



## Becoming one person: living with dissociative identity disorder

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### Becoming one person: living with dissociative identity disorder

Dissociative identity disorder is a rare diagnosis, although people currently with a diagnosis of psychosis may in fact be experiencing what is associated with the disorder. This article is co-authored by a nurse and a person who has lived with alters (multiple personalities) for nearly all of her life. Because of the rarity of the diagnosis, there is much misunderstanding and ignorance among lay people and mental health professionals. This article therefore clarifies historical and contemporary issues surrounding this particular mental health problem both through examining the literature and through narrative of the person's experience. Special attention is given to the reality of coping with the difficulties that dissociative identity disorder create.

**Keywords:** dissociative identity disorder, narrative

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### Introduction

Dissociative identity disorder (DID) has had a colourful history. Previously labelled '*multiple personality disorder*', it has received much media attention, which has been epitomized by the books and later films: *The Three Faces of Eve* and *Sybil*. Indeed, some have linked the growth of reports of the disorder with the screening of these films (Piper 1997). The disorder has grown in mythical status in the minds of some, and in others its existence has been hotly contested (Allen & Lacono 2001). Controversy continues to surround the diagnosis due to its association with false memory syndrome and links with child abuse and trauma (Acocella 1999, McAllister 2000). There have also been alleged numbers of copy-cat experiences, especially in the United States, while some have contested that therapists have projected the condition upon their patients (Piper & Merskey 2004). In certain cultures, DID may be explained by the presence of demon or 'spirit' possession (Swartz 2002). In the Western world, however, the disorder has

warranted serious attention in recent years and is now included in the DSM IV (APA 2000). While the original diagnosis of multiple personality disorder was almost unrecognized outside of the United States, the diagnosis of DID is now more likely to be applied in other Western countries (McAllister 2000).

The disorder remains poorly understood among mental health professionals, and considerably more so among the general public (Mohr 2002). The nature of the diagnostic criteria within DSM IV has also been contested (Gleaves & May 2001, Dell 2002), and a further disorder '*Major Dissociative Disorder*' has been called for (Dell 2001). Scant attention has been given to the disorder in the UK, for example, a search for the term 'dissociative identity disorder' within *the British Journal of Psychiatry* reveals one article (van der Hart & Nijenhuis 1998), and none in *the Journal of Mental Health*. Given the paucity of research literature in the UK regarding the disorder, it is understandable that mental health professionals are largely ignorant of the condition and treatment (Whewell 2002). de Zulueta

(2002), an expert in this field, believes that it is only now that professionals are beginning to recognize DID as a serious psychiatric disorder.

This article is authored by a person who has experienced DID for most of her life and who has also worked as a professional manager (R.N.) and an academic nurse (T.S.). It is rare for professional people to reveal their disorder, although one exception is Rhonda Coyle (Coyle & Thobaben 1995). As a nurse, Coyle acknowledges the risks of potential misunderstanding and discrimination in publishing her story. In this paper, we offer a brief overview of the disorder, and a discussion regarding the reality of coping with the condition from Rachel's experience. Much of this article therefore is taken up with Rachel's narrative, describing a first-hand account of living and coping with DID. To many, Rachel's story may appear extraordinary. This is exacerbated by the fact that to Rachel, her story is about the ordinariness of her life, and she cannot imagine what it is like not to dissociate.

## Dissociative identity disorder

Recognition of the existence of multiple personalities within the medical profession was first mooted by Janet, a French psychiatrist, in the early 19th century. Janet's work is difficult to access, although Merskey (1992) and Piper & Merskey (2004) provides an excellent critical account of this. Janet (1889) suggested that ideas fixed in the subconscious, often caused by traumatic events early in childhood, could split off from consciousness. These could interfere or even take control of the person, in the shape of dreams, traumatic flashbacks or even as a second personality (later known as multiple personalities) (Midgley 2002). Merskey (1992) and Piper & Merskey (2004) are among those who have been fiercely critical of the work of Janet and subsequent proponents of DID. For them, Janet made suggestions to his patients about memories of abuse and the existence of *other* personalities. Janet might be considered the first recorded culprit of false memory syndrome (FMS). The concept of dissociation found credence in Freud's theories of hysteria and repression. As such, dissociation in women was seen as an ego defence mechanism against unacceptable sexual fantasy that created internal conflict from the unconscious mind (McAllister 2000). The relationship between sexual trauma, and complex family patterns of secrecy and double bind was developed by Ferenczi (1933). Since then, much discourse has been offered to interpret and explain this phenomenon within the realms of psychiatry, psychology, feminism, social constructivism and anthropology (McAllister 2000). Piper & Merskey (2004), however, are sceptical about the growth of DID and question why so few cases have been recorded prior to

