

understanding



dissociative
disorders

Understanding dissociative disorders

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

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What is dissociation?

Dissociation is one way the mind copes with too much stress, such as during a traumatic event. The word dissociation can be used in different ways but it usually describes an experience where you feel disconnected in some way from the world around you or from yourself.

If you dissociate for a long time, especially when you are young, you may develop a dissociative disorder. Instead of dissociation being something you experience for a short time it becomes a far more common experience and often the main way you deal with stressful experiences.

When might I dissociate?

- For many people, dissociation is a **natural response to trauma** that they can't control. It could be a response to a one-off traumatic event or ongoing trauma and abuse. You can read more in 'What are the causes?' on p.9.
- **Some people choose to dissociate** as a way of calming down or focusing on a task. Or as part of a religious or cultural ritual.
- You might experience dissociation as **a symptom of a mental health problem** (for example schizophrenia, bipolar disorder, borderline personality disorder or post traumatic stress disorder) or as a side effect of some drugs, medication, coming off some medication and alcohol.

How might I experience dissociation?

Dissociation can be experienced in lots of different ways.

Psychiatrists have tried to group these experiences and give them names. This can help doctors make a diagnosis of a specific dissociative disorders. But you can have any of these dissociative experiences even if you don't have a diagnosed dissociative disorder.

<p>Some dissociative experiences include:</p>	<p>A doctor or psychiatrist might call these experiences:</p>
<ul style="list-style-type: none"> • having gaps in your life where you can't remember anything that happened • not being able to remember information about yourself or about things that happened in your life 	<p>dissociative amnesia</p>
<ul style="list-style-type: none"> • travelling to a different location and taking on a new identity for a short time (without remembering your identity) 	<p>dissociative fugue</p>
<ul style="list-style-type: none"> • feeling as though the world around you is unreal • seeing objects changing in shape, size or colour • seeing the world as 'lifeless' or 'foggy' • feeling as if other people are robots (even though you know they are not) 	<p>derealisation</p>
<ul style="list-style-type: none"> • feeling as though you are watching yourself in a film or looking at yourself from the outside • feeling as if you are just observing your emotions • feeling disconnected from parts of your body or your emotions • feeling as if you are floating away • feeling unsure of the boundaries between yourself and other people 	<p>depersonalisation</p>

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<ul style="list-style-type: none">• your identity shifting and changing• speaking in a different voice or voices• using a different name or names• switching between different parts of your personality• feeling as if you are losing control to 'someone else'• experiencing different parts of your identity at different times• acting like different people, including children	identity alteration
<ul style="list-style-type: none">• finding it very difficult to define what kind of person you are• feeling as though there are different people inside you	identify confusion

Triggers and flashbacks

A **trigger** is a reminder of something traumatic from the past, which can cause you to experience dissociation or other reactions. It could be a sight, sound, taste, smell or touch. It could be a situation or way of moving your body. Many different things can be or become triggers.

In a **flashback** you may suddenly experience traumatic sensations or feelings from the past. This might be prompted by encountering a trigger. You may experience the flashback as reliving a traumatic event in the present. A flashback may cause you to switch to another part of your identity.

👁️👁️ *I felt like my body didn't belong to me, it was like I was an outsider watching my own story unfold.* 🗨️🗨️

If you have dissociated memories (because of amnesia or because you experience different identity states with different memories) then you may find that these resurface during flashbacks.

What are dissociative disorders?

You may be diagnosed with a dissociative disorder if you experience dissociation regularly and these episodes of dissociation are severe enough to affect your everyday life.

You might experience dissociation and find it difficult to cope with even if you don't have a dissociative disorder (for example it might be a symptom of another mental health problem). You can still seek help for this.

Dissociative identity disorder (DID)

Dissociative identity disorder used to be called 'multiple personality disorder'.

If you have dissociative identity disorder you will experience severe changes in your identity. Different aspects of your identity may be in control of your behaviour and thoughts at different times.

- Each of your identity states may have different patterns of thinking and relating to the world.
- Your identity states may come across as different ages and genders.
- You may feel you have one 'main' part of your identity that feels most like 'you' – some people call this a host identity.
- The different parts of your identity may have memories or experiences that conflict with each other.
- Some people call these different parts of your identity 'alters' or 'parts'.
- You might not have control over when different parts of your identity take over.
- You may suffer from amnesia which means you don't remember what happens when another part of your identity is in control.

