vulnerable to depression and anxiety,
- finding stress hard to handle,
- worrying a lot about the future,
- being a perfectionist,
- controlling your emotions,
- having obsessive or compulsive feelings, or

- a fear of being fat.

Environmental factors could be:

- pressure at school,
- bullying,
- abuse,
- criticised for your body shape or eating habits,
- having difficult family relationships, or
- having a job or hobby where being thin is seen as ideal. Such as dancing or athletics.

Genetic factors could be:

- changes in the brain or hormone levels, or
- family history of eating disorders, depression or substance misuse.

Top

5. What should I do if I think I have an eating disorder?

Ask for help early if you think that you may have an eating disorder. You have a greater chance of recovery if you seek help early. The first step is usually to make an appointment with your GP. They can refer you to specialist support if you need it.

If you aren't ready to ask for professional help speak to someone that you trust such as friend or relative. You could also ask confidential charities such as 'Beat' for advice. Look at the end of this factsheet for contact information.

Top

6. What treatment should I be offered?

You can check what treatment and care is recommended for eating disorders on the National Institute for Health and Care Excellence (NICE) website. NICE produce guidelines for how health professionals should treat certain conditions. You can download these from their website at www.nice.org.uk But the NHS does not have to follow these recommendations. They should have a good reason for not following them.

Medication should not be offered as the only treatment for any eating disorder.[22]

Physical treatments like acupuncture, weight training and yoga should not be offered as treatment for eating disorders.[23]

There are different types of psychological treatments for eating disorders, and you may be offered a combination of these. All of the treatments will include guided self-help and psycho-education.

Guided self-help programme

This is a self-help programme. You will look at the thoughts, feelings and actions that you have in relation to your eating. You should also have some short support sessions to help you follow the programme.

Psycho-education

Psycho-education means that you will learn about your symptoms and how to manage them.

What is the treatment for anorexia?

When treating anorexia, a key goal is for you to reach a healthy weight. Your weight will be monitored. Doctors may share your weight with your family members or carers.

There are different psychological treatments for anorexia in adults. Your doctor should talk to you about different treatments. You should be given your preferred treatment if it is available.[24]

Individual eating-disorder-focused cognitive behavioural therapy (CBT-ED)[25]

This is a long-term therapy. You will have individual sessions with your therapist. You will usually have 40 sessions over 40 weeks. At the beginning of your therapy you will usually have 2 sessions a week.

The therapy aims to help you to:

- reduce the risks to your physical health,
- learn about nutrition and how you can change the way you think,
- think about your body image concerns and self-esteem, and
- monitor what you are eating and how this makes you think and feel.

Maudsley Anorexia Nervosa Treatment for Adults (MANTRA)[26]

This usually consists of 20 sessions. For the first 10 weeks you have weekly sessions. After that the sessions are more flexible. If you have a more complex problem, you may get up to 10 extra sessions.

The therapy:

- covers nutrition, how to manage your symptoms and how to change your behaviour once you are ready,
- helps you to develop a ‘non-anorexic identity’, and
- involves your family members and carers to help you to:
    - understand your condition and the problems it causes, and
    - change your behaviour.

Specialist supportive clinical management (SSCM)[27]

This therapy will usually be 20 or more weekly sessions. This will depend on the severity of your anorexia. Its aims to:

- help you to recognise the link between your symptoms and your eating behaviour,
- give you nutritional education and advice, and
- allow you to decide what else should be included as part of your therapy.

Eating-disorder-focused focal psychodynamic therapy (FPT)[28]

You will only be offered FPT if individual CBT-ED, MANTRA or SSCM hasn't worked. Or if your doctor thinks that the other therapies shouldn't be used.

FPT is a long-term therapy. You will have individual sessions with your therapist. You will usually have 40 sessions over 40 weeks.

FPT looks at:

- what your symptoms mean to you, how they affect you and how they affect your relationships with other people,
- the beliefs, values and feelings that you have about yourself,
- your relationships with other people and how they affect your eating behaviour, and
- helping you to take what you have learned into everyday life.

What is the treatment for bulimia?

Psychological treatments for bulimia have a limited effect on body weight.[29]

Bulimia-nervosa-focused guided self-help[30]

You should be given cognitive behavioural self-help materials. And you should be given short supportive sessions. For example, you may be given between 4 and 9 sessions of 20 minutes. These should be weekly at first.[31]

Individual eating disorder-focused cognitive behavioural therapy (CBT ED)

You should be offered individual CBT-ED if the self-help programme hasn't worked. Or your doctor doesn't think it should be used.[32]

Individual CBT-ED for adults with bulimia nervosa is usually 20 sessions over 20 weeks. At the very beginning of your therapy you may have 2 sessions a week. Its aims are to help you to:

- begin a regular pattern of eating,
- think about your concerns around body shape and weight,
- find other ways to deal with difficult thoughts and feelings, and
- involve your family members and carers, if this is appropriate.[33]

What is the treatment for binge eating disorder (BED)

Psychological treatments for BED have a limited effect on body weight. Weight loss isn't the aim of the therapy. Doctors can give you advice on weight loss.[34]

Binge-eating-disorder-focused guided self-help programmes[35]

You should be given cognitive behavioural self-help materials. And you should be given short supportive sessions. For example, you may be given between 4 and 9 sessions of 20 minutes. These should be weekly at first.[36]

Group eating disorder-focused cognitive behavioural therapy (CBT-ED)

You should be offered group CBT-ED if the self-help programme hasn't worked, or your doctor doesn't think it should be used.[37]

Group CBT-ED is usually 16 weekly sessions of 90 minutes over 4 months. It aims to help you to:

- monitor your eating behaviour,
- think about your problems and goals,
- identify your binge eating triggers,
- identify and change any negative beliefs you have about your body, and
- avoid relapses and identify ways to cope with your triggers.[38]

Individual CBT-ED for adults with BED[39]

Your doctor could offer you individual CBT-ED if group CBT-ED may not be available in your area. Or you may decide that you do not want group therapy.

You will have individual sessions with your therapist. You will usually have 16-20 sessions. You will work with your therapist to understand what makes you binge eat.

What is the treatment for Other Specified Feeding and Eating Disorder (OFSED)? [40]

There is no specific treatment for OFSED. You should be offered the treatments recommended for the type of eating disorder your symptoms are most similar to.

Top

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

If you are not happy with your treatment you can:

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

There is more information about these options below:

Second opinion

If you are not happy with your treatment you should talk to your doctor and see if you can resolve the situation with them. You can refer to the NICE guidelines if you feel your doctor is not offering you the right treatment. See section 6 for more about this.

You may feel that your treatment should be changed. If your doctor does not agree you could ask for a second opinion. You are not legally entitled to a second opinion, but your doctor might agree to it if it would help with treatment options.

Advocacy

An advocate is independent from the NHS. This means that the NHS doesn't employ them. Advocacy services are free to use. Usually a charity will run an advocacy service. An advocate is there to support you.

They can help to make your voice heard when you are trying to sort problems. They may be able to help you to write a letter to the NHS or go to a meeting with you.

There may be a local advocacy service in your area which you can contact for support. You can search online for a local service. You can also call our advice service on 0300 5000 927 or email us at advice@rethink.org and we can look for you.

'PALS'

The Patient Advice and Liaison Service (PALS) at your NHS trust are there to help you sort problems with a local service.

You can find your local PALS' details at www.nhs.uk/Service-Search/Patient%20advice%20and%20liaison%20services%20(PALS)/LocationSearch/363

Complaints

You can make a formal complaint. Your GP practice or mental health trust should be able to give you a leaflet about their complaints procedure.

If you need help to make a complaint you can get help from a complaints advocate.

You can find more information about:

- Second opinions
- Advocacy
- Complaining about the NHS or social services

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

Top

8. Can I be detained in hospital under the Mental Health Act?

Eating disorders are mental disorders. Your life may be at risk if your eating disorder is very bad. You may need treatment in hospital. If you refuse treatment you can be sent to hospital. You can be treated against your will under the Mental Health Act.

How will doctors decide if I should be detained under the Mental Health Act?

Doctors will look at risk to decide if you need to be sent to hospital. They should not base their decision on your weight or body mass index (BMI) alone.[41]Other things they will look at include: [42]

- your pulse, blood pressure and core temperature,
- muscle power,
- blood tests for things like your sodium, potassium and glucose levels, and
- your heart rate.

Can I be force-fed?[43]

Feeding is recognised as treatment for anorexia under the Mental Health Act.

The person in charge of your care under the Mental Health Act is called the responsible clinician. This person will be a psychiatrist or another professional who has had specialist training.

A responsible clinician must be appointed to look after your care if you are detained on a medical ward.

You can find more information about the **'Mental Health Act'** at www.rethink.org. Or call our General Enquires team on 0121 522 7007 and ask them to send you a copy of our factsheet.

Top

9. What can I do to manage my symptoms?

You can learn to manage your symptoms through self-care. Self-care is how you manage your daily routine, relationships and feelings. The healthcare professional who is working with you should give you advice about self-care.

The following website links have information about how you can deal with symptoms of anorexia, bulimia and BED.

- Anorexia Self-Help
  www.getselfhelp.co.uk/anorexia.htm

- Bulimia & Binge Eating Self-Help
  www.getselfhelp.co.uk/docs/BulimiaSelfHelp.pdf

Top

10. What are the risks and complications of eating disorders?

Eating disorders are often found alongside other problems such as:

- mental health conditions. Such as depression or anxiety,
- physical health conditions, and
- drug or alcohol abuse.

It is thought that nearly 50% of people with an eating disorder are abusing drugs or alcohol.[44] Substance abuse could affect your treatment. If this happens your doctor should work together with professionals from substance misuse services to give you support.[45] This may be under a package of care called the 'care programme approach.'

Anorexia

Around 50% of people with anorexia will make a full recovery. But relapses are common along the way. Other people will improve with treatment but will still have eating problems.

Anorexia can cause:

- weak muscles and bones,
- problems getting pregnant,
- a loss of your sex drive,
- problems with your heart, and
- problems with your brain and nerves, which may lead to seizures. And problems with your concentration and memory,
- kidney or bowel problems, and
- a weak immune system.[46]

Some complications may improve as your condition is treated, but others can be permanent.[47]People with anorexia have died because of physical complications or suicide. [48]

Bulimia[49]

Long-term bulimia can lead to physical problems. This is because you are not getting the right nutrients through vomiting or overusing laxatives.

You can get problems with:

- your teeth and the lining of your throat if you vomit a lot,
- your heart, kidney or bowel. Such as permanent constipation
- feeling tired and weak,
- irregular or absent periods.
- brittle fingernails.
- fits and muscle spasms,
- bone problems – such as osteoporosis.

Binge eating disorder[50]

Binge eating disorder can have long-term physical effects. Such as:

- obesity,
- high cholesterol,
- high blood pressure,
- heart disease,
- type 2 diabetes,
- problems getting pregnant,
- problems sleeping,
- arthritis,
- joint and back pain,
- gall bladder disease, and
- damage to your stomach.

Talk to your doctor if you are worried about long-term problems.

You can find more information about

- Drugs, alcohol and mental health
- Care Programme Approach

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

Top

11. Information for carers, friends and relatives

If you are a carer, friend or relative of someone who hears voices, you can get support.

How can I get support?

You can do the following.

- Speak to your GP about medication and talking therapies for yourself.
- Speak to your relative's care team about a carer's assessment.
- Ask for a carer's assessment from your local social services.
- Join a carers service. They are free and available in most areas.
- Join a carers support group for emotional and practical support. Or set up your own.

What is a carer's assessment?

A carer's assessment is an assessment of the support that you need so that you can continue in your caring role.

To get a carers assessment you need to contact your local authority.

How do I get support from my peers?

You can get peer support through carer support services or carers groups. You can search for local groups in your area by using a search engine such as Google. Or you can contact the Rethink Mental Illness Advice Service and we will search for you.

How can I support the person I care for?

You can do the following.

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

What is a care plan?

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

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

Can I be involved in care planning?

As a carer you can be involved in decisions about care planning. But you don't have a legal right to this.

Your relative or friend needs to give permission for the NHS to share information about them. And their care.

You can find out more about:

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

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

Top

Useful Contacts

The New Maudsley Approach
This website has materials and tools to help parents and carers of people with eating disorders to manage their caring role effectively and with less stress.
Website: www.thenewmaudsleyapproach.co.uk/Home_Page.php

Beat
A national UK charity who give information, help and support for people affected by eating disorders. They have online support groups, peer support, message boards, and helplines. They also have a search facility for support groups and eating disorder services. This is called Helpfinder.

Adult helpline: 0808 801 0677 (9am – 8pm Monday to Friday, 4pm - 8pm weekends and all bank holidays)
Studentline: 0808 801 0811 (as above)
Address: Unit 1 Chalk Hill House, 19 Rosary Road, Norwich, Norfolk, NR1 1SZ
Adult email: help@beateatingdisorders.org.uk
Student email: studentline@beateatingdisorders.org.uk
Webchat: www.beateatingdisorders.org.uk/support-services/helplines/one-to-one
Helpfinder: helpfinder.b-eat.co.uk
Website: www.beateatingdisorders.org.uk

Anorexia and Bulimia Care
A charity which gives on-going care, emotional support and practical guidance for anyone affected by eating disorders. In addition to their helpline they provide moderated peer support for individuals and family and friends via Zoom. They also offer 1-to-1 booked appointments for support and guidance both for individuals and family and friends.

Helpline: 03000 11 12 13 (Wednesdays, Thursdays and Fridays; 9am - 1pm and 2pm - 5pm)
Address: Saville Court, 10-11 Saville Place, Clifton, Bristol, BS8 4EJ
Email: support@anorexiabulimiacare.org.uk
Email for friends & family: familyandfriends@anorexiabulimiacare.org.uk
Website: www.anorexiabulimiacare.org.uk
Website link for peer support: www.anorexiabulimiacare.org.uk/help-for-you/pips-place-online
Website link for booked appointments:
www.anorexiabulimiacare.org.uk/help-for-you

Eating Disorders Support
A charity who give help and support to anyone affected by an eating problem. Support is offered through their helpline, email support and a self-help group in Buckinghamshire. They also have free online meetings.

Helpline: 01494 793223
Address: Sun House, 32 Church St, Chesham, Bucks, HP5 1HU
Email: support@eatingdisorderssupport.co.uk
Website: www.eatingdisorderssupport.co.uk

The Recover Clinic
Team of women who give care and advice to those suffering with eating disorders as well as Body Dysmorphic Disorder. This is not an NHS clinic, so you have to pay for treatment.

Telephone: 0845 603 6530

Email: help@therecoverclinic.co.uk
Website: www.therecoverclinic.co.uk

Top

References

[1] Beat. *Signs of anorexia.* www.beateatingdisorders.org.uk/types/anorexia/signs (accessed 25th August 2020).
[2] As note 1.
[3] NHS. *Bulimia nervosa.* www.nhs.uk/Conditions/Bulimia/Pages/Introduction.aspx (accessed 25th August 2020).
[4] Beat. *What is bulimia*. www.beateatingdisorders.org.uk/types/bulimia (accessed 25th August 2020).
[5] Beat. *Bulimia.* www.b-eat.co.uk/about-eating-disorders/types-of-eating-disorder/bulimia (Accessed 28th September 2017).
[6] Beat. *Signs of bulimia.* www.beateatingdisorders.org.uk/types/bulimia/signs (accessed 27th August 2020)
[7] As note 6.
[8] Beat. *Binge Eating Disorder.* www.beateatingdisorders.org.uk/types/binge-eating-disorder (accessed 7th September 2020).
[9] NHS. *Binge Eating*. www.nhs.uk/Conditions/Binge-eating/Pages/Introduction.aspx (accessed 27th August 2020).
[10] Beat. *Binge Eating Disorder.* www.beateatingdisorders.org.uk/types/binge-eating-disorder/signs (accessed 27th August 2020).
[11] National Institute for Health and Care Excellence. *Eating disorders: recognition and treatment.* Clinical Guidance 69. London: National Institute for Health and care Excellence: 2017. Page 2.
[12] National Eating Disorders Association. *Orthorexia Nervosa.* www.nationaleatingdisorders.org/orthorexia-nervosa (accessed 27th August 2020).
[13] Beat. *Pica* www.beateatingdisorders.org.uk/types/pica (accessed 27th August 2020)
[14] Beat. *Rumination Disorder. www.beateatingdisorders.org.uk/types/rumination-disorder* (accessed 27th August 2020).
[15] Ellern Mede. *Selective Eating Disorder.* https://ellernmede.org/eating-disorders-information/selective-eating-disorder/ (accessed 27th August 2020)
[16] Diabetes UK, *Diabulimia and diabetes.* www.diabetes.org.uk/guide-to-diabetes/life-with-diabetes/diabulimia (accessed 22nd September 2020)
[17] National Institute for Health and Care Excellence. *Eating Disorders.* Clinical Guidance 69. London: National Institute for Health and Care Excellence; 2017. Para 1.2.6
[18] NHS. *Eating Disorders - Causes.* www.nhs.uk/conditions/Eating-disorders/Pages/Introduction.aspx#Causes (accessed 7th September 2020).
[19] NHS. *Anorexia Nervosa – Causes*. www.nhs.uk/Conditions/Anorexia-nervosa/Pages/Causes.aspx (accessed 28th August 2020)
[20] NHS. *Bulimia – Causes.* www.nhs.uk/Conditions/Bulimia/Pages/Causes.aspx (accessed 28th August 2020).
[21] NHS. *Binge Eating*. www.nhs.uk/Conditions/Binge-eating/Pages/Introduction.aspx (accessed 28th August 2020).
[22] As note 17, Para 1.3.24, 1.4.9 & 1.5.11.
[23] As note 17, Para. 1.7.1.
[24] As note 17, Para 1.3.4
[25] As note 17, Para 1.3.5.
[26] As note 17, Para 1.3.6.
[27] As note 17, Para 1.3.7.
[28] As note 17, Para 1.3.9.
[29] As note 17, Para 1.5.1.

