

DERBYSHIRE

BORDERLINE PERSONALITY DISORDER SUPPORT GROUPS

Chesterfield

Meets on the 1st and 3rd Monday of the month between 7-9pm above the Saints Parish coffee shop, Church Way

Ilkeston

Meets on the 1st Monday of the month between 1-3pm at the Fire Station Community Room, Derby Road

Matlock

Meets on the 2nd Monday of the month between 1-3pm, Imperial Rooms, Town Council Building, Imperial Road

BPD is also known as Emotionally Unstable Personality Disorder, or EUPD

If you would like to know more, please email Sue on:
derbyshireborderlinepd@gmail.com
or, phone/text 07597 644558

A Report

on the needs of those affected by

Borderline Personality Disorder (BPD)

also known as

Emotionally Unstable Personality Disorder (EUPD)

in

Derbyshire



Calling for a
Personality Disorder

Pathway

by the
Derbyshire
Borderline Personality Disorder
Support Group

July 2019

Contents

	Page
1. Executive Summary	3
2. Introduction	3
3. Personality Disorders	4
4. Definition and Symptoms of BPD	5
5. Government (NICE) Guidelines	6
6. Stigma and Misconceptions	7-8
7. Members' Experiences of Services	9-13
8. What is it Really Like to Live with BPD?	14-15
9. What is Needed	16
10. Other Counties	17
11. One Member's Journey	18
12. Summary	19

12. Summary

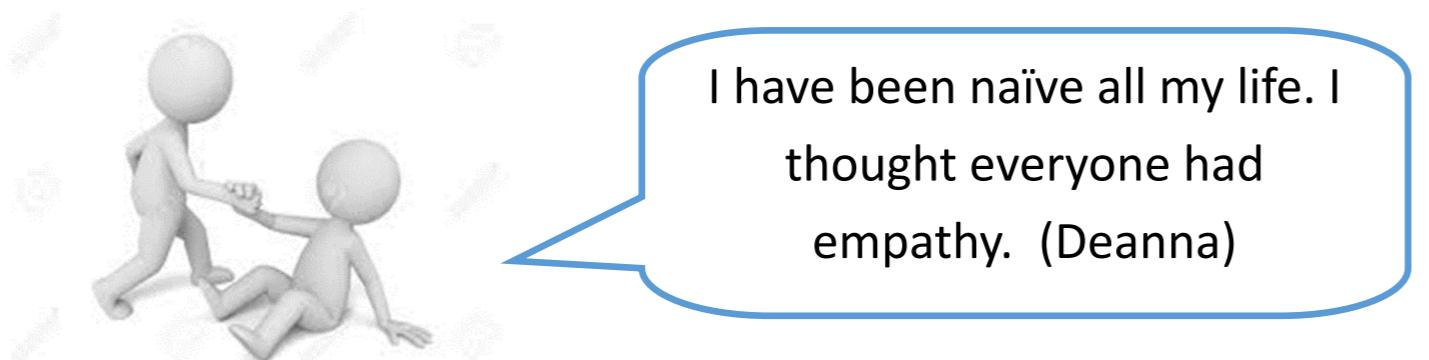
It is evident, from both our members' feedback and from the NICE guidelines, that the attitude and understanding of others are vital components for individuals with BPD successfully managing their condition. A good attitude, with empathy and compassion costs nothing. We would like to see zero tolerance on the use of terms such as attention-seeking, childish etc. Some of us are those things; this is the nature of BPD, but health professionals especially, should be able to find a way of dealing with this matter, with less derogatory terms. More training for healthcare professionals is a must if we are going to address this issue. Funding is in short supply but to deny it is short-sighted. To restate the facts, around 70% of people in prison have some form of PD, and BPD is one of the most common.

Decision-makers within Derbyshire have hinted that, finally, they may make better services for those with a PD a priority in the future. Yet, they still refuse to call it a pathway. Individuals will be expected to tap into services for other trauma-related conditions. This hasn't always worked in the past, for various reasons that have been addressed in this report. Increasing access to psychological therapies will not help if the specific needs of people with a PD continue to be misunderstood or ignored.

