

# INFORMATION LEAFLET FOR PROFESSIONALS



## DISSOCIATIVE IDENTITY DISORDER



POSITIVE OUTCOMES FOR  
DISSOCIATIVE SURVIVORS



## WHO ARE WE?

PODS is a project run by START (Survivors Trauma and Abuse Recovery Trust), a registered charity number 1161950. PODS makes recovery from dissociative disorders a reality through training, informing and supporting. We provide the UK's only national telephone helpline for dissociative disorders and deliver an extensive programme of CPD training to professionals. We also produce a range of publications and resources, hold a register of 'dissociation-friendly therapists' in the UK, and provide various support services for both survivors and professionals. More information can be found on our website at [www.pods-online.org.uk](http://www.pods-online.org.uk).

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## WHAT IS DISSOCIATIVE IDENTITY DISORDER?

DID is a severe psychiatric condition strongly correlated with a history of chronic and unremitting childhood abuse, characterised by identity alteration or confusion ('multiple parts of the personality') and difficulties in memory, for example amnesia for past traumatic events or for other personality states. Many people with DID exhibit similar symptoms as people with borderline personality disorder (difficulties in relationships and managing emotions) and with post traumatic stress disorder (flashbacks, autonomic hyperarousal, and emotional constriction). It can be understood as resulting from a combination of both developmental and incidental trauma, but is neither a personality disorder nor a psychotic disorder. It is simply an adaptive response to childhood trauma.

## DISSOCIATION AS A SURVIVAL MECHANISM DURING TRAUMA

Dissociative disorders are characterised by 'a disruption in the usually integrated functions of consciousness, memory, identity or perception of the environment'<sup>1</sup>. During traumatic experiences, these various aspects of our experience do not coalesce, and so memories may exist without their attendant feelings; there may be overwhelming affect, but with no conscious memory of their cause. Within DID there is often a lack of a coherent sense of autobiography, resulting in problems of identity—'Who am I?' and 'What has happened in my life?' It is common for there to be amnesia for large chunks of childhood or for any or all traumatic events. This all results from dissociation acting as a creative survival mechanism in the face of overwhelming trauma, whereby the mind shields itself by segregating the experience, or splitting it off into its constituent parts rather than experiencing it as what would be an unendurable 'whole'.

## SPECTRUM OF TRAUMA DISORDERS

There are a range of dissociative disorders on a spectrum of severity, and this spectrum is usually correlated to how extreme and chronic the trauma experienced in early childhood was. The least extreme on the spectrum is post-traumatic stress disorder (PTSD) and the most extreme is dissociative identity disorder (DID). Other disorders at points on this spectrum in between these two diagnoses include dissociative amnesia (with or without dissociative

fugue), depersonalisation/derealisation disorder, other specified dissociative disorder (OSDD) and unspecified dissociative disorder (UDD)<sup>2</sup>. OSDD and UDD were previously known as dissociative disorder not otherwise specified (DDNOS) which is a diagnosis given when the full diagnostic criteria for other dissociative disorders including DID are not met.

## DIAGNOSTIC CRITERIA

The DSM-5 states that DID involves a ‘disruption of identity characterised by two or more distinct personality states, which may be described in some cultures as an experience of possession. The disruption in identity involves marked discontinuity in sense of self and sense of agency, accompanied by related alterations in affect, behaviour, consciousness, memory, perception, cognition, and/or sensory-motor functioning.’<sup>2</sup> It goes on to state that this is accompanied by ‘Recurrent gaps in the recall of everyday events, important personal information, and/or traumatic events that are inconsistent with ordinary forgetting.’<sup>2</sup>

## DISSOCIATIVE DISORDER OR COPING MECHANISM?

The essence of DID is ‘dissociating’ or ‘splitting off’ from an experience—and then in time, splitting off from the ‘parts’ of the self that hold those experiences—in order to survive otherwise unendurable trauma. It is a creative coping mechanism, not a ‘dysfunction’. However, it becomes dysfunctional when the environment is no longer traumatic and yet the person, and all the ‘dissociated identities’ of that person, still act and live as if it is.

## HOW DOES DID MANIFEST?

In practice, the vast majority of people with DID do not obviously present as if they have ‘multiple personalities’. Instead they present with a number of both dissociative and post-traumatic symptoms, as well as many apparently non-trauma-related issues such as depression, substance abuse, eating disorders and anxiety. According to Richard Kluft<sup>3</sup>, a leading expert in the field, only 6 per cent of people with DID present their ‘multiple’ or ‘dissociated’ identities publicly and obviously. Elizabeth Howell<sup>4</sup> describes DID as ‘a disorder of hiddenness’, as the vast majority of people with DID, often motivated by shame, will attempt to conceal their symptoms and way of being. This in part explains why, despite DID being so prevalent, few people are properly

aware of it. In fact, many people with DID are high-functioning members of society with good careers before some crisis or build-up of stressors leads to a sudden and catastrophic 'breakdown'. Others spend a great deal of time in the psychiatric system without receiving appropriate help and never manage to establish a career. Still others manage a work life, but are severely hampered in their interpersonal relationships. Each person with DID is unique, even in the way that they respond to and handle their symptoms.

