

understanding



dissociative disorders

Understanding dissociative disorders

This booklet is for anyone who has, or thinks they may have, a dissociative disorder, and their family and friends. It describes what dissociation is and what types of dissociative disorders there are. It also discusses what might cause them and options for treatment.

Note: This booklet includes information on dissociative identity disorder (DID). This is also known as multiple personality disorder (MPD).

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What is dissociation?

Your sense of reality and who you are depend on your feelings, thoughts, sensations, perceptions and memories.

If these become 'disconnected' from each other, or don't register in your conscious mind, your sense of identity, your memories, and the way you see yourself and the world around you will change. This is what happens when you dissociate.

👁️👁️ *It's as if your mind is not in your body; as if you are looking at yourself from a distance; like looking at a stranger.* 🧠🧠

Everyone has periods when we feel disconnected. Sometimes this happens naturally and unconsciously. For example, we often drive a familiar route, and arrive with no memory of the journey or of what we were thinking about. Some people even train themselves to use dissociation (ie: to disconnect) to calm themselves, or for cultural or spiritual reasons. Sometimes we dissociate as a defence mechanism to help us deal with and survive traumatic experiences.

Dissociation can also be a side effect of some drugs, medication and alcohol.

Many mental health problems, such as schizophrenia, bipolar disorder and borderline personality disorder, have dissociative features.

The different types of dissociation

There are five types of dissociation:

Amnesia

This is when you can't remember incidents or experiences that happened at a particular time, or when you can't remember important personal information.

Depersonalisation

A feeling that your body is unreal, changing or dissolving. It also includes out-of-body experiences, such as seeing yourself as if watching a movie.

Derealisation

The world around you seems unreal. You may see objects changing in shape, size or colour, or you may feel that other people are robots.

Identity confusion

Feeling uncertain about who you are. You may feel as if there is a struggle within to define yourself.

Identity alteration

This is when there is a shift in your role or identity that changes your behaviour in ways that others could notice. For instance, you may be very different at work from when you are at home.

What are the different types of dissociative disorder?

Occasional, mild episodes of dissociation are part of ordinary, everyday life. Sometimes – at the time of a one-off trauma or during the prolonged ‘identity confusion’ of adolescence, for instance – more severe episodes are quite natural.

Dissociative disorders occur when you have continuing and repeated episodes of dissociation. These usually cause what many people describe as ‘internal chaos’, and may interfere with your work, school, social, or home life. However, you may be someone who appears to be functioning well, and this may hide the distress you are experiencing.

Dissociative amnesia

This is when you can’t remember significant personal information or particular periods of time, which can’t be explained by ordinary forgetfulness. You may also experience mild to moderate depersonalisation, derealisation and identity confusion.

👁️👁️ *I didn't know I had other personalities at first because I wouldn't remember them taking over – usually people closest to you are the first to know.* 🧠🧠

Depersonalisation disorder

You will have strong feelings of detachment from your own body or feel that your body is unreal. You may also experience mild to moderate derealisation and mild identity confusion.

Dissociative fugue

You may travel to a new location during a temporary loss of identity. You may then assume a different identity and a new life. Usually this 'fugue' will last for a few days, but it can last longer. To people who don't know you, your behaviour may appear normal.

When your memory of your identity returns, you may have a range of different feelings about what you did while in the fugue, such as depression, guilt, shame, fear and/or confusion.

If you experience dissociative fugue, you are likely to have experienced severe amnesia, with moderate to severe identity confusion and often identity alteration.

Dissociative identity disorder (DID)

This is the most complex dissociative disorder. It is also known as multiple personality disorder (MPD). This has led some to see it as a personality disorder, although it is not. The defining feature is severe change in identity.

👁️👁️ *I'd look in the mirror and it would be a different face. I was chaotic and unsettled.* 🧠🧠

If you experience DID, you may experience the shifts of identity as separate personalities. Each identity may be in control of your behaviour and thoughts at different times. Each has a distinctive pattern of thinking

and relating to the world. If you also have very severe amnesia, it may mean that one identity may have no awareness of what happens when another identity is in control. The amnesia can be one-way or two-way. Identity confusion is usually moderate to severe. DID also includes severe depersonalisation and derealisation.

Dissociative disorder not otherwise specified (DDNOS)

Each of the five types of dissociative response (see pp.4-5) may occur, but the pattern of mix and severity does not fit any of the other dissociative disorders listed above.

Additional problems

If you have a dissociative disorder, you may experience other problems too, e.g. depression, mood swings, anxiety and panic attacks, suicidal thoughts and feelings, self-harm, headaches, hearing voices, sleep disorders, phobias, alcohol and drug abuse, eating disorders, obsessive-compulsive behaviour and various physical health problems.