[30] As note 17, Para 1.5.2.
[31] As note 17, Para 1.5.3.
[32] As note 17, Para 1.5.4.
[33] As note 17, Para 1.5.5.
[34] As note 17, Para 1.4.1.
[35] As note 17, Para 1.4.2.
[36] As note 17, Para 1.4.3.
[37] As note 17, Para 1.4.4.
[38] As note 17, Para 1.4.5.
[39] As note 17, Para 1.4.6 &1.4.7.
[40] As note 17, Para 1.6.1.
[41] The Royal College of Psychiatrists. *MARSIPAN: Management of Really Sick Patients with Anorexia Nervosa 2nd edition.* www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-reports/college-report-cr189.pdf?sfvrsn=6c2e7ada_2 Page 6. (accessed 24th September 2020).
[42] The Royal College of Psychiatrists. *MARSIPAN: Management of Really Sick Patients with Anorexia Nervosa 2nd edition.* www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-reports/college-report-cr189.pdf?sfvrsn=6c2e7ada_2 Page 12 (accessed 7th September 2020).
[43] The Royal College of Psychiatrists. *MARSIPAN: Management of Really Sick Patients with Anorexia Nervosa 2nd edition.* www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-reports/college-report-cr189.pdf?sfvrsn=6c2e7ada_2 Page 40 (accessed 7th September 2020).
[44] NEDA. *Substance abuse and eating disorders.* www.nationaleatingdisorders.org/substance-abuse-and-eating-disorders (accessed 7th September2020)
[45] As note 17, Para 1.8.19.
[46] NHS. *Anorexia nervosa.* www.nhs.uk/conditions/anorexia/ (accessed 24th September 2020).
[47] Beat. *Signs of Anorexia.* www.beateatingdisorders.org.uk/types/anorexia/signs (accessed 7th September 2020).
[48] NHS. *Anorexia nervosa.* www.nhs.uk/Conditions/Anorexia-nervosa/Pages/Introduction.aspx (accessed 1st September 2020).
[49] NHS. *Bulimia – Health risks of bulimia.* www.nhs.uk/Conditions/Bulimia/Pages/Introduction.aspx (accessed 1st September 2020).
[50] Beat. *Signs of Binge Eating Disorder.* www.beateatingdisorders.org.uk/types/binge-eating-disorder/signs (accessed 7th September 2020).

Last updated September 2020
Next update September 2023
Version 7

This factsheet is available in large print.

Rethink Mental Illness Advice Service

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

Email advice@rethink.org

Did this help?

We'd love to know if this information helped you.

Drop us a line at: feedback@rethink.org

or write to us at Rethink Mental Illness:
RAIS
PO Box 17106
Birmingham B9 9LL

or call us on 0808 801 0525

We're open 9:30am to 4pm
Monday to Friday (excluding bank holidays)

Rethink Mental Illness.

Leading the way to a better quality of life for everyone affected by severe mental illness.

For further information
on Rethink Mental Illness
Phone 0121 522 7007
Email info@rethink.org

facebook.com/rethinkcharity
twitter.com/rethink_
www.rethink.org

Need more help?

Go to **www.rethink.org** for information on symptoms, treatments, money and benefits and your rights.

Don't have access to the web?

Call us on 0121 522 7007. We are open Monday to Friday, 9am to 5pm, and we will send you the information you need in the post.

Need to talk to an adviser?

If you need practical advice, call us on 0808 801 0525 between 9:30am to 4pm, Monday to Friday. Our specialist advisers can help you with queries like how to apply for benefits, get access to care or make a complaint.

Can you help us to keep going?

We can only help people because of donations from people like you. If you can donate please go to **www.rethink.org/donate** or call 0121 522 7007 to make a gift. We are very grateful for all our donors' generous support.

Rethink Mental Illness.

factsheet

Obsessive compulsive disorder (OCD)

Obsessive compulsive disorder (OCD) is an anxiety disorder. This factsheet gives information on the symptoms, causes and treatments for OCD. It also has information for carers and family members.

Key Points.

- If you have obsessive compulsive disorder (OCD), you have obsessive thoughts and compulsive rituals and behaviours.
- OCD affects 1.2% of the population in the UK.
- A mix of different factors can cause OCD.
- The usual treatment options for OCD are cognitive behavioural therapy (CBT) and medication.
- If you have OCD you may find that it affects areas of your life like work or relationships.

This factsheet covers:

1. What is obsessive compulsive disorder?

Obsessive compulsive disorder (OCD) is an anxiety disorder.

If you live with OCD, you will usually have obsessive thoughts and compulsive behaviours. These can be time-consuming, distressing and interfering in your day-to-day life.

Obsessive thoughts

An obsessive thought is a thought or image that repeatedly comes into your head.

These thoughts are unwanted and you can't control them. They can be hard to ignore. You may not want these thoughts and they can be upsetting. They can make you feel distressed, anxious or guilty. These thoughts can be in different areas.

Examples of common obsessions include:

- worries that you, or something like your food, might be contaminated,
- fear that something bad might happen if things are not in order or symmetrical,
- being worried about harm coming to yourself or other people,
- sexually disturbing images or thoughts,
- religious beliefs – focusing on the importance and significance of religion and religious matters,
- relationships – constantly thinking about your relationship, your sexuality, if your partner is unfaithful, that your relationship will end at any moment,
- magical thoughts – these are thoughts that if you do certain things you will stop bad things from happening. Or that imagining bad events will increase the possibility they will happen, and
- violent thoughts – thoughts of being violent to a loved one or other people. Such as killing innocent people, jumping in front of a train.

People who have intrusive thoughts can be afraid of telling health professionals about it. They are worried that they will label them or think they are a risk to people around them.

But health professionals will usually see your intrusive thoughts as a symptom of your condition. And they will use the information to think about the right support and treatment for you.

They can only take action without you agreeing if they think you are a serious risk to yourself or other people.

Compulsions

Compulsions are things you think about or do repeatedly to relieve the anxiety from your obsessive thoughts. You might also hear these being called ‘compulsive behaviours’.
You might believe that you, or someone close to you, might come to harm if you don’t do these things. You may realise that your thinking and behaviour isn’t logical but still find it difficult to stop.

When you carry out a compulsion, your relief usually doesn’t last long. This makes your original obsession stronger. You may then feel you need to carry out your compulsion again to feel better.

Not everyone with OCD show signs of compulsive behaviours to others. Their compulsions might not be seen by others, but might be things like repeating a word or phrase in your head.

Examples of compulsions include:

- checking things repeatedly - for example, whether an appliance has been switched off,
- washing or cleaning things excessively,
- carrying something out in a particular order, in a repeated pattern or a certain number of times, and
- counting to a particular number, or going through a standard sequence of numbers, repeatedly.

Thoughts and rituals can take up a lot of your time and affect your day-to-day life.

Fear of contamination, compulsive checking and hoarding can be common for people who live with OCD. There is more information about these things below.

Contamination

Some people who live with OCD have a fear of contamination. This means you might constantly feel the need to make sure that something is clean and free from germs or dirt. This is a compulsion.

Your obsessive thought is usually that any contamination will harm yourself or a loved one. You might fear:

- shaking someone’s hand,
- using public toilets or shared toilets,
- touching door handles,
- using plates, glasses or cutlery in a public place,
- using public telephones,
- visiting hospitals or GP surgeries,
- visiting someone else’s house, and

- touching shared objects. Such as remote controls, computer keyboards or money.

Checking

This is a compulsion where you will feel the need to check something repeatedly. You might be worried that something, or someone, might be harmed if you don't check something. Common checking can include:

- that a light is switched off,
- that an appliance is turned off. Such as a cooker, an iron, a tap or a lamp,
- that a window is closed or a door is locked,
- health conditions and symptoms online,
- that you have your wallet, purse, phone or keys on you, and
- re-reading something to check you have taken in all the information.

Hoarding

Hoarding is where you find it difficult to get rid of items in your home even when space is becoming limited. Or when most people would see the items as not being useful.

You may find that you buy, collect and store items even when you don't need them. You may hoard things because of:

- fear that you, or someone else, will be harmed if you throw something away,
- feeling an object may come in useful at a later point, or
- because you are emotionally attached to the item.

Ben's story

I realised at a young age that I had 'odd' rituals that I had to carry out. When I started university these became worse. I would not be able to leave our shared flat unless I had closed the bedroom door a number of times. Or until I heard the door click. I would repeat this endlessly until I felt comfortable and that it was 'enough'. I told a couple of friends but I felt stupid and embarrassed. It caused problems in my studying and social life. It developed into worse rituals. It was only after I got help that I managed to get the right support and treatment.

How common is OCD?

According to the charity OCD-UK, OCD affects 1.2% of the population in the UK.[1]

Many people have obsessive compulsive parts of their personality that don't have too much of an effect on their day to day life. For example, worrying that a window is closed, or preferring things in a particularly neat

or organised fashion. This might not mean you have OCD. However, if your thoughts or actions are so severe that they affect your day to day life, a doctor may diagnose you with OCD.

Top

2. How is OCD diagnosed?

Diagnosis

If you think you have OCD, you should share your concerns with a healthcare professional, like your GP.

When you first see a healthcare professional about your symptoms, they will want to consider whether they think you have OCD. If you see your GP, they may refer you to a specialist mental health service. They should do this if they think your symptoms are severe.

A specialist doctor, called a psychiatrist, may then see you for an assessment.

Healthcare professionals may ask you the following questions:

- Do you wash or clean a lot?
- Do you check things a lot?
- Is there any thought that keeps bothering you that you'd like to get rid of but can't?
- Do your activities take a long time to finish?
- Are you concerned about putting things in a special order or are you very upset by mess?
- Do these problems trouble you?

This will help the healthcare professional decide if you have OCD and how severe your symptoms are. And what course of treatment will be best for you.

You can find more information about preparing to see your GP in our **'What to expect from your GP'** factsheet at www.rethink.org. Or call our General Enquiries team on 0121 522 7007 and ask them to send you a copy of our factsheet.

Top

3. What causes OCD?

We don't know exactly why someone may develop OCD.

The following things could all play a part on why a person develops OCD:

- personal experience,
- biological and genetic factors, and
- personality.

Although it is not known exactly why OCD develops, it can be treated successfully.

Top

4. How is OCD treated?

OCD is usually treated with the following evidenced based treatments:

- cognitive behavioural therapy (CBT)
- exposure and response prevention (ERP), and
- medication.

Cognitive behavioural therapy (CBT)

CBT looks at the link between how you think, feel and behave. CBT focuses on problems and difficulties in the present rather than your past or childhood.

CBT can help you to understand how you think about yourself and the things around you and how that affects your reaction to situations.[2]

Exposure and response prevention (ERP)

NICE guidelines say that you should only be offered ERP alongside CBT.[3] You can read more about the NICE guidelines below.

ERP helps people deal with situations or things that make them anxious or frightened. With the support of your therapist, you are 'exposed' to whatever makes you frightened or anxious. For example, dirt or germs.

You learn other ways of coping with your fear or anxiety instead of avoiding the situation or repeating a compulsion. You repeat this until you are no longer anxious or afraid.

Medication

Your doctor may offer you a type of antidepressant called an SSRI to help with your OCD. SSRI stands for selective serotonin reuptake inhibitor. The main types of SSRIs doctors use for OCD are fluoxetine, fluvoxamine, paroxetine, sertraline and citalopram.[4]

If your doctor prescribes any medication, they should tell you how it might help and what side effects to expect.

NICE guidelines

The National Institute for Health and Care Excellence (NICE) produces guidance on recommended treatments for OCD. You can find this guidance at: www.nice.org.uk/guidance/cg31.

If you have OCD and your symptoms are mild, your doctor should offer you low intensity psychological treatments of up to 10 hours. Low intensity treatments include:[5]

- brief CBT, including ERP, using self-help materials,
- brief individual CBT, including ERP, by telephone, and
- group CBT, including ERP.

If you have moderate OCD, your doctor should offer you the choice of either:[6]

- a course of SSRIs, or
- arrange more intensive CBT, including ERP. The therapy should be one-to-one with a therapist.

You might have severe symptoms. Your doctor should offer you CBT including ERP, together with an SSRI.[7]

What if these treatments don't work?

If these have not helped, your doctor or therapist may suggest further treatment. This might be further psychological therapy or medication.[8] Your doctor may offer you a different type of SSRI or an antidepressant called clomipramine.[9]

If these treatments still don't work then you will be referred to a specialist OCD team. They should give you additional treatments, which might include:[10]

- having additional CBT with ERP or cognitive therapy,
- taking an antipsychotic drug in addition to an SSRI or clomipramine,
- taking clomipramine and a drug called citalopram at the same time.

Specialist OCD services

Further treatment by a specialist team may sometimes be necessary. This might happen if you've tried the treatments above and your OCD is still not under control.

If you have severe, long-term OCD you may be referred to a specialist national OCD service. Especially if you have not responded well to the treatments available from local or regional services.

The following webpage from the NHS Choices website gives details of some specialist OCD services: www.nhs.uk/conditions/obsessive-compulsive-disorder-ocd/treatment/.

Cultural or religious guidance[11]

OCD symptoms may sometimes involve a person's religion, such as religious obsessions or cultural practices.

The boundary between religious or cultural practice and OCD symptoms might sometimes be unclear to healthcare professionals. The NICE guidelines say if they need to professionals might seeking the advice and support of an appropriate religious or community leader. But they should only do this with your consent.

You can find more information about:

- Talking therapies
- Antidepressants
- Antipsychotics

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

Top

5. How can I get help and treatment?

To begin with you can:

- See your GP, and
- Get talking therapy.

Seeing your GP

You should make an appointment to talk with your GP if you are worried about your symptoms. Or they are causing problems in your day to day life.

Your GP will look at different things when deciding on your treatment such as the following.

- Your diagnosis and symptoms.
- What options you have tried already.
- Your goals and preferences.
- Any other conditions you have.
- Guidance from the National Institute for Health and Care Excellence (NICE).

The NHS should follow the NICE guidelines for the treatment and care of OCD. The guidelines aren't legally binding. This means that your GP can decide not to follow the guideline. But they should be able to explain their decision to you.

Your GP might think your symptoms are severe. They might refer you to a specialist mental health team, like the community mental health team (CMHT).

Getting talking therapy

You can access talking therapy by:

- Contacting your local NHS talking therapy service. These are known as Improving access to psychological therapies (IAPT) services, or
- Getting a private therapist.

You can find more information about:

- GPs – what to expect from your doctor
- NHS Mental Health Teams (MHTs)
- Talking therapies

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

Top

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

If you are not happy with your treatment you can:

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

There is more information about these options below.

Treatment options

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

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

Second opinion

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

You don't have a right to a second opinion. But your doctor should listen to your reason for wanting a second opinion.[12]

Advocacy

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

Community advocates can support you to get a health professional to listen to your concerns. And help you to get the treatment that you would like.

You can get an NHS Complaints advocate to help you make a complaint against an NHS service.

You can search online to search for a local advocacy service.

The Patient Advice and Liaison Service (PALS)

PALS is part of the NHS. They give information and support to patients. You can find your local PALS' details through this website link: www.nhs.uk/Service-Search/Patient-advice-and-liaison-services-(PALS)/LocationSearch/363.

Making a complaint

It is best to try and solve the problem with the team or doctor first. If this doesn't help you can make a formal complaint. You can get an NHS Complaints advocate to help you make a complaint against an NHS service.

You can find out more about:

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

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

Top

7. What risks and complications can OCD cause?

Compulsions can take up a lot of your time. They can affect things like work, personal relationships and home life. For example, checking something repeatedly can take up hours of your day.

If you have a fear of contamination, you may feel the need to clean or wash things multiple times. This could affect your day-to-day life. Washing yourself repeatedly could have physical effects, or you may be spending a lot of money on cleaning products.

Hoarding can make it difficult to live in your own home comfortably. You may experience problems with hygiene. For example, mounting clutter can lead to rodent infestations. In extreme cases, hoarding items may become a safety risk due to fire or injury.

You might find it difficult to leave your house or to be in a clinic because of your OCD. A therapist may be able to visit you at home. Or offer you CBT over the phone. You should speak to your doctor or therapist if you need this sort of help.

Top

8. Information for carers, friends and relatives

How can I get support?

You can speak to your GP. You should be given your own assessment through the community mental health team to work out what effect your caring role is having on your health. And what support you need.[13]

You can get peer support through carer support services or carers groups. You can search for local carers' groups and services on the Carers Trust website here**:** https://carers.org/search/network-partners.

You can ask your local authority for a carer's assessment if you need more practical and financial support to help care for someone.

As a carer you should be involved in decisions about care planning. But you don't have a legal right to this.[14]

Supporting the person you care for

You might find it easier to support someone with OCD if you understand their symptoms, treatment plan and self-management techniques. You could ask them to share this information with you.

The person that you care for may also have a care plan. This outlines the care that they will get and who is responsible for it. A care plan should always have a crisis plan. A crisis plan will have information about who to contact if they become unwell.

You can use this information to support and encourage them to stay well and get help if needed.

You can find out more information about:

- Supporting someone with a mental illness
- Getting help in a crisis
- Suicidal thoughts. How to support someone
- Responding to unusual thoughts and behaviours
- Carers' assessment and support planning
- Confidentiality and information sharing. For carers, friends and family
- Supporting someone with a mental illness
- Benefits for carers

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

Top

Useful Contacts

OCD-UK
Supporting children and adults with OCD. Their phone line is staffed by volunteers and may not always be answered. They advise you to email if you can't get through.

Phone: 03332 127 890
Address: OCD-UK, Harvest Barn, Chevin Green Farm, Chevin Road Belper, Derbyshire, DE56 2UN
Email via website: www.ocduk.org/contact-us
Website: www.ocduk.org

OCD Action
National charity focusing on OCD.

Phone: 0300 636 5478
Address: Suite 506-507 Davina House, 137-149 Goswell Road, London EC1V 7ET
Email: support@ocdaction.org.uk
Website: www.ocdaction.org.uk

Triumph Over Phobia (TOP UK)
A UK registered charity which aims to help people who experience phobias, obsessive compulsive disorder and other related anxiety. They do this by running a network of self-help therapy groups.

Phone: 01225 571740
Address: PO Box 3760 Bath BA2 3WY
Email: info@topuk.org
Website: www.topuk.org

Hoarding UK
The UK national charity for people impacted by hoarding behaviours.

