‘Doctors misdiagnosed me with a personality disorder. The stigma nearly ruined my life’

When Jess Matthews was asked by medics to identify her own mental health condition, it resulted in years of trauma and prejudice

Jess Matthews says she was labelled ‘attention-seeking and manipulative’ by doctors when she sought help for suicidal ideation Credit: Jay Williams

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Jess Matthews was just 21 when she was handed a booklet of psychiatric conditions by a doctor and asked to choose her own diagnosis. She was bright

and hardworking, about to graduate with a degree in nursing from a Welsh university, but she was also experiencing thoughts of suicide – as do almost a third of people aged under 24, from time to time.

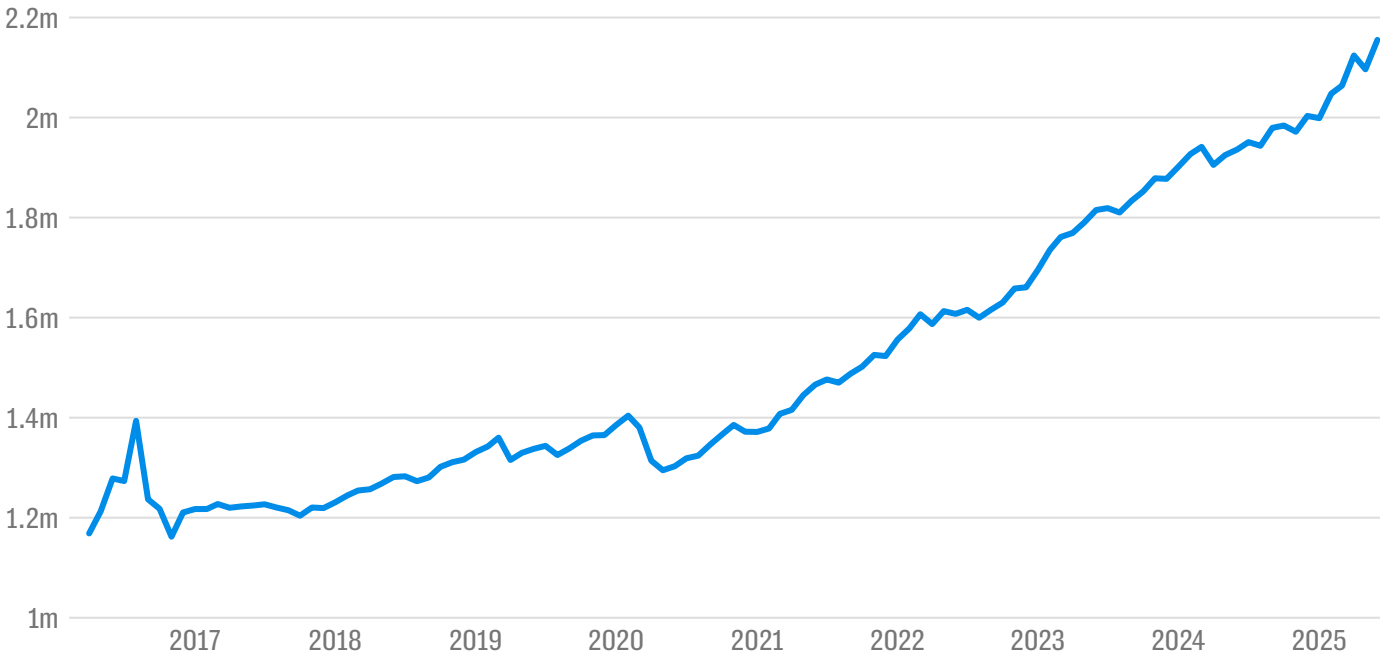
Thanks to her studies, she knew that her ill mental health required urgent help, so she went to hospital and was assigned to a crisis management team. That was when she was handed the list of conditions, printed by the mental health charity Mind. There was just one label that stood out to her in the array of different acronyms and disorders with long names.

"Borderline personality disorder (BPD) was the one that I related to out of them all, though I'd never heard of it before," says Matthews, now 29. "I went back the next day and told them that I had experienced some of the symptoms, like feeling hopeless and not knowing who I was. They said, 'Well, that's what you've got'."

Not a single doctor "took the time to assess me properly", says Matthews. "I told my original mental health team that I didn't relate to all of the symptoms. The response I always had for the next seven years was, well, that's what BPD patients would say, that they don't feel they have it. I was a 21-year-old female voicing thoughts of self-harm and suicide, so it was easy for me to be put into that box."

