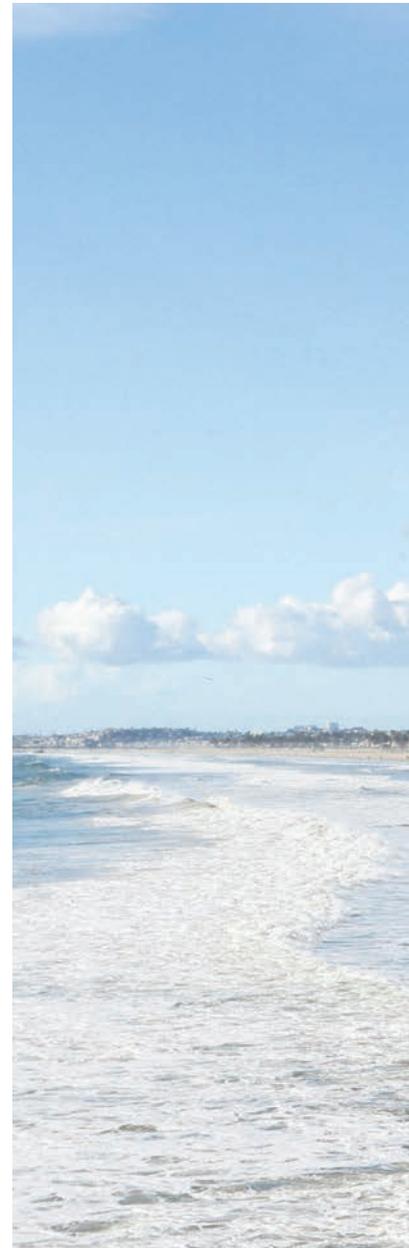


LIFE, interrupted

Hollywood's interpretation of a mental health diagnosis describing developmental arrest and trauma fuel misconceptions that may make recovery more difficult. While it's often maligned as a red flag, borderline personality disorder (BPD) requires reparative interpersonal experiences that build trust in the world.

