

# Complex Trauma resulting in Dissociative Identity and similar Dissociative Post-Traumatic Conditions

## For Clinicians, Service Providers, Strategic Planners and Commissioners

### 1. Who is this information resource for?

- GPs, nurses and other primary care clinical staff
- Clinical Psychologists, Psychiatrists, CBT and other psychological therapies practitioners, nurses and other professionals working in NHS Secondary and Tertiary Mental Health services
- NHS Trusts, their boards and strategic planners
- CCGs and other Commissioning or Funding bodies
- Voluntary Sector Services working with victims/survivors of sexual or other abuse in childhood
- Private Sector Psychological Therapy Practitioners
- People who know or suspect they have dissociative identity disorder or similar and others who know or suspect they are traumatised because of repeated, prolonged, complex abuse or other traumas which began in early childhood.

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### 3. Introduction

This information resource outlines the rationale, response and outcomes required for recovery from complex trauma when there is also a significant dissociative presentation. In particular, when Dissociative Identity Disorder (DID), similar trauma-related complex dissociative conditions or Complex PTSD (as a result of severe, prolonged and repeated traumas - usually abuse - beginning in early childhood) is the most accurate primary psychiatric diagnosis. Often such clients/patients are misdiagnosed or incompletely diagnosed with other conditions and consequently end up on non-effective, uneconomical, and commonly retraumatising treatment and care pathways.

Evidence-based international guidelines, together with relevant evolving NHS strategic directions and the extensive clinical and lived experience of the UK authors of this information resource, are the basis for the content of the document.

### 4. NICE, ISST-D & ESTD Guidelines and NHS-E Strategy

Post-Traumatic Stress Disorder (PTSD) is not the only condition which has its origins in past trauma, yet it is the only one for which the National Institute for Health and Care Excellence (NICE) has published guidelines [NICE, 2018]. These guidelines include a very brief section which makes a passing reference to Complex PTSD (C-PTSD) [NICE, 2018, p20]. The section is generically about those who meet diagnostic criteria for PTSD and have related additional needs, so it might mistakenly be considered to include those who have DID or similar trauma-related complex dissociative conditions or those with C-PTSD. In fact, the section is far from comprehensive so cannot be considered adequate guidance on managing and treating these complex post-traumatic presentations. For instance, it does not mention complex dissociative disorders. Nor does it give specific interventions for meeting the additional needs, or how such needs might alter how the client experiences their PTSD symptoms, or how the interventions the guidelines recommend for less complex PTSD might detrimentally affect those with these more complex presentations. However, the section makes clear that for these more complex traumatised clients/patients longer term and additional therapeutic work is required. In particular, in relation to building trust, ensuring safety and stability, managing issues including dissociation before doing trauma-focused work and planning support for continuing symptoms and co-morbidities.

Although the NICE guidelines for PTSD do not apply to complex trauma-related conditions where the patient/client experiences chronic dissociation and/or other features of C-PTSD, its brief mention of the subject is consistent with the 3-phase therapy for C-PTSD, recommended in the seminal book on the subject [Herman, 1997]. Specific guidelines for DID in adults which incorporate the 3 phase model of therapy have been published by the International Society for the Study of Trauma and Dissociation (ISST-D). These latter detailed evidence-based guidelines on complex trauma-related dissociative conditions were compiled by experienced leading clinicians and researchers. [International Society for the Study of Trauma and Dissociation, 2011]. Both the ISST-D and the European Society for Trauma and Dissociation (ESTD) have also published guidelines for the assessment and treatment of children and adolescents with dissociative symptoms. [International Society for the Study of Trauma and Dissociation, 2003; European Society for Trauma and Dissociation, 2017]

One of the main, but not the only, group of people who develop DID, C-PTSD and other complex trauma-related conditions are victims of sexual assault and sexual abuse including adults who were abused as children. In its “Strategic Direction for Sexual Assault and Abuse Services” NHS England recognises that this group is not currently served well by health and care services [NHS England, 2018]. The NHS Long Term Plan sets a clear ambition to ensure survivors of sexual assault are offered integrated therapeutic mental health support [NHS, 2019]. Following on from the publication of these two important national strategy documents, the Minister for Mental Health and the Director of Health & Justice, Armed Forces and Sexual Assault Services Commissioning at NHS England sent a letter to Clinical Commissioning Groups urging them “to consider how they are meeting their responsibilities for victims and survivors of sexual assault” [Doyle Price & Davies, 2019]. Further, an All Party Parliamentary Group was established in 2018 to explore and identify the support and justice needs of adult survivors of childhood sexual abuse [Parliamentary Commissioner for Standards, 2019] because of a recognition by some parliamentarians that such needs are not currently being met.

Clearly, there is a need to adapt treatment and care when there are issues of abuse and other childhood trauma in the history. Patients with histories resulting in complex traumatisation often do not respond to treatment as usual where the treatment is short term and/or focuses primarily, or only, on symptoms. This can have a devastating impact on patient outcomes and functioning. This in turn can lead to inappropriate and/or expensive modes of treatment, which do not lead to good outcomes.

