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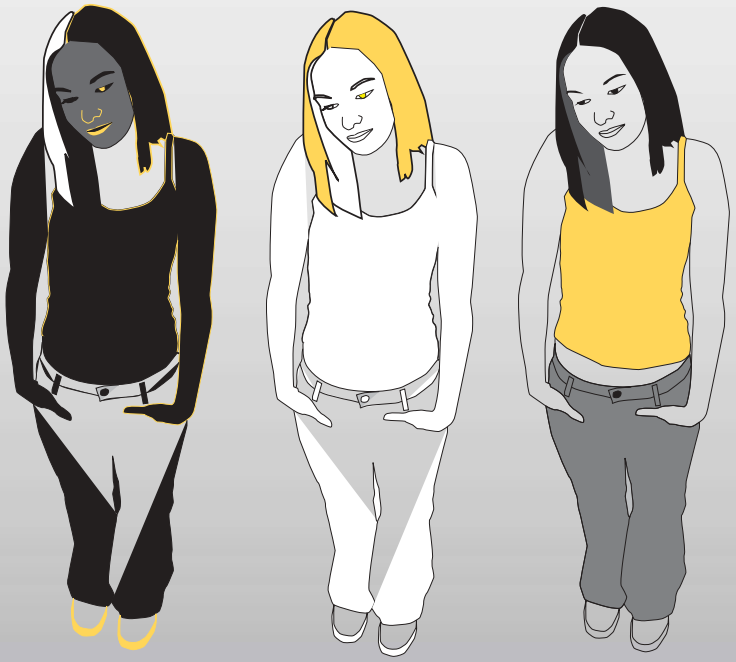
For better
mental health

Understanding dissociative disorders



'I felt that 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

'I watch a body that looks like me, doing things I'm ashamed of. I can't will myself back into that body. I can't control its movements, its thoughts, its feelings. I can only watch and feel the shame and fear. It's alarming to see the newspaper date, five days ahead of the date I know it to be. It's frightening to "wake" with the razor in my hand, my arms bleeding and yet know I could never cut myself.'
Survivor of dissociative identity disorder

'I feel like I've walked into an X-File. I'm at home; this is my family. I know that's true. Yet I feel these people are as strangers. I sit down to dinner in a room that seems unfamiliar and yet I know it is the kitchen in my house. A woman scoops potatoes onto my plate and I don't know who she is. Yet I know the reality is that she is my mother.'
Survivor of derealisation

'I can see the sun is shining outside, and I notice I'm wearing a tee shirt and shorts, and yet I think it is winter. What happened? Where did the time go?'
Survivor of dissociative amnesia

This booklet describes dissociative disorders, their probable causes and the options for effective treatment. This type of mental distress is difficult to distinguish, and diagnosis remains controversial. Consequently, low rates of diagnosis may not be a true reflection of the actual number of people who have these experiences. But, astounding progress has been reported by people whose dissociative distress has been recognised and treated appropriately.

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 a defence mechanism helping people to survive traumatic experiences. The bomb survivor, quoted opposite, 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.

Are there different forms of this 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. Five different forms of these disorders are defined in *DSM-IV*, the American diagnostic manual commonly used. They can be arranged, in order of complexity, along the 'dissociation continuum', which also includes everyday dissociation and post-traumatic stress disorder. A person's position on the continuum will depend on the severity and mix of the types of dissociation they experience.

The dissociation continuum
- everyday dissociation
- depersonalisation disorder
- dissociative amnesia
- dissociative fugue
- post-traumatic stress disorder (PTSD)
- dissociative disorder not otherwise specified (DDNOS)
- dissociative identity disorder (DID)

Depersonalisation disorder
This features strong feelings that you are detached from your body, or that your 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.

Post-traumatic stress disorder (PTSD)

Post-traumatic stress disorder is not currently classed as a dissociative disorder, but people who experience dissociative distress frequently also meet diagnostic criteria for PTSD. They may experience flashbacks, reliving the trauma repeatedly, which cause extreme distress. This, in turn, triggers a dissociative, numbing reaction. Moderate to severe amnesia is common to both PTSD and dissociative disorders, as is derealisation and depersonalisation.

Dissociative disorder not otherwise specified (DDNOS)

In DDNOS, each of the five types of dissociation may occur, but the pattern of mix and severity does not fit any of the other dissociative disorders.

Dissociative identity disorder (DID)

This is the most complex dissociative disorder. It's also known as multiple personality disorder (MPD) according to the *ICD10*, the British diagnostic manual. 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 and obsessive-compulsive behaviour. These may be directly connected with the dissociative problem, or could mean the person also has a non-dissociative disorder. In the case of DID, these problems may only emerge when a particular identity has control of the person's behaviour, thoughts and feelings. Many mental health problems, such as schizophrenia, manic depression and borderline personality disorder, have dissociative features.

