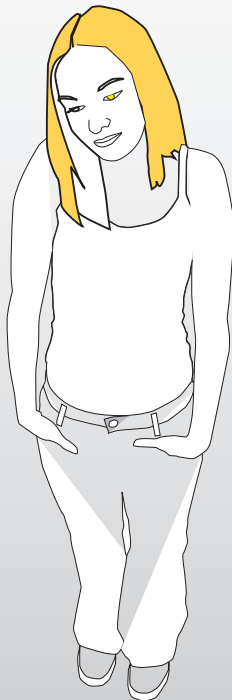




For better
mental health

Understanding dissociative disorders



'What was happening around me was like a scene from a war movie. I was observing it, not participating in it. I didn't feel frightened. It all seemed so strange and unreal.'

Bomb attack survivor

'The world around me seems unreal and alien, like a mist has descended and everything looks hazy and dreamlike; only I'm awake so I can't be dreaming.'

Survivor of derealisation

'For much of the time I look unremarkable and act unremarkably, but inside there is almost always noise and chaos – it sometimes sounds like I've walked into a theatre foyer during the interval, you know, the buzzing of many conversations, none of which I can fully tune into and make sense of. I have other odd experiences – like when my arm doesn't seem to belong to me, or when I feel like I'm a cardboard cut-out that someone else animates, or when I seem to know something I don't remember learning. And when I fully switch to another self my life can become chaotic. If it is a child personality, I behave like a child – often a very scared and traumatised child. Such behaviour looks bizarre, because all you see is the adult body. But this isn't an act, it's not something I can control – my experience of myself at these times is that I am a child. Sometimes, I lose time; one minute it's Monday and I'm at work, the next it's Wednesday and I'm in a hotel, 100 miles from home and my arms are bleeding. Only I don't know immediately that time has passed. I don't remember how I got there. Even though I know 'I' must have cut myself with the paper knife in my hand, I don't remember doing it and it feels like I have been attacked by someone else. It's very confusing, disorientating and distressing and it doesn't help when professionals and others don't understand about dissociative disorders and think I'm attention seeking or acting out.'

Survivor of dissociative identity disorder

This booklet describes dissociative disorders, their probable causes and the options for effective treatment. The most complex are difficult to recognise using standard mental health assessments, and, as many mental health professionals do not receive appropriate training on dissociative distress, they may fail to consider these conditions when making a diagnosis. Consequently, current low rates of diagnosis may not be a true reflection of the actual number of people who have these experiences.

Once correctly diagnosed and getting appropriate treatment the majority of people with dissociative disorders 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 is dissociation?

Your sense of identity, reality and continuity depend on your feelings, thoughts, sensations, perceptions and memories. If these become 'disconnected' from each other, or don't register in your conscious mind, it changes your sense of who you are, your memories, and the way you see things around you. This is what happens during dissociation.

Everyone has periods when disconnections occur naturally and usually unconsciously. 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 to calm themselves, or for cultural or spiritual reasons.

Dissociation is also a defence mechanism helping people to survive traumatic experiences. The bomb survivor, quoted on p. 2, is describing a normal dissociative response, which allowed her to focus on the things she needed to do to survive, including remembering where the nearest exit was.

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





What are the different forms of dissociative response?

There are five types of dissociation, which are listed below. Occasional, mild episodes are part of ordinary, everyday life. Sometimes – at the time of a one-off trauma or the prolonged identity confusion of adolescence, for instance – more severe episodes are quite natural.

Amnesia

This is when people can't remember incidents or experiences that happened at a particular time, or when they 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 dissociative disorders?

Dissociative disorders occur when people have persistent and repeated episodes of dissociation. These usually cause distressing internal chaos, and may interfere with work, school, social, or home life. However, some people apparently function well which hides their distress.

ICD-10 (the international diagnostic manual used by health professionals) describes all five of the dissociative disorders outlined below – most of them are listed in the category ‘dissociative (conversion) disorders’. Conversion symptoms are physical (e.g. paralysis, numbness, fits), but result from a psychological dissociative process. In the DSM-IV (the American diagnostic manual) conversion symptoms are also known as somatoform symptoms. Research from the Netherlands confirms the dissociative nature of somatoform symptoms and has led to the development of a diagnostic questionnaire for dissociative disorders which asks about somatoform experiences.