the 1980s. If DID is a result of childhood abuse, then why did it not exist prior to it being labelled? Childhood abuse existed long before DID was recognized. According to Putnam *et al.* (1986), more cases of DID were discovered between 1981 and 1986 than in the previous two centuries. It was at this time that the diagnosis was referred to as multiple personality disorder (MPD). The growth in reported cases of MPD brought with it the potential for people to recover in therapy previously repressed memories of abuse (Aldridge-Morris 1989). Thus, lawsuits began and rapidly increased between the alleged abused seeking recompense from their alleged abusers. For many, however, these repressed memories became considered 'false memories' and FMS became the alleged abusers' defence. Although DID has now become recognized as a mental disorder, it remains a contentious diagnosis (Piper & Merskey 2004).

In summary, DSM IV defines DID as existing when a person has two or more identities or personalities, each with its own way of being; its own relatively enduring pattern of perceiving, relating to and thinking about the environment and self. Additionally, at least two of these identities or personality states recurrently take control of the person's behaviour. These personalities are sometimes known as alters. The person will experience an inability to recall important personal information that is too extensive to be explained by ordinary forgetfulness (APA 2000).

## Causes

At the present time, the theories of the causes of DID fall into two main camps that Gleaves & May (2001) refer to as traumagenic and iatrogenic. Those of the traumagenic position believe that DID is a direct result of childhood trauma, especially of an abusive nature (historically, Spiegel 1984, Kluft 1985, Putnam 1989, Gleaves 1996). Those holding the iatrogenic position assert that the condition is a direct result of media influence and psychotherapeutic interference. Understandably, these critics have emerged more lately (Merskey 1992, McHugh 1993, Spanos 1994, Piper & Merskey 2004).

Psychoanalytical theory is most commonly applied for an understanding of the cause of DID from the traumagenic position. The hypothesis that a high level of abuse or trauma in childhood is essentially related to the development of dissociative symptoms has become significant to theory and research within this field (Bentovim 2002). Namely, DID is usually a result of childhood trauma, notably childhood sexual abuse (North *et al.* 1983; Midgley 2002). It is widely held that different personalities can develop within childhood, as a reaction to severe trauma (Sinason 2002). When the people dissociate, they leave their body to escape the pain or trauma. When this defence

is not strong enough to protect the person, different personalities emerge to handle the experience or trauma. Sinason (2002) provides numerous examples of individuals to which this has happened and maintains that these personalities or *alters* facilitate the child's psychological survival. When the child is experiencing traumatic episodes, the other personalities take the pain and/or watch, and this allows the child to return to his/her body after the trauma without any awareness of what has occurred. It is a survival mechanism consistent with Freud's theories of ego defence (i.e. repression and denial). Children develop the alters and it is the alters that carry the emotional hurt. After the trauma, this personality/alter goes inside and allows the child's main personality to return. This process allows the child to get up in the morning, go to school and not be aware of anything that has happened to him/her. There may be different personalities/alters developed to handle different situations. Each alter has a way of being with unique expressions, memories and reactions (Sinason 2002).

## Symptoms

DID is strongly linked to post-traumatic stress disorder (PTSD) (de Zulueta 2002), and consequently those experiencing DID may often exhibit similar symptoms as those displayed in PTSD. Many individuals who survive severe trauma will later experience marked anxiety and panic attacks, flashbacks, nightmares and body memories. Insomnia, primarily that which results in difficulty remaining asleep, is also frequently experienced.