What causes dissociative disorders?

This is open to argument. Some experts believe dissociative disorders are directly linked to trauma or abuse. Others suggest that they are a result of disruptions to the normal parent/child relationship. Still others believe they come from a disturbance in the stages of childhood development. There is one extremely sceptical view, particularly of DID, that symptoms are just a product of poor therapy with vulnerable, suggestible clients.

There are studies showing that a history of trauma is almost universal for people who have moderate to severe dissociative symptoms. Usually, this is abuse in childhood. But some people may develop PTSD, or more rarely dissociative amnesia or fugue, after a traumatic or extremely stressful experience in adulthood. Children generally have a greater natural ability to dissociate. This ability declines in adults, unless it has become habitual in response to repeated trauma during childhood. However, not all adult survivors of child abuse have a dissociative disorder. Several experts agree that the following factors have to be present for a person to develop the most complex dissociative disorders:

- 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 common are dissociative disorders?

Some experts suggest that dissociative disorders may be much more common than previously thought. Research among psychiatric inpatients shows that up to 22 per cent of them may have a dissociative disorder and five per cent have a high likelihood of having DID. It's significant that none of the people in this study had a diagnosis of dissociative disorder at the time. People who were eventually diagnosed with a dissociative disorder report having had several earlier misdiagnoses, such as schizophrenia, bipolar or borderline personality disorder. It may be that others never have their dissociative disorder recognised.

Current estimates for the number of adults who were abused in childhood is one in four. Not all will have a dissociative disorder, but the rates of diagnosis of dissociative disorders still seem too low by comparison. Many factors could be contributing to this. Mental health professionals receive insufficient training on dissociative disorders, and may not ask the right questions during assessment. UK professionals often use the *ICD10* diagnostic manual. This does not distinguish the dissociative disorders as clearly as *DSM-IV*. It uses the term multiple personality disorder and gives little detail about how to recognise it. It also states that MPD is rare and is sceptical about the causes. Lack of knowledge and information may lead to misdiagnosis, particularly when people are describing symptoms that are common to other mental health problems, such as depression. People may also deny any history of abuse, because they may 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. People can be doing responsible jobs or raising families. By using dissociation, and compensating for it with other exhausting strategies, people put up a good front.

Almost everyone coping with these difficulties strives to keep them hidden from others. Few people with a dissociative disorder will switch rapidly and openly between identities, in the way that is often 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 questionnaires that can be used as tools 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). These can provide a more accurate diagnosis than is possible for most psychiatric illnesses. But only when administered by a professional who has been trained in their use, and who is prepared to consider dissociative disorders. Some people, who have been in contact with mental health services for years, have made astounding progress once dissociative distress was recognised and treated.

It's also important to bear in mind that other cultures may have a different view of these symptoms. Dissociative states are a common and accepted feature of cultural activities or religious experience in many non-Western societies.

What helps recovery?

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 should create a greater sense of wholeness and internal order, and less disruption in work, social and home life.

Talking treatments

Effective treatment for the dissociative disorders may combine several methods, but always includes talking treatments. (See *Understanding talking treatments,* details on p. 14.) It is important that this helps people to approach underlying causes as well as the effects of the dissociative problems. It's helpful if the therapist is familiar with dissociation and trauma work, but it's the quality of the therapist–client relationship that is most important to recovery. The therapist should be accepting of the client's experience; willing to learn how to work with dissociation and trauma; able to tolerate high levels of frustration and bear extreme pain; and be prepared to work with the client long term, often for several years.

Getting talking treatment through the NHS may depend on where you live. Usually, only short-term therapy is available, which may do more harm than good for the dissociative client. You may be able to get low-cost or free psychotherapy through voluntary organisations. Therapists in the private sector are another option. Some offer fees on a sliding scale. (See *Useful organisations*.)

Medication

Medication may be helpful in treating symptoms of depression, anxiety, or insomnia, but there is no drug to treat the dissociation itself. Antipsychotic drugs are generally not helpful.

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.

Crisis intervention

If a person is suicidal or otherwise unable to stay safely in the community, a GP or community mental health 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 who 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 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 to an internal conference table 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 techniques include breathing slowly, walking barefoot, talking to someone, sniffing something with a strong smell, and many others.

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 these support groups are well organised and maintain very clear boundaries (see *Useful organisations,* on p. 13).

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 she or he wants to tell you about the experience. Don't expect her or him always to 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 rollercoaster of feelings brought out by living with a dissociative survivor.

If I think I may have a dissociative disorder, what can 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 (see opposite for contacts).

