

Talking About BPD

A Stigma-Free Guide to Living
a Calmer, Happier Life with
Borderline Personality Disorder

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The Stigma Surrounding BPD

Sometimes I think the hardest part of having BPD is not the intense emotions or the fear of abandonment, but how ashamed the stigma has made me feel. In the iconic book *Stigma: Notes on the Management of Spoiled Identity*, Erving Goffman writes that stigma is an ‘attribute that is deeply discrediting’ (1963, p.3). In other words, stigma is a thing that damages a person’s reputation or disgraces them. More recent research describes stigma as a form of power that can be used to keep people with mental health problems ‘down, in or away’ (Link and Phelan 2014, p.1). Put simply, stigma forces people with mental health problems to hide, stay silent or keep away. I can’t help but think of how opportunities for connection, enjoyment and fulfilment have been missed as a result.

Stigmatized people can be discriminated against in person-to-person interactions via prejudices (negative attitudes not based on facts) and stereotyping. They can also be discriminated against by the structures and institutions in society that make policies and hold the power, such as

law, healthcare, education or the police. Examples include not being offered a job because of a mental health condition, being denied healthcare or being treated inhumanely by law enforcement. According to the Mental Health Foundation (2015), of all people with long-term health conditions or disabilities, people with a mental health condition face the most problems finding work, decent housing and being socially included. If you have experienced stigma and discrimination, you are not alone. Let me now share some of my personal experiences and how they affected me.

My encounters with stigma

“It’s like Dr Jekyll and Mr Hyde”

In my last few months of university, after a long stint in the library preparing for my final exams, I went to grab a much-needed coffee with a friend. Only a couple of weeks earlier I had been diagnosed with BPD and I decided I would tell her about it. ‘Why should I have to stay silent about something that means so much to me?’ I thought.

Deciding to tell some of my friends about my diagnosis hadn’t been an easy decision to make. After weighing up the pros and cons of keeping it secret, I concluded that I felt more comfortable sharing my diagnosis than holding it back. Furthermore, weren’t the anti-stigma campaigns telling me that it was ‘good to talk’, and that mental health problems didn’t have to be hidden?

“So, you know I’ve been seeing doctors and having counselling for mental health problems,” I said as casually as I could. My skin felt sticky all over. I hoped I wouldn’t vomit across the table. “Well, a few weeks ago I had an assessment.

Turns out I don't have depression and anxiety; I have this other condition called 'borderline personality disorder'."

I had said it. Those three scary words: Borderline. Personality. Disorder.

"Oh yeah, I know BPD," she replied, "It's like Dr Jekyll and Mr Hyde."

Let me pause here. If you don't know *The Strange Case of Dr Jekyll and Mr Hyde* (Stevenson 1886/2002), allow me to explain. It's a book about a scientist, Dr Jekyll, who turns himself into a man called Mr Hyde. As Dr Jekyll, he is respectable and decent, but as Mr Hyde, he is violent and murderous. The kinds of violent acts this person commits as Mr Hyde include trampling on a little girl, beating people and murder.

As quickly as I could, I made an excuse to leave and rushed back to my student room. When my head finally lifted off my soggy pillow, I thought I would never again feel safe enough to tell people about my diagnosis. Dr Jekyll and Mr Hyde...is that how people would see me now? Ever the bookworm, I decided to do my own research. I went to a legal deposit library (a library holding a copy of every book published in the UK) and I summoned the small number of books with 'borderline personality disorder' in their title that had been published in the UK since 2000. Every page I turned unearthed further layers of stigma. Chapter after chapter told me that people with this diagnosis create havoc in romantic relationships, stir up conflict at work and are reckless parents. I read that they self-harm as manipulation and talk about suicide as a 'threat'.