The five DSM-IV dissociative disorders can be arranged, in order of complexity, along a ‘dissociative disorder continuum’. A person’s position on the continuum will depend on the severity and mix of the types of dissociation they experience.

The dissociation disorder continuum

Depersonalisation disorder

This features strong feelings of detachment from a person’s own body, or that their body is unreal. A person may also experience mild to moderate derealisation and mild identity confusion.

Dissociative amnesia

An inability to remember significant personal information or particular periods of time, which can’t be explained by ordinary forgetfulness. People may also experience mild to moderate depersonalisation, derealisation and identity confusion.

Dissociative fugue

A person travels to a new location during a temporary loss of identity. He or she may assume a different identity and a new life. There is severe amnesia, with moderate to severe identity confusion and often identity alteration.

Dissociative disorder not otherwise specified (DDNOS)

Each of the five types of dissociative response may occur, but the pattern of mix and severity does not fit any of the other dissociative disorders.

Dissociative identity disorder (DID)

The most complex dissociative disorder. It's also known as multiple personality disorder (MPD) according to the ICD-10. This has given rise to the idea that this is a personality disorder, although it is not. Its defining feature is severe identity alteration. Someone with DID experiences these shifts of identity as separate personalities. Each identity may assume control of behaviour and thoughts at different times. Each has a distinctive pattern of thinking and relating to the world. Severe amnesia means 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. It also includes severe depersonalisation and derealisation.

Additional problems

People may have other problems too such as depression, mood swings, anxiety and panic attacks, suicidal tendencies, 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 the person also has a non-dissociative disorder. In DID, these problems may only emerge when a particular part of the fragmented identity (an alter personality) has control of the person's behaviour, thoughts and feelings.

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



What causes dissociative disorders?

The causes of dissociative disorders are complex. Studies show that a history of trauma, usually abuse in childhood, is almost universal 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 children's early attachment to primary caregivers. One type of such attachment is called 'disorganised'. If a child with a disorganised attachment

style suffers abuse they are more likely (than children with other attachment styles) to respond to it by using dissociation as a defence. This combination of disorganised attachment, trauma and dissociation can affect the child's development in ways that may result in a complex dissociative disorder.

Recent studies show differences in the brains of people with trauma-related dissociative disorders, but it is hard to know if this is a cause or effect. Exactly how these or any other potential causal factors relate to each other in the development of dissociative disorders is not fully known.

A number of experts agree that the following factors 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.

There is a sceptical viewpoint that argues that DID is not a naturally occurring condition but its symptoms are caused by poor therapy with vulnerable, suggestible clients. It has also been suggested that DID is a North American phenomenon and should be viewed as a culture specific diagnosis. But dissociative disorders have been identified and studied in many different countries and cultures.

How common are dissociative disorders?

Dissociative disorders are likely to be much more common than low rates of diagnosis suggest. A British audit using a standard dissociative disorders screening questionnaire was undertaken with 59 mental health inpatients on an acute unit, none of whom had previously been diagnosed with a dissociative disorder. It found 30 per cent experienced significant levels of dissociation and it's probable that 50 per cent of these had an undiagnosed dissociative disorder. People who are eventually diagnosed with



DID or other complex dissociative disorder have often had several earlier misdiagnoses, such as schizophrenia, bipolar or borderline personality disorder. Others never have their dissociative disorder diagnosed. Prevalence of DID in the general population may be as high as one per cent.

Several factors may underlie the low rates of diagnosed dissociative disorders. Firstly, almost everyone coping with dissociative difficulties strives to keep them hidden from others. Secondly, 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, voice hearing) are common to other mental health problems more familiar to the clinician. Thus a standard assessment will often not identify a dissociative disorder. In addition, there is often confusion surrounding the term 'multiple personality disorder' (for DID) used in the diagnostic manual ICD-10. It can result in an invalid diagnosis, as the clinician may be looking for personality disorder symptoms instead of dissociative disorder symptoms.