As well as those symptoms described for PTSD, people who experience DID also experience unusual alterations of consciousness. Dissociation is a psychological state in which the individual's level of consciousness is altered. People describe being separated from their body, 'zoned out', floating above or apart from the body, detached. This altered state of consciousness includes feelings of memory and identity having created separate identities with separate lives and abilities (Dallam & Manderino 1997). People experience time loss and have difficulty in timekeeping. Minutes or hours can pass as if in an instant, and the person may have no recollection of what happened during that time, as in a fugue state (Jasper 2003). In reality, one or more of the alters/personalities may have been active during that time. To others, the person can appear to be functioning as usual. Elzinga *et al.* (2003) have studied the memories of people while dissociating, and they observed that '*Whereas DID patients may not be able to inhibit or selectively forget information within the same state, they seem to do so when switching to a different state*' (p. 241). People may also hear voices and describe these almost iden-

tically as people diagnosed with psychosis yet usually as voices from inside one's head (Coleman 2002). These voices are generally accepted to be the chatter of the alters/personalities. What is most common is a fugue state, when people find themselves in another place with no knowledge of how they got there. Bentovim (2002) records an account of a woman in her fifties who found herself on a beach and soaking wet with no explanation of how she got there. Hyper-vigilance is also common, as well as feelings of hopelessness, helplessness, worthlessness, pessimism and sadness. Suicidal thoughts or attempts are common because the feelings of depression and hopelessness may become severe. People who are diagnosed with DID are often forgetful. This has been largely attributed to the fact that no one alter takes overall responsibility for remembering (Mollon 2002). It is not uncommon for people to feel that they are sharing their body with others. DID is based on the idea that an individual has more than one distinct personality and people with DID usually experience the sensation that others are living in their body.

## An extraordinary upbringing

The oldest of six siblings, Rachel, grew up in a very disturbing environment. Her parents were aspiring middle class, with her father being a senior manager in a large international company. However, both her parents were sexually abusive and violent to their children. The atmosphere within the home was virtually always unpredictable. Both parents were openly verbally abusive and negative toward the children, who were periodically threatened with violence, even murder. There were regular small incidents of pinching or punching as the children went past their mother, but on occasions she threw knives and other objects at them. The eldest two boys were regularly strangled until they lost consciousness. Understandably, there was much fear, crying and screaming from the younger siblings. The children were not allowed to go to the lavatory in the night or get out of bed; subsequently the eldest two boys would urinate in a corner of the bedroom and one of them would hide faeces in a drawer. The children were often locked in a small cupboard under the stairs. The parents allowed friends of the family to also sexually abuse their children. The mother was also sexually inviting to strangers. For example, she would sunbathe naked when the dustmen were coming or parade naked in the front window. She was admitted to a psychiatric hospital in 1964. The father said she had been diagnosed as a *manic depressive schizophrenic*. She was given ECT and was sedated for long periods in hospital. Sinason (2002) identifies the difficulty in detecting childhood sexual abuse within middle-class families, and argues that it is far easier to detect in

children from lower classes who may already be receiving some form of social service. This was the case with Rachel's family, as her father was mostly even-tempered, talkative and friendly to the neighbours. This friendly exterior belied his sexual and violent nature. Her father was largely responsible for inviting relatives and friends into the house to sexually abuse her.

### Living in spite of (and unaware of) DID

Rachel found the unpredictable, violent and explosive nature of her mother's actions terrifying. She felt her whole life was being threatened and that she could die in a very unpleasant way. In order to cope with such persistent abuse, Rachel began to '*sit beside herself*' so that it didn't seem to be happening to her. She found a way of watching what happened rather than endure it herself. From an early age, Rachel often thought of suicide because then she could be in control of when and how she would die, rather than her mother. She would choose a pleasant death, not a terrible one like her mother threatened. Rachel realized early on that if she showed fear, it made her mother worse. She made a positive decision, even before school age, to show no reaction. While her head felt like exploding with fear, Rachel saw herself in a black circle with flashes of red. Rachel pushed these fears down by counting and stood as still as she could. She often saw herself standing still and emotionless. In this way, she felt safer and perhaps she wouldn't need to die. Rachel developed the art of thinking herself into a dream. She could imagine sitting outside the cupboard when she was actually locked inside it. She could see herself sitting quietly inside it. When Rachel was being sexually abused, she also '*dreamed*'. She developed the ability to be sitting next to her self or even outside the room. In this way, Rachel felt nothing, either emotionally or physically. She no longer felt pain when she was hit, and she was able to stop crying with fear.