## **5. Examples of emerging good practice in NHS Trusts**

It has long been the case that trauma and dissociation-informed individual clinicians working in the NHS have done their best to provide dissociation-informed services for their complex trauma clients, but this provision has necessarily been within the policy and strategy limitations of their employers and national NHS directives. Since 2017 ESTD-UK has facilitated an email peer support group for NHS clinicians in this position which has been much valued. In recent years the increasing recognition of the impact trauma and dissociation has on adult mental health, together with the development of the biopsychosocial model of psychiatry and psychological formulation [BPS Division of Clinical Psychology, 2011] as a replacement or adjunct for traditional diagnosis has led to emerging good practise by some NHS Trusts. Though not yet fully compliant with the aforementioned guidelines, they are welcome examples of what can be done and changed within the NHS. One example is the Tees, Esk and Wear Valleys NHS Foundation Trust (TEWV NHS FT) which is developing and implementing trauma-informed practice across their mental health services. [TEWV NHS FT, 2018]. Features include training and awareness-raising for staff, information for service users and carers, and the regular use of trauma and dissociation screening questionnaires as part of routine assessments. Another example is Norfolk & Suffolk NHS Foundation Trust which has developed a dissociation strategy with specialist clinical leads, skills training for all psychological therapies staff and awareness raising for other members of multi-disciplinary teams (MDT); an MDT case consultation service, clinical case supervision for psychological therapies staff, research & development and a service user and carer focus group. [Crockford et al, 2019].

The final example is a research study undertaken under the auspices of Lancaster University and the Cheshire & Wirral NHS FT [Parry, S et al, 2017] which identified a range of *"both negative and nurturing factors which affected the development of interpersonal therapeutic relationships between dissociative patients and multi-disciplinary staff on hospital wards. When an in-patient environment was developed that felt safe, structured and nurturing; when ward staff provided empathy, warmth, and acceptance around dissociative experiences, participants felt less distressed, reducing their need to rely on dissociative coping strategies. To conclude, a consistent approach to care is particularly important for people experiencing dissociation, because of disconnections experienced in relationships and specific needs around predictability and integration"*

Other examples of good practice in the NHS can be found in a special issue of Clinical Psychology Forum on improving services for trauma-related dissociation. [British Psychological Society - DCP, 2019]

## 6. What is the impact of chronic traumatisation?

Research has shown that abuse is particularly prevalent in people seeking help from mental health services. Psychiatric patient populations are at least three times more likely to have abuse histories than the general population [e.g., Chu and Dill, 1990]. The likelihood of hearing voices increases with the number of abuse types that someone experiences so that those with five types of abuse in their history are 193 times more likely to hear voices [Shevlin, Dorahy and Adamson, 2007]. Abuse histories are predictive of 54% of the variance in depression risk and 67% of the risk of suicide [Khan et al., 2015]. Those with abuse histories in mental health services can be those who are most disabled, have longer hospital admissions and find it harder to function socially [Lysaker et al., 2001].

PTSD definitions typically define a response to a single event or stressor by a person with no previous trauma history and when the event/stressor is not interpersonal. In the case of abuse leading to complex trauma with significant dissociation, the stressor usually begins in early childhood, is prolonged, and is usually deliberately perpetrated by the people the person was/is most dependent on as a child. It is often carried out in secret and sometimes accompanies emotional neglect. The younger the child when the abuse begins, the longer it goes on for, the severity of the abusive actions, and the closeness of the child's relationship with the perpetrator, correlate with a higher degree of later mental health difficulty. As outlined above the PTSD guidelines [NICE, 2018] do not apply to those whose traumatic experiences result in the ICD11 diagnoses of C-PTSD or a Dissociative Disorder. [WHO, 2018]. Many of the dissociative disorders, particularly the more complex e.g. DID, commonly result from repetitive childhood physical and/or sexual abuse [Putnam, 1985]. Dissociation can occur when there has been severe neglect or emotional abuse, even when there has been no overt physical or sexual abuse [West et al., 2001]. The closeness of the relationship to the perpetrator and the impact of disrupted attachment is a significant factor. Dissociation is a highly adaptive response when the only means of escape from such life and/or sanity threatening traumatic experiences can be psychological.

The Royal College of Psychiatrists (RCP) states that *'any of us can have an experience that is overwhelming, frightening, and beyond our control. This may occur due to becoming a victim of assault, involvement in a car crash or seeing an accident.'* The RCP emphasises that in most cases people, in time, recover naturally from such experiences without needing specialised treatment.