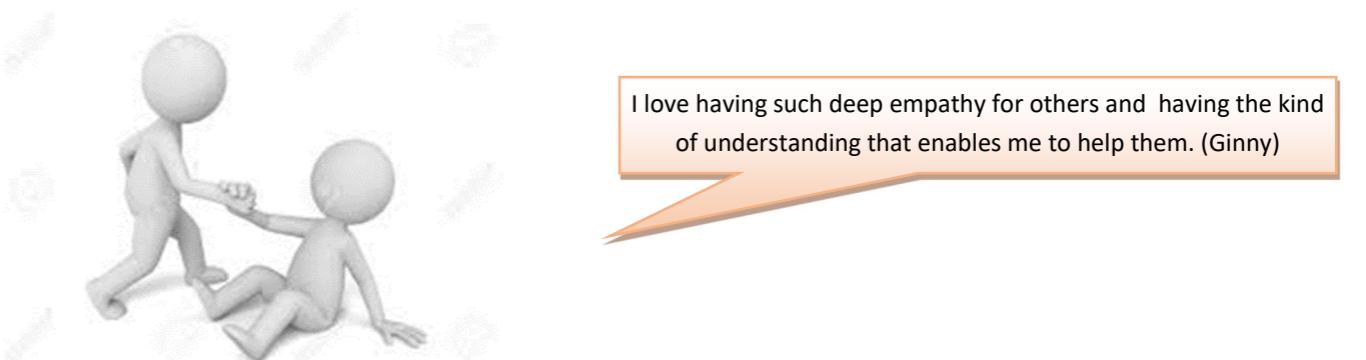
The term pathway is widely used and gives legitimacy to a 'condition'. A *personality disorder pathway* (along with adequate services) would give people a sense of being included, at last. This is a very important issue for the members. With a pathway, GPs and other health professionals would no longer be able to say there is nothing they can do because 'there is no pathway for BPD'.

Finally, and of equal importance, we hope that the quality and honesty of our members' contributions will convince decision-makers that, if/when the PD Pathway is developed, it will be co-produced with people with lived experience, whose insight is invaluable.

Sue Wheatcroft



I have been naïve all my life. I thought everyone had empathy. (Deanna)



I love having such deep empathy for others and having the kind of understanding that enables me to help them. (Ginny)

11. One member's journey through the Derbyshire Community Mental Health Services...



How would YOU interpret this?

1. Executive Summary

This report highlights the ways in which people with Borderline Personality Disorder (BPD) struggle to manage their condition on a day-to-day basis, often exacerbated by inadequate treatment, stigma, and a general lack of understanding of their condition within statutory services. We are asking for the establishment of a treatment pathway for all personality disorders (PDs) in Derbyshire in order to bring to an end, feelings of exclusion and inequality. We are also asking for adequate training to be provided to all relevant personnel.

The report includes a brief explanation of all PDs, examples of PD services in other counties and an excerpt from the NICE guidelines for the treatment of BPD. We ask that these guidelines are considered when establishing the pathway. The rest of the document is dedicated to the members of our BPD support groups so that they can explain the realities of living with the condition, in their own words. This section is split into themes that reflect experiences of stigma and misconceptions, statutory personnel and systems and, finally, what it really feels like to live with BPD.

Forty members have kindly allowed us to use their narratives and direct quotations; seventeen elected to remain anonymous, the remaining twenty-three have chosen to be identified by their first name only. We are extremely grateful to all of them.

2. Introduction

PD affects between 4 and 11% of the UK population, 50% of offenders managed by probation services, and 60-70% of prisoners. The most common PDs in criminal justice settings are antisocial personality disorder among men, and borderline personality disorder among women. Around 70% of people with BPD regularly self-harm, and 10% take their own lives. People with PD are often discriminated against, with access to services often denied, because they are stigmatised and regarded as a more difficult group with whom to work.

