

understanding

obsessive compulsive disorder (OCD)

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This booklet explains what OCD is, including possible causes and how you can access treatment and support. Includes tips for helping yourself, and guidance for friends and family.

Contents

What is OCD?	4
What are the symptoms of OCD?	7
What causes OCD?	12
What treatments can help?	14
What support can I get?	14
How can I help myself?	17
How can other people help?	21
Useful contacts	25

What is OCD?

Obsessive compulsive disorder (OCD) is an anxiety disorder. It has two main parts: obsessions and compulsions.

- Obsessions are unwelcome thoughts, images, urges, worries or doubts that repeatedly appear in your mind. They can make you feel very anxious (although some people describe it as 'mental discomfort' rather than anxiety). You can read more about obsessions here.
- Compulsions are repetitive activities that you do to reduce the anxiety caused by the obsession. It could be something like repeatedly checking a door is locked, repeating a specific phrase in your head or checking how your body feels. You can read more about compulsions here.

It's not about being tidy, it's about having no control over your negative thoughts. It's about being afraid not doing things a certain way will cause harm.

You might find that sometimes your obsessions and compulsions are manageable and other times they are impossible to live with. They may be more severe when you are stressed about other things like work, university or relationships.

If you experience OCD during pregnancy or after birth, you might get diagnosed with post-natal or ante-natal OCD. You can find out more about this diagnosis on the Royal College of Psychiatrists website (see 'Useful contacts' on p.X).

What's it like to live with OCD?

Although many people experience minor obsessions (such as worrying about leaving the gas on, or if the door is locked) and compulsions (such as avoiding the cracks in the pavement), these don't significantly interfere

with daily life, or are short-lived.

If you experience OCD, it's likely that your obsessions and compulsions will have a big impact on how you live your life:

- **Disruption to your day-to-day life.** Repeating compulsions can take up a lot of time, and you might avoid certain situations that trigger your OCD. This can mean that you're not able to go to work, see family and friends, eat out or even go outside. Obsessive thoughts can make it hard to concentrate and can leave you feeling exhausted.
- **Impact on your relationships.** You may feel that you have to hide your OCD from people close to you or your doubts and anxieties about the relationship may make it too difficult to continue it.
- Feeling ashamed or lonely. You may feel ashamed of your obsessive thoughts, or as if they are a permanent part of you and can't be treated. You might feel that you can't talk about this part of yourself with others. This can make you feel very isolated. If you find it hard to be around people or go outside then you may feel lonely.
- **Impact on your physical health.** Anxiety caused by obsessions can affect your physical health. You can read more about physical symptoms in our pages on anxiety.
- I knew it was irrational but tapping certain objects would ease the effect of the terrible intrusive thoughts. It would be time consuming but at least then I could feel like I wasn't a bad person.

Related disorders

There are some other mental health problems that are similar to OCD because they involve repetitive thoughts, behaviours or urges. They are sometimes called habit disorders.

- **Body dysmorphic disorder (BDD)** is an anxiety disorder related to body image.
- Compulsive skin picking (CSP) is the repetitive picking at your skin
 to relieve anxiety or urges. It can be experienced as part of body
 dsymorphic disorder. Read more about CSP on OCDAction's website.
- **Trichotillomania** is a compulsive urge to pull out your hair. Read more about trichotillomania on OCDAction's website.
- Some people with OCD have difficulties with hoarding.
- Obsessive compulsive personality disorder (OCPD) is sometimes confused with OCD - but they are not the same thing. OCPD is a type of personality disorder, while OCD is an anxiety disorder.

See 'Useful contacts' and Mind's guides, *Understanding body dysmorphic disorder* and *Understanding personality disorders* for more information.

Co-morbidity (having more than one diagnosis at the same time) with OCD is common, but it can sometimes make OCD difficult to diagnose and treat. For example, if you experience OCD you might be living with other mental health problems as well, such as anxiety or depression. See Mind's guides *Understanding anxiety* and *Understanding depression* for more information.

Experiences of facing stigma

Lots of people have misconceptions about OCD. Some people think it just means you wash your hands a lot or you like things to be tidy. They might even make jokes about it. This can be frustrating and upsetting, especially if people who think this are friends or family, colleagues or even healthcare professionals.