In some people though, traumatic experiences set off a reaction that can last for many months or years. How people respond to trauma is related to complex interrelating factors including: resilience/protective factors, age/developmental stage when the trauma was experienced, identity of any perpetrator, single or multiple experience, and the meaning of trauma to the person. Traumatization can occur from events that include, but are not limited to, the abuse of children (sexual, physical, psychological or neglect), rape and sexual assaults, physical and otherwise aggressive assaults (including domestic violence), accidents, and acts related to war. Many traumas are not one-off events, but rather a series of experiences over time and/or ongoing abusive situations. The witnessing of any of the above can also be experienced as significantly and deeply traumatizing. There are other causes such as traumatic bereavement or early hospitalisation, but childhood abuse is the most common.

The theory of structural dissociation of the personality [van der Hart, O et al, 2006] is a widely accepted concept which is useful in understanding how chronic traumatization impacts on personality development in ways that explain the dissociative presentations of the full range of trauma-related disorders including, but not only, C-PTSD and complex dissociative disorders. It assumes that no human is born with an integrated personality but develops increasing integration within a nurturing healthy environment and good enough attachment relationship with caregivers. It describes a dissociative organisation of personality in which integration has been impaired so that different psychobiological subsystems of an individual's personality are unduly rigid and cut off from each other. This results in a lack of coherence and coordination within the personality as a whole. Within this model "Apparently Normal [parts of the] Personality (ANP)" are fixated in trying to go on with the person's current normal everyday life while avoiding traumatic memories; and "Emotional [parts of the] Personality (EP) are fixated in characteristics that were activated at the time of traumatization, e.g. defence, sexuality, hypervigilance, flight, fight, freeze.

## 7. What is dissociation?

One of the main mediators between abuse and later problems is dissociation [Ross-Gower, 1998]. This can be defined as '*a state of affairs in which two or more mental processes co-exist without becoming connected or integrated*' [Rycroft, 1968]. Trauma-related dissociation is an integrative deficit of the personality [Van der Hart et al., 2006] as a result of extreme over arousal. It can produce a range of issues in its own right: flashbacks, out of body experiences, derealisation, depersonalisation, revictimization, amnesia, fugue state, disturbance in sense of self, and it can leave the person vulnerable to developing other psychiatric disorders, including the complex dissociative disorders e.g. DID.

People with dissociative problems often present with a range of other mental health difficulties that can re-occur or change over time. Comorbid conditions, (e.g. depression, headaches, eating disorders), may respond in the short term to medication and symptom-focused treatment, but this is unlikely to bring about lasting changes. People using mental health services are making the case for the full range of their experiences to be formulated as dissociated aspects of self as a result of trauma [Longden et al., 2012]. Dissociation and abuse can be related to medically unexplained symptoms [Brown, Schrag and Trimble, 2014], and this is a significant cost to the NHS. In ICD11 some medically unexplained symptoms are classified as dissociative disorders. Further, a number of investigations have noted the relation between dissociative disorders and DSM5 somatoform disorders, where dissociative patients present with symptoms of somatisation [Saxe et al., 1994].



Dissociative experiences are also normal ways of managing everyday living and will automatically become more defined when a person is experiencing heightened stress levels in their current life. Further, each can occur as a symptom within a person's experience of a more familiar mental health diagnosis. This is one of the reasons why it is important to differentially diagnose to ensure the primary diagnosis is not actually a complex dissociative disorder. Higher levels, frequency and chronicity of these experiences and how much distress and negative impact they have on the person in their work, family and social life suggests the person may have a complex dissociative disorder.

The five types of dissociative experiences (or symptoms) are depersonalisation, derealisation, dissociative amnesia, identity confusion and identity alteration [Mind, 2013]. In a person with a dissociative disorder, the mix, severity and chronicity of these experiences will help define which, if any, dissociative disorder the person has.

- **Depersonalisation** is the experience of feeling that your body is unreal, changing or dissolving. It can affect the whole or only part(s) of the person's body. It may make the person seem and/or feel robotic or spaced out. It also includes out-of-body experiences, such as floating above one's body or seeing yourself as if watching a movie.
- **Derealisation** alters the person's perception of their environment. The person experiences the world around them as unreal or distorted. They may see objects changing in shape, size or colour, or may feel that other people are robots. They may feel that people they cognitively recognise, including close friends or relatives, are nothing to do with them.
- **Dissociative amnesia** is when the person can't remember incidents or experiences that happened at a particular time or can't remember important personal information.
- **Identity confusion** is the experience of feeling uncertain about who one is. The person may feel as if there is a struggle within to define who they are to themselves or others.
- **Identity alteration** is when there are recurring switches between how the person experiences their role or identity. This may be a subjective switch which can only be self-reported. Or it can result in dramatic or commonly subtle changes in how the person presents (e.g. different voice, posture, priorities, behaviour, thinking pattern etc) which others might notice.

If a person experiences only one or two of these, on an infrequent and/or mild acute basis, or if identity confusion is experienced only as part of normal adolescent development, or in the case of identity alteration if the only switches are usual regular role shifts e.g. behaving differently at work than at home, or if the dissociative experience can be reliably linked exclusively to a current everyday stressor in the person's life it may be an adaptive normal response to current stress and not a symptom of any disorder.