More than two million people in England are now in contact with NHS mental health services

Open referrals to secondary mental health services at the end of the month



Source: NHS Digital

What is a personality disorder?

What Matthews did not know at the time was that plenty of psychologists don't believe that BPD – and other personality disorders – should be diagnosed at all. The concept of personality disorder came about in the early 1800s and was used to describe people who, in very Victorian terms, were suffering from "emotional insanity". These days the NHS defines a personality disorder as a condition that changes how someone "thinks, feels, behaves or relates to others", and makes them "very different" from the average person. One in 23 people in Britain have a diagnosable personality disorder, according to the Cassel Hospital Charity Trust.

It was only in 1953 that the label of borderline personality was created, to describe people whose symptoms fell somewhere between psychosis and "neurosis" (what we might think of today as a mixture of anxiety and depression). BPD itself is described as a serious mental illness, characterised by a consistent pattern of intense and unstable relationships and a strong fear of abandonment. It comes with a high risk of self-harm and suicide, which is the cause of death of around 10 percent of people diagnosed with it. Many people diagnosed with BPD struggle with drug or alcohol addictions, or show risky sexual behaviour, and report feeling very emotionally raw. It is sometimes referred to as emotionally unstable personalty disorder.

An estimated 8,000 people are treated by the NHS for suspected BPD every year. But experts still argue over what, exactly, makes someone's personality "disordered", especially when it comes to BPD, which includes symptoms such as an unstable sense of self or quickly changing beliefs – all common to very typical teenagers and young adults.

The label of a personality disorder "can be used to apply to almost anybody when they lose their temper or they're in a lot of emotional distress," says Peter Tyrer, an emeritus professor of community psychiatry at Imperial College, London. "I personally define it as a persistent inability to perform societal roles without generating conflict, combined with a failure of mutual understanding. Put bluntly, people with a personality disorder upset others but do not usually understand why or how."

The stigma against people with BPD

If you've ever heard of BPD before, it might have been in 2022, when the actor Johnny Depp took his ex-wife Amber Heard to court for libel. As an expert witness for Depp, the forensic psychologist Shannon Curry diagnosed Heard with BPD (and a second personality disorder) in open court. Heard displayed "reactive" and "overly dramatic" behaviours that were typical of people with BPD, Curry said. Such a person would be "concerned with image, attention-seeking and prone to externalising blame," or will "make threats using the legal system, threaten to file for a restraining order, claim abuse."

Behind closed doors in the NHS, the same harsh things are sometimes said about people diagnosed with BPD. The truth is that "most people working in mental health do not like working with people who have been diagnosed with a personality disorder," Prof Tyrer believes. "This is a major cause of stigma and professionals in mental health are probably more guilty of creating stigma than any other group."

After her records were stamped with BPD, Matthews was deemed unfit to practice as a nurse and thrown off of her nursing course (her university was aware that she was struggling with her mental health, and had previously been supportive). "I was so devastated that I didn't have the energy to appeal the decision," she says.

Matthews also struggled to get travel insurance, while getting life insurance proved impossible. She continued to suffer with severe depression and, when she presented at hospital again, on the verge of attempting suicide, doctors

refused to see her. “The message was: because you’re borderline, we don’t want to bring you into hospital and give you help, because you’ll rely on it,” she says. “I was told that I was attention-seeking and manipulative when I was in real danger.”

Following the diagnosis, Matthews was deemed unfit to continue her nursing course, and struggled to secure travel and life insurance Credit: Jay Williams

Such stories are common, says Rosie Weatherley, Information Content Manager at Mind. “We’ve heard of people with BPD being denied pain relief if they go to hospital having self-harmed; people being denied access to help for completely unrelated health issues because of what’s on their file,” Weatherley says. “A lot of damage has been done because of these ideas [about people with BPD], which many professionals don’t believe were ever scientifically valid in the first place.”

What causes BPD?

More than three quarters of people diagnosed with BPD are women. The average age of diagnosis is 30, with symptoms believed to start at around age 12 in both men and women. However, women aged between 18 and 34 are seven times more likely to be diagnosed with BPD compared with men in the same age bracket.

Some studies show that as many as 90 percent of those with BPD have a history of childhood trauma. “Environments don’t always meet people’s

needs, and people experience trauma in different ways," Matthews says. "I always found it quite difficult to accept that I may have experienced trauma. I didn't necessarily fit that standard version of trauma that people talk about or think about. But I would say that my experiences in hospital after my diagnosis were definitely traumatic, too, and did make my symptoms worse."