👁️👁️ *I have many separate, distinct and unique 'parts' of my personality. My 'parts' or 'alters' collectively add up to the total person that is me... They are each a letter, and I am a sentence.* 🧠🧠

See PODS and First Person Plural for more information on DID.

Do I have multiple personalities?

Dissociative identity disorder is still sometimes called multiple personality disorder (MPD). This is because many people experience the changes in parts of their identity as completely separate personalities in one body. In fact the parts of your identity are all part of one personality but they are not joined up or working together as a whole.

Dissociative identity disorder is not a personality disorder. It is the result of a natural way of coping with sustained childhood trauma. 'What are the causes?' on p.9 has more info.

Other dissociative disorders

There are a number of other dissociative disorders. The diagnosis you are given will depend on the symptoms you experience most and how these affect your life.

These are the main symptoms or characteristics of each disorder:

If you have...	You will...
depersonalisation or derealisation disorder	experience regular depersonalisation or derealisation
dissociative amnesia	be unable to remember important information about who you are, your life history or specific events

dissociative amnesia with fugue	experience a state of mind where you forget everything about who you are (a fugue) – in the fugue you may travel to a new location and act like a different person in a different life
other specified dissociative disorder (OSDD)	have dissociative symptoms that don't fit into any other diagnosis – the person making your diagnosis will explain why your symptoms don't fit into any other diagnosis
unspecified dissociative disorder (UDD)	have dissociative symptoms that don't fit into any other diagnosis but the person making your diagnosis hasn't explained why not or doesn't have enough information to make a full diagnosis (for example in an emergency)

Other mental health problems

Many people with dissociative disorders have other mental health problems too. These can include borderline personality disorder, depression, anxiety and panic attacks, suicidal feelings, hearing voices or OCD.

They may be associated with dissociation or they could be a separate problem.

What are the causes?

Dissociative disorders are usually caused when dissociation is used a lot to survive complex trauma over a long time and during childhood when the brain and personality are developing.

Dissociation is a normal defence mechanism that helps us cope during trauma. But it can become a dissociative disorder if your environment is

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no longer traumatic but you still act as if it is. And if the dissociation you needed to protect yourself means you haven't been able to process past traumatic experiences.

You may get so used to using dissociation as a coping strategy that you do not develop other strategies and you start to use dissociation to deal with any kind of stress.

●● *It became uncontrollable and it would happen in various places when I felt stressed or under threat.* ●●

How does trauma cause dissociation?

Trauma can cause dissociation because of the way we respond to threat. There are different theories about how exactly this leads to different dissociative disorders.

You may have heard of fight or flight. They are instinctive ways that we respond to threatening situations. But if you can't do these things (for example if you are very young) then you may respond by 'freezing' or 'flopping'.

- The **freeze** response makes the body immobile and releases chemicals which 'numbs' your body and mind. You might feel paralysed or unable to move.
- The **flop** response is where lots of the thinking processes in the brain are shut off. Your muscles become floppy and you act a bit like a zombie – doing what you are told without protest.

Our instinctive reactions to threat are the basis of dissociative experiences.

One theory suggests that whenever we think there is a threat, our body reduces blood flow to areas in the **front of our brain** (the thinking, analytical, rational part) and 'turns on' areas in our **back brain** (the automatic, instinctive part).

Using our back brain to freeze or flop helps protect us from trauma that we can't prevent or run away from. But reducing the blood flow to the front brain can make it more difficult to process what happens and may mean we experience dissociative symptoms.

The front brain includes areas which help us:

- understand where we are in time and space
- use language and speech
- feel connected to our body
- store memories
- make sense of information coming through our senses

You might separate different parts of an experience so you do not have to deal with it all together. Different parts of the experience (such as actions, memories, feelings, thoughts, sensations and perceptions) may not be 'joined up'.

👉👉 *I would disconnect myself from being in the room where the abuse was happening. I almost felt like I was watching it happen to me but I wasn't feeling it or wasn't part of it. It became something that happened automatically.* 👉👉

For example, you might store an experience in a way you can't access day to day (this is usually called amnesia). Or you might remember what happened but don't feel the emotions or sensations that were part of it (this is usually called derealisation).