It is evident then, that inadequate care in the community for these groups of people, has severe consequences for them, their loved ones, the criminal justice service, healthcare (many undergo one or more stays in psychiatric units) and the general taxpayer. Largely in recognition of this, many counties within the UK have established some form of PD pathway. In Derbyshire, however, there is no such pathway and, as found in *personality disorder: prison vs community* (Clinks blog, 2 May 2019), treatment for women with a PD in Derbyshire can be easier to access in HMP Foston Hall than in the community.

Our support groups, established in October 2017, and of which there are currently over 60 members in three areas within Derbyshire, provide a safe space in which those affected by BPD can come together, share their stories and, most importantly, support each other. However, we exist to supplement, not substitute statutory services, which is why we are committed to the establishment of a *Personality Disorder Pathway in Derbyshire*.

Sue Wheatcroft

Founder, Derbyshire BPD Support Groups

3. Personality Disorders

The essential features of a personality disorder are impairments in personality (self and interpersonal) functioning and the presence of pathological personality traits. Personality disorders are 'clustered' into three different types.

Cluster A

People with cluster A personality disorders can find it hard to relate to other people. Their behaviour might seem odd or eccentric to other people.

Paranoid personality disorder—You may feel very suspicious of others but without a reason if you have been diagnosed with paranoid personality disorder. This can make you feel other people are lying to you or using you. This can make it difficult to trust others, even friends. You may find it difficult to forgive insults and will bear grudges. Your doctor should rule out schizophrenia, psychosis, and mood disorders if you have been diagnosed with paranoid personality disorder.

Schizoid personality disorder—With schizoid personality disorder, you may have few social relationships and will prefer to be alone. You might actually be very shy, but other people may think you are quite cold and distant.

Schizotypal personality disorder—This is where you have problems relationships with other people. You may have strange thoughts, feel paranoid and see or hear things that aren't there. You may also lack emotion or be described as being 'eccentric'.

Cluster B

People with cluster B personality disorders can find it hard to control their emotions. Other people might see them as unpredictable.

Antisocial personality disorder (ASPD) - Being diagnosed with ASPD may mean you are impulsive, reckless and do not think about how your actions affect other people. You may get easily frustrated, aggressive and be prone to violence. You may do things to get what you want. Others may see this as acting selfishly and without guilt.

Borderline personality disorder (BPD) - You may have strong emotions, mood swings, and feelings you can't cope with if you have BPD. You may feel anxious and distressed a lot of the time. You may have problems with how you see yourself and your identity. You may self-harm or use drugs and alcohol to cope with these feelings. This can affect the relationships you have with other people. BPD is also known as 'emotionally unstable personality disorder' (EUPD).

Histrionic personality disorder—If you are diagnosed with histrionic personality disorder, you may like being the centre of attention. You may feel anxious about being ignored. This can cause you to be lively and over-dramatic. You may become bored with normal routines, worry a lot about your appearance and want to be noticed.

Narcissistic personality disorder—Narcissistic personality disorder can mean you have a high sense of self-importance. You may fantasise about unlimited success and want attention and admiration. You may feel you are more entitled to things than other people are. You might act selfishly to gain success. You may do this because inside, you don't feel significant or important.

Cluster C

People with cluster C personality disorders have strong feelings of fear or anxiety. They might appear withdrawn to other people.

Dependent personality disorder—If you have dependent personality disorder, you may allow other people to take responsibility for parts of your life. You may not have much self-confidence or be unable to do things alone. You may find that you put your own needs after the needs of others. You may feel hopeless or fear being alone.

Avoidant personality disorder—If you have avoidant personality disorder, you may have a fear of being judged negatively. This can cause you to feel uncomfortable in social situations. You might not like criticism, worry a lot and have low self-esteem. You may want affection but worry that you will be rejected.

Obsessive-compulsive personality disorder—If you have this condition, you may feel anxious about things that seem unorganised or 'messy'. Everything you do must be just right, and nothing can be left to chance. You may be very cautious about things and think a lot about small details. Others may see you as being controlling. This condition (OCPD) is different to obsessive-compulsive disorder (OCD). If you have OCPD you may believe your actions are justified. People with OCD tend to realise that their behaviour is not rational.