Phone: 020 3239 1600
Address: Suite 103 Davina House, 137-149 Goswell Road, London, EC1V 7ET
Email: info@hoardinguk.org
Website: https://hoardinguk.org/

References

[1] OCD-UK *'An Introduction to obsessive compulsive disorder)* (https://www.ocduk.org/ocd/introduction-to-ocd/ accessed 5th July, 2019)
[2] Royal College of Psychiatrists. *Cognitive Behavioural Therapy.* www.rcpsych.ac.uk/mentalhealthinfoforall/treatments/cbt.aspx (accessed 11th July 2019).
[3] National Institute for Health and Clinical Excellence. Obsessive-compulsive disorder and body
Institute for health and Clinical Excellence; 2005. Para 1.5.1.
[4] National Institute for Health and Clinical Excellence. Obsessive-compulsive disorder and body
dysmorphic disorder – Treatment. Clinical Guidance 31. London: National Institute for health and Clinical Excellence; 2005. Para 1.5.3.8.
[5] National Institute for Health and Clinical Excellence. Obsessive-compulsive disorder and body
dysmorphic disorder – Treatment. Clinical Guidance 31. London: National Institute for health and Clinical Excellence; 2005. Para 1.5.1.1.
[6] National Institute for Health and Clinical Excellence. Obsessive-compulsive disorder and body
dysmorphic disorder – Treatment. Clinical Guidance 31. London: National Institute for health and Clinical Excellence; 2005. Para 1.5.1.3.
[7] National Institute for Health and Clinical Excellence. Obsessive-compulsive disorder and body
dysmorphic disorder – Treatment. Clinical Guidance 31. London: National Institute for health and Clinical Excellence; 2005. Para 1.5.1.4.
[8] National Institute for Health and Clinical Excellence. Obsessive-compulsive disorder and body
dysmorphic disorder – Treatment. Clinical Guidance 31. London: National Institute for health and Clinical Excellence; 2005. Para 1.5.4.
[9] National Institute for Health and Clinical Excellence. Obsessive-compulsive disorder and body
dysmorphic disorder – Treatment. Clinical Guidance 31. London: National Institute for health and Clinical Excellence; 2005. Para 1.5.4.4.
[10] National Institute for Health and Clinical Excellence. Obsessive-compulsive disorder and body
dysmorphic disorder – Treatment. Clinical Guidance 31. London: National Institute for health and Clinical Excellence; 2005. Para 1.5.4.7.
[11] National Institute for Health and Clinical Excellence. Obsessive-compulsive disorder and body
dysmorphic disorder – Treatment. Clinical Guidance 31. London: National Institute for health and Clinical Excellence; 2005. Para 1.1.4.
[12] General Medical Council. *Good Medical Practice*. Manchester: GMC; 2013. Para 16(e).
[13] National Institute for Health and Clinical Excellence. Obsessive-compulsive disorder and body dysmorphic disorder – Treatment. Clinical Guidance 31. London: National Institute for health and Clinical Excellence; 2005. Para 1.1.5.5.
[14] National Institute for Health and Clinical Excellence. Obsessive-compulsive disorder and body dysmorphic disorder – Treatment. Clinical Guidance 31. London: National Institute for health and Clinical Excellence; 2005. Para 1.1.5.1 to 1.1.5.3.

First Version July 2019
Next update May 2020
Version number 1

This factsheet is available in large print.

Rethink Mental Illness Advice Service

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

Email advice@rethink.org

Did this help?

We'd love to know if this information helped you.

Drop us a line at: feedback@rethink.org

or write to us at Rethink Mental Illness:
RAIS
PO Box 17106
Birmingham B9 9LL

or call us on 0808 801 0525

We're open 9:30am to 4pm
Monday to Friday (excluding bank holidays)

Rethink Mental Illness.

Leading the way to a better quality of life for everyone affected by severe mental illness.

For further information
on Rethink Mental Illness
Phone 0121 522 7007
Email info@rethink.org

facebook.com/rethinkcharity
twitter.com/rethink_
www.rethink.org

Need more help?

Go to **www.rethink.org** for information on symptoms, treatments, money and benefits and your rights.

Don't have access to the web?

Call us on 0121 522 7007. We are open Monday to Friday, 9am to 5pm, and we will send you the information you need in the post.

Need to talk to an adviser?

If you need practical advice, call us on 0808 801 0525 between 9:30am to 4pm, Monday to Friday. Our specialist advisers can help you with queries like how to apply for benefits, get access to care or make a complaint.

Can you help us to keep going?

We can only help people because of donations from people like you. If you can donate please go to **www.rethink.org/donate** or call 0121 522 7007 to make a gift. We are very grateful for all our donors' generous support.

Registered in England Number 1227970. Registered Charity Number 271028. Registered Office 89 Albert Embankment, London, SE1 7TP. Rethink Mental Illness is the operating name of National Schizophrenia Fellowship, a company limited by guarantee.

Rethink Mental Illness.

factsheet

Personality disorders

This factsheet tells you what personality disorders are, what the symptoms are, and how you can get treatment. You might find it useful if you have a personality disorder yourself, or if you care for someone who does.

Key Points.

- A personality disorder can affect how you cope with life, manage relationships, how you behave, and how you feel.
- There are different types of personality disorders.
- There is no single cause of personality disorder. It is likely to be a combination of reasons, including genetic and environmental causes.
- Talking therapies are recommended as treatment for personality disorders.
- You can have a personality disorder alongside other mental health problems, such as anxiety and depression.

This factsheet covers:

1. What are personality disorders?

Everyone has different ways of thinking, feeling, and behaving. It is these thoughts, feelings, and behaviours that make up our 'personality'. These are often called our traits. They shape the way we view the world and the way we relate to others. By the time we are adults these will make us part of who we are.

You can think of your traits as sitting along a scale. For example, everyone may feel emotional, get jealous, or want to be liked at times. But it is when these traits start to cause problems that you may be diagnosed as having a personality disorder.

A personality disorder can affect how you cope with life, manage relationships, and feel emotionally. You may find that your beliefs and ways of dealing with day-to-day life are different from others. You can find it difficult to change them.

You may find your emotions confusing, tiring, and hard to control. This can be distressing for you and others. Because it is distressing, you may find that you develop other mental health problems like depression or anxiety.

You may also do other things such as drink heavily, use drugs, or self-harm to cope.

Research shows that personality disorders are fairly common.[1] Around one in 20 people live with some form of personality disorder.[2]

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

Top

2. What are the different types of personality disorder and how are they diagnosed?

Doctors use guidelines for diagnosing mental health problems. The main guidelines used are the:

- International Classification of Diseases (ICD-10) produced by the World Health Organisation (WHO), and
- Diagnostic and Statistical Manual (DSM-5) produced by the American Psychiatric Association.

When making a diagnosis your doctor will:

- think about your symptoms, and
- compare them to the guidelines.

A doctor will ask you questions about your life and what feelings, emotions, and behaviours you have. This is called an 'assessment'. The doctor should be a psychiatrist.

You shouldn't feel that it's your fault, or that you're to blame if you've been diagnosed with a personality disorder. Problems with diagnosis are explored in more detail in section 6.

Personality disorders diagnoses are grouped into three 'clusters', A, B, and C.

Cluster A personality disorders

People with cluster A personality disorders can find it hard to relate to other people. Their behaviour might seem odd or eccentric to other people.[3]

Paranoid personality disorder

If you have been diagnosed with this, you may feel very suspicious of others without good reason. This can make you feel that other people are being nasty to you. Even though this isn't true . You might feel easily rejected or hold grudges.[4]

Schizoid personality disorder [5]

With schizoid personality disorder, you may have few social relationships and will prefer to be alone. You may not enjoy or want to be part of a close relationship. This may include being part of a family. You might appear cold and removed from situations.

Schizotypal personality disorder[6]

Schizotypal personality disorder is where you have problems with relationships with other people. You may have strange thoughts, feel paranoid and have odd behaviour or appearance. You might have an inappropriate display of feelings

Cluster B personality disorders

People with cluster B personality disorders can find it hard to control their emotions. Other people might see them as unpredictable.[7]

Antisocial personality disorder (ASPD) [8]

Being diagnosed with antisocial personality disorder (ASPD) may mean you are impulsive and reckless. It might mean you don't think about how your actions affect other people.

You may get easily frustrated, aggressive and be prone to violence. You may lie to get what you want. Others may see this as acting selfishly and without guilt. You may blame others for problems you are having in your life.

Borderline personality disorder (BPD) [9]

You may have strong emotions, mood swings, and feelings you can't cope with if you have borderline personality disorder (BPD). You may feel anxious and distressed a lot of the time.

You may have problems with how you see yourself and your identity. You may self-harm or use drugs and alcohol to cope with these feelings. This can affect the relationships you have with other people.

BPD is also known as 'emotionally unstable personality disorder'.

You can find out more about '**Borderline personality disorder**' at www.rethink.org. Or call our General Enquiries team on 0121 522 7007 and ask them to send you a copy of our factsheet.

Histrionic personality disorder[10]

If you are diagnosed with histrionic personality disorder, you may like being the centre of attention. You may feel anxious about being ignored. This can cause you to be lively and over-dramatic.

You may become bored with normal routines, worry a lot about your appearance and want to be noticed. You might be easily influenced by others.

Narcissistic personality disorder[11]

Narcissistic personality disorder can mean you have a high sense of self-importance. You may fantasise about unlimited success and want attention and admiration.

You may feel you are more entitled to things than other people are. You might act selfishly to gain success. You may be unwilling or unable to acknowledge the feelings or needs of others.

Cluster C personality disorders

People with cluster C personality disorders have strong feelings of fear or anxiety.[12]

Dependent personality disorder[13]

If you have dependent personality disorder, you may allow other people to take responsibility for parts of your life. You may not have much self-confidence or be unable to do things alone. You may find that you put your own needs after the needs of others. You may feel hopeless or fear being alone or abandoned.

Avoidant personality disorder[14]

If you have avoidant personality disorder, you may have a fear of being judged negatively. This can cause you to feel uncomfortable in social situations. You might not like criticism, worry a lot and have low self-esteem. You may want affection but worry that you will be rejected.

Obsessive-compulsive personality disorder[15]

This is also known as anankastic personality disorder.

If you have this condition, you may feel anxious about things that seem unorganised or 'messy'. Everything you do must be just right, and nothing

can be left to chance. You may be very cautious about things and think a lot about small details. You may have problems completing tasks due to your own high standards. Others may see you as being controlling.[16]

Obsessive-compulsive personality disorder is different to obsessive-compulsive disorder (OCD). If you have obsessive-compulsive personality disorder, you may believe your actions are justified. People with OCD tend to realise that their behaviour isn't rational.[17]

You can find out more about '**Obsessive compulsive disorder (OCD)**' at www.rethink.org. Or call our General Enquiries team on 0121 522 7007 and ask them to send you a copy of our factsheet.

Top

3. What causes personality disorders?

It isn't clear what causes personality disorders. It seems that a mix of factors can mean some people develop personality disorders. These can include:

- biological factors, when it is passed on through your genes, and
- the environment around you when you were growing up.[18]

Many people diagnosed with personality disorders have experience of trauma. These might include difficulties growing up, including childhood neglect or physical, emotional or sexual abuse.

When you are growing up, you learn to cope with emotional changes and make relationships with other people. Children who are abused or neglected often don't learn these things. So, they may find it more difficult to manage how they feel when they are adults.[19]

This doesn't mean that all people who experience trauma will develop personality disorders. But they may be more likely to.

Top

4. How are personality disorders treated?

Personality disorders are usually treated with group psychological treatments or talking therapies. Below we explain more about the different types of therapies.

The options for treating personality disorders are continuously developing.

You and your doctor or healthcare team should agree on a treatment plan that works best for you.

If your GP feels you have a complex personality disorder, they may refer you to a:

- community mental health team, or

- specialist personality disorder service or unit, if there is one locally.

These services are made up of professionals such as psychologists, psychiatrists and therapists. They will have experience in helping people with personality disorders. Sometimes you can contact these services yourself to get help.

It's always worth asking why a certain treatment is being offered. And if there are other things that could help you to get better.

When thinking about what treatment to offer you professionals should consult guidelines NICE guidelines, if relevant. NICE stands for The National Institute for Health and Care Excellence. The NICE guidelines recommend treatment for conditions.

For personality disorders NICE only have guidelines for:

- Borderline personality disorder (BPD), and
- Anti-social personality disorder.

You can find these online, find link below:

www.nice.org.uk/guidance

Therapy for personality disorders is usually long term. You might have to complete the therapy to get the full benefit of it, to aid your recovery. If you are struggling with your therapy for any reason, you can tell your therapist this.

In some areas, services use pre-therapy preparation to help people understand the link between emotions and decisions. The aim is to help you recognise your emotions before starting therapy, and hopefully finish your sessions.

The following treatments can help if you have a personality disorder:

Cognitive behavioural therapy (CBT)

CBT can help you to change how you think and what you do. These are both linked to how you feel.

CBT looks at problems and difficulties in the 'here and now' more than your past or childhood.

CBT can help you understand how you think about yourself, the world and other people. And how that affects how you deal with things in your life.[20]

Dialectical behaviour therapy (DBT)

DBT can help you learn to spot and control your emotions and behaviour. It is adapted from CBT.

It helps you recognise then change unhelpful behaviour by learning new skills. Unhelpful behaviour might include thinking about suicide, self-harming, drinking alcohol or using drugs to cope with your emotions.

The National Institute for Health and Care Excellence (NICE) says DBT can be helpful if you have borderline personality disorder.[21]

A course of DBT usually takes place over 18 months.[22]

Cognitive analytical therapy (CAT)

CAT helps you recognise relationship patterns that can cause you problems and are difficult to change. You may have learnt these patterns while growing up to cope with difficult emotions.

You and the therapist will work together to recognise these patterns and then to try and change them. This therapy is based on the individual's needs. And takes into account their current situation and the problems they are having.[23]

This type of therapy can usually last between 4 – 24 weeks. But on average lasts 16 weeks.

You and your therapist will agree the end goal at the start of the therapy.[24]

Mentalisation based therapy (MBT)

Mentalising is about making sense of what other people think, need, or want. It is about being aware of what's going on in your own mind and in the minds of others. Mentalising refers to the fact that sometimes when you feel distressed, it can be harder to 'mentalise.'[25]

You would attend group and one-to-one therapy. This may help you better understand yourself and others and learn how to mentalise. Treatment programmes can last for 12 to 18 months.[26]

Psychodynamic or psychoanalytic therapy

This type of long-term therapy is a therapeutic process which helps patients understand and resolve their problems. It does this by increasing awareness of their inner world and its influence over relationships both past and present.

It differs from most other therapies in aiming for deep seated change in personality and emotional development.

It helps people to understand and change complex, deep-seated emotional and relationship problems. [27]

Therapeutic communities

A therapeutic community is a place you would get long-term group therapy.

You would visit, or sometimes stay, for a number of weeks or months. Sometimes you may visit for just a few days a week.

You learn from spending time with other people in the treatment group. It offers a safe place if there are any disagreements or upsets. People in a therapeutic community often have a lot of say over how the community runs.[28]

There are only a few therapeutic communities in the UK. You could check with your local Patient Advice Liaison Service (PALS) if your NHS trust has one. You can search for your PALS office here: www.nhs.uk/Service-Search/Patient-advice-and-liaison-services-(PALS)/LocationSearch/363

Medication

There is no recommended medication for the treatment of personality disorders.

But your doctor may give you medication to help with symptoms such as anxiety, anger, or low mood. These might include antidepressants, mood stabilisers, or antipsychotics.[29]

You can find out more about:

- Antidepressants
- Mood stabilisers
- Antipsychotics

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

If you are given any medication, your doctor should tell you how it should help. And about any side effects that you might get.

Care Programme Approach

Having a personality disorder may put you at risk, mean you have a lot of needs, and need a high level of care. You can be supported through the Care Program Approach (CPA).[30]

The CPA is used to plan and outline the support you need to manage complex needs and your mental health.

If you are on the CPA you will have a care coordinator. They will work with you to write a care plan. This will set out how the NHS will support you.

You can find more information about the '**Care Programme Approach**' at www.rethink.org. Or call our General Enquiries team on 0121 522 7007 and ask them to send you a copy of our factsheet.

Top

5. What if I'm not happy with my treatment?

Patient Advice and Liaison Service (PALS)

You could call the Patient Advice and Liaison Service (PALS) at your NHS trust if you:

- feel unhappy with how your treatment or care is being handled,
- You are struggling to get the right treatment, or
- feel that the relationship between you and a professional is not working well.

They can try to sort out any problems or questions you have. You can find your local PALS' details at www.nhs.uk/Service-Search/Patient-advice-and-liaison-services-(PALS)/LocationSearch/363.

Complaining

You can also complain if you aren't happy. You can find out more about '**Complaints'** at www.rethink.org. Or call our General Enquiries team on 0121 522 7007 and ask them to send you a copy of our factsheet.

Advocacy

You might find an advocate helpful if you are unhappy with your treatment. You can get help from an NHS Complaints advocate.

An advocate is independent from mental health services. They can help to make your voice heard when you are trying to sort out problems. They might help you write letters or support you in appointments and meetings.

You can search online for a NHS Complaints advocate or the Rethink Mental Illness Advice Service could search for you.

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

Top

6. What problems can be linked to personality disorders?

Diagnosis

Doctors sometimes find it difficult to diagnose personality disorders. This can be because of the following.[31]

- An overlap with other mental health problems can make it difficult to pinpoint or 'narrow down' symptoms.
- Personality disorders are complex. The symptoms may not easily fit into any one of the clusters.
- If you use drugs or drink alcohol a lot, it can make it more difficult for health professionals to reach a correct diagnosis.

- Some doctors are reluctant to give this diagnosis. They might feel that it may be ‘problematic’ or make it harder for you to get help.

You may feel you have been given a diagnosis of personality disorder because a professional is unsure of your diagnosis.

You may find it an unhelpful label or that it is stigmatising. But some people find that a diagnosis can help them to understand certain things they do and help with finding the right treatment and support.