These may be directly connected with the dissociative problem, or could mean that you also have a non-dissociative disorder. In DID, some problems may only emerge when a particular identity has control of your behaviour, thoughts and feelings.

What are the effects of a dissociative disorder?

Dissociation can affect your perception, thinking, feeling, behaviour, body and memory. If you experience a dissociative disorder you may have to cope with many challenges in life. The impact of dissociation varies from person to person and may change over time. How well a person appears to be coping is not a good way of telling how severely affected they are.

The effects of dissociative disorder may include:

- gaps in your memory
- finding yourself in a strange place without knowing how you got there
- out-of-body experiences
- loss of feeling in parts of your body

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- distorted views of your body
- forgetting important personal information
- being unable to recognise your image in a mirror
- a sense of detachment from your emotions
- the impression of watching a movie of yourself
- feelings of being unreal
- internal voices and dialogue
- feeling detached from the world
- forgetting appointments
- feeling that a customary environment is unfamiliar
- a sense that what is happening is unreal
- forgetting a talent or learned skill
- a sense that people you know are strangers
- a perception of objects changing shape, colour or size
- feeling you don't know who you are
- acting like different people, including child-like behaviour
- being unsure of the boundaries between yourself and others
- feeling like a stranger to yourself
- being confused about your sexuality or gender
- feeling like there are different people inside you
- referring to yourself as 'we'
- being told by others that you have behaved out of character
- finding items in your possession that you don't remember buying or receiving
- writing in different handwriting
- having knowledge of a subject you don't recall studying.

What causes dissociative disorders?

Childhood abuse

The causes of dissociative disorders are complex. Studies show that a history of trauma, usually abuse in childhood, is almost always the case for people who have moderate to severe dissociative symptoms. But not all trauma survivors have a dissociative disorder, so the relationship is not one of simple cause and effect.

A fuller understanding comes from looking at your childhood relationship with your parents or guardians. If the relationship was insecure and you were abused, then you were, and are, more likely to use dissociation to protect yourself from the trauma. The combination of an insecure relationship, trauma and dissociation can result in a complex dissociative disorder.

A number of experts agree that the following factors usually have to be present for a person to develop the most complex dissociative disorders e.g. DID, or DDNOS with features of DID:

- abuse begins before the age of five
- abuse is severe and repeated over an extended period
- the abused child has an enhanced natural ability to dissociate easily
- there is no adult to provide comfort; the child had to be emotionally self-sufficient.

How are dissociative disorders diagnosed?

Several questionnaires can be used to assess whether you have a dissociative disorder. Clinicians who use these assessment tools should have specialist training and a good understanding of dissociative disorders. Clinicians who have extensive knowledge and experience of working with dissociative disorders may be able to recognise a dissociative disorder using clinical judgement alone.

If you have experienced a combination of any of the symptoms (effects) on pp.7-8, you may need an assessment for dissociative disorders.

Diagnosing dissociative identity disorder (DID)

For DID, clinicians may also look for the following clues when making a diagnosis:

- history of childhood abuse/trauma
- reporting 'blank spells'
- hearing voices and/or believing there are external influences on the body and/or other unusual beliefs (apparently delusional thinking) and/or reports of other people's thoughts intruding

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- previous diagnosis or suspicion of borderline personality disorder
- previous unsuccessful treatment
- self-destructive behaviour
- no thought disorder.

More women than men are diagnosed with the DID. Many are diagnosed when they are aged 20-40. However, people both younger and older can experience DID.

Difficulty in diagnosing

There are quite low rates of diagnosis for dissociative disorders, and there may be several reasons why.

- GPs and mental health professionals often receive insufficient training on dissociative disorders, so may not ask the right questions or consider the possibility of a dissociative disorder.
- Many signs and symptoms identified during routine mental health assessments (e.g. depression, anxiety, insomnia, self-harming, hearing voices) are common to other mental health problems more familiar to the clinician. And so a standard assessment will often not identify a dissociative disorder.
- There is often confusion surrounding the term 'multiple personality disorder' (for DID). It can result in a diagnosis that is not valid, as the clinician may be looking for personality disorder symptoms instead of dissociative disorder symptoms.
- Some symptoms can be similar for several disorders. For example, many people who are diagnosed with dissociative identity disorder (DID) may previously have been diagnosed with borderline personality disorder; some may meet the criteria for both.
- Until recently, clinicians did not routinely ask about history of childhood abuse and trauma at assessment. Also, even if asked, people may deny a history of abuse. One reason for this may be because they do not remember it (dissociative amnesia).