Once she started school, Rachel '*dreamed*' a lot. Sometimes she couldn't remember how she had got to school. She often became mentally absent during lessons, almost constantly daydreaming, and was often accused of being erratic by teachers who thought her intelligent but not working to the best of her abilities. As a teenager, Rachel thought she could sleep anywhere at any time. If something was frightening her, she simply went to sleep. Rachel could sleep for 5–10 min to 1 or 2 h, at strange times and strange places; during playtime at school, going to the shops, on a bus, while reading and at odd times when at home. Rachel would often wake up in a different classroom or find herself on the wrong road on the way back from doing the shopping for her mother. She sometimes woke up to find herself walking across the fields near her house. Through-

out her childhood, teenage years and college years, Rachel either slept or dreamed significant periods of her life away. She couldn't understand that nobody commented about it, not even the boyfriend who was to become her husband. Rachel was puzzled and frightened, but didn't know what to do about it or how to explain it. She always had a lot of noise in her head; like lots of people talking all at once, she also saw herself, at different ages around her, in the room for much of the time. As no one else talked about this sort of thing, Rachel knew it was strange. She decided not to talk about such things, for fear of being regarded as 'mad'. As she progressed into adulthood, Rachel would frequently experience becoming a 6-year-old child. During these periods, she would not know where she was and would tell people that she was 6 years old. Rachel experienced other alters too, but the 6-year-old girl was the most frequently experienced.

### Personal coping

Because of her early childhood experiences, Rachel learned to become a great people watcher. She had to learn how to behave in different situations, and this was transferable into her professional life. In her adult life, she recalls never feeling emotions, which made it difficult to understand other people. She saw how people moved and reacted when they said or felt different things, and became very good at mimicking and convincing others of her own feelings and emotions. Clock watching has become a very real coping strategy for Rachel, as she attempts to keep aware of any time lost to dissociation. Once she knows she has lost time, then she also knows she needs to do something about it and seeks to find out what she has missed.

Sometimes, the floors move up and down and tilt when Rachel begins to dissociate. One way of coping with feelings associated with dissociation is to feel the elements of the environment, for example, cold of the walls in a corridor or window panes. By touching the hard cold surfaces, Rachel could remain living and sane knowing she was grounded in the real world. Singing also helps at these times. Rachel writes down where she is going either on paper or on the palm of her hand. Even when her 6-year-old alter takes over, this strategy works. Rachel usually has a teddy bear or a baby's rattle in her bag as a comfort to touch without people knowing. Rachel has harmed herself as a way of coping when very distressed. She has only ever cut her stomach. More recently, Rachel has taken to wearing an identity bracelet because of her experiences of finding herself in strange places with absolutely no idea how she got there. The police have on more than one occasion found her and been able to identify her through the bracelet. Although Rachel does not like this happening, she does

not intend to be housebound, and will therefore take the risk of dissociating believing that there are enough strategies in place to keep her safe.

### Coping as a professional manager

As Rachel started work, the sleeping and daydreaming became a real problem. She had to somehow overcome these experiences as well as the noise in her head. Additionally, she had constant feelings of wanting to die. Rachel felt so overcome with the feelings of death that she found the only way she could cope was to be really cheerful. She was noted for always smiling, being cheerful and letting nothing worry her. Rachel worked as a special needs teacher and was determined that this group of vulnerable children should have the same rights as every other child. Rachel was noted for being very assertive and insisting on change if it meant that groups of vulnerable children received better care and a better education. Rachel had failed to protect her brothers and sisters, but was determined she was not going to fail these children. It gave her the courage to work at a senior level within education, forensic mental health and later in education and social services. It gave her a purpose to live, maybe a chance to atone for failing her siblings.