Stigma can make OCD feel difficult to talk about but it's important to remember you are not alone. Here are some options for you to think about:

- Show people this information to help them understand more about what your diagnosis really means.
- Get more involved in your treatment. See The Mind guide to seeking help for a mental health problem for guidance on having your say in your treatment, making your voice heard, and steps you can take if you're not happy with your care.
- Talk about your experience. Sharing your story can help improve people's understanding and change their attitudes.
- Know your rights. Search 'legal rights' on Mind's website for more information.
- Take action with Mind. Search 'campaigns' on Mind's website for details of the different ways you can get involved with helping us challenge stigma.

One of the most difficult things about OCD is how people percieve it. Intrusive thoughts and compulsions take a greater toll, yet people don't seem to understand that.

What are the symptoms of OCD?

Obsessions

Obsessions are persistent thoughts, pictures, urges or doubts that appear in your mind again and again. They interrupt your thoughts against your control and can be really frightening, graphic and disturbing. They may make you feel anxious, disgusted or 'mentally uncomfortable'.

You might feel you can't share them with others or that there is something wrong with you that you have to hide. You do not choose to have obsessions - but you might feel upset that you are 'capable' of having such thoughts.

Remember: Obsessions are not a reflection of your personality. People with OCD are very unlikely to act on their thoughts because they find them so distressing and repugnant. There are no recorded cases of a

person with OCD carrying out their obsession.

I get unwanted thoughts all through the day, which is very distressing and affects my ability to interact with others and concentrate on my studies.

Type of obsession	Examples include
Fear of causing or failing to prevent harm	 worrying you've already harmed someone by not being careful enough. For example, that you have knocked someone over in your car. worrying you're going to harm someone because you will lose control. For example, that you will push someone in front of a train or stab them.
Intrusive thoughts, images and impulses	 Violent intrusive thoughts or images of yourself doing something violent or abusive. These thoughts might make you worry that you are a dangerous person. Religious or blasphemous thoughts that are against your religious beliefs. Relationship intrusive thoughts often appear as doubts about whether a relationship is right or whether you or your partner's feelings are strong enough. They might lead you to end your relationship to get rid of the doubt and anxiety. Sexual intrusive thoughts or images. These could be related to children, family members or to sexually aggressive behaviour. You might worry that you could be a paedophile or a rapist, or that you are sexually attracted someone in your family.

Fear of contamination	 Contamination (for example by dirt, germs or faeces). You might worry that you have been contaminated and that you - or other people - are spreading the contamination. You might worry that you have or might get a disease. Mental contamination. You might experience uncomfortable feelings of 'internal uncleanliness'.
Fears and worries related to order or symmetry	 You might have a fear that something bad will happen if everything isn't 'right' - for example if things are not clean, in order or symmetrical.

You might experience more than one type of obsession. They are often linked together. For example you might experience a fear of contamination and a fear of doing someone harm by accidentally making them ill.

You can read more about the different types of obsessions on OCD UK's website (see 'Useful contacts' on p.X).

Anxiety and arousal

Intrusive sexual thoughts may lead you to constantly monitor and check your genitals. This attention and the anxiety you are feeling may actually increase blood flow and physical arousal. This can make you feel as if you are aroused by the intrusive thoughts when in fact the opposite is true. Many people with this type of OCD call this 'groinal response'.

I would seek medical reassurance online and for a day or so I could breathe a sigh of relief... but then the doubt would set in and I started the process again.

Compulsions

Compulsions are repetitive activities that you feel you have to do. The aim of a compulsion is to try and deal with the distress caused by obsessive thoughts. You might have to continue doing the compulsion until the

anxiety goes away and things feel right again. You might know that it doesn't make sense to carry out a compulsion - but it can still feel too scary not to. Repeating compulsions is often very time consuming and the relief they give you doesn't usually last very long.

Compulsions can:

- be physical actions
- be mental rituals (people who only have mental compulsions sometimes refer to their OCD as Pure O)
- involve a number (for example, you might feel you have to complete a compulsion a specific number of times without interruption).