- Almost everyone coping with dissociative difficulties tries to keep them hidden from others.

Please note that dissociative states are a common and accepted feature of cultural activities or religious experience in many non-Western societies and are not regarded as a mental health problem.

If I think I may have a dissociative disorder, what should I do?

Be cautious about diagnosing yourself without the advice of a suitably experienced professional. First, call your GP, unless you are already a patient of the specialist mental health services. Ask your GP, care co-ordinator or psychiatrist to refer you to a mental health professional aware of dissociation, for a full diagnostic assessment. If this fails, you may want to look to the voluntary or private sector for help. (See 'Access to talking treatments' on pp.12-13 and Mind's booklet *Making sense of talking treatments* for more information.)

What treatments can help?

For all dissociative disorders the aim of treatment and self-help is to increase the connections between your feelings, thoughts, perceptions and memories, and to help you develop a sense of empowerment. This will make you feel more 'whole' and reduce the 'internal chaos' you may be feeling. In turn, this will lead to less disruption in your work, and social and home life. The International Society for the Study of Trauma and Dissociation gives guidelines for the treatment of dissociative identity disorder (DID) only. See 'Useful contacts' on p.18.

Health professionals, including your GP or psychiatrist, should discuss all your treatment options with you. They should listen to your views and take your preferences into account when they make decisions about your treatment.

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If you find it difficult to remember what is said and agreed in meetings with doctors or other health professionals, you may want to bring someone you trust with you. It can help if you have discussed and agreed with them what you hope to get from the meeting and how you want them to support you in the meeting.

You can also choose to bring along an advocate. This is someone who can both listen to you and speak for you (see Mind's booklet *The Mind guide to advocacy*).

Talking treatments

It is important to look at underlying causes as well as the effects of the dissociative problems. Although effective treatment for dissociative disorders may combine several methods, it always includes psychotherapy or counselling – usually over several years.

●● *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.* ●●

The client-therapist relationship

The therapist should be familiar with trauma work and ideally have experience of working with dissociation. However, it is the quality of the client-therapist relationship that is most important; and so inexperienced therapists may provide effective therapy if supervised by a professional who is experienced with dissociation.

The therapist should be:

- accepting of your experience
- willing to learn how to work with dissociation and trauma
- able to tolerate any level of frustration and extreme pain you may experience
- be prepared to work with you long term.

Access to talking treatments

Getting such help through the NHS may depend on where you live and may not always be easy to access. Those who have received appropriate NHS-funded help often report that it was only through their own persistence and/or with the help of someone else (an advocate). The short to medium-term therapy most commonly available from the NHS may not be effective in the long term for dissociative clients.

Low-cost or free therapy may be available through voluntary organisations. Mind Infoline can give you information about services available in your local area. Also, some of the organisations in 'Useful contacts' may be able to give you information on this.

Therapists in the private sector are another option if you can afford it – some offer fees based on your ability to pay.

Also see Mind's booklet *Making sense of talking treatments*.

Medication

There is no medication to treat dissociation. However, medication can help treat symptoms you may also be experiencing, such as depression, anxiety, or insomnia etc.

In dissociative identity disorder (DID), medication should only be used when the targeted symptom is widespread throughout the system of identities and/or is experienced by your dominant identity and the one who manages everyday life. It is important to monitor dosage and effects carefully. (See Mind's series of *Making sense* booklets for more information on medication.)

Care in the community

Supportive and community mental health services can help you to cope with the everyday effects of dissociation and related problems that impact on your daily life. Staff don't necessarily have to be professionally qualified, but they do need to know about dissociation and how to respond to you if you are in a dissociative state.

Crisis intervention

If you feel suicidal or don't feel you are able to keep yourself safe, you may need urgent help. You can contact your GP, your community mental health worker or your out-of-hours mental health crisis worker. They may refer you for admission to hospital or for intensive care from a home treatment team. (This is a community-based crisis-response service that can provide support in your own home as an alternative to hospital admission.)

Alternatively, you may ask for help at a hospital A&E department. Mainstream crisis intervention services are unlikely to understand or acknowledge the dissociative experience, but they may be the only option to help you get through the crisis.

Advance statements

Before a crisis occurs, it's a good idea to make a personal crisis plan with the help of a care co-ordinator, friend or other supporter. You can make an advance statement while you are well, explaining what you would like to happen if you are in crisis and become unable ('lose capacity') to make decisions about your treatment or domestic arrangements. If someone else needs to decide things in your best interests, your advance statement should always be taken into account. However:

- If you include a decision to refuse a type of treatment, this is legally binding, and should be followed by doctors and other health professionals.
- If you have included any positive preferences for treatment – what you would like to happen in a crisis– these should also be taken into consideration, but they are not legally binding.
- The Mental Health Act 1983 gives psychiatrists power to override your decisions, if you are sectioned and they believe that treatment is needed (although a decision to refuse electro-convulsive therapy (ECT) is usually respected).