Jenny’s story

I didn’t understand why I had been given the diagnosis of personality disorder. At first, it was insulting. It felt like I was being told my personality was wrong or that I was somehow ‘flawed’. Everyone has faults and traits and everyone does things wrong. However, after some encouragement from my partner, I started the therapy that was offered. Over time, I began to learn techniques and methods that slowly helped with how I was feeling.

Services and recovery

The Department of Health says that people with personality disorders should be able to get the right care and services.[32]

Some people aren’t always able to get the right treatment. This is because there aren’t specialist personality disorder units in every area.

If this is the case for you:

- You should still be offered treatment for your personality disorder by mental health services, and
- You can try to apply to get treated by a personality disorder service in another area. You can ask your GP about this.

You can find out more about ‘**NHS treatment – your rights**’ at www.rethink.org. Or call our General Enquiries team on 0121 522 7007 and ask them to send you a copy of our factsheet.

Self-harm

Self-harm is common if you have borderline personality disorder (BPD).

People might self-harm to help manage feelings that are triggered by specific events or strong emotions. It can also act as a way of coping with distressing events and communicating the stress that they feel.

You can find out about **‘Self-harm’,** at www.rethink.org. Or call our General Enquiries team on 0121 522 7007 and ask them to send you a copy of our factsheet.

Use of alcohol and drugs

People with personality disorders can find that they use drugs or drink alcohol to cope with difficult emotions and feelings. This is sometimes known as dual diagnosis.

Drinking alcohol or using drugs can lead to:

- doing things that you might not do normally,
- behaving impulsively – this means acting on the spur of the moment, and
- poor physical health.

Antisocial personality disorder and borderline personality disorder have the strongest links with alcohol and drugs.[33]

Some specialist personality disorder services may have some conditions if you use drugs or drink alcohol. They may say you need to cut down or stop before you can use the service.

Top

7. Information for carers, friends, and relatives

As a carer, friend, or family member of someone living with a personality disorder, you might find that you also need support. Caring for someone with a personality disorder can be challenging.

It is important to get emotional support for yourself if you are finding it hard to cope. You can contact one of the organisations in the 'useful contacts' section of this factsheet.

You can also check whether there are any local support groups for carers, friends and relatives in your area. New education and support programmes for families are being set up in some parts of the country.

You can ask for a carer's assessment if you feel you need more support to care for your loved one.

You should be involved with decisions about care planning. If your loved one is supported by a mental health team and you are their carer.

There are rules regarding confidentiality and carers. Unless the person you care for agrees, confidential information about them can't be passed on to you. Professionals should ask their permission and ask what they are happy for others to know. This would also include any care plans they have.

You can find out more about:

- Supporting someone with a mental illness
- Carers' assessments
- Confidentiality – for carers, friends and relatives

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

Top

Useful Contacts

BPD World
An organisation committed to raising awareness and reducing the stigma of mental health with a focus on borderline personality disorder (BPD). It provides online information, advice and support and has an online forum.

Website: www.bpdworld.org

Time to Change
Time to change offers a space for people to tell their own story. You can submit your own.

Website: www.time-to-change.org.uk/category/blog/borderline-personality-disorder

Tara (Treatment and Research Advancements) for BPD
An American education-based and support community for carers and families of people living with BPD.

Website: www.tara4bpd.org

Out of the Fog
They offer information on personality disorders and an online support forum.

Website: http://outofthefog.net/index.html

Carers4PD
It is a voluntary service dedicated to providing information, support and advocacy for carers of people diagnosed with a personality disorder.

Website: www.carers4pd.co.uk/default.html;
Yahoo chat group:
https://uk.groups.yahoo.com/neo/groups/carers4pd/info)
Email: info@carers4pd.co.uk

Personality Disorders UK
Information and news on personality disorders

Website: http://personalitydisorder.org.uk/;

Top

References

[1] Coid, J. & Ullrich, S. Prevalence and correlates of personality disorder in Great Britain. *The British Journal of Psychiatry.* 2006; 188: 423-431
[2] Royal college of Psychologists *Personality Disorder* https://www.rcpsych.ac.uk/mental-health/problems-disorder_s/personality-disorder (accessed 16 August 2019)

[3] Healthline *Cluster A Personality Disorders and Traits* https://www.healthline.com/health/cluster-a-personality-disorders (accessed 19 September 2019)
[4] Royal college of Psychologists *Personality Disorder* https://www.rcpsych.ac.uk/mental-health/problems-disorder_s/personality-disorder (accessed 16 August 2019) (accessed 16 January 2020)
[5] PsychCentral *Schizoid Personality Disorder* https://psychcentral.com/disorders/schizoid-personality-disorder/ (accessed 19 August 2019)
[6] Psychology Today *Schizotypal Personality Disorder* https://www.psychologytoday.com/gb/conditions/schizotypal-personality-disorder (accessed 13 August 2019)
[7] Medical News Today *What are Cluster B Personality Disorders?* https://www.medicalnewstoday.com/articles/320508.php (accessed 16 August 2019)
[8] NHS *Antisocial Personality Disorder* https://www.nhs.uk/conditions/antisocial-personality-disorder/ (accessed 16 August 2019)
[9] World Health Organisation. *International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10) F60.3.* http://apps.who.int/classifications/icd10/browse/2016/en#/F60.3 (accessed 16 August 2019)
[10] Psychology Today *Histrionic Personality Disorder* https://www.psychologytoday.com/gb/conditions/histrionic-personality-disorder (accessed 19 August 2019)
[11] American Psychiatric Association Desk Reference to the Diagnostic Criteria from DSM-5 2013 P. 327
[12] Healthline *Cluster C Personality Disorders and Traits* https://www.healthline.com/health/cluster-c-personality-disorders (accessed 23 August 2019)
[13] World Health Organisation. *International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10) F60.7.* http://apps.who.int/classifications/icd10/browse/2016/en#/F60.7 (accessed 23 August 2019)
[14] World Health Organisation. *International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10) F60.6.* http://apps.who.int/classifications/icd10/browse/2016/en#/F60.6 (accessed 26 October 2016)
[15] Psych Central *Obsessive Compulsive Personality Disorder* https://psychcentral.com/disorders/obsessive-compulsive-personality-disorder/ (Accessed 15 August 2019)
[16] Healthline *Obsessive-compulsive Personality disorder (OCPD)* https://www.healthline.com/health/obsessive-compulsive-personality-disorder (accessed 13th December 2019)
[17] Healthline *Obsessive-compulsive Personality disorder (OCPD)* https://www.healthline.com/health/obsessive-compulsive-personality-disorder (accessed 24th December 2019)
[18] National Health Service. *Personality Disorders.* http://www.nhs.uk/Conditions/Personality-disorder/Pages/Definition.aspx (accessed 30 August 2019)
[19] PMC *Childhood maltreatment and adult personality disorder symptoms: Influence of maltreatment type* https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2671800/ (accessed 30/08/2019)
[20]NHS *Cognitive Behavioural Therapy(CBT)* https://www.nhs.uk/conditions/cognitive-behavioural-therapy-cbt/ (accessed 30 August 2019)
[21] National Institute for Health and Clinical Excellence 2009. *Borderline personality disorder: recognition and management.* Clinical Guidance 78. London: National Institute for Health and Clinical Excellence. Para 2.2 https://www.nice.org.uk/guidance/cg78/chapter/2-Research-recommendations (accessed 19th September, 2019)
[22] National Institute for Health and Clinical Excellence 2009. *Borderline personality disorder: recognition and management.*

Clinical Guidance 78. London: National Institute for Health and Clinical Excellence. Para 2.2 https://www.nice.org.uk/guidance/cg78/chapter/2-Research-recommendations (accessed 24th December, 2019)

[23] Counselling Directory *Cognitive Analytic Therapy* https://www.counselling-directory.org.uk/cognitive-analytic-therapy.html (Accessed 15 August 2019)

[24] Association of Cognitive Analytical Therapists. *What is CAT?* http://www.acat.me.uk/page/about+cat (accessed 30 August 2019)

[25] NHS The Tavistock and Portman *Mentalization-based therapy (MBT)* https://tavistockandportman.nhs.uk/care-and-treatment/treatments/mentalisation-based-therapy/ *(acce*ssed 30 August 2019)

[26] NHS The Tavistock and Portman *Mentalization-based therapy (MBT)* https://tavistockandportman.nhs.uk/care-and-treatment/treatments/mentalisation-based-therapy/ *(acce*ssed 24 December 2019).

[27] British Psychoanalytic Council. *What is psychoanalytic psychotherapy?* https://www.bpc.org.uk/about-psychotherapy/what-psychotherapy (accessed 30August 2019)

[28] Community Care *How therapeutic communities can help rebuild lives* https://www.communitycare.co.uk/2009/04/27/how-therapeutic-communities-can-help-rebuild-lives*/* (Accessed 02 September 2019)

[29] National Health Service. *Personality disorder – treatment,* http://www.nhs.uk/Conditions/Personality-disorder/Pages/Treatment.aspx (accessed 02 September 2019).

[30] Department of Health. *Refocusing the Care Programme Approach: Policy and Positive Practice Guidance.* London: Department of Health 2008.

[31] Cloninger, R. A Practical Way to Diagnosis Personality Disorder: A Proposal. *Journal of Personality Disorders.* 2000; 14(2):99-108. https://www.researchgate.net/publication/12422694_A_Practical_Way_to_Diagnosis_Personality_Disorder_A_Proposal (accessed 02 August 2019)

[32] National Institute for Mental Health for England. *Personality Disorder - No Longer a Diagnosis of Exclusion. Policy Implementation Guidance for the Development of Services for People with Personality Disorder*, Gateway Reference 1055. London- NIMH(E). 2003 http://personalitydisorder.org.uk/wp-content/uploads/2015/04/PD-No-longer-a-diagnosis-of-exclusion.pdf (Accessed 16.01.20)

[33] Welch, S. Substance use and personality disorders. *Psychiatry*. 2007; 6(1), 27-29 https://www.sciencedirect.com/science/article/pii/S1476179306005076 (Accessed 16.01.20)

Last updated Sept 2019

Next update Sept 2022

Version 9

This factsheet is available in large print.

Rethink Mental Illness Advice Service

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

Email advice@rethink.org

Did this help?

We'd love to know if this information helped you.

Drop us a line at: feedback@rethink.org

or write to us at Rethink Mental Illness:
RAIS
PO Box 17106
Birmingham B9 9LL

or call us on 0808 801 0525

We're open 9:30am to 4pm
Monday to Friday (excluding bank holidays)

Rethink Mental Illness.

Leading the way to a better quality of life for everyone affected by severe mental illness.

For further information
on Rethink Mental Illness
Phone 0121 522 7007
Email info@rethink.org

facebook.com/rethinkcharity

twitter.com/rethink_

www.rethink.org

Need more help?

Go to **www.rethink.org** for information on symptoms, treatments, money and benefits and your rights.

Don't have access to the web?

Call us on 0121 522 7007. We are open Monday to Friday, 9am to 5pm, and we will send you the information you need in the post.

Need to talk to an adviser?

If you need practical advice, call us on 0808 801 0525 between 9:30am to 4pm, Monday to Friday. Our specialist advisers can help you with queries like how to apply for benefits, get access to care or make a complaint.

Can you help us to keep going?

We can only help people because of donations from people like you. If you can donate please go to **www.rethink.org/donate** or call 0121 522 7007 to make a gift. We are very grateful for all our donors' generous support.

factsheet

Post-Traumatic Stress Disorder (PTSD)

This factsheet has information about the symptoms and causes of post-traumatic stress disorder (PTSD). It explains who might develop PTSD and what treatment is available.

Key Points.

- You may develop post-traumatic stress disorder (PTSD) if you experience something which you find traumatic. Such as witnessing an assault, child birth, being bullied, being involved in a road traffic accident or natural disaster.
- The development of the illness depends on how you deal with the experience. It is not dependent on the severity of the experience.
- Not everyone who experiences trauma will develop PTSD
- Symptoms include traumatic memories or dreams, avoiding things that remind you of the event, not being able to sleep and feeling anxious. You may feel isolated and withdrawn.
- If you have PTSD, your doctor should offer you therapy. Medication can be suggested if you need extra support to access therapy. Or if you don't want therapy.
- You are likely to recover from PTSD.

This factsheet covers:

Top

1. What is post-traumatic stress disorder (PTSD)?

You may develop post-traumatic stress disorder after experiencing, or seeing, something that you find traumatic.

The symptoms of PTSD can start immediately or after a delay of weeks or months. It will usually start within 6 months of the traumatic event. [1]

You are likely to recover from PTSD. It is possible to be successfully treated from PTSD years after the trauma, so it's never too late to seek help.[2]

But a few people may deal with symptoms for many years. This can develop into a personality change.[3]

Top

2. What are the symptoms of PTSD?

Some of the symptoms are PTSD and complex PTSD are: [4,5]

- reliving the experience through flashbacks, dreams or nightmares,
- not being able to feel emotions,
- dissociation. This could include disconnecting from yourself or other people,
- negative alternations in mood,
- emotional dysregulation. This means it is difficult to control your emotions,
- problems relating to others,
- problems in relationships
- negative self-perception such as feeling worthless or defeated,
- hyperarousal such as anger, irritability or sleep issues,
- hypervigilance such as feeling on constant alert. Or being overly sensory to stimulus such as smell and noise, and
- avoidance. This could mean that you try to distract your thought from thinking about the trauma. Or you avoid situations that remind you of your trauma.

Is psychosis a symptom of PTSD?

There is a link between PTSD and psychosis. But it is not known if psychosis is a symptom of PTSD. Or a separate mental health condition.[6, 7]

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

Top

3. How is PTSD diagnosed?

A psychiatrist will diagnose PTSD through a mental health assessment. Your GP should carry out an initial assessment to decide what care you need. Your assessment should include information about:[8]

- your physical needs,
- your mental needs,
- your social needs, and
- risk.

As part of the assessment they will decide if you need to be referred to the community mental health team (CMHT).[9] You should be referred to the CMHT if you have had symptoms for more than 4 weeks. Or your symptoms are very bad. [10]A CMHT is part of the NHS. They are a team of mental health professionals.

Doctors use the following manuals to help to diagnose you:

- International Classification of Diseases (ICD-10) produced by the World Health Organisation (WHO), and
- Diagnostic and Statistical Manual (DSM-5) produced by the American Psychiatric Association.

The manuals are guides which explain different mental health conditions.

Top

4. What is complex post-traumatic stress disorder (PTSD)?

The main symptoms of PTSD and complex PTSD are the same. But if you have complex PTSD you will have extra symptoms such as:[11]

- constant issues with keeping a relationship,
- finding it difficult to feel connected to other people,
- constant belief that you are worthless with deep feelings of shame and guilt. This will be related to the trauma, and
- constant and severe emotional dysregulation. This means it is difficult to control your emotions

You are more likely to have complex PTSD if your trauma is linked to an event or series of events. The trauma will be very threatening or frightening. Most commonly from a trauma which you were not able to escape from such as:[12]

- torture
- slavery
- a long period of domestic abuse, or
- a long period of sexual or physical abuse

What is the treatment for complex PTSD?

You may respond to trauma focussed therapies if you have complex PTSD. For more information look at section 6, 'How do I get help if I have symptoms of PTSD' and section 7 'Additional needs and complex PTSD' for more information of this factsheet.

There is some overlap of symptoms for complex PTSD and borderline personality disorder (BPD). If you have complex PTSD you may benefit from certain treatments that help people with BPD.[13]

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

Top

5. What causes PTSD?

PTSD is caused by experiencing or witnessing single, repeated or multiple events. For example:[14]

- serious accidents
- physical and sexual assault abuse. This could include childhood or domestic abuse
- work-related exposure to trauma. Such as being in the army
- trauma related to serious health problems or childbirth
- war and conflict torture

Not everyone who experiences trauma will develop PTSD.

The risk of getting PTSD depends on how the experience affects you. PTSD is more likely to develop if the traumatic event:[15]

- is unexpected,
- goes on for a long time,
- involves being trapped,
- is caused by people,
- causes many deaths,
- causes mutilation to the body, or
- involves children.

If you already have depression when the trauma happens you are at a higher risk of developing PTSD. [16]

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

Top

6. How do I get help if I have symptoms of PTSD?

You can get help from:

- The NHS
- Adult social services
- Charities
- Self help

How can the NHS help me?

You can speak to your GP about your concerns. They will be able to talk to you about treatment options and coping strategies. You don't have to do what your GP thinks that you should do. But you should listen to them.

Make sure that you understand the pros and cons of your treatment options before you make a decision.

Your treatment with be managed by your GP or the community mental health team (CMHT). In some cases, your treatment maybe shared between both primary and secondary care. Healthcare professionals will agree who will monitor you.[17]

Some people will get care under the Care Programme Approach (CPA).[18] This means that you will have a care plan and care coordinator to make sure that you get the support that you need.

Look at section 7 of this factsheet, 'How is PTSD treated by the NHS?' for more information.

Adult social services

If you need help and support to look after yourself then you can have an assessment by social services. For example, you may need support so that you can:[19]

- get out of the house,
- keep in touch with friends and family,
- get a job or take part in education,
- clean your house,
- prepare meals or go shopping,
- keep safe,
- manage your money,
- take part in leisure activities, or
- contribute to society (e.g. volunteering, being in a club or group).

What other help is available?

Charities

In some areas, charities will support people who have PTSD. This may be through support groups where you can talk to other people who have PTSD and other mental health conditions. Group support can help you find ways to manage your symptoms and understand your condition.[20]

There may be a different service available, such as employment or isolation support.

You can look on our website www.rethink.org to see if we have any support groups or services in your area. Click on 'Help in your area' at the top of the webpage.

Some of the other main national mental health charities are:

- Assist
- Combat stress
- Rape crisis
- NAPAC
- Mind,
- Richmond Fellowship,
- Together, and
- Turning Point.

You can look on their websites to see what support they offer in your area.

Contact details for some of these charities are in the 'useful contacts' section of our website.

If you would like us to look for you please contact our advice line on 0300 5000 927 and let us know what sort of support you are looking for.