10. Other Counties

A few of the Counties that already have a Personality Disorder Pathway

Northamptonshire...

The Northants Personality Disorder Hub is a specialist countywide service. Our team aims to promote understanding and hope regarding the treatability of personality disorder, enhance the capabilities of staff in general services, and increase access to evidence based and psychologically-informed interventions. We provide a Dialectical Behavioural Therapy (DBT) programme that involves weekly attendance at 1:1 and group sessions for approximately one-year. Working in partnership with other services to provide Structured Clinical Management programmes and Understanding and Managing Emotions groups, we also offer consultation and training to members of staff across the Trust.

Lancashire...

The Personality Disorders Managed Clinical Network (PDMCN) facilitates the provision of specialist consultation and training to enhance the care and treatment of service users with complex needs. This approach aims to promote skills in the development of formulated care plans for people with severe personality disorders and/or particularly complex problems that take into account the views of different services involved and provides a unified approach to the management and/or therapy of the service user.

Sussex...

STEPPS for Borderline Personality Disorder (Systems Training for Emotional Predictability and Problem Solving) is a practical, evidence-based treatment for people with BPD, based on CBT principles. STEPPS interventions have been shown to be very effective in helping people manage intense emotions, unhelpful ways of thinking and behaving, as well as providing hope and positive engagement in making positive changes in their lives. Feedback from clinicians and service users indicates that the programme is accessible, popular and easy to implement.

Cambridgeshire and Peterborough...

The Personality Disorders Community Team offers assessment and treatment advice; help, advice, support and signposting; risk assessment, formulation and management; care plan developed with service user; daily crisis support; medication review and management; psychoeducation; relapse planning. Also, time-limited specialist interventions including: mentalisation-based group therapy; MOHO based goal setting group; DBT-based interventions for emotion regulation and distress tolerance.

9. What is needed

Better education

Before my girlfriend's diagnosis, I wasn't even aware of what BPD was. All we were taught about at school was depression, so it was a shock and I panicked. I didn't know how to help, so I had to do a fair bit of research and teach myself

Legitimacy

Our pain is real

We want/need/deserve help and support

Acknowledgment

We are a large group with a specific 'condition'. We deserve to be heard.



Insight

The criteria for getting help is too rigid. We do not all have the same needs.

An end to the stigma

Behavioural traits tend to be highlighted and taken negatively.

(Dan)

Understanding

Health and social care professionals, as well as police, prison and probation officers, should understand how and why we feel and act the way we do

Input

We are 'experts by experience' and, therefore, have a lot to contribute to the forming of the pathway

4. Definition and Symptoms of BPD

A pervasive pattern of instability of interpersonal relationships, self-image, and affects, and marked impulsivity beginning by early adulthood and present in a variety of contexts, as indicated by five (or more) of the following:

1. Frantic efforts to avoid real or imagined abandonment.
2. A pattern of unstable and intense interpersonal relationships characterized by alternating between extremes of idealization and devaluation.
3. Identity disturbance: markedly and persistently unstable self image or sense of self.
4. Impulsivity in at least two areas that are potentially self-damaging (e.g., spending, sex, substance abuse, reckless driving, binge eating).
5. Affective instability due to a marked reactivity of mood (e.g., intense episodic dysphoria, irritability, or anxiety usually lasting a few hours and only rarely more than a few days).
6. Chronic feelings of emptiness.
7. Inappropriate, intense anger or difficulty controlling anger (e.g., frequent displays of temper, constant anger, recurrent physical fights).
8. Transient, stress-related paranoid ideation or severe dissociative symptoms.

(DSM-5)



A friend sent me a link to the MIND page that explains BPD, as she thought the description sounded like me, and I agreed. I came to the support group to see if I related to anyone and 100% did, so I went to the doctors. They referred me for a psychiatric assessment and I was diagnosed with BPD.