Rachel became extremely organized at work in order to compensate for her absences. Her record keeping and note taking at meetings was excellent. If Rachel had '*dreamed*' her way through a meeting, she would get a copy of someone else's notes as soon as she could. Rachel would always try and read the notes before the next meeting. If she still couldn't remember anything about the purpose of a meeting she was chairing, she learned the knack of starting the meeting by agreeing its purpose with those present. Rachel found it hard to remember names of people, times and places of meetings, so she got everyone to believe that she had a dreadful memory and made a joke of it. As Rachel became a senior officer with management responsibility for 80 people, her colleagues believed she had a lot on her mind, making her *poor memory* story acceptable. On the whole, this strategy worked. As Rachel became more senior, she had a personal secretary, and between them they became renowned for their excellent record keeping.

Memo notes became essential to Rachel's working life. She constantly made notes to her self and requests to others. She would not always remember that she had sent the memos, and was frequently puzzled by staff coming to see her saying she had sent them a memo. She created a system whereby staff brought the note she had sent them with them, so that she could have her memory jogged. Once again this strategy worked and staff didn't seem to mind. Because Rachel often talked out loud, she had to cover this

up so she began to sing to her self. Rachel walked the schools she visited, office corridors and the town singing to her self; a sort of tuneless hum. Again, people would comment about her being cheerful.

### The breakdown of coping

Having worked in senior management for a number of years, eventually the stress of work got the better of her and Rachel's coping strategies began to prove inadequate. The breakdown of coping had a slow build-up with a swift ending. One example was Rachel began talking out loud more often, for example, in the middle of meetings so she subsequently needed to sing more and to claim she was just thinking out loud. Her daydreaming increased and were accompanied by uncontrollable panic attacks. She would often excuse herself from meetings feeling dizzy and needing air. The sound of talking in her head made listening to people very difficult. Eventually, Rachel needed to take time off work which was most unusual. This coincided with a wave of feelings of worthlessness and she began to self-harm. Most of her coping skills collapsed, and Rachel took a month off work. She never returned as she had to take early retirement on the grounds of ill-health.

### Care and treatment

It is noted that those experiencing DID usually have difficulty in coping with the demands of ordinary life (Bohn & Holz 1996). Rachel, however, fully succeeded in marriage, raising a family and rising to a senior management position before the diagnosis was applied. It was only much later in adulthood that Rachel first sought help. During a number of visits to her GP, Rachel complained of having panic attacks, and eventually disclosed the sexual abuse she had experienced as a child. Following this, she was referred to the local mental health services for counselling. Rachel had three assessments during which she told them very little except about her upbringing. She could tell this story without any emotion at all, although discussing anything deeper such as her other personalities was still beyond her, having no language to use and afraid of what their reaction would be.

Following a 2-year wait, she finally saw a psychodynamic psychotherapist, with whom she was able to share her other identities and personalities. She recalls this as a turning point in her acceptance of and being able to acknowledge to herself and someone else that she did see and hear others. Despite this, the more she talked about her feelings and childhood events, the more depressed she became and was subsequently referred to a psychiatrist, who prescribed medication which appeared to alleviate

some of her distress. Still no diagnosis was given. Needing a diagnosis and an explanation for her symptoms, Rachel decided to pay for a private report from a clinical psychologist. A diagnosis of DID was given, which Rachel struggled greatly with. She read up on it and became quite frightened – she didn't want to be that ill. Nevertheless, receiving a diagnosis helped her. She found words to describe what happened to her: losing time, dissociating, alters and other personalities. She began to dissociate frequently and became very suicidal. Things broke down altogether, and she was referred back to the psychiatrist and subsequently referred to a Psychiatric Day Unit (PDU). Her care was organized through the Care Programme Approach process, although this became a long and complicated process due to finding a professional who could competently conduct an assessment that involved the experience of DID. During this time, Rachel again became overwhelmed with her circumstances and was admitted to a psychiatric ward. Despite this, she describes her care through the PDU, in particular with her key worker, as supportive and helpful in listening, making suggestions, challenging and just being there. Much of this care also includes physiotherapy, which has helped Rachel to feel her body again. Previously, she did not feel knocks, nor had a very good sense of hot or cold. She has learnt to sometimes prevent dissociation by rubbing her hands together, stamping her feet on the ground and by reminding herself she is here, she is real. It has helped decrease the number of times she has cut herself in order to feel that she is alive.

