

mentalhealth

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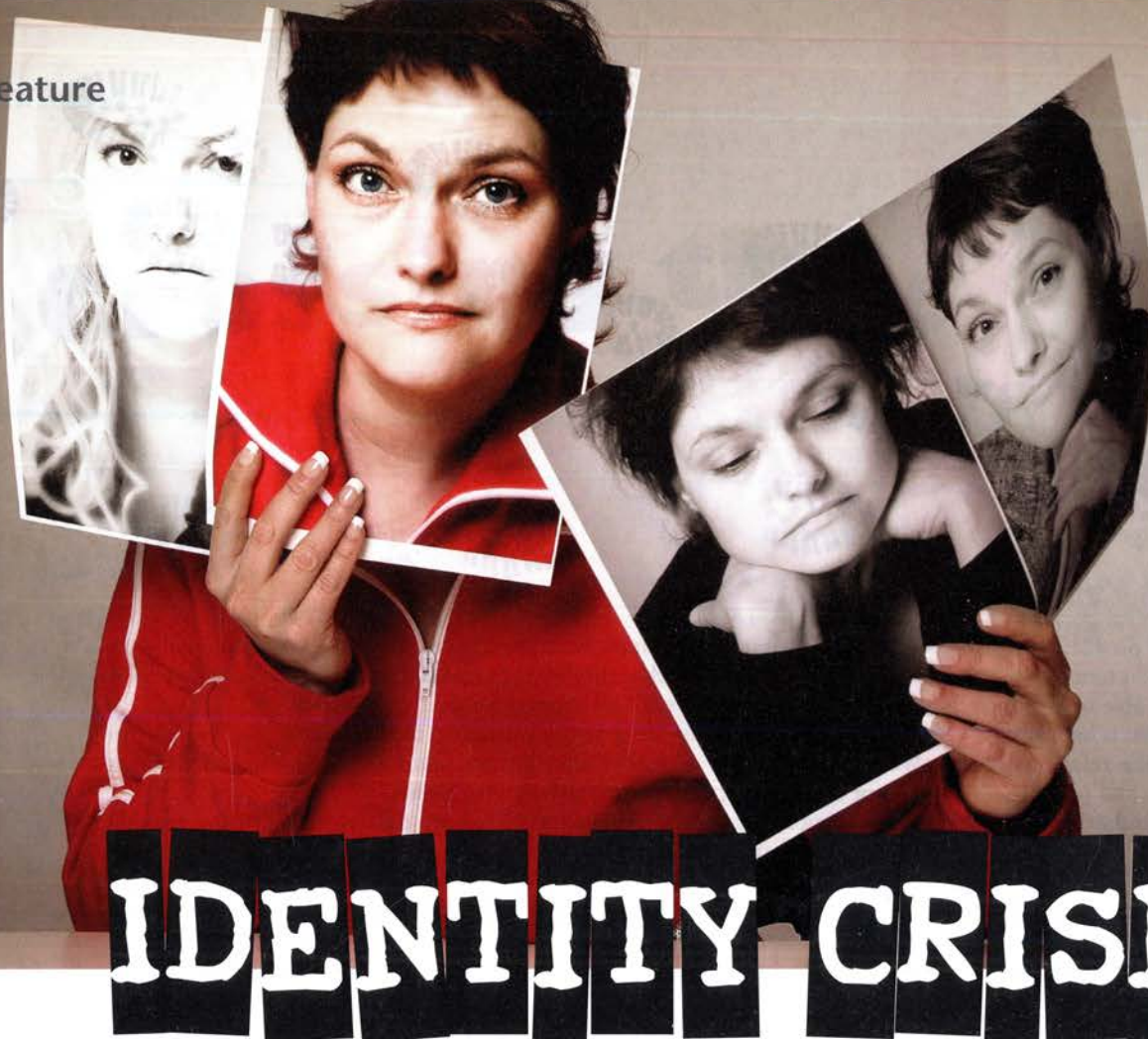
Sleep and mental health

Independent living



Identity crisis

Why many people with dissociative identity disorder do not even realise they have the condition



IDENTITY CRISIS

Dissociative identity disorder is a common mental illness, yet relatively few people know about it. Mary Salmon reports

Could there be a severe mental illness almost as common as schizophrenia and bipolar disorder, where most of those affected don't get the right diagnosis?

According to several experts, there is. The condition is dissociative identity disorder (DID), formerly known as multiple personality disorder.

While lots of figures are bandied about, mental health charity Mind estimates it may affect as many as one in every 100 people. Remy Aquarone, an independent NHS consultant and expert in dissociative disorders gives a more conservative figure of around one in 200.

Aquarone, who is also secretary of the European Society for Trauma and Disassociation (ESTD) and director of the Pottergate Centre for Disassociation and Trauma in Norwich, is now planning to work with ESTD on a pilot study to get a better idea of how many mental health in-patients have undiagnosed DID. He will work alongside Dr Mike Lloyd, a chartered clinical

psychologist with a special interest in DID who works in an adult community mental health team in Cheshire.

Aquarone already carried out a small survey in 1997 on 59 patients on an acute psychiatric ward in Norwich. Using the Dissociative Experiences Scale-2 as a screening tool, he found that 30.5% scored more than 30 on the self-reported questionnaire, indicating the possibility of a dissociative disorder. Of these, he estimated that at least 5% had undiagnosed DID. While disassociation is a sub-feature of several mental illnesses, with DID it is the primary defining feature.

