Issue Four — Summer 2019

Borderline Derbyshire

Newsletter of the

Derbyshire Borderline Personality Disorder Support Group

Accounts from those with BPD/EUPD

Info for group meetings

For anyone affected by Borderline Personality Disorder (BPD) also known as Emotionally Unstable Personality Disorder (EUPD)

Find out what's new in Derbyshire for those with Personality Disorders

Who we are…

Committee—core members

Sue—chair/founder

Vicky—secretary

John—treasurer

Other committee members

Jodie—activities co-ordinator

Ryan—volunteer

As our membership grows, so does our determination to campaign for better services. In March, we had a visit from the NHS; two people who are in a position to influence future services. Their feedback from this 'listening event', and our reaction to it, is on pages 6 and 7. To put all this in context, we have included the relevant NICE guidelines, on pages 8 and 9. These guidelines were written in 2009, checked in 2018, and will be reviewed in 2021.

As part of our new, more informative style newsletter, we will be including a series of stories on the symptoms of BPD and how they affect us as individuals. In this issue we have two personal accounts of 'attachment' (pages 10 to 13).

Derbyshire Borderline Personality Disorder

SUPPORT

Group

News

Thank you to...

Erewash CMHS (3 April)

and

Links CVS (5 April)

...for giving us the opportunity to talk about our support groups, and services for BPD and other personality disorders

Bryony

The group is fantastic! I meet new friends, have a laugh and get lots of information.

I'm Bryony's mum, and I enjoy the support and friendship of the group.

Annie

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

Also known as Emotionally Unstable Personality Disorder, or EUPD

Jodie

I get the support I need at the group. It makes me feel comfortable and safe.

I'm Jodie's partner. I get a better understanding of what BPD is and make new friends in the same position.

Ryan

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

Question!

Are you happy with the treatment you have received from the Mental Health Services? If not, do you get angry, frustrated and upset? Are you sick of being ignored, or treated as an attention-seeker? Do you feel helpless and don't know what to do next?

Have you heard the expression:

The pen is mightier than the sword!

Experience has taught me that angry words are easily ignored or forgotten, unless they are on paper and disseminated among the right individuals, departments and organisations.

Maybe, you have had a good experience?

We are compiling a report on the experiences of the NHS by people who have , or who have been affected by, BPD. This includes family members, friends, and carers. We would also welcome stories or information from health and social care professionals, and anyone else involved in the care of people with BPD.

This will be totally confidential, unless you wish to be identified.

Please email Sue at derbyshireborderlinepd@gmail.com

Listening Event at our Chesterfield group...

Notes from Gareth's and Darryl's visit to the Derbyshire Borderline Personality Disorder Support Group 4th March 2019

We would like to start by saying thank-you for inviting us to this meeting, but also thank you for your welcome and for your openness. We have done our best to summarise what we heard, but would welcome your comments or suggestions if we have not correctly understood what was being said.

We started with a conversation about what should be present when someone goes to their GP for help, and this was summarised as: a referral on to a mental health team, with a copy of this referral given to the person; for the person to receive an appointment letter; for an assessment to lead to a diagnosis; for the diagnosis to be given in person, not in a letter; for treatment options to be discussed in depth with the person, to include: timescales, a shared care plan (most people in the room said that they hadn't had a copy of a care plan), an option to re-start therapy or support after initial sessions have ended.

Other things we discussed included:

Diagnosis: The challenge of a late diagnosis, how a diagnosis can help things to make sense. It felt vital to share the diagnosis with the person.

Attachment: The potential value of an ongoing weekly or a monthly appointment, as a way of maintaining stability. The importance of stability in attachments, and the damage from abruptly ended relationships with health professionals. The importance of clear communication – being left in limbo and not knowing what is happening is distressing. Darryl talking about our 'Waiting well' procedure, but the communication expected in that procedure is not the experience of those in the room this evening.

Pathway: What is a pathway? Is it defined as a team with a dedicated focus on a diagnosis, or is it the journey of the person through our services? The Trust's current mental health structure is built around age, not specifically to individual diagnosis, and this might have disadvantages. People with a diagnosis of BPD share the same issues, irrespective of age. Communication whilst people were on the waiting list to reduce anxiety, but also to build clarity about what the services are for and what people can expect.

