An illness in the shadows: life with borderline personality disorder

BPD is one of the mental illnesses we still know least about, but now there is hope of a treatment

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It was while she was doing psychology A-level that Alison Graham came across Borderline Personality Disorder (BPD) for the first time.

"Two of my friends said: 'Not to be mean, but this does sound like you ...'," Graham remembers. The teenager from Peterborough had suffered a particularly volatile adolescence: mood swings, rage, suicidal thoughts. She'd been cutting herself since she was 12 or 13. And now here was her condition – in a textbook.

"I felt like I didn't have a chance, that I was the perfect storm for this illness."

Problems had started early. Graham says she was the child of an unhappy marriage, with a father who drank and a mother who suffered from depression. She was 12 when her father left, 13 when the divorce came through. She started self-harming, flying into temper tantrums, blowing up friendships on the slightest pretext. Doctors said it was exam stress.

She did very well in her GSCEs, but became more unstable in sixth form, and flunked her A-levels. Her first suicide attempt came at 18. "I got quite a lot of money for my 18th birthday and basically I drank it," she says. On New Year's Eve in 2018 she ended up in A&E. "I said I was going to jump off a building, so someone called an ambulance."

And then, after several years of trying to live with her condition, and trying to find out what that condition was, a doctor confirmed her suspicions. "She turned to me and said 'have you ever heard of BPD?" She was sent for an assessment and diagnosed in March last year.

The mental health issues that remain in the shadows

Attitudes towards many types of mental illnesses have been genuinely transformed in the developed world over the past generation, as people have opened up about their depression and anxiety, encouraged by the honesty of candid celebrities.

But in the shadows are a cluster of conditions that continue to face deep discrimination: schizophrenia, psychosis, bipolar disorder, and BPD. BPD in particular is one of the lesser-known mental illnesses, but all the same it is one of the hardest to reckon with. (Some people dislike the term so much they prefer to refer to emotionally unstable personality disorder.)

Those affected can experience dizzying ups and downs, along with paranoia, impulsiveness, obsession, fury, catastrophic black-and-white thinking, identity crisis and an inability to self-soothe. Promiscuity, recklessness, self-sabotage, substance abuse, broken relationships and homelessness are all part of the territory.

Some estimates put prevalence at up to 2% of the population, though most metrics relating to the extent of mental illnesses are approximate. An estimated one in 10 people with BPD take their own lives – and a far larger cohort will try to do so.

Some doctors believe the number of people with the condition may be increasing. Dr Ajeng Puspitasari, a psychologist at the Mayo Clinic in Minnesota, says she is treating more patients with BPD than she was two or three years ago.

"Young adulthood is typically where symptoms may emerge," she says. "There are very common symptoms, chronic suicide ideation or attempts. A lot of patients struggle with self-injury, burning, cutting. Many struggle with addiction, substance abuse, frantic efforts to cope with their suffering."

Experts believe the illness stems partly from genetic predisposition (nature) and partly from social and environmental factors (nurture), with a brutal childhood as a particularly common denominator. Katie Walsh believes that for her everything stemmed from being sexually abused by a family member as a child. She reported the abuse but wasn't taken seriously until three years later when the perpetrator did the same to other children. Her later relationships with men, who were often much older, featured physical and emotional abuse; Walsh ended up in prison, self-harming, and struggling just to stay alive.

Mick Finnegan, a 37-year-old Dubliner diagnosed with BPD, also believes the condition was rooted in his childhood. "I was just a kid whose family were all alcoholics and heroin addicts. I was 16 when I started sleeping rough. I got kicked out of the house. I had gone to the police about being raped and sexually abused. But when the police came back, they turned around and said they weren't going to prosecute."

A <u>recent study</u> by the University of Manchester found that people with BPD were 13 times more likely to report childhood abuse than people without mental illness. "The

more severe cases come from people who've suffered from childhood disorders – physical abuse, sexual abuse or abandonment," says Jerold Kreisman, an American psychiatrist who has worked with BPD patients for 30 years and authored books such as "I Hate You Don't Leave Me."

But where other mental health conditions are recognised and supported, the very nature of BPD means it can be challenging to help with. It's hard for friends and family, who can struggle to deal with the rapid ups and downs and mood changes, the fluctuations in confidence and self-image. "I've hurt a lot of people and I feel terrible about it. I don't want to be this way," says Graham. "I have to keep a secret, because people say don't be friends with someone with BPD because they are manipulative attention-seekers. They might not want to be my friend or date me, which hurts because I'm trying to get better. It's not my fault."

The condition is also incredibly challenging for medical services, police and emergency services, resulting in confrontation and mutual distrust. Graham was sectioned recently for trespassing on train tracks. "I'm 5ft tall, but it took three police officers to restrain me," she says. "I feel I get treated as if I'm an attention-seeker and they don't seem to take it seriously."

But there is a treatment that, though not widely available, is showing signs of promise. Dialectical behavioural therapy (DBT) is a long term programme of individual and group therapies in which the core ideas are acceptance of life as it is, not as it is supposed to be. Individuals learn new techniques to help tolerate distress, to replace catastrophic coping mechanisms such as self-harm, alcohol, drugs and rage. The "dialectic" in the name has echoes of the antithetical ideas proposed in ancient wisdoms and more modern faith-based teachings, such as the Christian Serenity Prayer, "to accept the things I cannot change; courage to change the things I can ..."

At St Andrew's Healthcare in Northampton – one of <u>some 450 facilities offering DBT</u> in the UK – women patients take part in group therapy, one-to-one sessions, and coaching. There is a weekly community meeting where patients and staff can raise issues, as well as sessions on mindfulness and other activities.

Patients often take medication alongside the therapy, but medication alone can never be the answer, says Dr Pete McAllister, a psychiatrist on the ward, who says that most women who engage in at least a year of DBT can be discharged. The average length of stay is 18 months.

"The treatment works really well but it's a bit like joining the gym," says McAllister. "It's not just joining that will help you, it's doing the exercises and doing them regularly. Coming into a DBT unit is not the cure, it's the hard work you do while you're here."

The great succour for anyone with BPD is that recovery is the rule, not the exception. After intensive rounds of DBT, Walsh hasn't self-harmed in two years. Now in her mid 30s, she is calm, collected and able to speak eloquently about her mental health struggles. Walsh talks about how she sees life in 10 years' time. Her aim is to travel

around the country speaking about BPD, sharing her story and holding workshops to raise awareness and to reach out to others who may be going through the same. "A lot of this goes on outside of services," she says. "It can be lonely and I want people to not feel so alone."

Finnegan says that recovery might not be the right word. "You don't just stop feeling the way you feel. You don't stop having those flashbacks. They don't go away but you learn how to cope with them. You develop coping mechanisms."

Graham has been holding down a job as a sales assistant for the past few months and is looking forward to getting a place on a DBT programme, now that she has been diagnosed. She **sounds** remarkably philosophical and sanguine about her case, and her prospects. But then that is the maddening thing about BPD. "One moment I am crying my eyes out, the next I'm feeling fine."