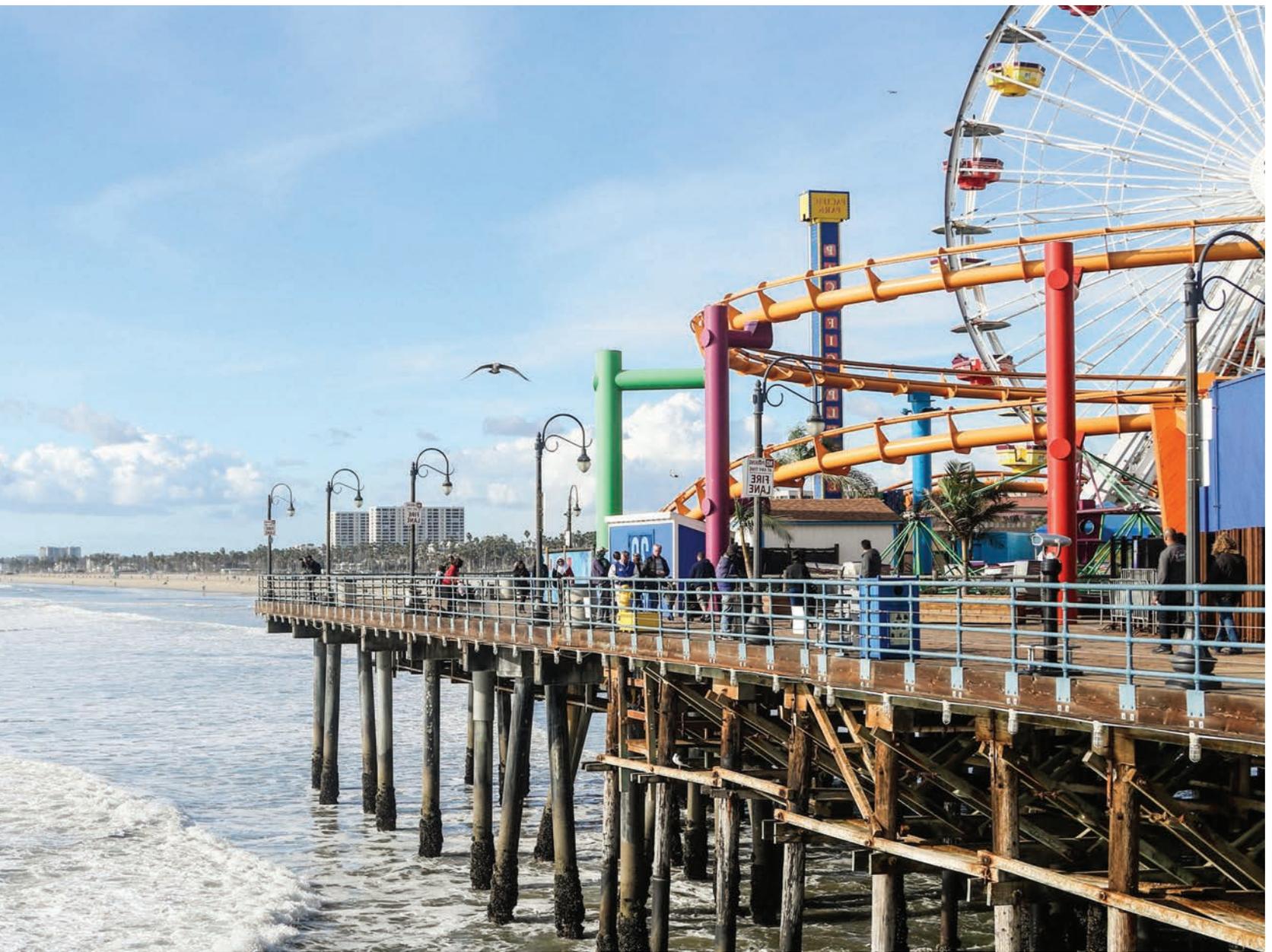


MAHLIE JEWELL, 35

Consumer advocate (mental health, brain injury, drugs and alcohol), not-for-profit brand and campaign designer, SANE Australia Speaker

DIAGNOSIS: Borderline personality disorder (BPD), complex post-traumatic stress disorder (C-PTSD), panic disorder, brain injury (acquired and traumatic)





I first experienced suicidal thoughts when I was seven years old and began self-harming at age 13. At 16, I was misdiagnosed with bipolar disorder and was an involuntary inpatient for six months, a stay which resulted in further trauma.

For two years after I was discharged, my drug and alcohol use became severe and, as a result, I ended up being forcibly detoxed from hard drugs. This led to a spike in mental ill-health, self-harming behaviour and three suicide attempts in one year.

From age 22 to 26, I received no treatment whatsoever, by choice. I avoided all services before my relationship broke down and I attempted suicide again. This attempt triggered a referral to the Cade Clinic, where I was diagnosed with BPD at age 26. My partner

returned and we accessed specialised therapy in Victoria, the only state it was available.

When I came back to New South Wales I began dialectical behaviour therapy (DBT) with a private specially trained psychologist. My partner left again and my self-harm was the worst it's ever been. I attempted suicide four times that year, entered the Psychiatric Emergency Care Centre unit five times and was finally referred to the DBT group outpatient program at Prince of Wales. They had a six-month waiting list, but I had become chronically, acutely suicidal and so was prioritised.

This program improved and minimised my self-harm and with the support of my private psychiatrist, I was slowly learning to control my behaviours. I was doing well. My

partner then returned and found it stressful because I had changed dramatically and my behaviour and actions were no longer what my partner knew. I attempted suicide again.

At age 29, I suffered a stroke. I was admitted to the neurology ward where I spent almost one month before being discharged back home with in-house occupational therapy support and an outpatient nurse. My partner became my primary carer as I had to learn to talk, walk and function again. One month later, an MRI revealed three undiagnosed brain injuries. One frontal lobe fracture (from childhood), one dissected artery (from head trauma as an adolescent) and one black spot on trigeminal nerve (the stroke).

[IN DEPTH]

I was unable to work, see my private trauma psychiatrist, or participate in the DBT program while recovering from my stroke. It took me three months to get back to work and I developed strong health anxiety, panic disorder and agoraphobia. I didn't go anywhere except work, home and hospital for six months. I went to a trauma specialist and we worked solely on my health anxiety and agoraphobia using exposure therapy. Things started to improve.

Eventually, I went back to the DBT program and Prince of Wales and continued with therapy. My relationship ended, I lost my job (lack of funding) and became homeless, unable to pay Sydney rent on my own. I attempted suicide during this time and self-harmed constantly.

I entered into a previous abusive relationship and my self-harm escalated. My psychologist supported me to leave this relationship a few months later and I was put in transitional housing.

After two years, I completed the DBT program at the Prince of Wales and my self-harming reduced. I spent nine months in acceptance and commitment therapy, narrative therapy and inner child therapy.