I hoped the internet would offer a different picture of BPD. It didn't. There was an infinite scroll of YouTube videos

with titles like ‘[...]The Impossible Connection: Loving Someone w/ Borderline Personality Disorder [...]’ (Rosenberg 2014), ‘Borderlines Will Cause Devastation to Your Sanity and Self-Esteem’ (Surviving BPD Relationship Break Up 2020) and ‘Shutting Down Your Borderline Ex: Chainsaw Style’ (Elam 2016). One video even had a picture of a zombie to depict someone with BPD. On the one hand, I knew these descriptions were inaccurate, unfair and often misogynistic. I had only ever had honest intentions and tried to care for others, hadn’t I? On the other hand, I felt terrified. Was I sucking the life out of my family and friends? Was I a terrible, horrible person? At times, this internal conflict felt almost unbearable.

“Leave, or we will call the police”

The stigma I encountered wasn’t only confined to books and the internet; it translated seamlessly into my interactions with mental health services. Some of the cruellest treatment I have ever been subjected to was in A&E when I was a young adult. A doctor had sent me to the crisis team there because I was suicidal and didn’t know how to keep myself safe. If 10 is the most distressed a person can be and 1 is the least distressed, I was a solid 9½.

Two mental health nurses escorted me along corridors of people with open wounds, broken bones and suspected blood poisoning. The destination was a cramped, windowless room where I was questioned. The nurses interrogated me as though I had been found with bloodied hands at a crime scene. Why was I suicidal? Why couldn’t I be happy? Why didn’t a “clever girl” like me know how to cope?

They acted as though in 10 minutes they knew everything

about me and my life. I was suffering from low self-esteem, apparently. They would add me to a seven-week waiting list for a self-esteem workshop. Shaking and sweating with fear, I explained that a self-esteem workshop in seven weeks' time wasn't the help I needed right now. I told them that my doctor had sent me to A&E because I was suicidal *right now* and needed help *now*. The nurses told me that I was "refusing the help being offered" and so needed to leave. I expressed again that I was suicidal, felt really frightened and didn't know how to manage. They had no reply except that I was not cooperating and needed to leave.

Anyone who has been suicidal, asked for help and been turned away will know this agony. It flung me to the floor, where I landed with a smack and writhed in terror. I was howling at the nurses' feet, begging for help. Any morsel of compassion they had thrown at my feet, I would have licked off the floor like a stray dog and dragged myself home. Instead, they told me that my yelling was "frightening the patients" and if I didn't leave immediately, they would call the police to remove me.

I got off the floor and walked out into the darkness.

Frightening the patients – But what about me? Wasn't I a patient too? What about how vulnerable I felt? My safety? My feelings? They did not matter. I did not matter.

It has taken nearly a decade to recover from this trauma. Three years passed and I had moved to another city before I dared ask a professional for help again.

"The nicely dressed lady"

I have been misunderstood by people who were supposed to

understand more times than I can remember. One psychiatrist used a hand gesture indicating wrist cutting when she asked whether I self-harm, and called out “Don’t do anything silly” as I left her consulting room. On another occasion, a mental health nurse told me that I “shouldn’t” feel suicidal because I have a loving family, friends, a job and “beauty”. “You have it all, so don’t waste your time feeling like this.” Wow. If only emotional distress were so simple! If only the love of my family, partner and friends, my fulfilling career, my degree certificate and my shiny hair made me immune to emotional distress!

My self-awareness, intelligence and how ‘put together’ I am have been used as excuses for why I don’t need help. At the same time, I have been deemed as too difficult, risky or challenging to support. Sometimes I have felt that as a person with BPD I cannot win. Why have I spent hours planning my clothes and make-up for an appointment with a new psychiatrist? Will blusher and a bright dress make me look too ‘put together’ to be offered help? Sometimes I have felt like wearing something a bit dirty, just so the report doesn’t state ‘The young lady presented with a neat appearance and arrived well dressed in a floral skirt.’ I know appearance can be an indicator of distress for some people, but I look the same no matter how I feel. My colourful necklace is just my colourful necklace. I would prefer it if professionals stopped using my clothes and make-up to make clinical judgements. Oh, and whilst I’m on the topic, telling me I’m “too nice to have BPD” is not a compliment.

Stigma and privilege

I am a disabled woman living with arguably one of the most stigmatized mental health conditions. I also have multiple

privileges and forms of power as a result of being white, middle class, straight, cis-gender and able-bodied. These multiple privileges and forms of power have given me protection, status and agency as a person with BPD and in my life as a whole. In other words, it is very likely that I experience far lower levels of stigma and discrimination than people with BPD who don't benefit from the privileges and power that undeniably benefit me.