To the uninitiated, DID may be superficially mistaken for a psychotic state given the very real psychotic component of the experience of the disorder (Kahr 2002, Mollon 2002). Given the apparent rarity of the condition and the reluctance of some psychiatrists to recognize it, there may be many experiencing DID but being treated for psychosis. de Zulueta (2002) records the experiences of working with people with DID at The Maudsley in London. She describes the shock that people experience once given the diagnosis; this may be largely due to the more common diagnosis of psychosis being more widely and therefore more readily accepted. DID is so little sought as a diagnostic possibility, and schizophrenia is so favoured by psychiatrists that an average of 8 years may pass before a succession of treatment failures forces a serious appraisal that leads to a correct diagnosis. There are comprehensive treatment guidelines published (ISSD 2005) that complements the growing research literature.

In view of the controversy surrounding this diagnosis, it is not surprising that controversy follows in the treatment of those with DID. There is much discourse within psychodynamic psychotherapy as well as psychiatry, as to the approaches for treatment. However, it is essential for other

mental health professionals, especially nurses, to be aware of DID in a broader sense. In attempting to identify or recognize DID, particularly within nursing care, Bohn & Holz (1996) indicate that a forum in which an individual can safely disclose history of abuse is paramount. Often, the person has been forced to keep this secret or may have not been believed when they have shared such information. This includes assurances that their feelings are legitimate, that they are worthwhile and did not deserve such abuse, and acceptance of their story with no judgements. In addition to this, Bohn & Holz (1996) are adamant that health-care providers need to see abuse as a public health issue rather than a private problem, and be willing to discuss it.

An environment of empathy is also seen as core to enabling an individual to disclose his/her multiplicity. This is particularly true where in childhood, the capacity to trust, attach and self-regulate may have been significantly disrupted, and therefore the role of empathy becomes central (Burton & Lane 2001). The goal of therapy is re-association and re-integration of the person's sense of self. This is most usually achieved through individual psychodynamic psychotherapy, often incorporating other techniques (Putnam & Loewenstein 1993). Nurses working with people experiencing DID are encouraged to hold the whole person to be responsible for the behaviour of any of the alters, even when the person has no memory of what has happened (ISSD 2005). Although it is not evident in the ISSD treatment guidelines, Rachel has found physiotherapy most useful, especially exercises where she is reminded to concentrate upon her body. This has enabled her to have a greater sense of her physical place in the world when she dissociates. When nursing a person who experiences dissociation, it is vital to stay with the person both physically and psychologically, even if that means adjusting to the presenting alter. As already discussed, empathic understanding is crucial in the nurse–client relationship.

## Conclusion

In authoring this paper, we are aware of the controversy surrounding the diagnosis, some consider the existence of DID as temporary and will be non-existent in 10-years time (Piper & Merskey 2004). It is interesting to note that with Rachel's experience, she lived most of her life with no diagnosis or psychotherapeutic interference but with the experience of textbook DID. Given this evidence, it is hard to see how such critics (including a professor of psychiatry) can justify such a hard-line iatrogenic position.

In reading this paper, we would like to think that nurses might further their understanding of DID and become more aware of the potential for misdiagnosis. This is an issue that mental health nurses should be acutely aware.

There are perhaps many in our care at the present time being treated for psychosis or schizophrenia that in fact experience dissociation and the presence of alters. It is worth highlighting Rachel's ability to cope through decades of work and family rearing before receiving a diagnosis. There are practical interventions that can help people sustain a normal life in spite of extraordinary inner experiences.

In Rachel's example, it is clear to see that some individuals may indeed be able to live for some time with DID, finding their own coping strategies to deal with life. Professionals clearly have a responsibility to increase knowledge of this condition and the needs of those who may experience it. For many, it may be confusing and difficult in knowing how to proceed. A starting point may be the breaking down of the stigma associated with this phenomenon; coming to terms with this disorder as a possible diagnosis and being willing to talk with those who experience it; also recognizing that this may be much more common than we are willing to admit. As the experience of childhood sexual abuse and trauma is beginning to be more openly talked about, there is a need for the recognition that a number of people may be experiencing dissociation that may not otherwise be detected.

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