## 8. C-PTSD and Dissociative Disorders diagnostic criteria

Psychological formulation, which bases interventions on "What happened to you?" as opposed to the medical model's "What is wrong with you?" is a useful approach, either on its own or alongside diagnosis. It is a personalised approach which readers of this document are advised to explore further. However, in a world where the medical model dominates, it is useful for all readers to have some understanding of the relevant diagnostic categories. The summaries below are for guidance only. The relevant classification systems include more than simple listings of criteria.

The international clinical and research literature and peer consensus is primarily based on the DSM criteria. For this reason, the DSM-5 [American Psychiatric Association, 2012] diagnostic categories and criteria are listed first. All listed DSM-5 & ICD diagnoses also include the requirement that the symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning. And exclusion criteria about the disturbance not being attributable to the physiological effects of a substance (e.g., a drug of abuse, medication) or other medical condition (e.g., seizures).

The DSM-5 criteria are followed by the comparable ICD11 [WHO, 2018] criteria. This latest update of the ICD has now been published in a preparation for implementation version. Finally, the relevant ICD10 diagnoses are listed.

Whichever (and whether or not a) diagnostic classification system is used, if a complex trauma and/or dissociative disorder is identified, this needs to be considered and worked with as the primary problem over any other previous or co-morbid diagnosis e.g. PTSD, depression, anxiety, borderline personality disorder (BPD), bi-polar, schizophrenia etc.

The information in this section 8 is largely copied and amended from the excellently referenced TraumaDissociation website [[Traumadissociation.com](http://Traumadissociation.com), 2019] under a Creative Commons Licence. The website provides a wealth of further useful information explaining trauma and dissociation in terms beyond symptoms and diagnoses.

### **DSM IV & 5 Complex Post Traumatic Stress Disorder**

Unlike ICD, the DSM does not include a diagnosis of Complex PTSD, (also known as Disorder of Extreme Stress Not Otherwise Specified (DESNOS) or Enduring Personality Change after Catastrophic Experience (EPCACE).

However, in DSM IV features of Complex PTSD were described within the PTSD category in a section entitled "PTSD and its Associated Features",

*The following associated constellation of symptoms may occur and are more commonly seen in association with an interpersonal stressor (e.g., childhood sexual or physical abuse, domestic battering, being taken hostage, incarceration as a prisoner of war or in a concentration camp, torture): impaired complaints; feelings of ineffectiveness, shame, despair, or hopelessness; feeling permanently damaged; a loss of previously sustained beliefs, hostility; social withdrawal; feeling constantly threatened; impaired relationships with others; or a change from the individual's previous personality characteristics. [American Psychiatric Association, 2000]*

This section is absent from DSM5 but some of the associated features described have been incorporated in the amended diagnostic criteria for PTSD.

## DSM-5 Dissociative Disorders

- Dissociative Amnesia

**A.** An inability to recall important autobiographic information, usually of a traumatic or stressful nature, that is inconsistent with ordinary forgetting.

**Note:** Dissociative Amnesia most often consists of localized or selective amnesia for a specific event or events; or generalized amnesia for identity and life history.

- Dissociative Amnesia with Dissociative Fugue

Criteria as for Dissociate Amnesia with the addition of apparently purposeful travel or bewildered wandering that is associated with amnesia for identity or other important autobiographical information.

- Depersonalisation/Derealisation Disorder

**A.** The presence of persistent or recurrent experiences of depersonalization, derealization or both:

**Depersonalization:** Experiences of unreality, detachment, or being an outside observer with respect to one's thoughts, feelings, sensations, body, or actions (e.g., perceptual alterations, distorted sense of time, unreal or absent self, emotional and/or physical numbing).

**Derealization:** Experiences of unreality or detachment with respect to surroundings (e.g., individuals or objects are experienced as unreal, dreamlike, foggy, lifeless, or visually distorted).

**B.** During the depersonalization or derealization experiences, reality testing remains intact.

- Dissociative Identity Disorder

**A.** Disruption of identity characterized by two or more distinct personality states, which may be described in some cultures as an experience of possession. The disruption of 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. These signs and symptoms may be observed by others or reported by the individual.

**B.** Recurrent gaps in the recall of everyday events, important personal information, and/or traumatic events that are inconsistent with ordinary forgetting.

**C.** The disturbance is not a normal part of a broadly accepted cultural or religious practice.

**Note:** In children, the symptoms are not better explained by imaginary playmates or other fantasy play.

- Other Specified Dissociative Disorder (OSSD)

The other specified dissociative disorder category is used in situations in which the clinician chooses to specify reason that the presentation does not meet the criteria for any specific dissociative disorder.