Let me illustrate this point. In their briefing paper 'The Impact of Racism on Mental Health', the Synergi Collaborative Centre states that 'ethnic minority people, when compared to White British people, are more likely to report adverse, harsh or distressing mental health experiences and poorer outcomes when in contact with mental health services' (Bhui *et al.* 2018). In 'On the Realities of Being a Black Woman with Borderline Personality Disorder', Christine Pungong describes being 'gaslighted, patronised, ignored, or just completely forgotten about' by the mental health system (2017, p.116). She asks why all people with BPD are treated as 'undeserving of care', and explains that 'being a black woman adds an intense extra dimension to that' (2017, p.117).

Stonewall's *LGBT in Britain - Health* report highlights the inequalities that LGBTQ+ people face in health services, including mental health services. Participants in the report describe having been told by professionals that their sexuality or their gender expression are to blame for their mental health problems (Bachmann and Gooch 2018). According to research from the Scottish Transgender Alliance, 63 per cent of trans people had experienced a negative interaction such as being belittled or ridiculed for being trans within mental health services (McNeil *et al.* 2012).

When researching this book, I found very few studies on how BPD stigma varies depending on protected characteristics such as race, gender, religion, sexuality, disability or socioeconomic status. This speaks volumes in itself. Whilst much more needs to be done to counter the stigma that hurts people with BPD, it is vital that these efforts do not disproportionately benefit the privileged groups that wield the most power in society. Attempts to reduce mental health stigma must urgently – without fail – address the intersections of race, gender, class, sexuality, disability and socioeconomic status.

Examining the stereotypes

I wanted to share my view on some of the most common stereotypes about people with BPD.

Stereotype #1: People with BPD are attention seekers

As discussed in Chapter 1, people with BPD tend to feel emotions very intensely – sadness can be experienced as crushing despair, and happiness can be an overwhelming feeling of joy. When a person with BPD is panicking or crying, it's not because they are being dramatic; it's because they are genuinely distressed and doing what they can to cope with those feelings.

Referring to someone in emotional distress as an attention seeker fails to see a person in pain and acknowledge their attempt to cope. Behind the thoughts, emotions and behaviour of someone in distress is often a strong need for safety, connection and comfort. Everyone deserves to be listened to, respected and taken seriously.

Stereotype #2: People with BPD are manipulative

Unfortunately, people with BPD often have their behaviour mislabelled as ‘manipulative’. As manipulation is the deliberate attempt to control someone’s behaviour using dishonest tactics, this judgement is rarely accurate about people with BPD. In my experience, when people with BPD want something from someone (time, support, to meet up), they ask upfront. People who are being manipulative usually conceal their attempts to control others and pretend to have honourable intentions.

Let’s look back at my story of being in A&E from earlier in this chapter. It would be easy for my behaviour to be labelled as manipulative: “She can threaten suicide and scream like a baby all she likes, but I won’t give her what she wants.” Yet, there was nothing manipulative about my behaviour because I was neither trying to use underhand tactics nor conceal my true intentions. Even if I had wanted to craft a cunning plan, I wouldn’t have had the thinking power when I was so distressed. I was suicidal and I asked for help. Asking for something is not being manipulative.

“BUT I AM MANIPULATIVE...”

Whenever I tweet that people with BPD are not manipulative, several people with the diagnosis reply that they are. Although everyone is free to describe their behaviour in their own words, I wonder if calling yourself manipulative is a result of being stereotyped and believing it to be true. Of course, there are people with this condition who use manipulation, but this is not a

characteristic of BPD. Any distress-related behaviour described as manipulative needs to be renamed as a matter of urgency, especially when this judgement is cast by a mental health professional. If you have been described as manipulative when you were in pain, please know that you are not.