The relationship between dissociative disorders and childhood abuse and trauma may be another reason for non-recognition as, until recently, trauma histories were not routinely asked about at assessment. Also, even when asked, people may deny a history of abuse for a variety of reasons, one of which may be because they do not remember it (dissociative amnesia).



What are the effects of dissociative disorders?

Dissociation can affect perception, thinking, feeling, behaviour, body and memory. So, the person with a dissociative disorder has 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. For instance, few people with DID will switch rapidly and openly between identities, in the way portrayed on TV and film. Nor is the classic 'Dr Jekyll and Mr Hyde' shift of identity common.

The effects of dissociative disorder may include:

- gaps in 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
- distorted views of your body
- forgetting important personal information
- inability 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 learned talent or 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.



How are dissociative disorders diagnosed?

There are several validated questionnaires that can be used to screen for and diagnose dissociative disorders. Two of the most common are the Dissociative Experiences Scale (DES) and the Structured Clinical Interview for DSM-IV Dissociative Disorders (SCID-D). Research shows these are accurate tools which discriminate DID from other dissociative disorders and from other mental health problems. Clinicians using these assessment tools should be trained in their use and have a good understanding of the dissociative disorders – sometimes it may be necessary to see a specialist outside of the NHS with the appropriate training. Combinations of any of the above described effects suggest an assessment for dissociative disorders may be needed. For DID the following are non-specific diagnostic clues. They are not the only indicators (e.g. men can also have DID and it is seen in older people) but they are a useful guide for when to seek assessment for dissociative disorders.

- history of childhood abuse/trauma
- female
- age 20-40
- 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
- previous diagnosis or suspicion of borderline personality disorder
- previous unsuccessful treatment
- self-destructive behaviour
- no thought disorder.

Clinicians who are knowledgeable and very experienced working with dissociative disorders may be able to recognise them using clinical judgement alone.

It should be noted 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. For this reason assessment needs to be culturally sensitive.

What helps recovery?



For all the dissociative disorders the aim of treatment and self-help is to bring about increased connection between feelings, thoughts, perceptions and memories, and to foster a sense of empowerment. This creates a greater sense of wholeness and internal order, and less disruption in work, social and home life. The International Society for the Study of Trauma and Dissociation provide guidelines for the treatment of DID (see 'Useful websites' on p.16).

Talking treatments

Effective treatment for the dissociative disorders may combine several methods, but always includes psychotherapy or counselling, usually over several years. It is important that this approaches underlying causes as well as the effects of the dissociative problems. The therapist should be familiar with trauma work and ideally have experience working with dissociation. However, it is the quality of the therapist-client 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 the client's experience; willing to learn how to work with dissociation and trauma; able to tolerate a client's high levels of frustration and extreme pain; and be prepared to work with the client long term.

Getting such help through the NHS may depend on where you live and may not be forthcoming even after a dissociative disorder has been diagnosed. Those who have received appropriate NHS-funded help often report that it was only through their own persistence and/or other's advocacy. The short to medium-term therapy most commonly available from the NHS may not be effective in the long term for dissociative clients. Appropriate low-cost or free therapy may be available through voluntary organisations. Therapists in the private sector

are another option if you can afford it – some offer fees based on your ability to pay.

Medication

There is no medication to treat dissociation. However, medication may be helpful in treating co-existing symptoms of depression, anxiety, or insomnia etc. Regular antipsychotic medication is not generally helpful. In DID, medication should only be used when the targeted symptom is widespread throughout the system of identities and/or is experienced by the dominant personality state(s) who manage everyday life. It is important to monitor dosage and effects carefully.

Care in the community

Supportive and creative community mental health services can help people to cope with the everyday effects of dissociation and related problems that impact on daily life. The workers don't necessarily have to be professionally qualified, but they do need to know about dissociation and how to respond to a person in a dissociative state. Social services direct payments, which pay the client an amount to provide for their own social support and care, can be very effectively used by some people with dissociative disorders.

Crisis intervention

If you are suicidal or otherwise unable to stay safely in the community, a GP, community mental health worker or out-of-hours mental health crisis worker may make a referral 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 accident and emergency department. Mainstream crisis intervention services are unlikely to understand or acknowledge the dissociative experience, but they may be the only option to help a person survive through the crisis. 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. Think about things that help you avoid going into crisis, and what helps you survive if a crisis does occur.