The main types of advance statement are advance decisions (also known as an 'advance directive' or 'living will'), joint crisis plans (JCP), and crisis cards. (See Mind's online booklet *The Mind guide to crisis services* for more details.) You can get a dissociative identity disorder (DID) crisis card from PODS (see 'Useful contacts' on p.18).

How can I help myself?

Recovery usually requires active self-help, and so it's common for therapists to set 'homework' that includes a variety of self-help techniques and exercises. If you want to try self-help techniques on your own, remember that dissociation can complicate this. In dissociative identity disorder (DID), for instance, the identity who self-harms must be involved in any self-help activity for managing behaviours.

Keeping a journal is one way to help improve connections, and (in DID) awareness and co-operation between identities. It can include the writings or artwork from any part of your dissociated self.

●● *Using a journal to express my inner turmoil, helps me deal with it.* ●●

Visualisation is a way to use your imagination to create internal scenes and environments which help you stay safe and contain difficult feelings and thoughts. With practice, you can also use this to bring different identities together to make co-operative decisions.

Grounding techniques, which keep you connected to the present, can help you avoid feelings, memories, flashbacks or intrusive thoughts that you can't yet cope with. The many techniques include breathing slowly, walking barefoot, talking to someone, touching something and sniffing something with a strong smell.

👁️👁️ *I feel things around me such as walls and other textures that remind me that I'm real and that things around me are real.* 🧠🧠

Planning for child, adolescent and other identities to have control, at times and in places that are safe, is essential self-help for people who have DID. This is time for them to do things they like, to have experiences they were denied during an abusive childhood.

Strategies for everyday challenges can help you cope with everyday life. For instance, a person who loses time, due to dissociation, may decide to wear a watch with the day and date on it.

Reading about the life and experiences of survivors with similar problems can give you insight and help you find new ways of dealing with your own difficulties.

Support groups

Sharing experiences with others who have the same problems can provide you with emotional release and practical assistance, if the support group is well organised and maintains very clear boundaries (see 'Useful contacts' on p.18). Some people with a dissociative disorder have reported that abuse self-help or support groups which include both people with complex dissociative disorders and people without this experience have been problematic.

Online forums and communities

Some organisations, for example PODS (Partners of Dissociative Survivors – see 'Useful contacts'), provide private online forums and communities where you can talk to others and share your experiences. Other organisations also provide open forums and communities. Unfortunately not all of these may be safe to use, so you may want to check with the organisations listed under 'Useful contacts' before you join any online communities. Also see Mind's online booklet *How to stay safe online*.

Will I get better?

Most people with a dissociative disorder who have been correctly diagnosed and provided with appropriate treatment are likely to make significant progress. Many report full recovery and most others have been able to take more control over their lives and reduce the frequency of crises.

What can friends or family do to help?

This section is for friends or family who wish to support someone they know who has dissociative disorder.

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

Partners, family and friends can have a key role to play in recovery. Below are some ways you can help.

- Learn as much as possible about dissociative disorders.
- Listen with acceptance to your friend or relative, if they want to tell you about their experience.
- Don't expect them to always know what you can do to help, or to be able to tell you.
- Be honest and non-judgemental.
- Be cautious about touching and intimacy – ask them what is OK.
- Do offer to help with everyday tasks to ease the pressure.

Remember not to neglect yourself. Talking treatments may help you cope with the vast array of feelings brought out by living with someone who experience, a dissociative disorder. See Mind's booklets *Making sense of talking treatments* and *How to cope as a carer* for more information.

Useful contacts

Mind

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

Clinic for Dissociative Studies

web: clinicfordissociativestudies.com
Accepts NHS referrals. Website has useful information about dissociative disorders.

Directory and Books Services (DABS)

tel: 01255 851 115
web: dabsbooks.co.uk
For survivors of childhood sexual abuse.

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 distress conditions, their family, friends.

International Society for the Study of Trauma and Dissociation

web: isst-d.org

PODS (Partners of Dissociative Survivors)

helpline: 0800 181 4420
web: pods-online.org.uk
Information and crisis cards for people who suffer from a dissociative disorder.

The Survivors Trust

tel: 01788 550 554
web: thesurvivorstrust.org
Lists local specialist organisations dealing with sexual abuse and violence.

Trauma and Abuse Group (TAG)

web: tag-uk.net
Details of UK organisations providing or listing counsellors or therapists.

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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