If you experience dissociative identity disorder (DID), you might feel as if different memories, sensations or beliefs happened to different people (usually called identity states) inside you.

This can help you cope if the things that happened would be too much for you to deal with all together as a child – but may prevent you from developing one clear identity as you grow up.

What makes dissociative disorders more likely?

Not everyone who experiences trauma will have a dissociative disorder but many experts agree that these things make it more likely:

- abuse begins at an early age (the younger you are the harder you will find it to cope with traumatic experiences without dissociation)
- abuse is severe and repeated over a long period – or by many people
- abuse is painful and makes you scared
- there is no adult who you have a good relationship with and is able to provide comfort and help you process and deal with the trauma
- the abuse is done by someone you feel attached to
- the abuser tells you that things didn't happen or that you were dreaming
- things are different at different times – for example things seem normal during the day but at night you are abused.

You can read more about the causes of dissociative identity disorder on the PODS website.

For more support you can contact:

- The National Association for People Abused in Childhood (NAPAC) offers support for adults who were abused as children.
- Survivors UK provides support for men who have been abused.
- Childline is there to help children who are upset or scared about anything, including abuse.
- If you are worried about a child you know, the National Society for the Prevention of Cruelty to Children (NSPCC) can help.
- See 'Useful contacts' on p.25.

How will I be diagnosed?

Diagnosing dissociative disorders

If you think you have a dissociative disorder, ask your GP or psychiatrist to refer you for a full assessment. You may have a meeting with both a psychotherapist and a psychiatrist as part of your assessment.

The person assessing you should have specialist training and a good understanding of dissociative disorders. (PODS can put you in touch with people who have this training).

They should check whether your experiences of dissociation might be explained by:

- drugs and some medication, which can sometimes cause dissociation
- a physical cause
- any cultural or religious practices that may explain your experiences.

If your dissociative symptoms are caused by drugs or medication then you won't be diagnosed with a dissociative disorder.

Your diagnosis will depend on:

- the way you experience dissociation
- whether you have other symptoms
- whether your symptoms are having an impact on your life and causing you distress.

Your mental health professionals might use questionnaires to help them make a diagnosis that fits best with your experience. If this seems to fit the description of another mental health problem better, then you may be given this diagnosis instead.

Not everyone finds it helpful to get a diagnosis. Even if you don't get a specific diagnosis you can still seek help for your symptoms.

What can I do if I disagree with my diagnosis?

If you are worried that your diagnosis doesn't fit the way you feel it's important to discuss it with a mental health professional so you can get the right treatment.

It may help to ask your doctor to refer you to a mental health professional who knows about dissociation for a full assessment. If you are not satisfied with the assessment and support you have received from local mental health services then The Clinic for Dissociative Studies may be able to help.

Mind's resource 'Seeking help for a mental health problem' has information about how to make sure your voice is heard, and what you can do if you're not happy with your doctor.

Why is it hard to get diagnosed?

Dissociative disorders can be difficult to diagnose. There are different reasons why you might not get the right diagnosis straight away:

- **Mental health professionals don't usually get enough training on dissociative disorders.** They might not even think about the possibility of a dissociative disorder, when assessing your mental health. This means that they might not ask you the right questions about your symptoms.
- **Understanding more about your life history can help mental health professionals make a diagnosis.** But they don't always ask about childhood abuse or trauma at an assessment. Even if they do ask, you may not remember it (if you experience amnesia) – or you may find it too hard to talk about.
- **Some people coping with dissociative symptoms try to keep them hidden from others.** It might feel difficult to talk openly about your experiences.
- **Some people still call DID 'multiple personality disorder',** so some doctors might be looking for personality disorder symptoms instead of dissociative disorder symptoms.

Dissociative disorders and other mental health problems

You might experience a dissociative disorder on its own, or alongside another mental health problem. If you do experience another mental health problem, this can make it hard for mental health professionals to understand whether it's appropriate to give you a diagnosis of a dissociative disorder.