Stereotype #3: People with BPD will never feel better

When BPD was added to the DSM-III in 1980, there was little evidence on how the lives of people with this diagnosis tended to progress. However, a number of long-term studies carried out over 20 years or more found that most people with BPD ‘improve with time’ and that ‘their prognosis is often better than expected’ (Biskin 2015, p.305/p.303). Research suggests that difficulties around self-harm and suicidality tend to improve the most quickly, whereas interpersonal symptoms such as fear of abandonment and rejection may take longer to resolve (Zanarini *et al.* 2007).

When I was first diagnosed, I thought that I would be acting impulsively on painful emotions forever. I never dreamed that my life would be as calm and happy as it is today. It would have given me some relief when I was going through the hardest times with my BPD to know that it wouldn’t be that painful forever. I hope that reading this reminds you that things can get better.

Stereotype #4: People with BPD are ‘difficult patients’

In 2016, I phoned an organization that matches individuals to private therapists. I summarized my difficulties to the staff

member, she told me the fee, and said she would find out which therapists were available near me. Just before the call ended, she asked me if I had a diagnosis, so I told her that I had been diagnosed with borderline personality disorder. The tone of the conversation changed. As I had BPD, I would have to see one of their senior therapists whose rate was double that of the standard-rate therapists. I know that BPD is a very serious mental health condition and that there is a shortage of professionals who work with people with personality disorders. However, at the moment of disclosing my diagnosis, therapy suddenly went from affordable to unaffordable. The scope of my difficulties had not changed, only the name I had given. I had been branded a 'difficult patient' not because of my actual difficulties, but because of my diagnosis. I felt crushed.

There are a number of reasons why some mental health professionals may be unable to work with people with personality disorders, such as a lack of dedicated training in how to support people with personality disorders, not having the skills or enough supervision. Research points out 'patients diagnosed with borderline personality disorder can raise anxiety in health professionals' (Warrender 2015, p.623). I can't help but wonder how much of this anxiety relates to the 'challenge' that people with BPD pose and how much relates to the perceptions of this patient group. I noted in the Preface that a 2006 study on so-called 'difficult patients' in mental healthcare found patients with a diagnosis of BPD 'were judged more negatively by staff than patients with other diagnoses, even when their behaviour was the same'. Similarly, when asked about the characteristics of 'difficult patients', psychiatrists mentioned 'borderline personality disorder' up

to four times more often than any other diagnosis (Koekkoek *et al.* 2006). Similarly, Woollaston and Hixenbaugh state that patients with BPD are perceived by nurses as ‘a powerful, dangerous, unrelenting force that leaves a trail of destruction in its wake’ (2008, p.703).

If you work in health or social care, then you will probably have heard someone being described as ‘refusing to engage’. It angers me when I hear people being described using these words because it usually signifies a service that is not meeting someone’s needs rather than a person who is deliberately being unresponsive. Instead of judging people with BPD as ‘difficult patients’, services need to ask themselves whether it is they, in fact, who are the ones making things difficult, and if they are offering people with BPD the support they need and deserve.

Stereotype #5: People with BPD are too ‘damaged’ to help others

There is still a myth that people with mental health conditions are too ‘damaged’ to be in helping roles such as doctors, nurses, carers, psychologists or teachers. People who have experienced, or still experience, emotional pain can – and frequently do – help others. A notable example is Dr Marsha M. Linehan, who developed DBT, the first evidence-based treatment for people with BPD. In a *New York Times* article, Dr Linehan shared that she spent over two years in a psychiatric facility as a young woman. She explains that she developed the therapy she needed for many years, but never had: ‘I was in hell. And I made a vow: when I get out, I’m going to come back and get others out of here’ (quoted in Carey 2011).

In the past, I struggled to reconcile my desire to help others with having a BPD diagnosis. As I mentioned in the Preface, I'm a special education teacher who has worked in both mainstream and special schools. Throughout my career, I have received nothing but praise from staff and families in relation to my work. I am a warm-hearted, empathetic person who is a caring friend, partner and family member. Yet I have worried (and still worry sometimes) that people will judge me as incapable or unreliable, even when there is no evidence to suggest this. I guess that this is stigma at its worst, and one of the reasons why I am writing this book. I hope more people can see that it is possible both to have BPD and to be a caring and responsible individual.