Type of compulsion	Examples include
Rituals	 washing your hands, body or things around you a lot touching things in a particular order or at a certain time arranging objects in a particular way
Checking	 checking doors and windows to make sure they are locked checking your body or clothes for contamination checking your body to see how it responds to intrusive thoughts checking your memory to make sure an intrusive thought didn't actually happen checking your route to work to make sure you didn't cause an accident
Correcting thoughts	 repeating a word, name or phrase in your head or out loud counting to a certain number replacing an intrusive thought with a different image

Reassurance	 repeatedly asking other people to tell you that
	everything is alright

Avoidance

You might find that some activities, objects or experiences make your obsessions or compulsions worse. For example if you are worried that you might stab someone then you might avoid the kitchen because you know there are knives there.

Sometimes it might feel easier to avoid situations that mean you have to do a compulsion. For example if you have to do a long and time consuming ritual every time you leave the house, you might just decide it's easier to stay indoors. But avoiding things can have a major impact on your life.

Getting ready involves so much hand washing and so many mental rituals. Sometimes, I feel like staying in bed and avoiding the day.

What is 'Pure O'?

Pure O stands for 'purely obsessional'. People sometimes use this phrase to describe a type of OCD where they experience distressing intrusive thoughts but there are no external signs of compulsions (for example checking or washing). The name is slightly misleading as it suggests that there are no compulsions at all.

If you have 'Pure O' you will still experience mental compulsions - but you might not be aware of them. Because they are not as obvious as physical compulsions it can sometimes be difficult to define exactly what these compulsions are. Here are some examples of internal compulsions:

- checking how you feel (for example, you might check to see if you are still in love with your partner)
- checking bodily sensations (for example, you might check to see if you were aroused by an intrusive thought)
- check how you feel about a thought (for example, you might check whether you are still 'appropriately disgusted' by the thought)
- repeating phrases or numbers in your head
- checking if you still have a thought (for example, first thing in the morning)

Pure O can be successfully treated. Treatment can sometimes start by helping your recognise your mental compulsions. Read more about Pure O on the OCD-UK website (see 'Useful contacts' on p.X)

What causes OCD?

There are different theories about why OCD develops. None of these theories can fully explain every person's experience. Even though we don't fully understand what causes OCD it can still be successfully treated.

'Dysfunctional' beliefs

One theory suggests that OCD develops because of 'dysfunctional' beliefs and interpretations. If you experience OCD you might believe that you have more responsibility for a situation than you actually do. Because of this, your reaction may be out of proportion.

For example, many people experience sudden and intrusive thoughts, such as thinking that they might push someone in front of a train on a crowded platform. Most people dismiss it as a passing thought and do not believe they would actually do it.

If you have 'dysfunctional' beliefs you might think that you could actually act on the intrusive thought. This makes you anxious or scared. You may

develop a compulsion to try and prevent it happening. This could start an OCD cycle.

Personal experience

Some theories suggest that OCD is caused by personal experience. For example:

- if you've had a painful childhood experience or suffered trauma or abuse, you might learn to use obsessions and compulsions to cope with anxiety. However this theory doesn't explain why people who can't point to any painful experiences might experience OCD.
- if your parents had similar anxieties and showed similar kinds of compulsive behaviour - and so you learned that compulsions are a coping technique.
- ongoing anxiety or stress or being part of a stressful event like a car accident could trigger the development of OCD or make it worse. Our pages on managing stress have more information on how to help yourself and get support for stress.

Biological factors

Some biological theories suggest that a lack of the brain chemical serotonin may have a role in OCD. However, experts disagree about what that role is. It's unclear whether a lack of serotonin causes OCD or is the effect of having the condition.

Studies have also looked at genetic factors and how different parts of the brain might be involved in causing OCD, but have found nothing conclusive.

Biological theories do not explain why the condition develops differently in different people; for example, why one person might develop a contamination obsession while another develops an obsession about harming.

You can read more about the possible causes of OCD on OCDUK's website (see 'Useful contacts' p.X).

Is childhood OCD caused by an infection?

Some experts have noted that some children seem to develop OCD symptoms very suddenly after having a streptococcal (or strep) infection such as strep throat or scarlet fever. However, we don't know why and no research has yet been able to identify a physical cause to explain the link. Some children show OCD symptoms for a while and then they fade.