What is DID?

There are several levels of disassociation with DID being the most complex. "It is an elaborate defence mechanism which can result from severe, usually prolonged abuse, and often starts in childhood," explains Lloyd. "Abused children are the most vulnerable, but it may develop in adults too, for example in those who have survived traumatic war experiences."

Disassociation can develop when an event is perceived as so awful that the conscious mind is unable to cope with it. For example, in cases of child sexual abuse, the child often reads signs from the abuser's body language that abuse is about to happen, and the child switches into an alternative personality.

"It can then be like the abuse is happening to someone else," adds Lloyd. "In DID, the disassociation is so complete that once the abuse is over, the person

Clinical clues a patient might have DID

- Several diagnoses given depending on how they present themselves
- May ask for stronger medication to calm voices in their head
- Moving from one professional to another with each professional seeing them in a different light
- Patient creates tensions and splits among the professionals treating them

Mary Salmon is a freelance journalist

Photo: mammamaart, istock

has no memory of it. When the abuse is ongoing, many people with DID develop several personalities – usually themselves at different ages and with separate identities.”

Professionals refer to the different personalities as ‘alters’ and many people with DID keep the alters in the unconscious mind and have a relatively normal life.

However, problems can develop later on. “Up to 10, 20 or even 40 years later, memories usually start to leak through. What was an excellent defence in childhood isn’t as useful in the adult world,” says Aquarone. “Many things such as smells, certain noises, life events and gestures can trigger memories.”

At this stage the individual may end up in the care of mental health services, perhaps suffering from confusion, memory loss and terrifying flashbacks. The alternative personalities may emerge to take over the dominant personality at various times. The person might not recognise themselves in the mirror, may experience internal voices, believe that friends and family are strangers, and may take on child-like behaviour.

While studies on the prevalence of DID are scarce, it is a well documented condition, detailed in both the DSM-IV (the American diagnostic manual) and the ICD-10 (the European manual).

There are thought to be several reasons why the condition often goes undiagnosed. “Many psychiatrists don’t believe the condition exists in its own right. Others say the patient is just pretending or that the symptoms are caused by poor therapy,” says Aquarone.

Hard to pick up

Another problem is that DID is hard to pick up using standard questionnaires and mental health professionals and GPs get very little training.

“To be fair, it is a difficult condition to diagnose if you aren’t familiar with it,” says Aquarone. “By its nature,

disassociation is a way of hiding trauma from one’s self so many people won’t realise they are doing it. Others know, but are terrified to speak up as they may have been severely threatened as a child if they told anyone.

“Unfortunately, it is fairly typical to end up with the wrong diagnosis – usually schizophrenia, bipolar disorder or borderline personality disorder, all of which can have some dissociative features.”

According to Aquarone and Lloyd, the availability of treatment is very patchy around the country. “Because of the severe attachment problems often seen with DID, long-term psychotherapy is what makes a difference. Unfortunately the typical NHS model of very limited therapy isn’t helpful.”

Other professionals feel that treating DID is just too expensive. Aquarone and Lloyd both disagree. “Some people with the condition receive up to six inaccurate diagnoses over several years and can be revolving door patients who are self-harming, abusing drugs and suicidal. Treating these symptoms is more costly than the two years of specially adapted psychotherapy that can make a real difference.”

Lloyd and Aquarone regularly give talks and train other professionals on the diagnosis and treatment of DID.

“I hope that like with autism and ADHD, which were hard to get treatment for until fairly recently, DID will soon be well recognised so that people can get appropriate treatment,” says Lloyd. ■

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For more information on dissociative disorders and DID, Mind’s website has a booklet called ‘Understanding Dissociative Disorders’. This can be bought or downloaded from www.mind.org.uk

First Person Plural is producing a DVD featuring three DID survivors and three professionals – available in spring/early summer. For more information visit www.firstpersonplural.org.uk

ESTD can be located on www.estd.org



Melanie’s story

Melanie Goodwin, 59, is the chairperson and a trainer at First Person Plural, a UK survivor-led organisation for disassociation survivors of abuse and trauma. Melanie led an outwardly normal life until age 40 when the symptoms of DID were triggered by memories leaking through.

“I was sexually abused as a baby right up until the age of 16. But until I was 40, I had no idea it had happened. Until then, my life seemed relatively normal. I had friends, went to school and played like a normal child.

“I was lucky to marry a kind and gentle man. We have four lovely children – now grown up.

“When I was 40, my sister tragically died in a car accident. One of my abusers had said he would badly hurt my sister if I ever told anyone about the abuse. Now that she was dead, memories filtered into my consciousness.

“I had no idea where these terrible flashbacks were coming from. I was in severe distress, felt suicidal and slept only a couple of hours a night. Because different personalities were taking over at various times, I had memory losses, behaved out of character and was very erratic. I tried to cover it up and the mental suffering was tremendous.

“I saw a private therapist for a while who wasn’t trained in disassociation. After a couple of years, I came across a book on DID and diagnosed myself.

“Eventually, I found another private therapist who works with disassociation and started seeing him instead. I was lucky as some of the cost of seeing both therapists was subsidised through my GP.

“The current therapy, which has gone on for 13 years has transformed my life for the better. However, I feel angry thinking about all the other people with this awful condition who aren’t getting the right help.”