Some problems include:

- **Borderline personality disorder.** This can also be caused by long-term trauma, and dissociative experiences can be a symptom.
- If you are experiencing **dissociative symptoms as part of another mental health problem** the person assessing you may not identify that you have a dissociative disorder as well.
- You might have **symptoms of other mental health problems** that you experience as well as – or because of – your dissociative disorder. If your doctor is more familiar with these mental health problems they may only diagnose these problems without realising that you also have a dissociative disorder.

How can I help myself cope?

Looking after yourself with dissociative identity disorder

DID can make looking after yourself harder. You might find that different parts of your identity have different needs. You may need to use different techniques for coping and looking after yourself depending on which part of your identity is in control.

Keep a journal

Keeping a journal can help you understand and remember different parts of your experience. It could:

- include writing and artwork you do at different times and, if you have DID, in different identity states

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- help improve the connections and awareness between different parts of your identity by reading entries from them
- help you remember more about what happened in the gaps in your memory.

👁️👁️ *Using a journal to express my inner turmoil helps me deal with it.* 🗨️🗨️

Try visualisation

Visualisation is a way of using your imagination to create internal scenes and environments that help you stay safe and contain difficult feelings and thoughts. For example:

- you might find that imagining you are wearing protective clothing helps you feel more relaxed in stressful situations
- it might help to imagine a place that feels safe to you (and your different identity states) – when you feel anxious or threatened, you can imagine going to this place for peace and safety.

If you experience different identity states, you might be able to imagine a place where they can all meet together and talk. Your therapist might help you to do this too.

Try grounding techniques

Grounding techniques can keep you connected to the present and help you avoid feelings, memories, flashbacks or intrusive thoughts that you don't feel able to cope with yet. You could try:

- breathing slowly
- listening to sounds around you
- walking barefoot
- wrapping yourself in a blanket and feeling it around you
- touching something or sniffing something with a strong smell.

Focus on the sensations you are feeling right now. You might find it helpful to keep a box of things with different textures and smells (for example perfume, a blanket and some smooth stones) ready for when you need it.

First Person Plural has more tips for grounding and dealing with flashbacks on their website (see 'Useful contacts' on p.25).

●● *It's strange because it took me a long time to realise I didn't need to dissociate to keep myself safe.* ●●

Think about practical strategies

Dissociation can make day to day life difficult. Practical strategies could help you cope, such as:

- wearing a watch with the time and date
- keeping a list of friends and family and their contact details
- writing notes to yourself in the house or on a whiteboard

Make a personal crisis plan

A personal crisis plan is a document you make when you are well. It explains what you would like to happen if you are not well enough to make decisions about your treatment or other aspects of your life. Sometimes it is called an 'advance statement'. Mind has lots more information about making crisis plans on its website (mind.org.uk).

PODS produces DID Emergency Information cards which you can order for free from its website (pods-online.org.uk).

Talk to other people with similar experiences

- **Try peer support.** Unfortunately, there are not many peer support groups specifically for people with complex dissociative disorders, but you can contact First Person Plural for more information, and see Mind's pages on 'Peer support'.
- **Read other people's experiences.** If you don't want to talk, you may still find it helpful to read about other people's experiences. This can give you new perspectives and help give you ideas about new ways of dealing with dissociation. You can read others' experiences on online forums or find some on the PODS website.

Look after yourself

- Try to get enough sleep. Sleep can give you the energy to cope with difficult feelings and experiences. You might find it helpful to learn relaxation techniques. Mind's pages on 'Coping with sleep problems' and 'Relaxation' have more information.
- Think about your diet. Eating regularly and keeping your blood sugar stable can make a difference to your mood and energy levels. Mind's pages on 'Food and mood' have more information.
- Try to take some exercise. Exercise can be really helpful for your mental wellbeing. Mind's pages on 'Sport, physical activity and mental health' have more information.

●● *Depersonalisation, derealisation and dissociation are now only occasional features in my life. But when I am under a lot of stress or not sleeping properly, I find I dissociate more.* ●●

Dealing with stigma

Unfortunately, a lot of people don't understand much about dissociative disorders, and may hold misconceptions about you. This can be really upsetting, especially if the people who feel this way are family, friends or colleagues.