What treatments can help?

OCD is usually treated with cognitive behavioural therapy (CBT). You may also be offered medication. Most people who get the right treatment see a significant improvement in their OCD.

How can I access treatment?

To get treatment on the NHS you should visit your doctor (also known as your GP). If your GP thinks you may have OCD they will refer you to a psychiatrist (or another mental health professional) for an assessment, so you can be given a diagnosis of OCD if the mental health professional thinks that's correct.

What treatment you are offered will depend on how severe your OCD is and how you respond to initial treatment. If the treatment you have been offered isn't helping, talk to your doctor or psychiatrist. There may be a more intensive treatment available.

If your OCD is very severe then you may be referred to a specialist OCD service. Unfortunately not all areas have specialist services and you might have to travel outside your local area.

I started to learn how to manage my OCD when I spoke to a therapist.

If you think that you are starting to experience symptoms of OCD again, talk to your doctor. You should be referred directly to the waiting list for more treatment rather than being placed on the waiting list for assessment again.

I'm worried about talking to my doctor

You might feel scared about telling anyone, even a doctor, about how graphic or distressing your obsessive thoughts can be. You may be ashamed of your obsessions or worry that the doctor might report you to the police or social services. Or you may find it hard to admit how much time your compulsions take up.

These feelings can make it difficult to get the right help. But the type of treatment you are given depends on the intensity of your OCD and how much it affects your life, so the more honest you are, the more likely you are to get the best help for you.

It's hugely frustrating and exhausting trying to break out of patterns that you know aren't helpful or healthy. But you can eventually achieve fresh change that seemed impossible.

Cognitive behavioural therapy (CBT)

Cognitive behavioural therapy is a talking treatment that focuses on how your thoughts, beliefs and attitudes affect your feelings and behaviour.

There's a lot of evidence that CBT is effective for treating OCD. But it can be challenging and may make you feel more anxious at first. Talk to your doctor or psychiatrist about whether you are ready to start CBT.

OCDAction have a CBT checklist to help you make sure that the CBT you are receiving is the most effective for treating OCD (see 'Useful contacts' on p.X).

Can I go private?

Unfortunately, waiting times for talking treatments on the NHS can be long. If you feel that you don't want to wait you may choose to see a therapist privately. You can find a therapist through The British Association for Behavioural and Cognitive Psychotherapies (see 'Useful contacts' on p.X).

What is exposure and response prevention (ERP)?

ERP is a type of CBT that is recommended for treating OCD. ERP works by helping you confront your obsessions and resist the urge to carry out compulsions.

During ERP your therapist will support you to deliberately put yourself in a situation that would usually make you feel anxious. Instead of performing your usual compulsion you will be encouraged to try and tolerate the anxiety. Your therapist may even suggest that you do something that makes you feel even more anxious.

ERP helps you to see that the uncomfortable feelings will eventually go away even if you don't perform a compulsion. As ERP continues people find that their obsessions cause them less anxiety and the anxiety they do feel goes away faster. They feel less need to do compulsions. This is called habituation.

You would always start by confronting situations you find easy and building up slowly to more difficult situations.

What medication is available for OCD?

Your doctor may offer you medication alongside CBT. If there is a long waiting list for CBT your doctor may suggest you take medication while you are waiting as well.

- Antidepressants are recommended by NICE for the treatment of OCD.
- Tranquillisers: if you are experiencing very severe anxiety you may be offered tranquillisers.
- Beta-blockers are occasionally prescribed to treat the physical symptoms of anxiety.

Search 'psychiatric medication' on Mind's website for more information.

I've been on meds for the last three years and my OCD is so much more controllable.

Can neurosurgery be used to treat OCD?

Neurosurgery is not a recommended treatment for OCD. It is very occasionally offered in severe cases when all other treatments have been unsuccessful. Neurosurgery is strictly regulated under the Mental Health Act. Search neurosurgery on Mind's website for more information.

How can I help myself?

This section is for friends and family members who want to support someone with BDD.