Self-help

There are things that you can do to help manage your mental health. This is called 'self-help.' You can read more about self-help in section 9 of this factsheet.

You can find more information about:

- Community mental health team
- Care Programme Approach
- Social care assessment - under the Care Act 2014

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

Top

7. How is PTSD treated by the NHS?

The National Institute for Health and Care Excellence (NICE) says that the NHS should offer treatment if you have a diagnosis of PTSD. Or you have important symptoms of PTSD.[21] The treatment that you are offered should be the following.

- Trauma focussed cognitive behavioural therapy (CBT)
- Eye movement desensitisation and reprocessing (EMDR)
- Supported trauma-focused computerised cognitive behavioural therapy (CBT)

- CBT to target an issue
- Medication

You can refer yourself for trauma therapies[22] in most areas. Click the below link to search for psychological therapy services in your area:

https://beta.nhs.uk/find-a-psychological-therapies-service/

Watchful waiting

Watchful waiting may be suggested if you have mild symptoms of PTSD. Or the trauma has happened within the last 4 weeks. This means that your symptoms should be monitored, and you should have a follow up appointment in 1 month.

Watchful waiting is sometimes recommended because 2 in every 3 people who experience a trauma will recover without treatment.[23]

What is trauma-focused cognitive behavioural therapy (CBT)?

Cognitive behavioural therapy (CBT) helps you deal with your symptoms by making changes to how you think and act.

Your therapy should: [24]

- be delivered by a trained practitioner,
- last between 8-12 sessions. You can have more if needed. For example, if you have had different or repeated traumas,
- include psychoeducation about:
  - reaction to trauma,
  - how to manage hyperarousal such as anger
  - how to manage flashbacks, and
  - safety planning
- help you how to process trauma related emotions, such as shame and guilt,
- help you to manage relationships,
- help you to deal with avoidance, and
- plan a booster session if needed. Such as support near to trauma anniversaries.

What is Eye movement desensitisation and reprocessing (EMDR)?

You will make eye movements while thinking about the traumatic event. Therapists think that this works by making your brain deal with painful memories in a different way.

Your therapy should:[25]

- be delivered by a trained practitioner,
- last between 8-12 sessions. You can have more if needed such as if you have had different or repeated trauma,

- be delivered in phases,
- include psychoeducation about:
    - reaction to trauma,
    - how to manage distressing memories and situations,
    - treat certain memories, often they will be visual, and
    - teach you how to think positively about yourself
- use eye stimulation to help you manage certain memories. This should be used until the memories are no longer distressing,
- teach you self-calming techniques to help in-between sessions, and
- teach you techniques to manage flashbacks in-between sessions.

What is supported trauma-focused computerised cognitive behavioural therapy (CBT)?

You will have therapy through a computer programme.

You may be able to have supported trauma-focused computerised CBT if you prefer it to face to face trauma focused CBT or EMDR. And if it is more than 3 months since the trauma. You should only be offered this therapy if:[26]

- your PTSD symptoms aren't severe,
- you don't have any dissociative symptoms, and
- you are not a risk of harm to yourself or others.

Your therapy should:[27]

- usually be 8 to 10 sessions long,
- help you to learn to process your trauma,
- help you to deal with avoidance,
- help you manage relationships,
- involve guidance and support from a trained practitioner, and
- involve feedback and a review of your progress and outcomes with your practitioner.

What is CBT to target an issue?

This is a CBT aimed at specific symptoms of PTSD such as sleep problems or anger. You may be offered this type of CBT if you:[28]

- are unable to engage with trauma focussed therapies
- don't want trauma focussed therapies, or
- you still have some PTSD symptoms after trauma focussed therapy.

Medication

Your doctor might offer you venlafaxine or a selective serotonin reuptake inhibitor (SSRI) if you would prefer drug treatment. The treatment will need to be reviewed regularly.[29]

You may be offered antipsychotic medication, such as risperidone at the same time as talking treatments. This may be offered if you have severe symptoms such as psychosis. The treatment will need to be reviewed regularly by a specialist.[30]

How is PTSD treated if I have complex needs?

Depression

If you have depression and PTSD, your doctor might treat your PTSD first. Your depression may improve after you get treatment for PTSD. Your doctor should treat your depression first if:[31]

- it makes it difficult for you to take part in therapy for PTSD, or
- you are a risk of harm to yourself or other people

Additional needs and complex PTSD

You should not be excluded from treatment because you have a drug or alcohol issue.[32] If you have a drug or alcohol issue then this would be considered as an 'additional need'.

Your health professional should:[33]

- give you more therapy sessions or give you longer therapy sessions to help build trust,
- think about the impact that your personal situation will have on the outcome of therapy,
- help you to manage any issues that might stop you from being able to engage with trauma focused therapies. Such as substance misuse, dissociation or problems controlling your emotions, and
- plan any ongoing support that you need after the end of treatment. Such as managing other mental health conditions.

You can find out more about:

- Talking therapies
- Antidepressants
- Antipsychotics
- Psychosis
- Depression
- Drugs, alcohol and mental health
- Medication. Choice and managing problems

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

Top

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

If you are not happy with your treatment you can:

- talk to your doctor about your treatment options,
- ask for a second opinion,
- ask a relative, friend or advocate to help you speak your doctor,
- contact Patient Advice and Liaison Service (PALS), or
- make a complaint.

There is more information about these options below.

Treatment options

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

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

Second opinion

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

You don't have a legal right to a second opinion. But your doctor should listen to your reason for wanting a second opinion.[34]

Advocacy

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

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

The Patient Advice and Liaison Service (PALS)

PALS is part of the NHS. They give information and support to patients. You can find your local PALS through this website link:

https://www.nhs.uk/Service-Search/Patient-advice-and-liaison-services-(PALS)/LocationSearch/363

You can find out more about:

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

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

Top

9. What self-care and management skills can I try?

There are things that you can do to help yourself. This is also known as self-care. When it comes to what helps people, everyone is different. You may need to different lifestyle changes until you find what works for you. Such as the following.

Learn ways to relax. Such as listening to meditation CDs or relaxing music. You can find free meditation videos on websites like YouTube.

Practise mindfulness and meditation. You can find out more here: www.mindful.org/meditation/mindfulness-getting-started/

Eat healthy foods and have a balanced diet. You can find out nutritional advice here: www.nhs.uk/livewell/healthy-eating/Pages/Healthyeating.aspx

Keep physically active. Exercise can help to reduce stress and anxiety. It can increase the levels of serotonin and endorphins which are your body's natural 'happy' chemicals. www.weareundefeatable.co.uk.

Drink enough water.

Have a daily routine. Keeping a routine can help you to keep your mind occupied and focused on healthy thoughts and activities.

Have healthy relationships. You can find more tips on how to maintain healthy relationships here: www.mentalhealth.org.uk/sites/default/files/guide-investing-relationships-may-2016.pdf

Get enough sleep. Without regular sleep, your mental health can be affected. You can find out more about improving your sleep at: www.rethink.org/advice-and-information/living-with-mental-illness/wellbeing-physical-health/sleep

Be aware of your alcohol intake. Unhealthy drinking habits can lead to poor mental health. Some people use alcohol to deal with their emotions. This is called 'self-medication.' If you recognise that you do this, you could avoid alcohol or cut down. Try a different coping technique to help you manage how you feel. You may need professional help to do this.

You should also consider the effect of alcohol on any medication you take. You can ask your doctor if you need more information.

Avoid smoking or cut down. Smoking can affect your medication and your health. If you are not sure how your medication is affected speak to your doctor.

Keep a mood diary. This can help you to be more aware of your symptoms and what makes you better and worse. You can simply use a notebook for this. Or you may want to try online resources or smartphone apps like:

- MoodPanda: http://moodpanda.com/
- Daylio: https://daylio.webflow.io/
- Evernote: https://evernote.com/

Self-help online

There are websites which give information about how to manage your mental health. There are also websites which explain how you can use cognitive behavioural therapy (CBT) techniques to improve and manage your mental health. Some people find these useful.

- **Mood Juice PTSD self-help:** www.moodjuice.scot.nhs.uk/posttrauma.asp
- **Northumberland, Tyne and Wear NHS self-help leaflets** www.ntw.nhs.uk/pic/selfhelp
- **Public Health England. One You:** www.nhs.uk/oneyou/every-mind-matters/
- **Mood Gym**: https://moodgym.anu.edu.au/welcome/new/splash;
- **Live life to the Full**: Online courses. www.llttf.com/index.php?section=page&page_seq=8&;
- **Psychology Tools:** http://psychologytools.com/.

Recovery College

Recovery colleges are part of the NHS. They offer free courses about mental health to help you manage your symptoms. They can help you to take control of your life and become an expert in your own wellbeing and recovery. You can usually self-refer to a recovery college. But the college may tell your care team.

Unfortunately, recovery colleges are not available in all areas. To see if there is a recovery college in your area you can use a search engine such as Google. Or contact Rethink Mental Illness Advice Service on 0300 5000 927.

You can find out more about:

- Recovery
- Complementary and alternative treatments

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

Top

10. What risks are associated with PTSD?

Alcohol and drug use

You might use drugs or alcohol to help you to manage your symptoms.[35,]

Drugs or alcohol can make you more unwell and more likely to try and harm yourself or take your own life.[36]

Mental health conditions

Symptoms of PTSD can be made worse by other disorders such as:[37]

- depression
- substance abuse, and
- memory problems

Most people with PTSD will have at least 1 other mental health condition. The most common disorders are:[38]

- depressive disorders,
- substance use disorders, and
- anxiety disorders.

Other mental health conditions have the some of the same symptoms as PTSD. This may be why PTSD is hard to diagnose. [39]

Suicidal thoughts and behaviours

In severe cases PTSD can last long enough and have a large impact on day to day life. This can cause suicidal thoughts and behaviours.[40]

Physical health issues

PTSD has been linked to physical symptoms such as dizziness, tinnitus and blurry vision.[41]

It has also been linked to physical illnesses such as heart disease, high blood pressure and obesity.[42]

- You can find more information about: Drugs, alcohol and mental health
- Depression
- Anxiety
- Suicidal feelings – How to cope

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

Top

11. Information for carers, friends and relatives

If you are a carer, friend or relative of someone who hears voices, you can get support.

How can I get support?

You can do the following.

- Speak to your GP about medication and talking therapies for yourself.
- Speak to your relative's care team about a carer's assessment.
- Ask for a carer's assessment from your local social services.
- Join a carers service. They are free and available in most areas.
- Join a carers support group for emotional and practical support. Or set up your own.

What is a carer's assessment?

A carer's assessment is an assessment of the support that you need so that you can continue in your caring role.

To get a carers assessment you need to contact your local authority.

How do I get support from my peers?

You can get peer support through carer support services or carers groups. You can search for local groups in your area by using a search engine such as Google. Or you can contact the Rethink Mental Illness Advice Service and we will search for you.

How can I support the person I care for?

You can do the following.

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

What is a care plan?

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

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

Can I be involved in care planning?

As a carer you can be involved in decisions about care planning. But you don't have a legal right to this.

With the permission from your relative or friend, the NHS can give you information about:[43]

- Common reactions to traumatic events,
- Symptoms of PTSD,
- Assessment for PTSD,
- Treatment and support options, and
- Where treatment will take place.

You can find out more about:

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

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

Top

Further Reading

Armed forces healthcare
Information about how the NHS can help you if you're in military service or a veteran.

www.nhs.uk/using-the-nhs/military-healthcare

Useful Contacts

Anxiety UK
User-led charity which supports people with anxiety disorders, including PTSD.

Telephone: 08444 775 774. (Monday – Friday 9:30am -5:30pm)
Address: Anxiety UK, Nunes House 447 Chester Road, Manchester, M16 9HA
E-mail: support@anxietyuk.org.uk
Text: 07537 416905
Website: www.anxietyuk.org.uk

ASSIST (Assistance Support and Self Help in Surviving Trauma)
Charity providing therapists trained in trauma-focused therapies for PTSD and traumatic bereavement and grief.

Office: 01788 551919

E-mail: admin@assisttraumacare.org.uk
Website: www.assisttraumacare.org.uk

Combat Stress
Charity who offer support to ex-service men and women of all ages who have mental health conditions.

Telephone: 0800 138 1619 (24 hours a day, 7 days a week)
Helpline text: 07537 404719
Address: Tyrwhitt House, Oaklawn Road, Leatherhead, Surrey, KT22 0BX
Email: helpline@combatstress.org.uk
Website: www.combatstress.org.uk

Freedom from Torture
Charity offering one to one therapy, group activities and other support for physical pain to survivors of torture. Such as people with complex PTSD.

Telephone: 020 7697 7777
Email: through the website www.freedomfromtorture.org/contact-us
Website: www.freedomfromtorture.org

NAPAC
Charity supporting adult survivors of childhood abuse.

Telephone: 0808 801 0331 (Monday – Thursday 10am – 9pm, and Friday 10am – 6pm)
E-mail: through the website. https://napac.org.uk/contact/
Address: NAPAC, CAN Mezzanine, 7-14 Great Dover St, London, SE1 4YR
Website: www.napac.org.uk

Rape Crisis
Have a network of independent rape crisis centres.

Address: Rape Crisis England & Wales, Suite E4, Josephs Well, Hanover Walk, Leeds, LS3 1AB
Email: rcewinfo@rapecrisis.org.uk
Website: www.rapecrisis.org.uk

PTSD Resolution
Charity who provide counselling for former armed forces, reservists & families.

Telephone: 0300 302 0551 (Monday – Friday, 9am – 5pm)
E-mail: contact@ptsdresolution.org
Website: www.ptsdresolution.org

UK Psychological Trauma Society
Online list of UK trauma services.

Website: www.ukpts.co.uk/trauma.html

Veterans UK
Government body offering support for veterans. They provide welfare support for veterans of any age, and their families through the Veterans Welfare Service and the Veterans UK helpline.

Telephone for South and Central Wales, Midlands and East England: 01562 825527
Telephone for London, South East and South West England: 02392 702232
Telephone for North West England, Yorkshire and Humber, North Wales and the Isle Of Man: 01253 333494
Telephone for North East England: 0141 2242709

Email: There are different email addresses depending on your location. You can find the correct email address through the website.
Website: www.veterans-uk.info

References

[1] Royal College of psychiatrists. *Post-Traumatic Stress Disorder.* https://www.rcpsych.ac.uk/mental-health/problems-disorders/post-traumatic-stress-disorder#faq-accoridon-collapsec4199279-0665-413d-b3e0-0180832839a2 (accessed 8th July 2019)
[2] NHS. *Post-Traumatic Stress Disorder.* https://www.nhs.uk/conditions/post-traumatic-stress-disorder-ptsd/treatment/ (accessed 9th July 2019)
[3] World health Organization. *The ICD-10 Classification of Mental and Behavioural Disorders Clinical descriptions and diagnostic guidelines*. Geneva: WHO; 2015 at F43.1.
[4] As note 3 at F43.1.
[5] NICE. Post-traumatic stress disorder (NG116) 1.1.1
[6] The British Journal of psychology. *Evaluation of evidence for the psychotic subtyping of post-traumatic stress disorder* https://www.cambridge.org/core/journals/the-british-journal-of-psychiatry/article/evaluation-of-evidence-for-the-psychotic-subtyping-of-posttraumatic-stress-disorder/8F8481E87E89B8D45E0B8BAB2217CDD0# (accessed 9th July 2019)
[7] Pubmed. *Distinguishing schizophrenia from posttraumatic stress disorder with psychosis.* https://www.ncbi.nlm.nih.gov/pubmed/25785709 (accessed 9th July 2019)
[8] As note 5. Para 1.2.2
[9] As note 5. Para 1.2.1

[10] NHS. *Treatment: Post-Traumatic Stress Disorder.* https://www.nhs.uk/conditions/post-traumatic-stress-disorder-ptsd/treatment/ (accessed 9th July 2019)
[11] As note 5. Page 22 'complex PTSD'
[12] As note 5. Page 22 'complex PTSD'
[13] de Zulueta, F. Post-traumatic stress disorder and attachment: possible links with borderline personality disorder. *Advances in Psychiatric Treatment* 2009. Conclusion 15: 172–180. At 173.
[14] As note 5. Para 1.1.2
[15] Royal College of Psychiatrists. *Post-traumatic Stress Disorder* http://www.rcpsych.ac.uk/mentalhealthinfo/problems/ptsd/posttraumaticstressdisorder.aspx (Accessed July 2015)
[16] Pubmed. *Comorbidity of psychiatric disorders and posttraumatic stress disorder.* https://www.ncbi.nlm.nih.gov/pubmed/10795606 (accessed 9th July 2019)
[17] As note 5. Para 1.2.3.
[18] As note 5. Para 1.2.3.
[19] Department of Health and Social Care. *Care and Support Statutory The Care Act 2014*, www.gov.uk/guidance/care-and-support-statutory-guidance (Accessed 9th July 2019) Para. 1.5.
[20] As note 2
[21] As note 5. Para 1.6.16
[22] As note 2
[23] As note 2
[24] As note 5. Para 1.6.17
[25] As note 5. Para 1.6.20
[26] As note 5. Para 1.6.23
[27] As note 5. Para 1.6.22
[28] As note 5. Para 1.6.23
[29] As note 5. Para 1.6.25
[30] As note 5. Para 1.6.26
[31] As note 5. Para 1.7.1
[32] As note 5. Para 1.7.2
[33] As note 5. Para 1.7.3
[34] General Medical Council. *Good Medical Practice*. Manchester: GMC; 2013. Para 16(e)
[35] NIH. The Role of Uncontrollable Trauma in the Development of PTSD and Alcohol Addiction. https://pubs.niaaa.nih.gov/publications/arh23-4/256-262.pdf Page 256 (accessed 9th July 2019)
[36] HM Government. *Preventing suicide in England: Third progress report of the cross-government outcomes strategy to save lives.* London: HM Government; 2017. Page 23, para 78. https://www.gov.uk/government/publications/suicide-prevention-third-annual-report (accessed 9th July 2018).
[37] NCBI. Post-Traumatic Stress Disorder: Evidence-Based Research for the Third Millennium https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1297500/ Post Traumatic Stress Disorder (accessed 8th July 2019)

[38] Pubmed. *Comorbidity of psychiatric disorders and posttraumatic stress disorder.* https://www.ncbi.nlm.nih.gov/pubmed/10795606 (accessed 9th July 2019).
[39] As note 38
[40] Post-Traumatic Stress Disorder: Evidence-Based Research for the Third Millennium https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1297500/ Post Traumatic Stress Disorder (accessed 9th July 2019)
[41] Gupta, MA. Review of somatic symptoms in post-traumatic stress disorder. *International Review of Psychiatry* 2013 Feb; 25(1): 86-99. Abstract available at http://www.ncbi.nlm.nih.gov/pubmed/23383670 (accessed 8th July 2019).
[42] McFarlane, A.C. The long-term costs of traumatic stress: intertwined physical and psychological consequences. *World Psychiatry* 2010 Feb; 9(1) 3-10. Abstract available at www.ncbi.nlm.nih.gov/pubmed/20148146 (accessed 19th September 2019).
[43] As note 5. Para 1.4.2

Last updated July 2019
Next update January 2022
Version 2

This factsheet is available

in large print.