This is done by recording "other specified dissociative disorder" followed by the specific reason (e.g., "dissociative trance"). Example presentations that can be specified using the "other specified" designation include the following:

- 1. Chronic and recurrent syndromes of mixed dissociative symptoms** This category includes identity disturbance associated with less than marked discontinuities in sense of self and agency, or alterations of identity or episodes of possession in an individual who reports no dissociative amnesia.
- 2. Identity disturbance due to prolonged and intense coercive persuasion** Individuals who have been subjected to intense coercive persuasion (e.g., brainwashing, thought reform, indoctrination while captive, torture, long-term political imprisonment, recruitment by sects/cults or by terror organizations) may present with prolonged changes in, or conscious questions of, their identity.
- 3. Acute dissociative reactions to stressful events** This category is for acute, transient conditions that typically last less than 1 month, and sometimes only a few hours or days. These conditions are characterized by constriction of consciousness; depersonalization; derealization; perceptual disturbances (e.g., time slowing, macropsia); micro-amnesias; transient stupor; and/or alterations in sensory-motor functioning (e.g., analgesia, paralysis).
- 4. Dissociative trance** This condition is characterized by an acute narrowing or complete loss of awareness of immediate surroundings that manifest as profound unresponsiveness or insensitivity to environmental stimuli. May be accompanied by minor stereotyped behaviours of which the individual is unaware and/or that he or she cannot control, as well as transient paralysis or loss of consciousness. The dissociative trance is not a normal part of a broadly accepted collective cultural or religious practice.

**Ganser's syndrome** (the giving and receiving of approximate answers) is described as fitting within this category, despite not appearing as an example presentation.

- **Unspecified Dissociative Disorder (UDD)**

This category applies to presentations in which symptoms characteristic of a dissociative disorder predominate, but do not meet the full criteria for any of the disorders in the dissociative disorders diagnostic class. This diagnosis will be used in an emergency settings where a full assessment is not possible.

### **ICD-11 Complex Post-Traumatic Stress Disorder**

Complex post-traumatic stress disorder (C-PTSD) is a disorder that may develop following exposure to an event or series of events of an extremely threatening or horrific nature, most commonly prolonged or repetitive events from which escape is difficult or impossible (e.g., torture, slavery, genocide campaigns, prolonged domestic violence, repeated childhood sexual or physical abuse).

All the diagnostic requirements for PTSD are met i.e.

- 1.** Re-experiencing the traumatic event or events in the present in the form of vivid intrusive memories, flashbacks, or nightmares. These are typically accompanied by strong or overwhelming emotions, particularly fear or horror, and strong physical sensations.
- 2.** Avoidance of thoughts and memories of the event or events, or avoidance of activities, situations, or people reminiscent of the event or events.
- 3.** Persistent perceptions of heightened current threat, for example as indicated by hypervigilance or an enhanced startle reaction to stimuli such as unexpected noises.
- 4.** The symptoms persist for at least several weeks.

In addition, Complex PTSD is characterized by severe and persistent:

- 5.** Problems in affect regulation;
- 6.** Beliefs about oneself as diminished, defeated or worthless, accompanied by feelings of shame, guilt or failure related to the traumatic event;
- 7.** Difficulties in sustaining relationships and in feeling close to others.

## ICD-11 Dissociative Disorders

- **Dissociative amnesia**

Characterized by an inability to recall important autobiographical memories, typically (*but not exclusively*) of recent traumatic or stressful events, that is inconsistent with ordinary forgetting. The amnesia does not occur exclusively during another dissociative disorder.

- **Depersonalization-derealization disorder**

Characterized by persistent or recurrent experiences of depersonalization, derealization, or both. **Depersonalization** is characterized by experiencing the self as strange or unreal, or feeling detached from, or as though one were an outside observer of, one's thoughts, feelings, sensations, body, or actions. **Derealization** is characterized by experiencing other persons, objects, or the world as strange or unreal (e.g., dreamlike, distant, foggy, lifeless, colourless, or visually distorted) or feeling detached from one's surroundings. During experiences of depersonalization or derealization, reality testing remains intact. The experiences of depersonalization or derealization do not occur exclusively during another dissociative disorder.

- **Dissociative identity disorder**

Characterized by disruption of identity in which there are two or more distinct personality states (dissociative identities) associated with marked discontinuities in the sense of self and agency. Each personality state includes its own pattern of experiencing, perceiving, conceiving, and relating to self, the body, and the environment.

At least two distinct personality states recurrently take executive control of the individual's consciousness and functioning in interacting with others or with the environment, such as in the performance of specific aspects of daily life such as parenting, or work, or in response to specific situations (e.g., those that are perceived as threatening). Changes in personality state are accompanied by related alterations in sensation, perception, affect, cognition, memory, motor control, and behaviour. There are typically episodes of amnesia, which may be severe.