Help: Would there be an option of spacing out IAPT appointments from weekly to monthly, to better meet the needs of people with this diagnosis. We have inconsistency across the Trust in the level of staff training and confidence to work with people with this diagnosis We have approached our colleagues in the Clinical Commissioning Group to support us in funding and recruiting staff with these skills. Would there be things that the Trust can do to help with GP's understanding of borderline personality disorder? The potential of peer support roles, recognising the value of. The fundamental value of being able to speak to someone who understands. The impact of staff attitudes on accessing the services in an effective way. The potential helpfulness of personal health budgets and how these could be made to work.

Thank-you all once again; we look forward to our next visit and would be happy to discuss any of this further.

With good wishes,
Gareth Harry
Director of Business Improvement and Transformation
Darryl Thompson
Deputy Director of Nursing & Quality Governance

After reading Gareth and Darryl's feedback, the group further responded:
Thank you for taking the time to visit our group and for feeding back to us. We have read your notes and have made a few of our own. We appreciate your involvement in making services better for people with BPD, and all personality disorders, and we look forward to your next visit.

***The referral** to be acknowledged by the MH team so that the person knows the MH team have received it. A note to be included in the referral letter stating that the person should contact the MH team if they have not received acknowledgment within, say, two weeks? If the person is on a waiting list before being given an appointment, the person to be given regular updates as to their place on the list and/or timescale. The person's case to be kept open indefinitely. No discharge, even if that person is seemingly 'well'.*

***Attachment:** Bear in mind that everyone is different and that some may not have a problem with attachment. Others may experience the problem on different scales of seriousness. However, most people with BPD experience feelings of abandonment when the relationship with MH ends.*

*The term **pathway** is widely used and gives legitimacy to a 'condition'. Those with BPD have suffered more as a result of the condition being ignored/stigmatised/misunderstood. The term 'personality disorder pathway' 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'.*

*Every person should have the choice of **treatment**, as everyone's needs are different. Many members say that IAPTs are of no use, as they are too short and then the person feels either abandoned or back to where they were in the beginning.*

***Educating professionals**: We understand that Borderline Derbyshire have a contract to do this. Could we have an update please?*

*The potential of **peer support roles**, recognising the value of lived experience: not just in peer support roles, but also as part of the education/training of health professionals.*

*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 addressing these problems with less derogatory terms.*

NHS NICE Guidelines

Borderline personality disorder (BPD) is characterised by significant instability of interpersonal relationships, self-image and mood, and impulsive behaviour. There is a pattern of sometimes rapid fluctuation from periods of confidence to despair, with fear of abandonment and rejection, and a strong tendency towards suicidal thinking and self-harm. Transient psychotic symptoms, Including brief delusions and hallucinations, may also be present. It is also associated with substantial impairment of social, psychological and occupational functioning and quality of life. People with BPD are particularly at risk of suicide.

The extent of the emotional and behavioural problems experienced by people with BPD varies considerably. Some people with BPD are able to sustain some relationships and occupational activities. People with more severe forms experience very high levels of emotional distress. They have repeated crises, which can involve self-harm and impulsive aggression. They also have high levels of comorbidity, Including other personality disorders, and are frequent users of psychiatric and acute hospital emergency services. While the general principles of management referred to in this guideline are intended for all people with BPD, the treatment recommendations are directed primarily at those with more severe forms of the disorder.

BPD is present in just under 1% of the population, and is most common in early adulthood. Women present to services more often than men. BPD is often not formally diagnosed before the age of 18, but the features of the disorder can be identified earlier. Its course is variable and although many people recover over time, some people may continue to experience social and interpersonal difficulties.

BPD is often comorbid with depression, anxiety, eating disorders, post-traumatic stress disorder, alcohol and drug misuse, and bipolar disorder (the symptoms of which are often confused with BPD).

1.1.1.1 People with BPD should not be excluded from any health or social care service because of their diagnosis or because they have self-harmed.