It can be upsetting and frustrating to see a loved one's obsessive worries and compulsive behaviours impact their day-to-day life. But there are a number of things you can do to support them:

Try self help resources

Some people with mild OCD find that they can use self help resources to develop their own coping strategies - or you may use them while you are waiting for treatment or alongside it. These are often based on cognitive behavioural therapy (CBT). You may have to try a few different options to find the one that works for you:

- OCD Action offers a range of self help resources and information.
- You could ask your doctor if there are any self help books available on prescription.
- You can access online cognitive behavioural therapy for free at Moodgym or through your doctor at Beating the Blues.

See 'Useful contacts' on p.X.

Build your support network

Many people find it hard to talk about OCD. You might worry that people won't understand. You might have kept your OCD secret for such a long time that it feels very scary to put some of your experiences into words. Strengthening the relationships around you may help you feel less lonely and more able to cope.

- Talk to someone you trust about your OCD. Find a quiet space to talk where you won't be interrupted. You could show them this information (especially our section for family and friends) to help them understand. Some people find it helpful to write their feelings down in a letter and then talk about it together.
- **Spend time with friends and family.** You might not feel ready to talk openly about your OCD yet. But spending more time with friends and family may help you feel more comfortable around them and, in time, more able to share your experiences.

Sharing the obsessive thoughts made them feel less powerful.

Try peer support

Peer support brings together people who've had similar experiences to support each other. Peer support can offer many benefits, such as:

- feeling accepted for who you are
- increased self-confidence
- helping you feel less isolated you might be relieved to find others with very similar experiences
- give you a safe, non judgmental space to talk with people who understand
- finding out new information and places for support
- challenging stigma and discrimination

You could contact your local Mind to find a support group near you. You can also find specific support groups for OCD through OCDAction and OCD-UK. See 'Useful contacts' on p.X.

Online support

If you don't want to attend a support group or can't find one locally then you could think about looking for online support:

- OCDAction run online support groups over Skype and an online community.
- OCDUK has an online community.
- Mind runs a supportive online community called Elefriends.

See 'Useful contacts' on p.X and search 'online support' on Mind's website for more information.

I remember wishing I could just talk to someone who could tell me they had felt what I was feeling.

Learn to relax

- Manage your stress. Your OCD can get worse if you are stressed and anxious.
- Try some relaxation techniques. Relaxation can help you look after your wellbeing when you are feeling stressed, anxious or busy.
- **Try mindfulness.** You might find that your CBT therapist includes some principles of mindfulness in your therapy. Mindfulness can help you manage unwanted thoughts and reduce stress and anxiety. It can be helpful as part of recovery from OCD.

Search 'stress', 'relaxation' and 'mindfulness' on Mind's website for more information.

Look after yourself

- **Try to get enough sleep.** Sleep can give you the energy to cope with difficult feelings and experiences.
- Think about your diet. Eating regularly and keeping your blood sugar stable can make a difference to your mood and energy levels.
- Try and take some exercise. Exercise can be really helpful for your mental wellbeing.

Search 'sleep', 'food and mood' and 'exercise' on Mind's website for more information.

How can other people help?

This section is for people who want to support someone who has obsessive compulsive disorder (OCD).

If someone you love has a diagnosis of OCD, knowing how to support them can be hard. You may struggle to understand their experiences, or feel that their obesssions and compulsions get in the way of daily life. But your support and understanding can make a big difference, and there are things you can do to help.

Be open about OCD

Your loved one may find it difficult to talk about their obsessions and compulsions. They may have kept them secret for a long time and be very worried about your reaction. It can help to acknowledge this and encourage them to talk about their experience in a way that feels comfortable to them.

- **Be patient.** Remember that their fears are very real to them, even if they seem unrealistic, irrational or extreme to you.
- **Stay calm and don't judge.** It can be upsetting to hear about some obsessive thoughts, but your loved one may be scared you will judge them or think that there is something wrong with them. Make it clear that you love and support them regardless.
- Find out as much as you can about OCD. This will help you understand what your loved one is going through. Reading personal experiences can help too.

I could feel loved ones' frustration at my need to still carry out these compulsions, despite us both knowing it was illogical.