It's important to remember that you aren't alone and you don't have to put up with people treating you badly. Here are some options for you to think about:

- Show people this information to help them understand more about dissociative disorders.
- Talk to other people who have dissociative disorders by going to a support group – or setting one up for yourself.
- Share your experience with others. Mind publishes blogs and video blogs (mental health selfies) on its website.
- Know your rights. Mind's legal rights resources provide more information.
- Take action with Mind. See our campaigning page for details of the different ways you can get involved with helping us challenge stigma.

What treatments can help?

Can I recover from a dissociative disorder?

Yes – if you have the right diagnosis and treatment, there is a good chance you will recover. This might mean that you stop experiencing dissociative symptoms and any separate parts of your identity merge to become one sense of self.

Not everyone will stop experiencing dissociative symptoms completely but treatment can help you feel more in control of your life and your identity. Some people find that being able to dissociate is comforting and don't feel ready to stop dissociating completely.

Talking treatments

Talking treatments are the recommended treatment for dissociative disorders. Counselling or psychotherapy will help you explore traumatic events in your past, help you understand why you dissociate and develop alternative coping mechanisms. It can also help you manage your emotions and your relationships.

👉👉 *Slowly my other parts are telling me about their memories of my abuse and I am telling them about my life now and, bit by bit, we are piecing things together and working through it with the help of counselling.* 👉👉

Accessing therapy

Most talking treatments for dissociative disorders take several years, but unfortunately in most areas the NHS offers short or medium term therapy. This isn't usually effective in treating dissociative disorders.

You may need to be very persistent to get the right help from the NHS, or consider alternative ways to access treatment. An advocate may be able to help. See Mind's online pages on 'Advocacy' for more information.

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You might want to seek therapy outside the NHS:

- The European Society for Trauma and Dissociation provides contact details for people who can help you find a therapist.
- The Survivors Trust and PODS have more information about organisations and therapists too. You may be able to get low cost or free therapy through voluntary organisations.
- PODS can also help you find a private therapist.



Choosing a therapist

Not all therapists are familiar with dissociation or working with trauma. It may take time to find a therapist that feels right for you.

It's absolutely fine to meet with as many therapists as you need to find the one you want to work with. The therapist you choose should be:

- accepting of your experience
- willing to work with or learn to work with dissociation and trauma
- be prepared to work with you long term

See Mind's pages on 'Talking treatments' for more information on choosing a therapist.

 *I have learnt ways to control it and have began to be able to explore my feelings about my past without using dissociation to cope with it.* 

Medication

There are no drugs that are licensed to treat dissociation. Your doctor might offer you psychiatric medication to treat other symptoms or problems you might experience because of – or as well as – a dissociative disorder, such as depression, anxiety and panic attacks, suicidal feelings, hearing voices and OCD.

These might include antidepressants, antipsychotics or mood stabilisers.

You will only be given medication for dissociative identity disorder (DID) if most of the different parts of your identity (or at least the dominant one) experience the problem you want to treat.

Can eye movement desensitisation and reprocessing (EMDR) be used to treat dissociative disorders?

EMDR was created to help people process traumatic memories. But standard EMDR is not helpful for most people with dissociative disorders and the treatment should be adjusted to make it safe and effective. EMDR for dissociative disorders focuses on specific individual memories and usually for shorter time periods.

This helps make it less intense and prevents too many traumatic memories appearing too quickly (flooding). It should only be used when you are feeling reasonably stable and by professionals who are knowledgeable about treating dissociative disorders.

What is non-epileptic attack disorder (NEAD)?

Some people with dissociative disorders also experience physical symptoms such as seizures. These seizures don't seem to have a physical cause. These are called dissociative seizures or non-epileptic attacks. You may be given the diagnosis of non-epileptic attack disorder (NEAD).

Although they don't have a physical cause this does not mean that they are not real or that you are acting.

If you have a dissociative seizure you may:

- have convulsions of the arms, legs, head or body (on one side or affecting the whole body)
- lose control of your bladder
- bite your tongue

- go blank or stare in an unseeing way
- have other symptoms that look like epilepsy.

●● *My own non-epileptic seizures are similar to a tonic epileptic seizure – going stiff and rigid, gasping. This is combined with visual disturbances.* ●●

It is thought that dissociative seizures are caused by the brain dealing with overwhelming stress by 'shutting down'. You can find out more about non-epileptic attacks on:

- the Non-Epileptic Attack Disorder (NEAD) website
- Epilepsy Action's website (see 'Useful contacts' on p.25).