At age 32, I had a traumatic experience and attempted suicide once more before I briefly relapsed into alcohol and drug abuse. Afterward, I made a conscious decision to live clean, sober and self-harm free. On my birthday I started a new chapter, free from all harm. My meds were adjusted and stabilised to manage the conflicting brain issues. I moved into short-term housing and my mental health stabilised. I started working as a mental health advocate and worked part-time in domestic violence. I also started studying a bachelor's degree.



At age 33, I went back to full-time work and six months later I suffered a second minor stroke from stress-induced high blood pressure. I left my job and focused on my health, maintaining my sobriety and recovery. I adopted a vegan diet and took a small break from college but continued on. I was doing well.

I moved into permanent disability housing after four years on the priority waiting list. My clinician and I worked on changing the narrative in my mind, rewriting the blueprint and navigating interpersonal relationships. We also did some trauma work when needed. I was well enough to handle this without doing more harm.

I started my own freelance business working to bring progressive design to the not-for-profit and ethical business world.

I now see my psychologist once a fortnight and I have regular contact with my GP. I take medication to treat my brain injuries and mental health and am studying and working freelance. I am three years clean, sober, and self-harm and suicide attempt free.

Who is Mahlie?

I live with borderline personality disorder (BPD) and educate others about the intense trauma and distress many people with BPD experience. My focus is to help the healthcare system change so others won't have to experience the traumatising things I went through.

I've worked with not-for-profit organisations for more than 10 years in areas including homelessness, drug and alcohol abuse, adolescent mental health and domestic violence – all of which I have lived with and experienced. I now provide freelance graphic design services through my own business, Graphics for Good, to not-for-profit and ethical businesses.

How do you describe your diagnosis and what misconceptions do you target?

There is nothing wrong with my personality. I have a great personality. What is confused and maladaptive is my ability to regulate my emotions, self-soothe and react in ways that are socially acceptable. Trauma caused my diagnosis of BPD and the term 'complex post-traumatic stress disorder' more accurately describes my experience.

I don't believe that borderline personality disorder can exist



without a history of trauma. This isn't everyone's belief and is sometimes a controversial view, but this is my experience and the experience of those I know and speak on behalf of. I find it frustrating that we don't talk enough about the impact of trauma.

I also hate that people think we will hurt other people because we self-harm or that we are just seeking attention. People think we shouldn't be allowed to have contact with other BPD consumers because we will encourage each other to self-harm, which is not the case. But this is changing – I just finished working on a program for Project Air [Strategy] to start the first ever peer-led support groups for BPD.

What did you think your symptoms were and how did you then view them?

I've been mentally unwell my whole life, which was normal where I grew up and not something you whined about. I started pulling out my hair when I was two years old, I had my first suicidal thoughts at seven years of age, and started self-harming at 13. I

had a violent temper and a short fuse. My violence meant that others rarely challenged my behaviour and there were no resources in my community to address this, so it wasn't until I was in my mid-20s and moved to different surroundings before my behaviour was challenged. At that time, I found it concerning I was being challenged for being myself.

How was your diagnosis explained to you and how did you respond?

I received a borderline personality diagnosis nine years ago, at 26 years of age. At that time there were no services in New South Wales that dealt with personality disorders so there was no psycho-education available.

I didn't reject my diagnosis – it's something I agreed with and I actually felt relieved. It was helpful to have a name for the symptoms I was experiencing and know that many people were also living with BPD.

It took me many years to come to terms with the idea that my BPD was caused by trauma. I was not comfortable accepting that or seeing myself as a victim. It did not fit in with how I saw myself, my brain blueprint or what I had been told, taught and felt. I saw it as weakness and I was not open to weakness at all.

I have read most things about BPD and believe that there are many things that need to be challenged about it. I continue to go to conferences and question what is being taught to clinicians about BPD. I feel there is information that is incorrect and harmful, simply because we don't have a lot of BPD advocates. My ideal goal is to have consumers in every lecture hall with every psychology student and work with them to truly create the best treatment for BPD.

Did the DSM-V diagnostic criteria fit with your experience?

The only criteria for BPD that I have never met is having identity disturbance issues. This is very unusual, as it's one of the most common criteria for diagnosis. I've always had a strong sense of self and have a dominant personality.

How did those in your life respond to it?

The process of getting diagnosed meant that I had to become more open about the situations I had experienced in the past, many of which I had never voiced before. My partner learnt that I had hidden a lot and I think it allowed her to have more empathy and compassion for me. It was never the illness itself that caused the issues – it was the symptoms, especially the self-harm and explosive moods.