## PREVALENCE

DID is a well-researched, valid, and cross-cultural diagnosis which despite widespread opinion is not rare: research indicates that it affects between one and three per cent of the general population<sup>5</sup>. This corresponds to between approximately 650,000 and 1.85 million people in the UK.

## CAUSES

DID is normally caused by severe and chronic childhood trauma, which may include physical and sexual abuse and/or neglect, episodes of extreme terror, and/or repeated medical trauma. Disorganised attachment<sup>6</sup> in one or both parents is also a contributory factor. According to a recent study by Brand et al<sup>7</sup>, 86 per cent of the sample of DID patients reported a history of sexual abuse. DID is best understood in a post-traumatic framework.

Many experts in dissociative disorders believe that alternate identities (sometimes known as 'alters' or 'parts' etc) result from overwhelming traumatic experiences in early childhood, in the context of disturbed caretaker-child interactions resulting in disruptions to the child's attachment system. It is this failure of normal developmental integration which many believe leads to the proliferation of separate 'not-me' parts of the personality. DID always develops during childhood but may only become manifest in adulthood as a result of dissociative defences giving way following a build-up of life stresses or 'triggers'.

## DIAGNOSIS

People with DID often spend many years in the mental health system, and it is often misdiagnosed as schizophrenia or other psychotic disorders, affective disorders, substance abuse disorders, or a personality disorder (most commonly borderline personality disorder).

There are a number of well-validated tools available to assist in diagnosis, most notably the screening tool the Dissociative Experiences Scale (DES)<sup>9</sup> the Somatoform Dissociation Questionnaire (SDQ-20)<sup>9</sup> (available for free scoring and reporting at [www.pods-online.org.uk/screeningtools](http://www.pods-online.org.uk/screeningtools)) and the 'gold-standard', the Structured Clinical Interview for DSM-IV Disorders (SCID-D)<sup>10</sup>. For further information and details of where assessments can be carried out, please contact PODS.

## SYMPTOMS

Most people with dissociative disorders report a wide range of fluctuating symptoms, including the following:

- switching to other parts of the personality when experiencing stressors, resulting in amnesia for their actions whilst in this 'alternate' personality
- generalised anxiety and autonomic hyperarousal, resulting in rapid heartbeat, 'panic attacks' etc
- excessive social anxiety, leading to isolation and lack of peer or community support
- cognitive deficits including problems with memory, attention and concentration, and fluctuating intellectual ability
- chronic headaches, confusion and dizziness
- pseudo-seizures (dissociative or non-epileptic seizures)
- hearing voices and other 'psychotic'-type symptoms including smelling smells that do not objectively exist in the present
- paranoia
- emotional instability and mood swings, resulting in frequent crying, self-soothing (e.g. rocking) and out-of-control behaviours, or lack of affect, resulting in a numbed-out sense of depression and blankness
- problems with sleep including excessive need for sleep; insomnia; nightmares and waking night terrors; sleepwalking
- flashbacks and 'reliving' of dissociated aspects of prior abuse
- identity confusion, resulting in a lack of a coherent sense of self and unified 'purpose' in life
- inconsistent body reactions, such as being very cold in a hot room

- sexual revictimisation and frequent risk-taking behaviours in sexual relationships
- self-harm, suicidal ideation and feelings of despair
- eating disorders
- difficulties in maintaining relationships, and a proclivity for harmful and unhealthy relationships (often leading to further revictimisation)
- a range of physical impacts including:
  - chronic unexplained pain
  - autoimmune disorders such as fibromyalgia, chronic fatigue syndrome, rheumatoid arthritis and lupus
  - migraine-type headaches
  - reduced ability to urinate
  - gastrointestinal disturbances, including chronic constipation, diarrhoea, ‘irritable bowel syndrome’
  - exhaustion
  - above-mentioned sleep difficulties
  - transient functional disorders including partial paralysis, visual difficulties, anaesthesia, etc.

It is important to note that these symptoms fluctuate not just from day to day or week to week, but from hour to hour. Many dissociative survivors will instinctively present as ‘normal’ in situations such as medical appointments or assessments due to ingrained learned behaviours from childhood abuse requiring them to hide their symptoms. In the presence of authority figures, these masking behaviours are difficult to resist and are in effect automatic. It is therefore part of the syndrome within dissociative disorders that both psychological and physical impacts are outwardly hard to detect.