5. Government (NICE)* Guidelines (2009 & 2013)

When treated consistently with primarily psychological approaches the outcome is good and relapse unlikely, so these longer-term treatments are much more cost-effective.

For people with BPD, overcoming the difficulties associated with this diagnosis can be a huge struggle. However, this struggle is made much more difficult by the frequent lack of understanding and the stigma people with this disorder receive from both inside and outside mental health services; they can be denied services, told they are untreatable, or seen as being blamed for their difficulties. It is frequently overlooked that people with this diagnosis often have had difficult early experiences and difficult lives. This guideline is an important step forward in addressing these issues. If people with this diagnosis are able to have better access to treatment that addresses their needs and are in an environment that encourages understanding, optimism and hope, then more people will be able to move on from this disorder to live fulfilling lives. Recovery is possible.

The implementation of these guidelines will ensure that individuals who are often extremely vulnerable and have complex health and social care needs are no longer excluded from mental health services but are able to access responsive, equitable, quality care.

Source: www.nice.org.uk/CG78

*NICE—National Institute of Clinical Excellence
Sets guidelines for the NHS to follow

8. What does it really feel like to live with BPD/EUPD?

Annie (the mother)...

I don't have BPD, but my daughter does. Watching her emotions, extreme mood swings, researching ideas for her suicide, together with hearing her catastrophe events is heart-breaking, but I can deal with it because that is my emotion. Seeing her fight to see her GP, on a regular basis, hearing the crisis team label her a drama queen, witness her tears of frustration when the only support is an infrequent recurrence of 6 weeks counselling, 3 of which are taken up repeating the background and setting the scene... There is no consistent support. How can we look to the future? It's almost impossible. I don't expect a miracle cure, I expect directional support, patience, knowledge, consistency, continued effort to improve the support available. I just want the health-care my daughter deserves.

Bryony (the daughter)...

It's like living two lives sometimes, one rational, one irrational. It's battling at 3am with suicidal thoughts, all because earlier in the evening something happened out of the blue (such as a neighbour knocking on the door). It's being on medication and not knowing if or when you will ever come off it, or when the dose will go up/come down, and how your body and mind will react to it. It's living day to day, only being able to do 'safe' things, such as going on the same dog-walking routes, eating the same food which is 'safe', only being able to go out with 'safe' people. Not being able, at age 25, to have knives in my house, as they may be used to hurt myself in crisis times. It's not being able to do what people my age can, such as meeting friends out and about. It's being in and out of services, not always knowing if/when it's going to end.

xxx

Bridget (the mother)...

My daughter has BPD, newly diagnosed. It's been hard living with her as a child, thinking she was naughty. Then she diagnosed herself at age 18 and mental health diagnosed it 2 months ago, having never heard of it! We have no support or guidance.

Elisa (the daughter)...

Before being diagnosed, I attempted suicide. I was brought into A&E in an ambulance. In the ambulance, I was asked if I meant to end my life or if it was 'just a cry for help', which, despite it being a serious attempt, made me feel like I was just attention-seeking. In hospital, I spoke with a mental health nurse for half an hour, then discharged with no diagnosis, treatment or medication; nothing at all... Two years later, I finally have a diagnosis and medication, after a lot of fighting to get GPs to listen to me. I have now been on the waiting list for therapy, six months. Still waiting!

Xxx

A friend...

I don't live with my friend with BPD. It's very concerning, always in the back of my mind that something might have happened. Having to balance supporting her with the rest of my life and responsibilities (I don't always get this right!). I feel very responsible, as she has a very small support network.

8. What does it really feel like to live with BPD/EUPD?

Shane...

It's like I have everything I need around me but it's very hard to see the positive in this. I feel more of a burden at times, not able to STOP-THINK-LISTEN before I snap over things. I can feel empty and lost, and feel I am better dead, or self-harm to the point that I have used various methods to cause pain, cutting, putting vinegar into my eyes, burn myself using candles and things that come out of the oven. I have trust issues and abandonment issues, can be confrontational and aggressive to people I don't know, suicide ideation with a few serious attempts, hurt people who mean the most to me and feel they don't really get my issues, always wanted to choose another way of life but to achieve this I need to leave the life I am living now.