Rethink Mental Illness Advice Service

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

Email advice@rethink.org

Did this help?

We'd love to know if this information helped you.

Drop us a line at: feedback@rethink.org

or write to us at Rethink Mental Illness:
RAIS
PO Box 17106
Birmingham B9 9LL

or call us on 0808 801 0525

We're open 9:30am to 4pm
Monday to Friday (excluding bank holidays)

Rethink Mental Illness.

Leading the way to a better quality of life for everyone affected by severe mental illness.

For further information
on Rethink Mental Illness
Phone 0121 522 7007
Email info@rethink.org

facebook.com/rethinkcharity
twitter.com/rethink_
www.rethink.org

Need more help?

Go to **www.rethink.org** for information on symptoms, treatments, money and benefits and your rights.

Don't have access to the web?

Call us on 0121 522 7007. We are open Monday to Friday, 9am to 5pm, and we will send you the information you need in the post.

Need to talk to an adviser?

If you need practical advice, call us on 0808 801 0525 between 9:30am to 4pm, Monday to Friday. Our specialist advisers can help you with queries like how to apply for benefits, get access to care or make a complaint.

Can you help us to keep going?

We can only help people because of donations from people like you. If you can donate please go to **www.rethink.org/donate** or call 0121 522 7007 to make a gift. We are very grateful for all our donors' generous support.

Registered in England Number 1227970. Registered Charity Number 271028. Registered Office 89 Albert Embankment, London, SE1 7TP. Rethink Mental Illness is the operating name of National Schizophrenia Fellowship, a company limited by guarantee.

factsheet

Post-Traumatic Stress Disorder (PTSD)

This factsheet has information about the symptoms and causes of post-traumatic stress disorder (PTSD). It explains who might develop PTSD and what treatment is available.

Key Points.

- You may develop post-traumatic stress disorder (PTSD) if you experience something which you find traumatic. Such as witnessing an assault, child birth, being bullied, being involved in a road traffic accident or natural disaster.
- The development of the illness depends on how you deal with the experience. It is not dependent on the severity of the experience.
- Not everyone who experiences trauma will develop PTSD
- Symptoms include traumatic memories or dreams, avoiding things that remind you of the event, not being able to sleep and feeling anxious. You may feel isolated and withdrawn.
- If you have PTSD, your doctor should offer you therapy. Medication can be suggested if you need extra support to access therapy. Or if you don't want therapy.
- You are likely to recover from PTSD.

This factsheet covers:

Top

1. What is post-traumatic stress disorder (PTSD)?

You may develop post-traumatic stress disorder after experiencing, or seeing, something that you find traumatic.

The symptoms of PTSD can start immediately or after a delay of weeks or months. It will usually start within 6 months of the traumatic event. [1]

You are likely to recover from PTSD. It is possible to be successfully treated from PTSD years after the trauma, so it's never too late to seek help.[2]

But a few people may deal with symptoms for many years. This can develop into a personality change.[3]

Top

2. What are the symptoms of PTSD?

Some of the symptoms are PTSD and complex PTSD are: [4,5]

- reliving the experience through flashbacks, dreams or nightmares,
- not being able to feel emotions,
- dissociation. This could include disconnecting from yourself or other people,
- negative alternations in mood,
- emotional dysregulation. This means it is difficult to control your emotions,
- problems relating to others,
- problems in relationships
- negative self-perception such as feeling worthless or defeated,
- hyperarousal such as anger, irritability or sleep issues,
- hypervigilance such as feeling on constant alert. Or being overly sensory to stimulus such as smell and noise, and
- avoidance. This could mean that you try to distract your thought from thinking about the trauma. Or you avoid situations that remind you of your trauma.

Is psychosis a symptom of PTSD?

There is a link between PTSD and psychosis. But it is not known if psychosis is a symptom of PTSD. Or a separate mental health condition.[6, 7]

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

Top

3. How is PTSD diagnosed?

A psychiatrist will diagnose PTSD through a mental health assessment. Your GP should carry out an initial assessment to decide what care you need. Your assessment should include information about:[8]

- your physical needs,
- your mental needs,
- your social needs, and
- risk.

As part of the assessment they will decide if you need to be referred to the community mental health team (CMHT).[9] You should be referred to the CMHT if you have had symptoms for more than 4 weeks. Or your symptoms are very bad. [10]A CMHT is part of the NHS. They are a team of mental health professionals.

Doctors use the following manuals to help to diagnose you:

- International Classification of Diseases (ICD-10) produced by the World Health Organisation (WHO), and
- Diagnostic and Statistical Manual (DSM-5) produced by the American Psychiatric Association.

The manuals are guides which explain different mental health conditions.

Top

4. What is complex post-traumatic stress disorder (PTSD)?

The main symptoms of PTSD and complex PTSD are the same. But if you have complex PTSD you will have extra symptoms such as:[11]

- constant issues with keeping a relationship,
- finding it difficult to feel connected to other people,
- constant belief that you are worthless with deep feelings of shame and guilt. This will be related to the trauma, and
- constant and severe emotional dysregulation. This means it is difficult to control your emotions

You are more likely to have complex PTSD if your trauma is linked to an event or series of events. The trauma will be very threatening or frightening. Most commonly from a trauma which you were not able to escape from such as:[12]

- torture
- slavery
- a long period of domestic abuse, or
- a long period of sexual or physical abuse

What is the treatment for complex PTSD?

You may respond to trauma focussed therapies if you have complex PTSD. For more information look at section 6, 'How do I get help if I have symptoms of PTSD' and section 7 'Additional needs and complex PTSD' for more information of this factsheet.

There is some overlap of symptoms for complex PTSD and borderline personality disorder (BPD). If you have complex PTSD you may benefit from certain treatments that help people with BPD.[13]

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

Top

5. What causes PTSD?

PTSD is caused by experiencing or witnessing single, repeated or multiple events. For example:[14]

- serious accidents
- physical and sexual assault abuse. This could include childhood or domestic abuse
- work-related exposure to trauma. Such as being in the army
- trauma related to serious health problems or childbirth
- war and conflict torture

Not everyone who experiences trauma will develop PTSD.

The risk of getting PTSD depends on how the experience affects you. PTSD is more likely to develop if the traumatic event:[15]

- is unexpected,
- goes on for a long time,
- involves being trapped,
- is caused by people,
- causes many deaths,
- causes mutilation to the body, or
- involves children.

If you already have depression when the trauma happens you are at a higher risk of developing PTSD. [16]

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

Top

6. How do I get help if I have symptoms of PTSD?

You can get help from:

- The NHS
- Adult social services
- Charities
- Self help

How can the NHS help me?

You can speak to your GP about your concerns. They will be able to talk to you about treatment options and coping strategies. You don't have to do what your GP thinks that you should do. But you should listen to them.

Make sure that you understand the pros and cons of your treatment options before you make a decision.

Your treatment with be managed by your GP or the community mental health team (CMHT). In some cases, your treatment maybe shared between both primary and secondary care. Healthcare professionals will agree who will monitor you.[17]

Some people will get care under the Care Programme Approach (CPA).[18] This means that you will have a care plan and care coordinator to make sure that you get the support that you need.

Look at section 7 of this factsheet, 'How is PTSD treated by the NHS?' for more information.

Adult social services

If you need help and support to look after yourself then you can have an assessment by social services. For example, you may need support so that you can:[19]

- get out of the house,
- keep in touch with friends and family,
- get a job or take part in education,
- clean your house,
- prepare meals or go shopping,
- keep safe,
- manage your money,
- take part in leisure activities, or
- contribute to society (e.g. volunteering, being in a club or group).

What other help is available?

Charities

In some areas, charities will support people who have PTSD. This may be through support groups where you can talk to other people who have PTSD and other mental health conditions. Group support can help you find ways to manage your symptoms and understand your condition.[20]

There may be a different service available, such as employment or isolation support.

You can look on our website www.rethink.org to see if we have any support groups or services in your area. Click on 'Help in your area' at the top of the webpage.

Some of the other main national mental health charities are:

- Assist
- Combat stress
- Rape crisis
- NAPAC
- Mind,
- Richmond Fellowship,
- Together, and
- Turning Point.

You can look on their websites to see what support they offer in your area.

Contact details for some of these charities are in the 'useful contacts' section of our website.

If you would like us to look for you please contact our advice line on 0300 5000 927 and let us know what sort of support you are looking for.

Self-help

There are things that you can do to help manage your mental health. This is called 'self-help.' You can read more about self-help in section 9 of this factsheet.

You can find more information about:

- Community mental health team
- Care Programme Approach
- Social care assessment - under the Care Act 2014

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

Top

7. How is PTSD treated by the NHS?

The National Institute for Health and Care Excellence (NICE) says that the NHS should offer treatment if you have a diagnosis of PTSD. Or you have important symptoms of PTSD.[21] The treatment that you are offered should be the following.

- Trauma focussed cognitive behavioural therapy (CBT)
- Eye movement desensitisation and reprocessing (EMDR)
- Supported trauma-focused computerised cognitive behavioural therapy (CBT)

- CBT to target an issue
- Medication

You can refer yourself for trauma therapies[22] in most areas. Click the below link to search for psychological therapy services in your area:

https://beta.nhs.uk/find-a-psychological-therapies-service/

Watchful waiting

Watchful waiting may be suggested if you have mild symptoms of PTSD. Or the trauma has happened within the last 4 weeks. This means that your symptoms should be monitored, and you should have a follow up appointment in 1 month.

Watchful waiting is sometimes recommended because 2 in every 3 people who experience a trauma will recover without treatment.[23]

What is trauma-focused cognitive behavioural therapy (CBT)?

Cognitive behavioural therapy (CBT) helps you deal with your symptoms by making changes to how you think and act.

Your therapy should: [24]

- be delivered by a trained practitioner,
- last between 8-12 sessions. You can have more if needed. For example, if you have had different or repeated traumas,
- include psychoeducation about:
  - reaction to trauma,
  - how to manage hyperarousal such as anger
  - how to manage flashbacks, and
  - safety planning
- help you how to process trauma related emotions, such as shame and guilt,
- help you to manage relationships,
- help you to deal with avoidance, and
- plan a booster session if needed. Such as support near to trauma anniversaries.

What is Eye movement desensitisation and reprocessing (EMDR)?

You will make eye movements while thinking about the traumatic event. Therapists think that this works by making your brain deal with painful memories in a different way.

Your therapy should:[25]

- be delivered by a trained practitioner,
- last between 8-12 sessions. You can have more if needed such as if you have had different or repeated trauma,

- be delivered in phases,
- include psychoeducation about:
    - reaction to trauma,
    - how to manage distressing memories and situations,
    - treat certain memories, often they will be visual, and
    - teach you how to think positively about yourself
- use eye stimulation to help you manage certain memories. This should be used until the memories are no longer distressing,
- teach you self-calming techniques to help in-between sessions, and
- teach you techniques to manage flashbacks in-between sessions.

What is supported trauma-focused computerised cognitive behavioural therapy (CBT)?

You will have therapy through a computer programme.

You may be able to have supported trauma-focused computerised CBT if you prefer it to face to face trauma focused CBT or EMDR. And if it is more than 3 months since the trauma. You should only be offered this therapy if:[26]

- your PTSD symptoms aren't severe,
- you don't have any dissociative symptoms, and
- you are not a risk of harm to yourself or others.

Your therapy should:[27]

- usually be 8 to 10 sessions long,
- help you to learn to process your trauma,
- help you to deal with avoidance,
- help you manage relationships,
- involve guidance and support from a trained practitioner, and
- involve feedback and a review of your progress and outcomes with your practitioner.

What is CBT to target an issue?

This is a CBT aimed at specific symptoms of PTSD such as sleep problems or anger. You may be offered this type of CBT if you:[28]

- are unable to engage with trauma focussed therapies
- don't want trauma focussed therapies, or
- you still have some PTSD symptoms after trauma focussed therapy.

Medication

Your doctor might offer you venlafaxine or a selective serotonin reuptake inhibitor (SSRI) if you would prefer drug treatment. The treatment will need to be reviewed regularly.[29]

You may be offered antipsychotic medication, such as risperidone at the same time as talking treatments. This may be offered if you have severe symptoms such as psychosis. The treatment will need to be reviewed regularly by a specialist.[30]

How is PTSD treated if I have complex needs?

Depression

If you have depression and PTSD, your doctor might treat your PTSD first. Your depression may improve after you get treatment for PTSD. Your doctor should treat your depression first if:[31]

- it makes it difficult for you to take part in therapy for PTSD, or
- you are a risk of harm to yourself or other people

Additional needs and complex PTSD

You should not be excluded from treatment because you have a drug or alcohol issue.[32] If you have a drug or alcohol issue then this would be considered as an 'additional need'.

Your health professional should:[33]

- give you more therapy sessions or give you longer therapy sessions to help build trust,
- think about the impact that your personal situation will have on the outcome of therapy,
- help you to manage any issues that might stop you from being able to engage with trauma focused therapies. Such as substance misuse, dissociation or problems controlling your emotions, and
- plan any ongoing support that you need after the end of treatment. Such as managing other mental health conditions.

You can find out more about:

- Talking therapies
- Antidepressants
- Antipsychotics
- Psychosis
- Depression
- Drugs, alcohol and mental health
- Medication. Choice and managing problems

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

Top

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

If you are not happy with your treatment you can:

- talk to your doctor about your treatment options,
- ask for a second opinion,
- ask a relative, friend or advocate to help you speak your doctor,
- contact Patient Advice and Liaison Service (PALS), or
- make a complaint.

There is more information about these options below.

Treatment options

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

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

Second opinion

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

You don't have a legal right to a second opinion. But your doctor should listen to your reason for wanting a second opinion.[34]

Advocacy

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

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

The Patient Advice and Liaison Service (PALS)

PALS is part of the NHS. They give information and support to patients. You can find your local PALS through this website link:

https://www.nhs.uk/Service-Search/Patient-advice-and-liaison-services-(PALS)/LocationSearch/363

You can find out more about:

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

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

Top

9. What self-care and management skills can I try?

There are things that you can do to help yourself. This is also known as self-care. When it comes to what helps people, everyone is different. You may need to different lifestyle changes until you find what works for you. Such as the following.

Learn ways to relax. Such as listening to meditation CDs or relaxing music. You can find free meditation videos on websites like YouTube.

Practise mindfulness and meditation. You can find out more here: www.mindful.org/meditation/mindfulness-getting-started/

Eat healthy foods and have a balanced diet. You can find out nutritional advice here: www.nhs.uk/livewell/healthy-eating/Pages/Healthyeating.aspx

Keep physically active. Exercise can help to reduce stress and anxiety. It can increase the levels of serotonin and endorphins which are your body's natural 'happy' chemicals. www.weareundefeatable.co.uk.

Drink enough water.

Have a daily routine. Keeping a routine can help you to keep your mind occupied and focused on healthy thoughts and activities.

Have healthy relationships. You can find more tips on how to maintain healthy relationships here: www.mentalhealth.org.uk/sites/default/files/guide-investing-relationships-may-2016.pdf

Get enough sleep. Without regular sleep, your mental health can be affected. You can find out more about improving your sleep at: www.rethink.org/advice-and-information/living-with-mental-illness/wellbeing-physical-health/sleep

Be aware of your alcohol intake. Unhealthy drinking habits can lead to poor mental health. Some people use alcohol to deal with their emotions. This is called 'self-medication.' If you recognise that you do this, you could avoid alcohol or cut down. Try a different coping technique to help you manage how you feel. You may need professional help to do this.

You should also consider the effect of alcohol on any medication you take. You can ask your doctor if you need more information.

Avoid smoking or cut down. Smoking can affect your medication and your health. If you are not sure how your medication is affected speak to your doctor.

Keep a mood diary. This can help you to be more aware of your symptoms and what makes you better and worse. You can simply use a notebook for this. Or you may want to try online resources or smartphone apps like:

- MoodPanda: http://moodpanda.com/
- Daylio: https://daylio.webflow.io/
- Evernote: https://evernote.com/

Self-help online

There are websites which give information about how to manage your mental health. There are also websites which explain how you can use cognitive behavioural therapy (CBT) techniques to improve and manage your mental health. Some people find these useful.

- **Mood Juice PTSD self-help:** www.moodjuice.scot.nhs.uk/posttrauma.asp
- **Northumberland, Tyne and Wear NHS self-help leaflets** www.ntw.nhs.uk/pic/selfhelp
- **Public Health England. One You:** www.nhs.uk/oneyou/every-mind-matters/
- **Mood Gym**: https://moodgym.anu.edu.au/welcome/new/splash;
- **Live life to the Full**: Online courses. www.llttf.com/index.php?section=page&page_seq=8&;
- **Psychology Tools:** http://psychologytools.com/.

Recovery College

Recovery colleges are part of the NHS. They offer free courses about mental health to help you manage your symptoms. They can help you to take control of your life and become an expert in your own wellbeing and recovery. You can usually self-refer to a recovery college. But the college may tell your care team.

Unfortunately, recovery colleges are not available in all areas. To see if there is a recovery college in your area you can use a search engine such as Google. Or contact Rethink Mental Illness Advice Service on 0300 5000 927.