- **Partial dissociative identity disorder**

Characterized by disruption of identity in which there are two or more distinct personality states (dissociative identities) associated with marked discontinuities in the sense of self and agency. Each personality state includes its own pattern of experiencing, perceiving, conceiving, and relating to self, the body, and the environment. One personality state is dominant and normally functions in daily life but is intruded upon by one or more non-dominant personality states (dissociative intrusions). These intrusions may be cognitive, affective, perceptual, motor, or behavioural. They are experienced as interfering with the functioning of the dominant personality state and are typically aversive. The non-dominant personality states do not recurrently take executive control of the individual's consciousness and functioning, but there may be occasional, limited and transient episodes in which a distinct personality state assumes executive control to engage in circumscribed behaviours, such as in response to extreme emotional states or during episodes of self-harm or the re-enactment of traumatic memories.

- **Trance disorder**

Characterized by trance states in which there is a marked alteration in the individual's state of consciousness or a loss of the individual's customary sense of personal identity in which the individual experiences a narrowing of awareness of immediate surroundings or unusually narrow and selective focusing on environmental stimuli and restriction of movements, postures, and speech to repetition of a small repertoire that is experienced as being outside of one's control. The trance state is not characterized by the experience of being replaced by an alternate identity. Trance episodes are recurrent or, if the diagnosis is based on a single episode, the episode has lasted for at least several days. The trance state is involuntary and unwanted and is not accepted as a part of a collective cultural or religious practice. The symptoms do not occur exclusively during another dissociative disorder.

- **Possession trance disorder**

Characterized by trance states in which there is a marked alteration in the individual's state of consciousness and the individual's customary sense of personal identity is replaced by an external 'possessing' identity and in which the individual's behaviours or movements are experienced as being controlled by the possessing agent. Possession trance episodes are recurrent or, if the diagnosis is based on a single episode, the episode has lasted for at least several days. The possession trance state is involuntary and unwanted and is not accepted as a part of a collective cultural or religious practice. The symptoms do not occur exclusively during another dissociative disorder

- **Other specified dissociative disorders & Dissociative disorders, unspecified**

These two categories exist with separate codes in ICD-11. However, they are described as 'residual categories' and no criteria or examples are given.

## ICD-10 Enduring Personality Change After Catastrophic Experience

equivalent to the ICD-11 diagnosis of Complex PTSD

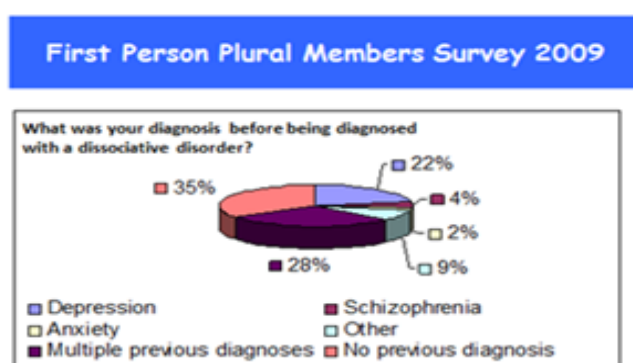
## ICD-10 Dissociative (*Conversion*) Disorders

- Dissociative amnesia
- Dissociative fugue
- Depersonalization-derealization syndrome
- Dissociative stupor
- Other dissociative and conversion disorders
  - Multiple personality disorder (Dissociative Identity Disorder)
  - Other specified dissociative [conversion] disorder

## 9. Research: Prevalence, Myths, and Neurobiology

DID and other complex dissociative disorders are **not rare** conditions. A UK audit of a locality's NHS acute psychiatric wards showed 5% of the 59 respondents had a DES score indicating they were highly likely to have DID and up to 22% were likely to have a dissociative disorder. At the time of the audit none of the respondents had a current diagnosis of dissociative disorder. These figures are in line with prevalence studies from other countries [Aquarone & Hughes 2005]. In studies of the general population, a prevalence rate of DID of 1% to 3% of the population has been described [e.g., Johnson et al, 2006; Şar et al 2007]. Clinical studies in North America, Europe, and Turkey found that 1% to 5% of patients in inpatient psychiatric units and in programs that treat substance abuse, eating disorders, and obsessive-compulsive disorder may meet DSM IV criteria for complex dissociative disorders. [e.g. Şar, V. 2011].

A survey of 52 people with complex dissociative disorders conducted by a UK charity [First Person Plural, 2009] showed 48 responders were diagnosed with a dissociative disorder at the time of the survey, 38 of these had a diagnosis of DID. They had received their diagnoses from a range of clinicians. Significantly 47 had received other diagnoses, many multiple, prior to being diagnosed with a dissociative disorder.



It is recognised that many people with DID may have comorbid conditions, but the survey demonstrated that treatment had been ineffective, at times producing negative responses, until the dissociative disorder was worked with as the primary diagnosis.

A growing evidence base is countering long standing myths about dissociation and complex trauma-related dissociative disorders.

A 2016 paper examined "the empirical literature pertaining to recurrently expressed beliefs regarding DID: (1) belief that DID is a fad, (2) belief that DID is primarily diagnosed in North America by DID experts who over-diagnose the disorder, (3) belief that DID is rare, (4) belief that DID is an iatrogenic, rather than trauma-based, disorder, (5) belief that DID is the same entity as borderline personality disorder, and (6) belief that DID treatment is harmful to patients.