Work out how to deal with compulsions together

One of the hardest things about living with someone with OCD is work-

ing out how to deal with their compulsions. You may find it difficult not to help with compulsions, or get involved (this is sometimes called accommodation). For example you might:

- check locks for them
- reassure them that they didn't cause an accident
- reassure them that an obsessive thought doesn't mean anything

You may have found that refusing to help with rituals, or offer reassurance, increases their anxiety and makes life harder for both of you. But helping someone with their compulsions is not usually helpful in the long term.

Every time someone acts on a compulsion (including asking for reassurance) it reinforces the belief that the compulsion is the only way to deal with their anxiety. Treatment for OCD helps people learn that their anxiety will reduce naturally, even if compulsions are not completed.

Your first thought is why aren't they helping me check... but if you step back, breathe you realise they are not helping because they care.

How can we manage compulsions in other ways?

Try and work out some alternatives together. Your approach might depend on what your loved one thinks about their compulsions and whether they are receiving treatment. Here are somethings you could try:

- Agree on an approach that feels right for you both. For example, you
 might decide that you will say 'we've agreed I won't answer questions
 like that to help you overcome your OCD' or 'I'm here for you and I
 love you but I'm not playing OCD's game today'.
- Encourage them to challenge compulsions where appropriate. For example, instead of offering reassurance you could try and help them think about why they want to do a compulsion again.
- Offer a hug or other emotional support instead of helping with a

- compulsion.
- Seek advice. If they are getting treatment you could both talk to their doctor or therapist about the best way to manage compulsions.
- Accept that sometimes it will be impossible not to offer reassurance or to help with a compulsion.

OCD-UK suggests that it can help to see OCD as something external to you both. This can help everyone understand that you are challenging the OCD and not the person themselves. See 'Useful contacts' on p.X.

My husband knows he has to tell me when I start collecting things and my daughter will remind me by asking if something is what I want or an OCD problem.

Help them to access treatment

Your loved one may find it difficult to talk to their doctor about their OCD and seek treatment. Here are some ways you could support them:

- Remind them that the appointment will be confidential and the GP is there to help them access treatment. Offering to go with them could also help make things easier. Take a look at our page on supporting someone to seek help.
- Some parts of treatment for OCD can be challenging. During treatment they may be agitated, tired, anxious and depressed. Try to be patient and ask them what you can do to make things easier.
- They may feel that things will never get better, especially if they are finding treatment hard or their symptoms come back. You can offer hope. Remind them that most people with OCD do benefit from treatment and show them personal stories of people who have recovered.

Look after yourself

Supporting someone with OCD can be exhausting and upsetting at times. Make sure you take time to look after yourself too. It can help to share experiences, ask questions and get support. OCDAction and OCD-UK have sections in their forum for family, friends and carers.

You can find out more about looking after yourself in our pages on how to cope as a carer and improving and maintaining your wellbeing. You can also visit the Carers UK website. See 'Useful contacts' on p.X.

Useful contacts

Beating the blues

web: beatingtheblues.co.uk

Provides free computerised CBT with a referral from a GP.

British Association for Behavioural and Cognitive Psychotherapies (BABCP)

tel: 0161 705 4304 web: babcp.com

An interest group for people involved in the practice and theory of behavioural and cognitive psychotherapy. It has an online register of accredited CBT therapists.

Carers UK

tel: 0808 808 7777 web: carersuk.org

Independent information and support for carers.

Elefriends

web: elefriends.org.uk

Elefriends is a friendly, supportive online community for people experiencing a mental health

problem.

MoodGYM

web: moodgym.anu.edu.au

Provides free computerised CBT.

OCD Action

tel: 0845 390 6232 web: ocdaction.org.uk

Information and support for people with experience of OCD, and their friends, family and carers.

OCD UK

tel: 0845 120 3778 web: ocduk.org

A charity run by people with OCD who campaign and can help with local support group information.

Royal College of Psychiatrists

tel: 020 7235 2351 web: rcpsych.ac.uk

Mental health information including information on perinatal OCD.

Further information

Mind offers a range of mental health information on:

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

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

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

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Providing information costs money. We really value donations, which enable us to get our information to more people who need it.

Just £5 could help another 15 people in need receive essential practical information.

If you would like to support our work with a donation, please contact us on:

tel: 020 8215 2243

email: dons@mind.org.uk web: mind.org.uk/donate

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Mind

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

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