I didn't realise how entrenched the stigma and disdain for BPD was, even within mental health services. I started to notice the diagnosis excluded me from many mainstream services and my self-harm and suicidal ideation was used as an excuse to prevent me from accessing services. I also noticed that I was not truly welcome in the consumer movement. That was shocking, but thankfully that has changed.

The stigma of BPD is very pervasive. Many people do not even reveal their diagnosis because of it. I've had personal experiences with my diagnosis affecting career opportunities and access to services.

What made you seek help – was there an epiphany or turning point?

I knew from a young age that my self-harming behaviour was problematic. The reactions I received from people told me I needed to be shameful and protecting of this behaviour.

I came to realise that my actions were hurting people I loved, but I seemed to be unable to stop the hurtful behaviour, even though I wanted to. This added to my internalised shame, guilt and self-hatred.

I didn't truly commit to addressing my behaviour until I had my first stroke at 29 years old. I nearly died and that changed everything.

I had always believed I would die by suicide. In fact, by the time I had my first stroke, I had attempted suicide 10 times. So it was a shock for my life to have almost ended beyond my control. I realised then how precious life is and how much time I had wasted. My heart, soul and spirit were exhausted from living a life of anger, hatred and blame.

How was your experience with the mental healthcare system?

I have been part of the mental healthcare system for more than 20 years. I've spent hours waiting and being ignored in emergency departments despite having physical health issues that needed to be addressed. I have had wounds that needed stitches become infected because I was not given the physical care that hospitals are required to give. I've been called attention-seeking, dramatic and a narcissist. I've been sent home alone even though I was saying I was actively suicidal. I was misdiagnosed and put on medication that caused me harm. And this continued even after I had made complaints.

What aspect or symptom won't let you forget it?

I'm different to almost every other BPD advocate I have met in that I embrace my diagnosis and don't want to push it away. I am quite proud of my diagnosis and that I have come so far and am doing so well despite being labelled with one of the most hopeless, severe, disabling and undertreated diagnoses in the world.

Instead of forgetting my mental health issues, I want to embrace them like a cancer survivor might embrace their battle and be proud of living well WITH it. My mental health experience reminds me to live life mindfully and be more aware of how I affect the people around me and how I allow them to affect me. There is nothing bad about that.

How does BPD affect your relationships?

My relationship broke down during therapy because I was changing so much. People who experience mental ill-health are either incredibly vulnerable to others with predatory behaviour or drawn to those who need to save others. It means our relationships can become confusing and maladaptive.

These days I clearly see the signs that someone isn't good for me, or that we aren't good for each other. I also see my own behaviour and reactions objectively and monitor my responses to people carefully and mindfully.

Part of my recovery was to step away from people who did not contribute in a positive way to my life or had routinely and repeatedly caused pain and suffering. This is common in recovery patterns for people who experience addiction of any kind.



Which relationships have helped you most and what characteristics do you credit?

Continuity of care has been key. I've been helped by appropriately trained and experienced clinicians who had appropriate boundaries, which may be different to commonly accepted or understood clinician/client boundaries but that make sense in a BPD environment. Having them understand the appropriate way to disengage or transfer care has been key to avoiding abandonment issues being triggered.

I have strong friendships but the most important relationship has been with myself. I have learnt that friends cannot be therapists and to ask them to do that role is dangerous, selfish and disastrous. I have also learnt to advocate for myself when I can and be proactive in my recovery by having things such as wellness plans and advanced directives in my toolkit for when I am unwell, so that even when I feel unable to advocate for myself, my choices are still my own.

What has it taught or given you?

We need to talk about the positive aspects of having BPD, such as being empathetic and compassionate people. The deep kindness and care we have for others and the way we experience emotions and experiences so vividly. The reason I do my consumer advocacy is to show people that we are smart, kind, resilient, empathetic, loving and passionate people who are struggling with trauma. Many of us also have cognitive challenges and our brains have been altered by our experiences.

For more information on borderline personality disorder visit sane.org/bpd

DAY IN THE LIFE...

I don't have a standard or typical day. I hate routine, I hate structure and normality. I live my life to fit the way of being that makes me happiest, strongest and most successful.

I wake up around 10.30am and cuddle my dog, Skylar, while I do stretches for 10 minutes to loosen up my hips, which were fractured when I was younger. I take my morning meds and take Skylar outside and we say hello to the native birds that live in our trees and get some sun. I am always grateful to have woken up in a safe place with my best friend (Skylar) and to be able to walk out to the garden without help. This hasn't always been possible and it's important for me to be thankful for that.