*The absence of research to substantiate these beliefs, as well as the existence of a body of research that refutes them, confirms their mythical status. Clinicians who accept these myths as facts are unlikely to carefully assess for dissociation. Accurate diagnoses are critical for appropriate treatment planning. If DID is not targeted in treatment, it does not appear to resolve.”* [Brand et al 2016]

An important body of neurobiological research related to dissociation is emerging. [Brand et al 2012]. For example, a neuroimaging study supports the Theory of Structural Dissociation of the Personality by showing that "Apparently Normal Parts" of the personality (ANP) & "Emotional Parts" (EP) have different biopsychosocial reactions to stimuli (under and overactivated respectively) which cannot be replicated by actors. [Schlumpf, et al 2013]

In 2009 (2015 paperback) an award winning overview of knowledge and research was published. It encompasses dissociation, its history, neurobiology, developmental approaches, relationship to psychosis & borderline personality disorder, assessment & treatment. [Dell & O'Neil, 2009, 2015]

## 10. How to identify dissociation

Clients/patients will rarely volunteer information about trauma experiences or dissociative symptoms during standard assessment interviews. For this reason, specific screening for dissociation should ideally be incorporated into all mental health assessment procedures. It should certainly be considered when a person seeking help reports traumatic responses and/or childhood abuse independently or when asked. It should also be considered for anyone who hasn't had a positive enduring response to treatment for previous (possibly co-morbid) psychiatric diagnoses, and for anyone when significant signs or symptoms which may be dissociative in origin are observed or reported. These latter are because people who have complex dissociation sometimes have no knowledge of their abuse/trauma histories because of dissociative amnesia and/or dissociative amnesic barriers between 'parts' of the personality in people who have DID. Specialist screening tools are easy to administer and will offer guidance for the need to investigate further for dissociation and/or whether it would be helpful to administer the SCID-D which is a validated diagnostic questionnaire.

### 1. Screening tools

**The Dissociative Experience Scale (DES - 2)** [Carlson, E.B. & Putnam, F.W. 1993].

The DES-2 is a 28-item self-report instrument that can be completed in 10 minutes and scored in less than 5 minutes. It is easy to understand, and the questions are framed in a way that does not stigmatise the respondent for positive responses. When done in conversation with the clinician it can be a useful starting point to explore the dissociative experiences the patient/client has.

**Somatoform Dissociation Questionnaire (SDQ-20)** [Nijenhuis, et al 1996].

The 20-item SDQ-20 evaluates the severity of current somatoform dissociation. The SDQ-20 items were derived from a pool of 75 items describing clinically observed dissociative state-dependent somatoform responses that in clinical settings had appeared upon reactivation of particular dissociative states and that could not be medically explained. The items pertain to negative (e.g. analgesia) and positive dissociative phenomena (e.g. site-specific pain).

## 2. Diagnostic Tool

The Structured Clinical Interview for *DSM-IV Dissociative Disorders-Revised (SCID-D-R)* [Steinberg, 1994] is a diagnostic tool that is widely used and respected internationally. The person administering it requires specific training in its use and it needs to be fully completed to be effective. ESTD-UK can be commissioned to provide training on using the SCID-D-R.

The interview assesses the five symptoms (experiences) of dissociation described above: amnesia, depersonalisation derealisation, identity confusion and identity alteration. Most items have follow-up questions that ask for a description of the experience, specific examples, and the frequency of the experience and its impact on social functioning and work performance. The SCID-D if used sensitively is seen as part of the therapeutic journey with positive outcomes being anecdotally recorded.

The DSM IV version of the SCID-D is currently being updated to bring it in line with the DSM 5. In the meantime, professionals are continuing to use the original version.

## 11. Treatment

Treatment for complex trauma-related dissociation is primarily longer term psychological therapy (with possible adjunctive pharmacological and other treatment, support and care) which encompass the accepted best practice phases outlined by Herman's model of the treatment of trauma [Herman, 1992]:

1. Stabilisation [ensuring safety], symptom-oriented treatment
2. Exploration of traumatic memories
3. Personality integration and rehabilitation

The ISST-D' s Guidelines for Treating Dissociative Identity Disorder in Adults [International Society for the Study of Trauma and Dissociation. 2011] re-iterate these phases and state: *'while it resembles that for complex PTSD, treatment has specific features based on specialist knowledge of dissociation. The recommended treatment is phase-orientated using individual psychodynamic orientated psychotherapy on an outpatient basis.'*

For some patients, at certain times, inpatient treatment which continues the psychological therapies input may be useful e.g. for those people with extreme levels of self-harm or suicidality.

Frankel says, *'... it is increasingly clear that people vary as to the pathways followed towards healing'*. [Frankel, 2009] He states that therapists need to be flexible in their approaches, have a range of frameworks and technical skills, and be responsive to ways that people let them know what they need. The American Psychological Association found *'...that sensitivity and flexibility in the administration of therapeutic interventions produces better outcomes than rigid application of principles* [American Psychological Association, Presidential Task Force on Evidence-Based Practice., 2006].