What can friends or family do to help?

This page is for family and friends who want to support someone with a dissociative disorder.

It can be really hard to see someone you care about experiencing the symptoms of a dissociative disorder. But family and friends can really help. This page has some suggestions for ways you can support them while also looking after your own wellbeing.

●● *Having understanding family and friends helps me.* ●●

Try to be patient and understanding in daily life

- Dissociative symptoms may mean they do not always respond to you as you expect.
- Ask them what would help but be aware that they may not always know or be able to tell you.
- If they want to tell you about their experience try to listen with acceptance.

- Touching and intimacy can be difficult for some people. It might help to ask them what is OK and talk about this together.

Think about how to deal with identity alteration

If they experience identity alteration you may find that you have to communicate with different parts of their identity at different times.

- You may need to develop different ways of managing when different parts of their identity are in control.
- Positive Outcomes for Dissociative Survivors (PODS) suggests that you try to find some way of relating to each part of their identity. Its website has more suggestions for supporting someone with dissociative identity disorder.
- Try to stay calm and be a safe and soothing presence even if they are upset, angry or scared.

Help them to find the right support

You can:

- help them find an advocate and support them to meet with different therapists
- offer extra support and understanding before and after therapy sessions
- help them to make a crisis plan if they think it would be helpful.

There may be times when you can't offer them the support they need. Think about who is the best person to contact at these times. Have a look at our information on supporting someone to seek help.

Think about how you could help keep them safe

- **Your loved one may have triggers** that bring on dissociative symptoms and flashbacks. Understanding their triggers means you can help them avoid them, and feel more prepared for dissociative symptoms when they occur.
- **If someone you love is hurting themselves or struggling**

with suicidal thoughts, it can feel really scary. See Mind's pages on 'Supporting someone who feels suicidal' and 'Self harm' for more information.

- **If they experience amnesia, flashbacks or identity alteration** they may need more help to stay safe during these times. Talk to them about what you can do to help.

Look after yourself

It's important to make sure you look after yourself too.

- You might find it helpful to find a therapist for yourself too. Have a look at Mind's information on 'Talking treatments'.
- Have a look at our information on 'How to cope as a carer' and 'How to improve your mental wellbeing'.
- It can help to talk to other people with similar experiences. PODS online forum has a section for carers and supporters.

Useful contacts

Clinic for Dissociative Studies

Web: clinicds.co.uk

Accepts NHS referrals. Website has useful information about dissociative disorders.

Childline

Tel: 0800 1111

Web: childline.org.uk

Support for children who are worried or upset about anything – including abuse.

Epilepsy Action

Web: epilepsy.org.uk

Information about non epileptic attack disorder (NEAD).

European Society for Trauma and Dissociation

Web: estd.org

Includes links to online information on psychological trauma and dissociative disorders.

First Person Plural

Web: firstpersonplural.org.uk

Support and information for people who experience complex dissociative disorders and their family and friends.

The International Society for the Study of Trauma and Dissociation (ISSTD)

Web: isst-d.org

Academic society providing information for professionals and the general public about trauma and dissociation research.

National Association for People Abused in Childhood

Tel: 0808 801 0331 (freephone from landline and mobiles)

Web: napac.org.uk

Provides a range of services which offer direct support to survivors of abuse.

NEAD Non-Epileptic Attack Disorder

Web: nonepilepticattackdisorder.org.uk

Provides information and support for people who experience non-epileptic attacks.

National Society for the Prevention of Cruelty to Children (NSPCC)

Tel: 0808 800 5000

Web: nspcc.org.uk

Help for adults concerned about a child.

Useful contacts

PODS (Positive Outcomes for Dissociative Survivors)

Tel: 0800 181 4420

web: pods-online.org.uk

Information, support and crisis cards for people with a dissociative disorder.

Survivors UK

Web: survivorsuk.org

Support for men who have experienced rape or sexual abuse.

The Survivors Trust

Tel: 01788 550 554

web: thesurvivorstrust.org

Lists local specialist organisations dealing with sexual abuse and violence.

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tel: 0300 999 1946

email: supportercare@mind.org.uk

web: mind.org.uk/donate

This information was written by Clare Foster.

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

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