Liberty...

I feel I am annoying to everyone I meet. I am a burden. I feel like I don't deserve a place on this earth. I am always tired and VERY stressed. I bite and snap but to others I am just over-reacting. I try and keep quiet and to myself, but my head is noisy, busy and won't leave me alone. My mood changes so quickly. I am TRAPPED. No-one cares, no-one ever will. I am a weird freak that doesn't matter. I genuinely hate myself. I can't stand the sight of myself.

Verity...

It feels like I am on a piece of string, constantly swinging from mood to mood, idea to idea, personality to personality, person to person, and it can be very scary as well as making me feel physically dizzy. One minute, I want to sell everything I own and go explore the world because I'm so bored with life and feel I need to do something drastic, then in a heartbeat, that changes to being scared to even leave my own house, and wanting to surround myself with possessions. I don't feel I have my own identity so I'm always looking at other people and copying them (style, mannerisms, hobbies). I've changed so much I don't know which is the original me.

Miranda...

BPD feels like no-one understands you and what you think or say is never validated. You're always over-reacting or taking it the wrong way. It's near impossible for people with no experience of this mental illness to understand just how hard it is to have a simple life. You always feel like someone is going to leave you or everything is going to go wrong. This can be triggered by the smallest influence that wouldn't really bother anyone else. But to us, it means so much more. On the other hand, we can be on top of the world and everything goes perfectly. This can only last so long before someone close to you cancels plans and you feel like you're alone in the world. However, with patience, kindness and understanding, anyone can be there for someone with BPD, and understand it. When most mental health services can't help, it's hard for anyone else to. It's rare for a workplace to understand it, for GPs to understand it, or for anyone close to you to understand it. Sometimes, I can be filled with rage and irrational anger and then a couple of hours later, I'm fine. My partner finds it so hard to know which Miranda will walk in from work. I've packed my bags to leave more times than I can remember but I don't really want to leave him because I'm attached to him.

Ginny...

Having BPD isn't always as awful as people make out. I try to look for the positives, feeling higher 'highs' and forming deeper friendships. I've learnt to laugh at myself and try my hardest to see the light in situations because you never know when you are going to plummet.

6. Stigma and Misconceptions

Attention-seeking; needy

The A&E staff said I was an attention-seeker because of my self-harming.

We can't always handle our emotions, and we don't know what we want when in crisis. There is no planning of words. The words just come out.

People think self-harming is a choice. I don't do it because I want attention. I do it to relieve the emotional pain.

I am constantly changing my appearance. It's not to get attention. It's because I don't know who I am!

If attention is needed, then there should be a right to the correct service, as with any other condition.

I am alone with it, and I have no treatment because they don't know what to do with me, and so I feel like I am being made to feel isolated and attention-seeking, which reflects the reaction of my family. This, from the medical profession, does not help. (Ruth)



6. Stigma and Misconceptions

Manipulative; refuses to engage

Because I found it difficult to talk to people, I was labelled manipulative. I was just scared that I was going crazy.

The approach seems to be that if you don't get on with one treatment, you are deemed to be not engaging. They will not offer alternative treatment and you may even be black-listed for refusing to engage.

If someone is having a bad episode/in crisis, they are less likely to be able to engage in some services at those times, but may be better able to do so when they are feeling more stable.

A service may be unavailable when you need it, then be not needed after the lengthy waiting time.

I always accept help/support because I'm afraid of being told I'm not engaging, and then not offered anything else. So, I feel I have to give everything a go, even if it's not suitable for me.