I check my email briefly while drinking peppermint tea to settle my stomach from the nauseous feelings my morning meds give me and see if there is anything urgent I need to respond to for work, which might be a client response or a request to do some consumer advocacy.

Today I had a morning tea at the NSW Mental Health Commission for an art exhibition I was in. The commissioner is new and I had a good connection with the previous one, so it's important for me to be there. The commission has also just supported me to go to the Arts and Health Conference this year and give them feedback on the event.

I called my friend on the drive to the commission just to check in with her. This connection with my friends, who are my chosen family, is important for maintaining healthy relationships and keeping me supported and supporting others, and it's something that I still have to do consciously but is becoming more automatic.

The commission's office is located at an old psychiatric hospital and I have a dark feeling at this place.

At the previous commissioner's request, I am one of their representatives and often called on to contribute to certain things. It's always great to share my thoughts on how the commission is affecting the lives of consumers. I spoke to the commissioner and her communications officer, who I've known well for a while, and posed for a photo.

A few people introduced themselves to me; they know who I am but I didn't recognise them. It always makes me anxious when this happens. I'm fighting against brain injury that has damaged my short-term memory as well as the anxiety and adrenaline of being a presenter. If I can't recall who the person is after a few minutes, I tell them I struggle with memory due to brain injury and let them know that it's not personal.

The event ended quickly, so it was time to do life stuff. I registered my car, swung by my PO box and grabbed lunch on my way home.

I changed into comfortable clothes, put on a load of washing and did dishes. I answer email, check social media and then pack Skylar into the car and go to the park. This time with her is essential to my wellbeing. There were times when getting her outside onto the street, let alone to an off-leash dog park, was impossible because of my mental health. I spent days not leaving my bed let alone my house. I lay in bed struggling to fight against my suicidal thoughts and desperately tried to starve my need to self-harm. Skylar saved my life and I never forget that. Having to be responsible for her pulled me out of many dark places and although she failed her therapy dog exam, she's a therapy animal to me.

Afterward I do some work, making lists of current graphic work projects and the tasks each one needs to have done. It gets to 5pm and I get dressed again, feed Skylar and catch the ferry to the quay, walking to the Art Gallery of NSW, where I met a friend and listened to the participants of an arts disability program who are incredibly inspiring. Both of us are vegan and in recovery, living a straightedge lifestyle, so we left before the wine and cheese were opened and headed to the park across the road to eat vegan muffins before we decide to walk to the quay, catching up on life as we walk and ride a ferry home. We part ways when I get off at the stop before her and I walk home.

Skylar runs in the garden for a few minutes, we cuddle and scratch and I have dinner, of which she eats half, and I start working. I respond to more emails, write a draft speech I'm doing next month at an event, work on the amendments to the resource I've gotten during the day, design a flyer and respond to a few requests for mental health surveys and consultations that have come through from SANE Australia, the BPD Foundation or Being NSW. I'm also listening to the new Lana Del Rey album and talking to my friends in a few different group chats. I often send them screen grabs of what I'm working on and get their feedback. This is an important part of my work/life balance that keeps me well and able to function. Working as a freelancer I often am isolated and work in a silo. I have a Skype session at 10pm with a client in the United States to discuss her book that I'm formatting and, before I know it, it's midnight and my alarm is going off, telling me to take my night meds.

The only part of my day that is strictly routine-driven is my nightly meds. The meds I take (that serve as a dual treatment for my neurology and psychiatry) are dangerous and can easily cause fatal overdose. I have my meds pre-packed and colour coded. I do this practice incredibly mindfully. I mark the date, time, and colour of the section on a chart that lives on my fridge when I take my meds.

Around 2am my meds kick in and I start to feel sleepy. They also give me terrible dry mouth, so I have a cup of ice cubes I periodically suck on. I finish up my work, send the last of my emails for the day that will greet the rest of the world shortly as they wake up and shut down my design programs.

I have a terrible habit of watching TV to wind down before sleep and my therapist hates it. I avoid the news at all costs as I think it has a detrimental effect on my mental health and often makes me feel hopeless and ineffective. I will watch something interesting but not super engaging like a game show (I love learning new information) or re-watch some of my favourite comedies and am normally asleep by 3 or 4am (on a good night). I get about seven hours of sleep and then the next day begins. ■