You can find out more about:

- Recovery
- Complementary and alternative treatments

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

Top

10. What risks are associated with PTSD?

Alcohol and drug use

You might use drugs or alcohol to help you to manage your symptoms.[35,]

Drugs or alcohol can make you more unwell and more likely to try and harm yourself or take your own life.[36]

Mental health conditions

Symptoms of PTSD can be made worse by other disorders such as:[37]

- depression
- substance abuse, and
- memory problems

Most people with PTSD will have at least 1 other mental health condition. The most common disorders are:[38]

- depressive disorders,
- substance use disorders, and
- anxiety disorders.

Other mental health conditions have the some of the same symptoms as PTSD. This may be why PTSD is hard to diagnose. [39]

Suicidal thoughts and behaviours

In severe cases PTSD can last long enough and have a large impact on day to day life. This can cause suicidal thoughts and behaviours.[40]

Physical health issues

PTSD has been linked to physical symptoms such as dizziness, tinnitus and blurry vision.[41]

It has also been linked to physical illnesses such as heart disease, high blood pressure and obesity.[42]

- You can find more information about: Drugs, alcohol and mental health
- Depression
- Anxiety
- Suicidal feelings – How to cope

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

Top

11. Information for carers, friends and relatives

If you are a carer, friend or relative of someone who hears voices, you can get support.

How can I get support?

You can do the following.

- Speak to your GP about medication and talking therapies for yourself.
- Speak to your relative's care team about a carer's assessment.
- Ask for a carer's assessment from your local social services.
- Join a carers service. They are free and available in most areas.
- Join a carers support group for emotional and practical support. Or set up your own.

What is a carer's assessment?

A carer's assessment is an assessment of the support that you need so that you can continue in your caring role.

To get a carers assessment you need to contact your local authority.

How do I get support from my peers?

You can get peer support through carer support services or carers groups. You can search for local groups in your area by using a search engine such as Google. Or you can contact the Rethink Mental Illness Advice Service and we will search for you.

How can I support the person I care for?

You can do the following.

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

What is a care plan?

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

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

Can I be involved in care planning?

As a carer you can be involved in decisions about care planning. But you don't have a legal right to this.

With the permission from your relative or friend, the NHS can give you information about:[43]

- Common reactions to traumatic events,
- Symptoms of PTSD,
- Assessment for PTSD,
- Treatment and support options, and
- Where treatment will take place.

You can find out more about:

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

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

Top

Further Reading

Armed forces healthcare
Information about how the NHS can help you if you're in military service or a veteran.

www.nhs.uk/using-the-nhs/military-healthcare

Useful Contacts

Anxiety UK
User-led charity which supports people with anxiety disorders, including PTSD.

Telephone: 08444 775 774. (Monday – Friday 9:30am -5:30pm)
Address: Anxiety UK, Nunes House 447 Chester Road, Manchester, M16 9HA
E-mail: support@anxietyuk.org.uk
Text: 07537 416905
Website: www.anxietyuk.org.uk

ASSIST (Assistance Support and Self Help in Surviving Trauma)
Charity providing therapists trained in trauma-focused therapies for PTSD and traumatic bereavement and grief.

Office: 01788 551919

E-mail: admin@assisttraumacare.org.uk
Website: www.assisttraumacare.org.uk

Combat Stress
Charity who offer support to ex-service men and women of all ages who have mental health conditions.

Telephone: 0800 138 1619 (24 hours a day, 7 days a week)
Helpline text: 07537 404719
Address: Tyrwhitt House, Oaklawn Road, Leatherhead, Surrey, KT22 0BX
Email: helpline@combatstress.org.uk
Website: www.combatstress.org.uk

Freedom from Torture
Charity offering one to one therapy, group activities and other support for physical pain to survivors of torture. Such as people with complex PTSD.

Telephone: 020 7697 7777
Email: through the website www.freedomfromtorture.org/contact-us
Website: www.freedomfromtorture.org

NAPAC
Charity supporting adult survivors of childhood abuse.

Telephone: 0808 801 0331 (Monday – Thursday 10am – 9pm, and Friday 10am – 6pm)
E-mail: through the website. https://napac.org.uk/contact/
Address: NAPAC, CAN Mezzanine, 7-14 Great Dover St, London, SE1 4YR
Website: www.napac.org.uk

Rape Crisis
Have a network of independent rape crisis centres.

Address: Rape Crisis England & Wales, Suite E4, Josephs Well, Hanover Walk, Leeds, LS3 1AB
Email: rcewinfo@rapecrisis.org.uk
Website: www.rapecrisis.org.uk

PTSD Resolution
Charity who provide counselling for former armed forces, reservists & families.

Telephone: 0300 302 0551 (Monday – Friday, 9am – 5pm)
E-mail: contact@ptsdresolution.org
Website: www.ptsdresolution.org

UK Psychological Trauma Society
Online list of UK trauma services.

Website: www.ukpts.co.uk/trauma.html

Veterans UK
Government body offering support for veterans. They provide welfare support for veterans of any age, and their families through the Veterans Welfare Service and the Veterans UK helpline.

Telephone for South and Central Wales, Midlands and East England: 01562 825527
Telephone for London, South East and South West England: 02392 702232
Telephone for North West England, Yorkshire and Humber, North Wales and the Isle Of Man: 01253 333494
Telephone for North East England: 0141 2242709

Email: There are different email addresses depending on your location. You can find the correct email address through the website.
Website: www.veterans-uk.info

References

[1] Royal College of psychiatrists. *Post-Traumatic Stress Disorder.* https://www.rcpsych.ac.uk/mental-health/problems-disorders/post-traumatic-stress-disorder#faq-accoridon-collapsec4199279-0665-413d-b3e0-0180832839a2 (accessed 8th July 2019)
[2] NHS. *Post-Traumatic Stress Disorder.* https://www.nhs.uk/conditions/post-traumatic-stress-disorder-ptsd/treatment/ (accessed 9th July 2019)
[3] World health Organization. *The ICD-10 Classification of Mental and Behavioural Disorders Clinical descriptions and diagnostic guidelines*. Geneva: WHO; 2015 at F43.1.
[4] As note 3 at F43.1.
[5] NICE. Post-traumatic stress disorder (NG116) 1.1.1
[6] The British Journal of psychology. *Evaluation of evidence for the psychotic subtyping of post-traumatic stress disorder* https://www.cambridge.org/core/journals/the-british-journal-of-psychiatry/article/evaluation-of-evidence-for-the-psychotic-subtyping-of-posttraumatic-stress-disorder/8F8481E87E89B8D45E0B8BAB2217CDD0# (accessed 9th July 2019)
[7] Pubmed. *Distinguishing schizophrenia from posttraumatic stress disorder with psychosis.* https://www.ncbi.nlm.nih.gov/pubmed/25785709 (accessed 9th July 2019)
[8] As note 5. Para 1.2.2
[9] As note 5. Para 1.2.1

[10] NHS. *Treatment: Post-Traumatic Stress Disorder.* https://www.nhs.uk/conditions/post-traumatic-stress-disorder-ptsd/treatment/ (accessed 9th July 2019)
[11] As note 5. Page 22 'complex PTSD'
[12] As note 5. Page 22 'complex PTSD'
[13] de Zulueta, F. Post-traumatic stress disorder and attachment: possible links with borderline personality disorder. *Advances in Psychiatric Treatment* 2009. Conclusion 15: 172–180. At 173.
[14] As note 5. Para 1.1.2
[15] Royal College of Psychiatrists. *Post-traumatic Stress Disorder* http://www.rcpsych.ac.uk/mentalhealthinfo/problems/ptsd/posttraumaticstressdisorder.aspx (Accessed July 2015)
[16] Pubmed. *Comorbidity of psychiatric disorders and posttraumatic stress disorder.* https://www.ncbi.nlm.nih.gov/pubmed/10795606 (accessed 9th July 2019)
[17] As note 5. Para 1.2.3.
[18] As note 5. Para 1.2.3.
[19] Department of Health and Social Care. *Care and Support Statutory The Care Act 2014*, www.gov.uk/guidance/care-and-support-statutory-guidance (Accessed 9th July 2019) Para. 1.5.
[20] As note 2
[21] As note 5. Para 1.6.16
[22] As note 2
[23] As note 2
[24] As note 5. Para 1.6.17
[25] As note 5. Para 1.6.20
[26] As note 5. Para 1.6.23
[27] As note 5. Para 1.6.22
[28] As note 5. Para 1.6.23
[29] As note 5. Para 1.6.25
[30] As note 5. Para 1.6.26
[31] As note 5. Para 1.7.1
[32] As note 5. Para 1.7.2
[33] As note 5. Para 1.7.3
[34] General Medical Council. *Good Medical Practice*. Manchester: GMC; 2013. Para 16(e)
[35] NIH. The Role of Uncontrollable Trauma in the Development of PTSD and Alcohol Addiction. https://pubs.niaaa.nih.gov/publications/arh23-4/256-262.pdf Page 256 (accessed 9th July 2019)
[36] HM Government. *Preventing suicide in England: Third progress report of the cross-government outcomes strategy to save lives.* London: HM Government; 2017. Page 23, para 78. https://www.gov.uk/government/publications/suicide-prevention-third-annual-report (accessed 9th July 2018).
[37] NCBI. Post-Traumatic Stress Disorder: Evidence-Based Research for the Third Millennium https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1297500/ Post Traumatic Stress Disorder (accessed 8th July 2019)

[38] Pubmed. *Comorbidity of psychiatric disorders and posttraumatic stress disorder.* https://www.ncbi.nlm.nih.gov/pubmed/10795606 (accessed 9th July 2019).
[39] As note 38
[40] Post-Traumatic Stress Disorder: Evidence-Based Research for the Third Millennium https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1297500/ Post Traumatic Stress Disorder (accessed 9th July 2019)
[41] Gupta, MA. Review of somatic symptoms in post-traumatic stress disorder. *International Review of Psychiatry* 2013 Feb; 25(1): 86-99. Abstract available at http://www.ncbi.nlm.nih.gov/pubmed/23383670 (accessed 8th July 2019).
[42] McFarlane, A.C. The long-term costs of traumatic stress: intertwined physical and psychological consequences. *World Psychiatry* 2010 Feb; 9(1) 3-10. Abstract available at www.ncbi.nlm.nih.gov/pubmed/20148146 (accessed 19th September 2019).
[43] As note 5. Para 1.4.2

Last updated July 2019
Next update January 2022
Version 2

This factsheet is available

in large print.

Rethink Mental Illness Advice Service

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

Email advice@rethink.org

Did this help?

We'd love to know if this information helped you.

Drop us a line at: feedback@rethink.org

or write to us at Rethink Mental Illness:
RAIS
PO Box 17106
Birmingham B9 9LL

or call us on 0808 801 0525

We're open 9:30am to 4pm
Monday to Friday (excluding bank holidays)

Rethink Mental Illness.

Leading the way to a better quality of life for everyone affected by severe mental illness.

For further information
on Rethink Mental Illness
Phone 0121 522 7007
Email info@rethink.org

facebook.com/rethinkcharity
twitter.com/rethink_
www.rethink.org

Need more help?

Go to **www.rethink.org** for information on symptoms, treatments, money and benefits and your rights.

Don't have access to the web?

Call us on 0121 522 7007. We are open Monday to Friday, 9am to 5pm, and we will send you the information you need in the post.

Need to talk to an adviser?

If you need practical advice, call us on 0808 801 0525 between 9:30am to 4pm, Monday to Friday. Our specialist advisers can help you with queries like how to apply for benefits, get access to care or make a complaint.

Can you help us to keep going?

We can only help people because of donations from people like you. If you can donate please go to **www.rethink.org/donate** or call 0121 522 7007 to make a gift. We are very grateful for all our donors' generous support.

Registered in England Number 1227970. Registered Charity Number 271028. Registered Office 89 Albert Embankment, London, SE1 7TP. Rethink Mental Illness is the operating name of National Schizophrenia Fellowship, a company limited by guarantee.

factsheet

Schizophrenia

This factsheet covers what schizophrenia is, what the symptoms are and how you can get treatment. You might find it useful if you live with schizophrenia, or if you care for someone who does.

Key Points.

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

This factsheet covers:

1. What is schizophrenia?

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

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

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

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

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

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

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

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

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

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

Top

2. What myths are there about schizophrenia?

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

- 'Schizophrenia means someone has a split personality'

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

- 'Schizophrenia causes people to be violent'

Research shows that only a small number of people with the illness may become violent. The same way as a small minority of the general public may become violent.[4]

People with schizophrenia are far more likely to be harmed by other people than other people are to be harmed by them.[5] But as these incidents can be shocking, the media often report them in a way which emphasises the mental health diagnosis. This can create fear and stigma in the general public.

Top

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

How is schizophrenia diagnosed?

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

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

The 2 main manuals used by medical professionals are the:

- International Classification of Diseases (ICD-10) which is produced by the World Health Organisation (WHO), or
- Diagnostic and Statistical Manual (DSM-5) which is produced by the American Psychiatric Association (APA).

NHS doctors use the ICD-10.[6]

The manuals explain which symptoms should be present, and for how long for you to receive a diagnosis. For example, according to the NHS you need to be hearing voices for at least 1 month before you can be diagnosed.[7] Mental health professionals may say you have psychosis before they diagnose you with schizophrenia.

What is the future of diagnosis in schizophrenia?

There are many research studies being conducted across the world on how to better diagnose schizophrenia. For example, a recent study found through looking at images of the brain, there may be different sub-types of schizophrenia. [8]

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

What are the symptoms of schizophrenia?

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

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

The negative symptoms of schizophrenia can often appear several years before somebody experiences their first episode of psychosis. [9]

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

What are the 'positive symptoms' of schizophrenia?

The term 'positive symptoms' is used to describe symptoms that are experienced in addition to reality . These symptoms can also happen in other mental illnesses. They are usually called 'psychotic symptoms' or 'psychosis'.[10]

The following are some examples of positive symptoms.[11]

- Hallucinations
- Delusions
- Disorganised thinking

Hallucinations

These are when you see, smell, hear or feel things that other people don't.[12] For example:

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

Hearing voices or other sounds is the most common hallucination. [13] Hearing voices is different for everyone. For example, voices may be:

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

You might hear voices sometimes or all of the time.

Delusions

These are beliefs that are not based on reality. Even though they feel real to you. [14] Other people are likely to disagree with your beliefs. A delusion is not the same as holding a religious or spiritual belief which others don't share. For example, you may believe:

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

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

Disorganised thinking[15]

Disorganised thinking means you might start talking quickly or slowly. Things you say might not make sense to other people. You may switch

topics, or your words may become jumbled, making conversations difficult for other people to understand..

This is sometimes known as ‘word salad’.

What are the ‘negative symptoms’ of schizophrenia?

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

The following are some examples of negative symptoms. [16,17]

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

Cognitive Impairment

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

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

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

You can find more information about:

- Psychosis
- Hearing voices

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

Top

4. What are the types of schizophrenia?

There are different types of schizophrenia.[18] The International Classification of Diseases (ICD-10) manual describes them as below.

Paranoid schizophrenia[19]

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

Hebephrenic schizophrenia[20,21]

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

Catatonic schizophrenia[22]

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

Simple schizophrenia[23]

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

Undifferentiated schizophrenia[24]

Your diagnosis may have some signs of paranoid, hebephrenic or catatonic schizophrenia, but doesn't obviously fit into one of these types alone.

Residual schizophrenia[25]

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

Other schizophrenia[26]

There are other types of schizophrenia' according to the ICD-10, such as.

- **Cenesthopathic schizophrenia**. This is where people experience unusual bodily sensations.
- **Schizophreniform.** Schizophreniform disorder is a type of psychotic illness with symptoms similar to those of schizophrenia. But symptoms last for a short period.[27]

Unspecified schizophrenia[28]

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

Top

5. What causes schizophrenia?

Nobody knows exactly what causes schizophrenia, it is likely to be the result of several factors. For example:[29]

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

There is research to suggest that may be an association between menopause and schizophrenia. This may be due to the hormonal changes during this stage of life for women.[30]

You can find more information about:

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

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

Top

6. How is schizophrenia treated?

There are different types of treatment available. Medical professionals should work with you to find the right treatment for you. The National Institute for Health and Care Excellence (NICE) recommends that you should be offered a combination of medication and talking therapies.[31]

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

For every 5 people with schizophrenia:[32]

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

What medication should I be offered?

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

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

If you have been on an antipsychotic for a few weeks and the side effects are too difficult to cope with, you should ask your doctor about trying a different one. NICE state that people who have not responded to at least 2 other antipsychotic drugs should be offered clozapine.[33]

Antipsychotic medication can come as tablets, a syrup or as an injection. The injections are called a depot. You may find a depot useful if you struggle to remember to take your medication, or might take too much.[34] Your doctor should take your views into account when prescribing you medication.

Your medication should be reviewed at least once a year.[35]

What type of psychosocial treatment will I be offered?

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

Cognitive behavioural therapy for psychosis (CBTp)

NICE says the NHS should offer cognitive behavioural therapy for psychosis (CBTp) to all adults with psychosis or schizophrenia.[36] CBTp does not get rid of your symptoms. CBTp can help you to manage your feelings and symptoms better.

Family intervention

NICE recommend family members of people with psychosis and schizophrenia should be offered family intervention.[37] This can help to

improve how you feel about family relationships. This can help reduce any problems in the family caused by your symptoms.

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

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

Your family should get support for 3 months to 1 year and should have at least 10 planned sessions.[38]

Family intervention could be to[39]

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

Family intervention could help you and your family to:

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

Psycho-education

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

Arts therapies

This can help to reduce the negative symptoms of the illness.[40] It can help you to express yourself more creatively.

Early intervention teams

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

Your doctor should refer you to an early intervention team when they diagnose you with a first episode of psychosis. NICE suggests that you should start treatment within 2 weeks of referral.[41] Early intervention services operate differently across the country. If there is not a service in

your area, then you should have access to a crisis or home treatment team.

You can find more information about:

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

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

Top

6. Is it possible to recover from schizophrenia?

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

Recovery can be thought of in terms of:

- clinical recovery, and
- personal recovery.