Stereotype #6: People with BPD are incapable of having happy relationships

It breaks my heart when people with BPD want happy, fulfilling relationships but believe that this is impossible due to their diagnosis. As you may know, there is a prejudice that people with BPD are too fragile, dramatic, needy, volatile and, in short, too much like hard work to have happy relationships. This stigma extends into relationships of all types, including family, friends and work, as well as medical or therapeutic relationships. Before I started DBT, I could easily overwhelm friends with my overflowing emotions. Even though I never intended to make my friends feel powerless, worried, exhausted or frustrated, I didn't know how to stop this from happening, which left me feeling ashamed and even more unlovable. Since learning techniques to regulate my emotions, I don't overwhelm people like I used to sometimes. It is such a

relief to feel more able to cope. Yet, looking back at the times loved ones felt overwhelmed by me, I wish I had been able to see through the shame I felt. I wish I had known that I was still kind, lovable, loving and all those things I wanted to be.

From personal experience and speaking with others, it seems that the strongest stigma about BPD and relationships concerns romantic relationships. For many years, I thought that I would only be able to have a happy romantic relationship if I no longer met the criteria for BPD. I believed that nobody could love me because I cried too much, panicked too much, hurt too much, felt too much and even loved too much. Whilst some people feel that they are 'not enough' for others, I always felt that I was 'too much'.

In the months after I met my partner, I was surprised to learn that he had fallen in love with me for the person I am today. In the context of our relationship, crying was a sign of empathy, not fragility. To him, panicking simply meant I was feeling anxious, not that I was being 'needy'. He doesn't see my expressive and affectionate nature as 'over the top', but as evidence of thoughtfulness and generosity. This relationship has completely reframed how I see myself. There is no such thing as being 'too emotional'. I believe it's a question of finding people who respect, understand and celebrate the qualities that make you who you are.

Stereotype #7: BPD only affects women

BPD can affect anyone, regardless of gender. Whilst 'three times as many women as men are diagnosed with borderline personality disorder' (Harvard Health Publishing 2019), some studies suggest that women are possibly more likely

than men to be diagnosed with BPD as a result of clinicians' gender biases (Sansone and Sansone 2011). In other words, professionals may be associating BPD disproportionately with women, rather than more women actually having the condition. Researchers have also argued that the statistics may be misleading due to 'sampling bias', as women are more likely than men to be found in psychiatric services where the studies usually take place (Sansone and Sansone 2011).

Reframing the stereotypes

It has been seven years since I was diagnosed with BPD. In the last few years, I have reframed the stereotypes. I use this list wherever stigma bites to remind myself that I am someone with intense emotions, and not a stereotype.

- ✘ People with BPD are attention seekers and will do anything to get attention.
- ✓ People with BPD often experience intense distress. It's only natural that a person's behaviour will reflect how distressed they feel inside.
- ✘ People with BPD are manipulative. They use dishonest tactics to try to control others.
- ✓ People with BPD are not inherently manipulative. Manipulation involves dishonesty. Therefore, if someone has honest intentions, they are not being manipulative.
- ✘ A person with BPD will always have BPD. They will never feel better.
- ✓ People with BPD can, and do, feel better over time. Accessing treatment can be a struggle, but whilst you are pursuing or waiting for support, there are things

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you can do to help manage your emotions and make life calmer.

- ✘ People with BPD are difficult patients.
- ✓ The phrase 'difficult patient' says more about a service than the patient. It reflects a service's inability to meet a patient's needs rather than anything about the patient. It is a very unprofessional judgement.
- ✘ People with BPD are dangerous.
- ✓ There is no evidence at all to suggest that people with BPD are dangerous. The vast majority of people with BPD are caring people who try hard to avoid hurting others.
- ✘ People with BPD cannot work in helping professions or care for others because they are too damaged.
- ✓ The first effective therapy for people with BPD was designed by Dr Linehan, who had experienced the symptoms of BPD herself. There are many people with BPD who are skilled at looking after others as part of work or family life.
- ✘ People with BPD are incapable of having happy relationships.
- ✓ It is perfectly possible to have BPD and have happy relationships. Many people with this condition enjoy fulfilling relationships and can be great friends, partners, family members and parents.