Weatherley believes the reason that BPD has been disproportionately diagnosed in young women is because they are more likely to have experienced some kinds of trauma, such as domestic violence or sexual abuse. "People who might be labelled as having BPD are often reacting to difficult life experiences, rather than having a problem with their personality, which is quite a cruel way to frame it," says Weatherley.

Such experiences "seem especially likely to cause the symptoms related to BPD," agrees Prof Tyrer, though he believes there is more to the issue. "Women who meet the criteria to be diagnosed with a personality disorder are less likely to be happy with the way that they are, and to seek treatment," he says. Men are more likely to be "treatment rejecting". People diagnosed with BPD in particular "are classically the treatment-seeking type" and may desperately want to change to avoid hurting themselves or others.

How BPD is treated

The most effective treatment for BPD is a form of talking therapy called dialectical behaviour therapy. It can be used in group settings, or one-to-one, and is meant to help people diagnosed with BPD to manage their emotions and impulses and have healthier relationships with others.

DBT is offered on the NHS, but access to it is patchy. In 2015, shortly before Matthews was diagnosed, little over half of people with a diagnosed personality disorder had access to specialist services. "One of the reasons that it was easy to fob me off with this diagnosis was that the therapy was only offered by one health board in Wales, where I live," says Matthews. "I had to wait a long time to access it, and I wasn't offered any other kind of therapy in the meantime." Many people with BPD are prescribed both antidepressant and antipsychotic drugs, as Matthews was (she did not find them helpful, and was not informed of the side-effects of either).

Personality disorders have always been treated as conditions for life, which can be managed rather than cured. "It's the person's environment that needs to be changed carefully," by avoiding lines of work that trigger symptoms, or

possibly moving to a calmer, more predictable place to live, says Prof Tyrer. “Personality disorder can only be manifested by interaction with others. If the interaction with others can be changed so that more harmonious relationships could develop, then the personality disorder will disappear.”

At the start of this year, Matthews had her diagnosis officially changed to complex post-traumatic stress disorder (cPTSD) Credit: Jay Williams

Should the label be scrapped?

At the start of this year, Matthews had her diagnosis officially changed to complex post-traumatic stress disorder (cPTSD). In 2018, cPTSD was added as an official diagnosis to the ICD-11, the manual which is used to diagnose mental health conditions in Britain. Since then “many people with BPD have had their diagnoses changed to cPTSD, in recognition of the fact that they’re responding to trauma,” says Weatherley. Others have instead been diagnosed with autism or other conditions. Official diagnosis guidelines have also been updated to refer to people as having either mild, moderate or severe personality disorders, with “borderline traits” (or other features) -- though in practice, diagnoses of BPD persist.

It was when Matthews saw a consultant who was new to her hospital, last year, that her BPD diagnosis was reviewed. “He went through my notes and agreed that the diagnosis I received and the way in which I received it was wrong,” she says. After a number of sessions with her new consultant, “we came to the

mutual conclusion that cPTSD was a better fit for my experiences," she says. "It wasn't that he just had the last word. I was finally listened to. It was very refreshing."

Last year more than 1,300 doctors signed a letter to Victoria Atkins, then the Health Secretary, demanding that BPD be abandoned entirely as a diagnosis. "It is misleading, stigmatising and masks the nature of the problem it is supposed to address," the letter read.

Matthews agrees that it might be time to overhaul the diagnosis, but believes that it can also be a helpful label for people with similar difficulties to her, to explain how they feel. "I am an advocate for taking ownership of your behaviour and finding a word or diagnosis or label that fits you and helps you understand the world, but I think professionals can be very quick to label people without understanding their experiences," says Matthews.

"I have stable relationships, and a good job, which I was told I'd never have. I'm healthy and happy, with normal ups and downs." At the time of her diagnosis, "I was a young woman who was having a difficult time with my mental health. I know now that there was never anything wrong with who I am."

How to get help | Do you need someone to talk to?

The following organisations offer free and confidential support over the phone:

Samaritans - 116 123. Round the clock support, every day of the year | samaritans.org
Mind - 0300 123 3393, 9am - 6pm, Mon - Fri (except Bank Holidays). Advises on a range of mental health issues | mind.org.uk
Young Minds - 0808 802 5544, 9.30am - 4pm, Mon - Fri. Supports parents and carers worried about a child's welfare | youngminds.org.uk
The Mix - 0808 808 4994, 2pm - 11pm, Mon - Sun. Helpline for people under the age of 25 | themix.org.uk

For more helplines and mental health resources, see the NHS on stress, anxiety and depression