What is clinical recovery?

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

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

Sometimes this is called 'clinical recovery'.

Everyone's experience of clinical recovery is different.

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

What is personal recovery?

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

Personal recovery means that you can live a meaningful life.

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

Below are some ways you can think of recovery.

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

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

What can help me recover?

You may want to think about the following questions.

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

The following things can be important in recovery.

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

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

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

Sarah's story

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

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

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

Top

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

If you are not happy with your treatment you can:

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

There is more information about these options below.

Treatment options

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

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

Second opinion

A second opinion means that you would like a different doctor to give their opinion about what treatment you should have. You can also ask for a second opinion if you disagree with your diagnosis.
You don't have a right to a second opinion. But your doctor should listen to your reason for wanting a second opinion.[42]

Advocacy

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

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

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

The Patient Advice and Liaison Service (PALS)

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

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

Complaints

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

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

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

You can find out more about:

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

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

Top

8. What can I do to manage schizophrenia?

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

Support groups

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

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

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

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

Recovery College

Recovery colleges are part of the NHS. They offer free courses about mental health to help you manage your experiences. They can help you to take control of your life and become an expert in your own wellbeing and recovery. You can usually self-refer to a recovery college. But the college may tell your care team.

Unfortunately, recovery colleges are not available in all areas. To see if there is a recovery college in your area you can use a search engine such as Google. Or you can call our advice service on 0808 801 0525 for more information.

Peer support through the NHS

Your doctor may offer you peer support. Peer support is when you work with someone who has lived experience of psychosis. And who are now in recovery.[43] They should be able to offer advice and support with: [44]

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

Self-management techniques

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

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

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

Taking control of the voices

If you hear voices, you could:

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

You can find out more about:

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

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

Top

9. What risks and complications can schizophrenia cause?

Physical health

Research suggests that people with serious mental illness (SMI), such as schizophrenia, have a shorter life expectancy. People with mental illness may die 15 to 20 years earlier than the general population.[45,46] This may because people who live with SMI are at higher risk of having a range of health issues. Such as being overweight, having heart disease, smoking and diabetes.[47 ,48]

Because of these issues, NICE recommends that when you start taking antipsychotic medication, your doctor should do a full range of physical health checks. This should include weight, blood pressure and other blood tests. These checks should be repeated regularly. [49]

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

Suicide

The risk of suicide is increased for people with schizophrenia. Research indicates that around 5–13% of people who live with with schizophrenia die by suicide.[50]

Research has found that the increased risk is not usually because of positive symptoms. The risk of suicide is associated more to affective symptoms, such as low mood.[51]

Key risk factors for suicide include: [52]

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

Top

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

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

How can I get support for myself?

You can do the following.

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

What is a carers assessment?

NICE guidelines state that you should be given your own assessment through the community mental health team (CMHT) to work out what effect your caring role is having on your health. And what support you need. Such as practical support and emergency support.[53]

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

How do I get support from my peers?

You can get peer support through carer support services or carers groups. You can search for local groups in your area by using a search engine

such as Google. Or you can call our advice service on 0808 801 0525. They will search for you.

How can I support the person I care for?

You can do the following.

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

What is a care plan?

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

A care plan should always include a crisis plan. A crisis plan will have information about who to contact if they become unwell. You should be given information about what to do in a crisis. [54] You can use this information to support and encourage them to stay well and get help if needed.

Can I be involved in care planning?

As a carer you should be involved in decisions about care planning. But you don't have a legal right to this. The healthcare team should encourage the person that you care for to allow information to be shared with you.[55]

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

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

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

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

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

What is a Mental Health Act Assessment?

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

How do I ask for a Mental Health Act assessment?

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

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

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

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

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

Think about the following questions:

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

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

You can find out more about:

- Supporting someone with a mental illness
- Getting help in a crisis
- Suicidal thoughts. How to support someone
- Responding to unusual thoughts and behaviours

- Carers assessment
- Confidentiality and information sharing. For carers, friends and family
- Money matters: dealing with someone else's finances
- Worried about someone's mental health
- Benefits for carers
- Stress
- Nearest Relative
- Mental Health Act

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

Further Reading

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

Eleanor Longden – The voices in my head

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

Website: www.ted.com/talks/eleanor_longden_the_voices_in_my_head

The BBC – Why do people hear voices in their heads?

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

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

Understanding Voices

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

Website: https://understandingvoices.com/

Me and My Mind

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

Website: www.meandmymind.nhs.uk/

Avatar Therapy

Researchers have been looking into how computer-based treatment may help with hearing voices. [56,57] This treatment is known as avatar therapy. Avatar therapy is not available on the NHS at the moment.

In this therapy you create a computer-generated face with a voice which is like a voice you hear. This is called an 'avatar'. You work with a therapist to talk to the avatar and gain more control over the voice you hear.

Results show that this therapy is helpful for some people. But there is more research taking place. You can read about the study by following the link below.

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

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

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

Useful Contacts

The Royal College of Psychiatrists
Their website has reliable information about different mental illnesses.

Telephone: 020 7235 2351
Email through online form: www.rcpsych.ac.uk/about-us/contact-us
Website: www.rcpsych.ac.uk/

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

Email: info@hearing-voices.org
Website: www.hearing-voices.org

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

Email: info@intervoiceonline.org
Website: www.intervoiceonline.org

Headway
Help people with a brain injury and their families.

Telephone: 0808 800 2244
Address: Headway - the brain injury association, Bradbury House, 190 Bagnall Road, Old Basford, Nottingham, NG6 8SF
E-mail: helpline@headway.org.uk
Website: www.headway.org.uk

References

[1] Royal College of Psychiatrists. *Schizophrenia* www.rcpsych.ac.uk/healthadvice/parentsandyouthinfo/parentscarers/schizophrenia.aspx (accessed 14th December 2020).
[2] Larson et al. *Early signs, diagnosis and therapeutics of the prodromal phase of schizophrenia and related psychotic disorders.* 2010; 10(8): 1347–1359. DOI: 10.1586/ern.10.93
[3] Psychology Today. *A brief history of schizophrenia.* www.psychologytoday.com/gb/blog/hide-and-seek/201209/brief-history-schizophrenia (accessed 16th December 2020).
[4] Hodgins, S. (2008). Violent behaviour among people with schizophrenia: a framework for investigations of causes, and effective treatment, and prevention. *Philosophical Transactions of the Royal Society B: Biological Sciences*, *363*(1503), 2505-2518.See para 3 under 'Violent criminal offending among persons with schizophrenia.'
[5] Royal College of Psychiatrists. *Schizophrenia* www.rcpsych.ac.uk/healthadvice/parentsandyouthinfo/parentscarers/schizophrenia.aspx (accessed 9th February 2021).
[6] NHS Digital. *Information Standards - Clinical Classifications.* 2017 https://digital.nhs.uk/services/terminology-and-classifications/clinical-classifications (accessed 14th December 2020).
[7] NHS Choices. *Schizophrenia – diagnosis.*www.nhs.uk/conditions/schizophrenia/diagnosis/ . (accessed 14th December 2020).
[8] Chand, G. B., Dwyer, D. B., Erus, G., Sotiras, A., Varol, E., Srinivasan, D., ... & Kahn, R. S. (2020). Two distinct neuroanatomical subtypes of schizophrenia revealed using machine learning. *Brain*, *143*(3), 1027-1038.
[9] NHS Choices. *Schizophrenia – symptoms.* www.nhs.uk/conditions/schizophrenia/symptoms/ (accessed 17th December 2020).
[10] Royal College of Psychiatrists. *Schizophrenia: What is schizophrenia?* www.rcpsych.ac.uk/mental-health/problems-disorders/schizophrenia (accessed 17th January 2021).
[11] NHS Choices. *Schizophrenia – symptoms.* www.nhs.uk/conditions/schizophrenia/symptoms/ (accessed 14th December 2020).
[12] NHS. *Hallucinations and hearing voices* www.nhs.uk/conditions/hallucinations/ (accessed 28th January 2021)
[13] NHS. Hallucinations and hearing voices https://www.nhs.uk/conditions/hallucinations/ (accessed 28th January 2021)
[14] NHS. *Symptoms. psychosis* www.nhs.uk/conditions/psychosis/symptoms/ (accessed 2nd February 2021)

[15] NHS Choices. *Schizophrenia – symptoms.* www.nhs.uk/conditions/schizophrenia/symptoms/ (accessed 17th January 2021).
[16] NHS. *Schizophrenia: symptoms.* www.nhs.uk/conditions/schizophrenia/symptoms/ (accessed 17th January 2021).
[17] Royal College of Psychiatrists. *Schizophrenia: What are the symptoms of schizophrenia?* www.rcpsych.ac.uk/mental-health/problems-disorders/schizophrenia (accessed 17th January 2021).
[18] World Health Organization (1994) *The ICD-10 Classification of Mental and Behavioural Disorders Clinical descriptions and diagnostic guidelines F20 – F20.9* http://apps.who.int/classifications/icd10/browse/2015/en#/F20 (accessed 16th December 2020)

[19] World Health Organization (1994) *The ICD-10 Classification of Mental and Behavioural Disorders Clinical descriptions and diagnostic guidelines F20.0* http://apps.who.int/classifications/icd10/browse/2016/en#/F20.0
[20] World Health Organization (1994) *The ICD-10 Classification of Mental and Behavioural Disorders Clinical descriptions and diagnostic guidelines F20.1* http://apps.who.int/classifications/icd10/browse/2016/en#/F20.1
[21] Mental Health Reference. *Hebephrenic Schizophrenia Diagnostic Criteria.* https://mhreference.org/schizophrenic/schizophrenia-icd/hebephrenic/ (accessed 2nd February 2021).
[22] World Health Organization (1994) *The ICD-10 Classification of Mental and Behavioural Disorders Clinical descriptions and diagnostic guidelines F20.2* http://apps.who.int/classifications/icd10/browse/2016/en#/F20.2
[23] World Health Organization (1994) *The ICD-10 Classification of Mental and Behavioural Disorders Clinical descriptions and diagnostic guidelines F20.6* *http://apps.who.int/classifications/icd10/browse/2016/en#/F20.6*
[24] World Health Organization (1994) *The ICD-10 Classification of Mental and Behavioural Disorders Clinical descriptions and diagnostic guidelines F20.3* http://apps.who.int/classifications/icd10/browse/2016/en#/F20.3
[25] World Health Organization (1994) *The ICD-10 Classification of Mental and Behavioural Disorders Clinical descriptions and diagnostic guidelines F20.5* http://apps.who.int/classifications/icd10/browse/2016/en#/F20.5
[26] World Health Organization (1994) *The ICD-10 Classification of Mental and Behavioural* Disorders Clinical descriptions and diagnostic guidelines F20.8 http://apps.who.int/classifications/icd10/browse/2016/en#/F20.8
[27] WebMD, *What Is Schizophreniform Disorder?* https://www.webmd.com/schizophrenia/mental-health-schizophreniform-disorder#*1* *(accessed 9th February 2021).*

[29] Royal College of Psychiatrists. *Schizophrenia: What causes schizophrenia?* www.rcpsych.ac.uk/mental-health/problems-disorders/schizophrenia (accessed 17th January 2021).
[30] González-Rodríguez, A., & Seeman, M. V. (2018). Pharmacotherapy for schizophrenia in postmenopausal women. *Expert Opinion on Pharmacotherapy*, *19*(8), 809-821.
[31] National Institute of Health and Care Excellence. *Psychosis and schizophrenia in adults: preventionand management*.Clinical Guidance178. London: National Institute for Health and Clinical Excellence; 2014 para 1.3.4.2.
[32] Royal College of Psychiatrists. *Schizophrenia.* http://www.rcpsych.ac.uk/healthadvice/problemsdisorders/schizophrenia.aspx
[33] National Institute of Health and Care Excellence. *Psychosis and schizophrenia in adults: preventionand management*.Clinical Guidance178. London: National Institute for Health and Clinical Excellence; 2014 para 1.5.7.2.
[34] Royal College of Psychiatrists. *Antipsychotics.* http://www.rcpsych.ac.uk/healthadvice/treatmentswellbeing/antipsychoticmedication.aspx (accessed 27th January 2021).
[35] National Institute of Health and Care Excellence. *Psychosis and schizophrenia in adults: preventionand management*.Clinical Guidance178. London: National Institute for Health and Clinical Excellence; 2014 para 1.5.1.3.

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

[37] National Institute of Health and Care Excellence. *Psychosis and schizophrenia in adults: preventionand management*.Clinical Guidance178. London: National Institute for Health and Clinical Excellence; 2014 para 1.5.4.2.
[38] National Institute of Health and Care Excellence. *Psychosis and schizophrenia in adults: preventionand management*.Clinical Guidance178. London: National Institute for Health and Clinical Excellence; 2014 para 1.3.7.2.
[39] National Institute of Health and Care Excellence. *Psychosis and schizophrenia in adults: preventionand management*.Clinical Guidance178. London: National Institute for Health and Clinical Excellence; 2014, para 1.3.7.2.
[40] National Institute of Health and Care Excellence. *Psychosis and schizophrenia in adults: preventionand management*.Clinical Guidance178. London: National Institute for Health and Clinical Excellence; 2014. 1.4.4.3
[41] National Institute of Health and Care Excellence. *Psychosis and schizophrenia in adults quality standard [QS80]*. London: National Institute for Health and Clinical Excellence; 2015 Statement 1.
[42] General Medical Council. *Good Medical Practice*. Manchester: GMC; 2013. Para 16(e).
[43] National Institute for Health and Clinical Excellence. Psychosis and schizophrenia in adults: prevention and management. Clinical Guidance 178. London: National Institute for Health and Clinical Excellence; 2014.Para 1.1.6.1.
[44] National Institute for Health and Clinical Excellence. Psychosis and schizophrenia in adults: prevention and management. Clinical Guidance 178. London: National Institute for Health and Clinical Excellence; 2014.. Para 1.1.6.3.
[45] Chang et al. Life Expectancy at Birth for People with Serious Mental Illness and Other Major Disorders from a Secondary Mental Health Care Case Register in London. PLoS ONE 6(5): e19590. doi:10.1371/journal.pone.0019590 (Accessed: 16 December 2020)

[46] Rethink Mental Illness. *The Schizophrenia Commission Progress Report 2017.* Available at: https://www.rethink.org/aboutus/who-we-are/the-schizophrenia-commission/ (accessed 2nd February 2021)
[47] Chang et al. Life Expectancy at Birth for People with Serious Mental Illness and Other Major Disorders from a Secondary Mental Health Care Case Register in London. PLoS ONE 6(5): e19590. doi:10.1371/journal.pone.0019590 (Accessed: 16 December 2020)

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

[49] National Institute of Health and Care Excellence. *Psychosis and schizophrenia in adults: preventionand management*.Clinical Guidance178. London: National Institute for Health and Clinical Excellence; 2014para, 1.3.6
[50] Pompili, M., Amador, X. F., Girardi, P., Harkavy-Friedman, J., Harrow, M., Kaplan, K., ... & Montross, L. P. (2007). Suicide risk in schizophrenia: learning from the past to change the future. *Annals of general psychiatry*, *6*(1), 1-22. See Abstract
[51] Hawton, K., Sutton, L., Haw, C., Sinclair, J. and Deeks, J.D. Schizophrenia and suicide: systematic review of risk factors. *British Journal of Psychiatry* 2005;187: 9-20 DOI: 10.1192/bjp.187.1.9
[52] Cassidy, R. M., Yang, F., Kapczinski, F., & Passos, I. C. (2018). Risk factors for suicidality in patients with schizophrenia: a systematic review, meta-analysis, and meta-regression of 96 studies. *Schizophrenia bulletin*, *44*(4), 787-797.
[53] National Institute for Health and Clinical Excellence. *Psychosis and schizophrenia in adults: prevention and management.* Clinical Guidance 178. London: National Institute for Health and Clinical Excellence; 2014.
Para 1.1.5.1.
[54] National Institute for Health and Clinical Excellence. *Psychosis and schizophrenia in adults: prevention and management.* Clinical Guidance 178. London: National Institute for Health and Clinical Excellence; 2014.Para 1.1.5.3.
[55] National Institute for Health and Clinical Excellence. *Psychosis and schizophrenia in adults: prevention and management.* Clinical Guidance 178. London: National Institute for Health and Clinical Excellence; 2014.Para 1.1.5.4.
[56] Leff, J et al. *Computer-assisted therapy for medication-resistant auditory hallucinations: proof-of-concept study*. The British Journal of Psychiatry. Jun 2013; 202(6): pp 428-433.
[57] NHS Choices. *Avatars may help control 'voices' in schizophrenia* www.nhs.uk/news/2013/05May/Pages/Avatars-may-help-control-voices-in-schizophrenia.aspx (accessed January 2019).

Last updated December 2020
Next update April 2023
Version number 10

This factsheet is available in large print.

Rethink Mental Illness Advice Service

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

Email advice@rethink.org

Did this help?

We'd love to know if this information helped you.

Drop us a line at: feedback@rethink.org

or write to us at Rethink Mental Illness:
RAIS
PO Box 17106
Birmingham B9 9LL

or call us on 0808 801 0525

We're open 9:30am to 4pm
Monday to Friday (excluding bank holidays)

Rethink Mental Illness.

Leading the way to a better quality of life for everyone affected by severe mental illness.

For further information
on Rethink Mental Illness
Phone 0121 522 7007
Email info@rethink.org

facebook.com/rethinkcharity
twitter.com/rethink_
www.rethink.org

Need more help?

Go to **www.rethink.org** for information on symptoms, treatments, money and benefits and your rights.

Don't have access to the web?

Call us on 0121 522 7007. We are open Monday to Friday, 9am to 5pm, and we will send you the information you need in the post.

Need to talk to an adviser?

If you need practical advice, call us on 0808 801 0525 between 9:30am to 4pm, Monday to Friday. Our specialist advisers can help you with queries like how to apply for benefits, get access to care or make a complaint.

Can you help us to keep going?

We can only help people because of donations from people like you. If you can donate please go to **www.rethink.org/donate** or call 0121 522 7007 to make a gift. We are very grateful for all our donors' generous support.