References

Amongst ourselves – A self-help guide to living with dissociative identity disorder T. Alderman, K. Marshall (New Harbinger 1998)
Child abuse factsheet (Rape Crisis Federation of England and Wales 2001) (web: www.rapecrisis.co.uk/child abuse/htm)
DiUK research R. Aquarone (Dissociation in the UK 2002) (web: www.dissociation.co.uk/research.htm)
Getting through the day – strategies for adults hurt as children N. J. Napier (Norton and Company 1993)
The stranger in the mirror – dissociation, the hidden epidemic M. Steinberg, M. Schnall (Cliff Street Books 2001)
What is dissociative identity disorder? (Sidran Institute 1994) (web: www.sidran.org/didbr/html)

Useful organisations

Mind
Mind is the leading mental health organisation in England and Wales, providing a unique range of services through its local associations, to enable people with experience of mental distress to have a better quality of life. For more information about any mental health issues, including details of your nearest local Mind association, contact the Mind website: www.mind.org.uk or Mind*info*line on 0845 766 0163.

British Confederation of Psychotherapists (BCP)
West Hill House, 6 Swains Lane, London N6 6QS
tel. 020 7267 3626, web: www.bcp.org.uk
Can provide a register of members

Directory and Books Services (DABS)
4 New Hill, Conisbrough, Doncaster DN12 3HA
tel./fax: 01709 860 023, email: info@dabsbooks.co.uk
web: www.dabsbooks.co.uk
Support and services for survivors of childhood sexual abuse

First Person Plural
PO Box 2537, Wolverhampton WV4 4ZL
email: fpp@firstpersonplural.org.uk
web: www.firstpersonplural.org.uk
Survivor-led organisation for dissociative survivors and their allies

United Kingdom Council for Psychotherapy (UKCP)
167–169 Great Portland Street, London W1W 5PF
tel. 020 7436 3002, fax: 020 7436 3013
email: ukcp@psychotherapy.org.uk
web: www.psychotherapy.org.uk
Umbrella organisation for psychotherapy in UK.

United Kingdom Society for the Study of Dissociation
26 Princes Street, Norwich NR3 1AE
tel. 08707 454 726, email: info@ukssd.org
web: www.ukssd.org
A non profit professional society promoting the identification and treatment of dissociative disorders

Further reading

- ☐ *Accepting voices* Prof. M. Romme, S. Escher (Mind 1993) £13.99
- ☐ *A can of madness* J. Pegler (Chipmunka Publishing 2002) £9.99
- ☐ *Coping with post-trauma stress* F. Parkinson (Sheldon Press 2000) £6.99
- ☐ *The day the voices stopped* K. Steele, C. Berman (Basic Books 2002) £11.50
- ☐ *From psychiatric patient to citizen: overcoming discrimination and social exclusion* L. Sayce (Macmillan 2000) £15.99
- ☐ *Going mad? Understanding mental illness* M. Corry, A. Tubridy (Newleaf 2001) £8.99
- ☐ *Hearing voices: a common human experience* J. Watkins (Hill of Content 1998) £10.99
- ☐ *How to assert yourself* (Mind 2003) £1
- ☐ *How to cope as a carer* (Mind 2003) £1
- ☐ *How to increase your self-esteem* (Mind 2003) £1
- ☐ *How to look after yourself* (Mind 2002) £1
- ☐ *Living with mental illness: a book for relatives and friends* E. Kuipers, P. Bebbington (Souvenir Press 1997) £9.99
- ☐ *Mental illness: a handbook for carers* eds. R. Ramsay, C. Gerada, S. Mars, G. Szmukler (JKP 2001) £15.95
- ☐ *Mind rights guide 1: civil admission to hospital* (Mind 2003) £1
- ☐ *Mind rights guide 2: mental health and the police* (Mind 1995) £1
- ☐ *Mind rights guide 3: consent to medical treatment* (Mind 2003) £1
- ☐ *Mind rights guide 4: discharge from hospital* (Mind 2003) £1
- ☐ *Mind rights guide 5: mental health and the courts* (Mind 1995) £1
- ☐ *Mind rights guide 7: managing your finances* (Mind 1999) £1
- ☐ *National Self-Harm Network Information Pack* (NSHN 1998) £3.50
- ☐ *Understanding borderline personality disorder* (Mind 2001) £1
- ☐ *Understanding manic depression* (Mind 2003) £1
- ☐ *Understanding post-traumatic stress disorder* (Mind 2003) £1
- ☐ *Understanding schizophrenia* (Mind 2003) £1
- ☐ *Understanding self-harm* (Mind 2003) £1
- ☐ *Understanding talking treatments* (Mind 2002) £1

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Scottish Association for Mental Health tel. 0141 568 7000

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This booklet was written by Kathryn Livingston in consultation with members of First Person Plural
First published by Mind 2002. Revised edition © Mind 2003

ISBN 1-903567-39-4

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