People should be better educated about BPD. Many people think mental health, and focus on depression. It should be mandatory that BPD, and other personality disorders, are included in the school curriculum. Then, it will not be such a grey area and people won't be so afraid of the condition. People fear the unknown. (Oliver)



7. Members' experiences of..... the NHS

The NHS has saved my life so many times. Thank you! (Amy)

They saved my life after my suicide attempt. A&E, paramedics and ICU doctors were amazing. (Jesse)

The staff genuinely do the best they can with the budgets and resources given. The State needs to support the staff financially and with training, to enable them to do their jobs in the best way they can. (Ellie)

If people could get help quicker, the problems would not be so deep-set. People need to understand what is going on their head. (Ryan)

I was under the crisis team for 3 weeks, then discharged. A friend took me to the GP who advised me to go to A&E, but if Chesterfield couldn't help, then to go to Sheffield. In Sheffield I sat in a room alone until 10pm, before being told they wouldn't help because it's not their area! I then had to arrange for a taxi home, which I had to pay for, and I was left at home in crisis.

They're not compassionate. They need to understand each individual's needs. They should take the time to listen, and talk to people with BPD. (Martin)

My daughter has BPD, newly diagnosed. It's been hard living with her as a child, thinking she was naughty. She diagnosed herself at 18 years old, and mental health diagnosed it 2 months ago. We have no support or guidance. (Brigidet)

The provision of services in Derbyshire for those with a personality disorder, is shockingly poor. There is no clear path for assistance and support, and those with a BPD often get told they're either not ill enough to need services, or too ill to be treated. Additionally, the care in different locales differs massively (even at the level of GPs in the same surgery) and it is a lottery as to how much help you may receive.

7. Members' experiences of.....GPs

There seems to be a distinct lack of knowledge of what is being done to support our NHS professionals to understand BPD, which in turn, would help us. Having a pathway would help those professionals to know what support is available and where they should refer people with BPD to.

The GPs need to be more open-minded in their diagnosis. I feel I was 'pigeon-holed' with depression for 10 years, which led to feeling misunderstood, isolated and hopeless.

I never see the same GP. It's very difficult to build trust and they never listen. The only doctor that did, ended up leaving.

They just increase medication and pass the buck, rather than finding out the reason why. (Clare)

My GP was a key person for me to talk to but after we spoke about attachment, my appointments were moved from weekly to bi-monthly.

My GP sees me every 4-8 weeks and will fit me in whenever things get tough. She also encourages me to make changes in my life that will help, e.g. finding a new job, yoga, and mindfulness apps. (Miranda)

and of..... Psychiatrists

My psychiatrist is fantastic. He's always supportive and helpful. He always has solutions and options, and ensures that I see him every four months. (Amy)

Have been told by senior psychiatrist, 'as we can't medicate your symptoms and treat you, we will discharge you from the service'. (Pinder)

It's not helpful to have loads of different psychiatrists—no continuity of care, plus some are really helpful and others aren't. (Laura)

7. Members' experiences of..... A&E

Readily discharge patients that require further treatment, who then fall out of the health care system. These individuals can end up taking their own lives or seriously self-harming. This could have been prevented if the patient had received the appropriate care and treatment.

The A&E staff were amazing at talking to me when my partner had tried to commit suicide. (Ellie)

In my experience of living with a mental illness, A&E is not the place for someone who is in crisis to be. The waiting time alone, can add to the crisis.

The long waiting times in A&E for the crisis team is crazy and stressful.

Following my suicide attempt, I saw the OT in A&E before being discharged, without any follow-up. (Jesse)

and of.....Therapy

I saw two therapists. Both discharged me because I was too much in a bad place.

We need more than 8 weeks of therapy, as it is simply not enough time to engage with the therapist and make 'break-throughs'

Family therapy made me feel even more rejected by my family.

I was told by my IAPT provider that BPD is too complex so there is no help available.

I found it very difficult to access talking therapies for my anxiety because of my BPD diagnosis. I was told by two separate therapy agencies that they can't help me because of my diagnosis. I felt like I had a black mark against my name.

7. Members' experiences ofCPNs/ Mental Health Nurses/ OTs etc



7. Members' experiences ofthe Police, Crisis House, Crisis Team and Street Triage

