

# Clinical Toolkit

## Borderline Personality Disorder: Impact on Family and Friends

To better understand the impact of Borderline Personality Disorder on the family unit, we spoke to a mother whose daughter has been living with a diagnosis. Her responses are included below.

### What impact does your daughter's Borderline Personality Disorder have on the family?

"Borderline Personality Disorder puts a family under enormous stress. Often the person with this condition has behaviour that is unpredictable [...], and it can go on for days. The symptoms can be extreme and triggered easily. The family can gain insight and support from advisory groups [...] and family counselling. It's almost impossible to deal with without such support. Families can help ease and calm the loved one and have an important role to play in managing their condition in the home. There is a lot of misinformation out there both online and indeed amongst some psychologists and psychiatrists. It takes a specialist in Borderline Personality Disorder to help navigate this illness and it's not always easy to find the right therapist. It's often about finding a therapist who has a special interest and extra training and the connection they make with the patient, making the person with BPD feel validated, understood and above all not judged."

### What were the positive and negative aspects of your daughter receiving a diagnosis from a family/carer's point of view?

"The positives are that once diagnosed you can seek the correct treatment and find the right therapy, specifically targeting this illness<sup>11</sup>. DBT is not commonly practised by every psychologist and is a very helpful therapy. It's important to find a psychologist who specialises in this [or another recommended] treatment.

Other types of psychological therapies are also available but the average psychologist practising CBT will not be the right one. [BPD] must be treated by someone who knows a lot about this condition. It can get worse very quickly, so to get correct treatment started as soon as possible is crucial. Self-harm can be stopped but only with the correct treatment. Suicide is a real risk.

The negatives are that this is a misunderstood condition which comes with stigmatisation in the community. I cannot emphasise enough how important it is to not judge the patient no matter how difficult their behaviour is. The family also should not be judged."

### Was the diagnosis accepted by your daughter member/you?

"Yes but we also keep an open mind as we are aware that our daughter does not fit the exact picture for the Borderline Personality Disorder diagnosis. She ticks the boxes in terms of criteria but she did not show any real symptoms until she was destabilised in her late teens and early twenties. There is no family history of this as far as we know. I'm sure the treatment she's getting is helping her, so for us, that is the crucial outcome and means we accept the diagnosis. There is a terrible stigma attached to this illness making it hard for friends and extended family to understand and be supportive. The last thing anyone wants is to feel judged and isolated when to a person with BPD isolation and abandonment is so painful, yet the diagnosis can isolate them as their close friends can find their behaviour to be intolerable. Often people will read stories on line of what can happen to someone with Borderline Personality Disorder leading to them being harshly judged. Also there is misinformation about what causes someone to have this condition. In our household we had a critically sick sibling and that may have had a big impact as to why our daughter felt unstable in her adolescent years. Our attention was on our sick son and his life threatening illness and not so much on her day to day needs."

### How does the family help to support your daughter?

"As her mum, I go to a parent-run group that educates family members in a very helpful and useful way. We learn strategies and coping skills as well as a better understanding of the treatment options and what is actually involved in treating BPD. We gain a better understanding of the illness and how to navigate a person with BPD's difficult behaviour before it becomes extreme. Sometimes, as a family, we meet with her psychologist as a group to have things explained to us. Education is vital and necessary both to support the family and that in turns supports the person with BPD."

## What support do families need from GPs and other health care providers when they have a young person in the family with BPD?

“The GP is often the first person to be contacted when someone feels mentally unwell. My daughter presented with terrible anxiety three times. I sat in the waiting room as she went into the appointment and told her GP what she was experiencing. He had known her since she was a baby. She talked about her troubling anxiety and the inability to sleep. He knew our entire family history and he advised her take vitamins. She was asking for anti-anxiety medication by name and that alarmed him and meant this GP did not feel he could help her. In fact, the experience made her feel like it was wrong to ask for the anti-anxiety medication. We changed to a different GP and the new one organised a psychologist referral, but after ten sessions of Cognitive Behavioural Therapy she felt even worse [Note that CBT is not a recommended treatment for BPD]. She was going backwards not forwards. She went back to the new GP who then recommended she try smoking marijuana to calm herself (my daughter had asked him for sleeping tablets as she was not sleeping at all). My daughter did not take his advice, but she did go looking for illegal anti-anxiety medication online and that lead her into a world of drug dealers which was the last thing she needed to know about. She was looking at self-medicating. The worse thing in the world.

“After some research I tried a 3rd GP. It was a well-known, highly regarded clinic and the person we saw ran the clinic. She knew nothing of our family history and did not know my daughter at all. This time, I accompanied her to the appointment and sat quietly beside her while she described in brief her anxiety. The GP immediately arranged a psychiatric referral, as well as a list of different psychiatrists to see as she explained that they all have waiting lists that can be quite long, so if one did not work there were six other names she could try. We [also] left that appointment with a mental health plan and some sedatives.

“My daughter then came back to see this GP again and again, until she could finally get in to see the psychiatrist recommended. She waited some six weeks and while things were initially unstable for her, the GP was able to help by seeing my daughter as often as needed and talking through ways that might help her cope. My daughter initially had a good experience with the recommended psychiatrist but still there was no diagnosis and we found this Dr was often away with no medical back up in her office. My daughter was put on anti-depressants and still she was not getting better so we went back to the new GP for guidance. Finally my daughter put herself into hospital with the GP's referral, and that then lead to the correct diagnosis. To this day she still sees that GP who is always understanding, clear, direct and most importantly remains non-judgemental at all times. She is not at all afraid to answer questions that my daughter may ask and is

happy to be helpful in working out the best way forward at all times. People with BPD can find themselves in terrible situations - both alarming and dangerous, and again this GP rides with that and helps her in all manner of ways and above all has my daughter's trust.”

## Is there any further information, experiences or thoughts you'd like to share that you think would help GPs to engage with carers when treating young people with issues similar to those that your daughter experienced?

“When a young person presents with anxiety to a GP's office, it's usually quite a problem or they would not bother to go. If they are young, they are inexperienced with navigating the health care system and dealing with doctors on their own, so take the anxiety and depression seriously and treat promptly by referring to a specialist.

Connect with the young person to gain their trust. Be non-judgemental at all times. This relationship will need to build over time and they must feel comfortable. Help the family with any medication they may need to get through. In our house, we need Valium [...] in case someone is having a really rough time. We might need one script a year or so but it's definitely useful.

Understand this condition is very painful for the person who has it so they must be legitimately listened to. If they are feeling suicidal it can be a very real threat.

The family is under extreme pressure and probably not able to discuss this with other family members and friends due to stigma. They may need counselling to cope.

It can take a while to find the right therapy and therapist so be involved and available in case something goes wrong and to offer guidance to look for a fresh new approach.

Link in with the treating psychologist and or psychiatrist so communication is flowing between the team.

Be prepared to write scripts if the psychiatrist is away and the patient has been put on medication. Often treatment is expensive and ongoing. Any bulk billing you can do for this patient is helpful, especially if they are a student. Help them navigate the most cost effective options as a mental health plan runs out after ten sessions and there are some other options and plans available that a GP can give advice about. Be hopeful to the person with BPD and the family as therapy does help and they can get better.

Arm yourself with a list of psychologists specialising in DBT and Borderline Personality Disorder. It can be hard to diagnose and treat so finding an expert is crucial.”