The first stage of "treatment involves developing safety of self and stabilising self and other-destructive behaviour, teaching affect regulation, educating the patient about their diagnoses and symptom management, and developing a good treatment alliance".



The second stage involves “identifying, accepting, and talking about their histories of abuse and trauma; cognitive processing of trauma-related themes and misattributions (e.g. believing that they were and are “bad” and that the childhood maltreatment was deserved); emotional processing, including the grieving of related losses (such as the loss of innocence, loss of potential); and creating a cohesive rather than a disjointed and dissociative narrative.

In the last stage of treatment, self-states continue to be integrated, patients learn to cope with stress and emotions without dissociating, and they work to develop healthy relationships, an enhanced ability to work, and an increased sense of purpose in life” [Brand et al., 2010].

People with complex dissociative conditions whose traumatic experiences include mind control and/or victimisation within an organised ritual abuse setting are likely to need longer therapy, and probably additional support and care.

## 12. Outcomes and Cost-Effectiveness

An international randomised controlled trial has shown that therapy targeting the dissociative divisions is not only beneficial but also is significantly better than other therapies [Brand et al 2014]. Attention to parts does not have detrimental impact but actually is the main factor in predicting a positive outcome.

Positive outcomes and cost effectiveness of treatment of dissociative identity disorder consistent with the ISST-D’s guidelines has been demonstrated within an NHS service. [Lloyd 2016]. The figures relate to two DID patients and show the positive clinical and financial benefits of a dissociation informed therapeutic intervention in reducing crises by stabilising the person. The therapy, begun in 2010, resulted in a reduction of inpatient and out-of-hours contacts. This has been maintained throughout the stabilisation and trauma exploration phases. Abstract of this article is available from <http://www.ncbi.nlm.nih.gov/pubmed/26523531>

Treatment of Patients with Dissociative Disorders (TOP DD) Studies is a prospective, naturalistic longitudinal international treatment outcome study of dissociative disorders. It is the largest and only international prospective treatment study of dissociative disorders to date. Participants were 280 patients with dissociative disorder and 292 community therapists from 19 countries. Results showed that patients treated with a 3-phase model as recommended in the ISST-D guidelines [International Society for the Study of Trauma and Dissociation. 2011] who were in the later stages of treatment had fewer symptoms of dissociation, PTSD, and general distress; fewer recent hospitalizations; and better adaptive functioning than those in the early stages of treatment (Brand et al., 2009). Longitudinal follow-up indicated that patients showed less dissociation, PTSD, general distress, depression, suicide attempts, self-harm, dangerous behaviours, drug use, physical pain, and hospitalizations as well as improved functioning over 30 months of treatment (Brand et al., 2013). Participants were more frequently involved in volunteer jobs and/or attending school and socializing, and reported feeling good, as treatment progressed. A six year follow up with 61 of the therapists who participated in the initial TOP DD study asked about their corresponding clients progress. The results continue to support the initial results of the TOP DD study that, despite marked initial difficulties and functional impairment, DD patients benefit from specialized treatment. [Myrick et al 2017]

### 13. Service context

There are eight core competencies of trauma informed services [adapted from Elliot et al., 2005] that support the identification of complex trauma related disorders:

- Outreach and engagement with trauma survivors in other parts of the mental health system
- Screening and assessment that includes dissociation
- Face to face goal setting and treatments that are collaborative
- Parent skills training to avoid trans-generational transmission
- Resource coordination and advocacy for integrated care plans
- Trauma/ dissociation specialists for psychotherapy
- Crisis interventions that acknowledge that many 'symptoms' or 'risky behaviours' are survival mechanisms
- Peer run services and an empowerment.

In general, a multidisciplinary approach is useful, linking primary and secondary care services. Consistent, informed support is an integral part of the therapeutic journey.

### 14. Further information and resources

- European Society for Trauma and Dissociation, [www.estd.org](http://www.estd.org)
- International Society for the Study of Trauma and Dissociation, [www.isst-d.org](http://www.isst-d.org)
- First Person Plural - dissociative identity disorders association  
<https://firstpersonplural.org.uk>
- Ritual Abuse Information Networking Support (RAINS) [rains\\_home@icloud.com](mailto:rains_home@icloud.com)
- Online training courses from ESTD-UK, <https://estduk.org/online-courses/>
- Training Film: A Logical Way of Being: The reality of Dissociative Identity Disorder and other complex dissociative conditions.
- Training Film: No Two Paths the Same: Living and working therapeutically with dissociative identity disorder.

Above films available for purchase as DVDs or downloadable MP4 files from

<https://firstpersonplural.org.uk/training/learning-resource-films/>

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- Steele, K; Boon, S; and Van der Hart, O (2017). Treating Trauma-Related Dissociation: A Practical, Integrative Approach

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