Self-help

Recovery usually requires active self-help. It's common for therapists to set 'homework'. This may include 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 DID, for instance, the identity who self-harms must be involved in any self-help activity for these 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 aspect or identity of the dissociated self.

Imaging or 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, it can also be used to bring different identities together to make co-operative decisions.

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

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.

You may wish to develop coping strategies for everyday challenges. For instance, a person who loses time, due to dissociation, may decide to wear a watch with the day and date on it.

Many people have found that reading about the life and experiences of survivors with similar problems has helped them.

Support groups

Sharing experiences with others who have the same problems can provide emotional release and practical assistance, provided that the support group is well organised and maintains very clear boundaries. Some dissociative survivors have reported that abuse self-help or support groups which include both those with complex dissociative disorders and those without this experience have been problematic.



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. Your first port of call is 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 professional aware of dissociation, for a full diagnostic assessment. Or if this fails, look to the voluntary or private sector.



What can friends or relatives do to help?

Partners, family and friends can have a key role to play in recovery. It's important for you to learn as much as possible about dissociative disorders. Listen with acceptance to your dissociative friend or relative, if they want to tell you about their experience. Don't expect them to always know what to do to help, and to be able to tell you. Be consistent, honest and non-judgemental. You should be cautious about touching and intimacy – check out what is OK. Do offer to help with, or take over, everyday tasks to lighten the pressure. Don't neglect yourself. Talking treatments may help you cope with the vast array of feelings brought out by living with a dissociative survivor.

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Useful organisations

Directory and Books Services (DABS)

4 New Hill, Conisbrough, Doncaster DN12 3HA

tel: 01709 860 023

web: www.dabsbooks.co.uk

Books and directory of services for survivors of childhood sexual abuse

First Person Plural

PO Box 2537, Wolverhampton WV4 4ZL

tel: 01902 763490

web: www.firstpersonplural.org.uk

Survivor-led national association for people who experience complex dissociative distress and for their family, friends and professional allies. Provides support, information and training.

The Survivors Trust

27b William Street, Rugby, Warwickshire CV21 3HA

tel: 01788 550 554 web: www.thesurvivorstrust.org

National umbrella agency for specialist sexual abuse and violence voluntary sector organisations

Useful websites

www.clinicfordissociativestudies.com

Clinic for Dissociative Studies

www.estd.org/resources.html

European Society for Trauma & Dissociation

www.isst-d.org

International Society for the Study of Trauma & Dissociation

www.dissociation.co.uk

Pottergate Centre for Trauma & Dissociation

www.sidran.org

Sidran Institute for Traumatic Stress Studies

www.tag-uk.net and www.tag-uk.net/articles/organisations.php

Trauma & Abuse Group (TAG)

To find UK organisations providing or listing counsellors or therapists

Further reading

- About self-harm* [for young people] (Mind and Barnardo's 2008) £1
- Accepting voices* Prof. M. Romme, S. Escher (Mind 1993) £13.99
- How to cope with panic attacks* (Mind 2008) £1
- How to cope with sleep problems* (Mind 2008) £1
- How to cope with suicidal feelings* (Mind 2008) £1
- Making sense of antidepressants* (Mind 2008) £2.50
- Making sense of psychotherapy and psychoanalysis* (Mind 2004) £2.50
- The survivors guide to recovery from rape or sexual abuse* R Kelly and F Maxstead (ROSA 2005) £15.99
- Understanding addiction and dependency* (Mind 2007) £1
- Understanding anxiety* (Mind 2008) £1
- Understanding borderline personality disorder* (Mind 2007) £1
- Understanding bipolar disorder* (Mind 2006) £1
- Understanding post-traumatic stress disorder* (Mind 2009) £1
- Understanding schizophrenia* (Mind 2008) £1
- Understanding self-harm* (Mind 2007) £1
- Understanding talking treatments* (Mind 2005) £1
- Understanding eating distress* (Mind 2007) £1
- Understanding obsessive-compulsive disorder* (Mind 2008) £1
- Understanding phobias* (Mind 2004) £1

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