## **BASIS OF TREATMENT GUIDELINES OR PATHWAY**

There are no National Institute of Health and Care Excellence (NICE) guidelines for the treatment of dissociative identity disorder (DID) yet and so the best available treatment guidelines are those supplied by the International Society for the Study of Trauma and Dissociation (ISSTD)<sup>5</sup>. There is a link to them on the PODS website at [www.pods-online.org.uk/isstdguidelines](http://www.pods-online.org.uk/isstdguidelines).



## TREATMENT

The treatment of choice for DID is long-term, one-to-one, relationally-based psychotherapy. In most cases, therapy will be at minimum once weekly, but this would be dependent on a number of factors such as the client's level of functioning, resources, support and motivation. Longer sessions (of 75 to 90 minutes, or in some cases longer) are often required, and therapy may extend typically for five or more years. An eclectic use of techniques such as cognitive behavioural therapy (CBT), dialectical behaviour therapy (DBT), eye movement desensitisation and reprocessing (EMDR), and sensorimotor psychotherapy<sup>11</sup>, amongst others, can also be helpful. However, EMDR protocols need to be modified for working with DID as standard EMDR treatment, especially at the hands of a practitioner unfamiliar with dissociative disorders, can lead to dangerous flooding of traumatic material and subsequent destabilisation of the client<sup>12</sup>.

The consensus of experts<sup>13</sup> is that phase-oriented treatment is most effective. The three stages most commonly used are:

1. Establishing safety, stabilisation and symptom reduction;
2. Working through and integrating traumatic memories;
3. Integration and rehabilitation.

In reality, there is unlikely to be a linear progression through these three stages: more commonly the work will spiral through each phase, with a frequent need to return to stabilisation work during the middle and later stages. As well as addressing dissociative symptoms, and working through and integrating the underlying trauma, a third area of treatment is that of 'attachment', with the vast majority of DID clients presenting with disorganised attachment patterns.

## THE NEED FOR LONG-TERM TREATMENT

Working with DID clients is demanding and often long-term. Due to the unremitting nature of trauma that has been suffered previously by the client and the strong element of disorganised attachment, the best prognosis can only be achieved if there is consistency in the client-patient relationship. Short-term work such as solution-focused CBT, along with group therapy settings, have not been shown to provide benefit to clients with DID. The TOPDD study<sup>7</sup> has shown that effective treatment for DID is possible and leads to long-term cost savings, as evidenced in the UK by Dr Mike Lloyd<sup>14</sup>

from Cheshire & Wirral Partnership FT who shows that investing in therapy costs less (63% less, down from £29,942 per year prior to therapy beginning to £10,695 a year later) than traditional case management in the NHS. However, given the complex nature of this disorder and its etiology, it is essential that the therapy is extended into the long-term for as long as is required for the client to gain autonomy and mastery of his or her life again. The alternative is the 'revolving-door patient' who is further retraumatized by the abandonments of repeated cycles of beginning and ending of therapeutic relationships and who continues to need help from primary care.

## MEDICATION

There is no medication specifically licensed for treating DID. In addition, patients with DID report different responses to the same medication when 'alternate personalities' are present, and prescribers should beware of the danger of polypharmacy in this patient group. Medication can be helpfully used to ameliorate traumatic stress symptoms and comorbidities, but neuroleptics are not recommended. For further information go to [www.pods-online.org.uk/medication](http://www.pods-online.org.uk/medication).

## ISSUES FOR COUNSELLORS/PSYCHOTHERAPISTS

The extreme and chronic nature of the trauma suffered by many DID clients can lead to complex and changeable transference and countertransference responses in the therapy. Extreme care must be given to the issue of boundaries: the history of many DID clients is steeped in boundary violations and so there is significant potential for re-enactments in the therapeutic setting. There must be open and honest discussion and negotiation of boundaries at every stage of the treatment. 'Crisis' may occur regularly at many points during the therapy, but especially when dealing with traumatic memories in phase 2 work. Boundaries that are flexible but hold the treatment frame consistently are essential, especially as it impacts upon the attachment issues evoked by working with 'alternate identities'.

It is the quality of the relationship between therapist and client which is the best predictor of therapeutic success, and so a warm, empathic, consistent, engaged therapist who is willing to be flexible and work long-term with extremely distressing material is essential. Specialist supervision from

someone experienced in working with dissociative disorders is advised, as is avoiding isolation by being part of supportive professional groups working in this field. Attention must be paid at all times to the risk of secondary traumatisation due to the extreme and prolonged nature of the abuse suffered by most DID clients.

## **RESPONDING WELL TO 'ALTER PERSONALITIES'**

Some people with DID may present to professionals with their 'alternate personalities', otherwise known as 'alters', 'parts' etc. These may present as having different ages, a different gender, different characteristics and often different levels of awareness of their autobiography. Some will be aware of or 'co-conscious' with other 'parts' of the personality, whilst others will not: when there is no co-consciousness, there will often be brief amnesic blanks when that part is 'out' or 'in executive control'. This can be distressing and worrying for the client, who may feel that they are 'going crazy' as they do not know what they have done or said during the preceding period of minutes, hours, or (rarely) days. It is helpful for professionals to normalise these experiences and understand these symptoms in the light of the history of trauma that caused them.

It is important to bear in mind that the parts 'are not actually separate identities or personalities in one body, but rather parts of a single individual that are not yet functioning together in a smooth, coordinated, and flexible way'<sup>15</sup>. The ultimate work of recovery is to facilitate an increased coordination between these parts, so that they can indeed function together and perhaps even merge or 'fuse'<sup>15</sup>. By working on increased communication and cooperation between parts, often there is a corresponding increase in levels of co-consciousness, which can help the DID client to feel in much better control of his or her life.

It is helpful for all professionals to engage with these 'alternate personalities' in a non-prejudicial, affirming way. However, it must be understood that information shared with one part of the personality may not be shared across the entire personality system, and so may need to be repeated. The issue of informed consent should be discussed thoroughly so that the professional can be sure that the person is making decisions having been given time to assimilate and process information across the various personality states.

Many professionals are sceptical of DID people's claims that they were unaware of their actions whilst in an alternate personality state. However, this is an experience that is central to the nature of dissociative disorders. When one part appears in A&E, for example, highly distressed and agitated with signs of self-harm, the most productive response is to show care, concern and be non-judgmental, rather than blaming the DID person for what 'they' (or another part of them) have done. The experience of multiplicity is real, and further judgment and stigma is unhelpful.

When someone has 'switched' to another part of the personality, in many situations it may be necessary to attempt to bring back the main 'adult' part of the personality. This can be encouraged by talking gently but directly to the DID person and asking for the adult to return, using their given name. Often they will have switched due to high levels of anxiety or fear; therefore, a calm, reassuring approach, in a quiet environment with clear verbal communication of what is happening, is usually most helpful. The person with DID may need help to 'ground' by becoming aware of their surroundings and being 'present' in their body. PODS provides useful resources to this effect, for example the *Emotional Resource Guide*: go to [www.pods-online.org.uk/resources](http://www.pods-online.org.uk/resources).

## **GUIDELINES FOR ASSESSMENTS AND MEETINGS**

People with DID may under only mild stress, such as situations where they are being assessed, in a new environment or meeting new people, 'switch' to another part of the personality. This may be a trauma-based part who is stuck in unprocessed trauma (similar to 'regression'), or it may be an emotionally-shut down adult-presenting part who is unduly compliant and answers questions in a way that they believe the assessor wants them to be answered, rather than in a way that reflects reality. The results of the assessment, interview or meeting may therefore be skewed in a way that discriminates against the person with DID by not taking into account the psychological difficulties they have in such a situation. Where possible, a supporter/advocate should be allowed to attend with the person if they request it.

## VULNERABLE ADULTS

We strongly recommend that people suffering from a dissociative disorder be treated, should they so request, as a Vulnerable Adult under the definitions supplied by the Police Act 1997, Law Commission 1999, Department of Health 2000 and the Safeguarding Vulnerable Groups Act 2006: 'A vulnerable adult is a person aged 18 years or over who is or may be in need of community care services by reason of mental or other disability, age or illness; and who is or may be unable to take care of him or herself, or unable to protect him or herself against significant harm or exploitation.' **Agencies should consider the risk of self-harm and suicide to be high when dealing with clients with dissociative disorders, and should adapt their practices accordingly.**

## FURTHER INFORMATION AND SUPPORT

PODS (Positive Outcomes for Dissociative Survivors):

- runs a helpline for survivors and professionals on Tuesdays—phone 0800 181 4420 or email [elisabeth@pods-online.org.uk](mailto:elisabeth@pods-online.org.uk).
- provides an extensive training programme throughout the UK for professionals, which are also suitable for 'stable survivors'. For more information go to [www.pods-online.org.uk/training](http://www.pods-online.org.uk/training).
- holds a register of 'dissociation-friendly therapists' throughout the UK who are willing to work with clients experiencing dissociation. For more information go [www.pods-online.org.uk/dft](http://www.pods-online.org.uk/dft).

The PODS website provides a wealth of articles, resources and publications about trauma, dissociation and abuse: [www.pods-online.org.uk](http://www.pods-online.org.uk).

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