1.1.4.1 When working with people with borderline personality disorder:

- **explore treatment options in an atmosphere of hope and optimism, explaining that recovery is possible and attainable**
- **build a trusting relationship, work in an open, engaging and non-judgemental manner, and be consistent and reliable**
- **bear in mind when providing services that many people will have experienced rejection, abuse and trauma, and encountered stigma often associated with self-harm and BPD.**

1.1.6.1 When assessing a person with BPD:

- **explain clearly the process of assessment**
- **use non-technical language whenever possible**
- **explain the diagnosis and the use and meaning of the term borderline personality disorder**
- **offer post-assessment support, particularly if sensitive issues, such as childhood trauma, have been discussed.**

People with BPD have sometimes been excluded from any health or social care services because of their diagnosis. This may be because staff lack the confidence and skills to work with this group of people.

Mental health trusts should develop multidisciplinary specialist teams and/or services for people with personality disorders. These teams should have specific expertise in the diagnosis and management of BPD and should:

- **provide assessment and treatment services for people with borderline personality disorder who have particularly complex needs and/or high levels of risk**
- **provide consultation and advice to primary and secondary care services**
- **offer a diagnostic service when general psychiatric services are in doubt about the diagnosis and/or management of borderline personality disorder**
- **develop systems of communication and protocols for information sharing among different services, including those in forensic settings, and collaborate with all relevant agencies within the local community including health, mental health and social services, the criminal justice system, CAMHS and relevant voluntary services**
- **be able to provide and/or advise on social and psychological interventions, including access to peer support, and advise on the safe use of drug treatment in crises and for comorbidities and insomnia**
- **work with CAMHS to develop local protocols to govern arrangements for the transition of young people from CAMHS to adult services**
- **ensure that clear lines of communication between primary and secondary care are established and maintained**
- **oversee the implementation of this guideline**
- **develop and provide training programmes on the diagnosis and management of BPD and the implementation of this guideline**
- **monitor the provision of services for minority ethnic groups to ensure equality of service delivery.**

1.1.7 Managing endings and supporting transitions

1.1.7.1 Anticipate that withdrawal and ending of treatments or services, and transition from one service to another, may evoke strong emotions and reactions in people with BPD.

Ensure that:

- **such changes are discussed carefully beforehand with the person (and their family or carers if appropriate) and are structured and phased**
- **the care plan supports effective collaboration with other care providers during endings and transitions, and includes the opportunity to access services in times of crisis**
- **when referring a person for assessment in other services (including for psychological treatment), they are supported during the referral period and arrangements for support are agreed beforehand with them.**

nice.org.uk/guidance/cg78

Local commissioners and providers of healthcare have a responsibility to enable the guideline to be applied when individual professionals and people using services wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with complying with those duties.

‘Favourite People’ and Attachment

Unless you have an association with the BPD community, it is unlikely that you are aware of the type of attachment issues some people with BPD experience. Many people have a ‘favourite person,’ perhaps a friend or family member., who they like to spend time with. To some people with BPD, however, it can mean so much more. A favorite person (also called an FP) is someone they can have an emotional dependence on, someone who can make or break their day. Two personal accounts follow; the first of which shows how extreme those emotions, and their consequences, can be.

The first meeting with my Probation Officer (PO) started off badly. She had read my case notes, which said I was ‘high risk’, and made it clear she had reservations about supervising me. I had BPD), and was known to struggle to manage my emotions. The Community Mental Health Services (CMHS) had refused to help me, saying first that there is no treatment for BPD, and then after my arrest, that I was obviously in crisis and so unable to engage, so I was used to knock backs. Nevertheless, I was a little disappointed with her attitude and the fact that she had pre-judged me. I had never had a PO before and didn’t know what to expect. I was 55 years old and this was my first time in prison. I was looking forward to going home to my partner and was sure that I would not be returning to prison.

After my release, I saw the PO twice a week. I attended all my appointments and did not offend further, so after a couple of months they were cut down to once a week. I frequently asked if, and when, I would receive input from the CMHS. I received two stock answers. It was either ‘you can obviously manage your emotions, so you don’t need any help’, or ‘you cannot manage your emotions and so will not be able to engage’. I never did get any help, but it didn’t seem to matter because I could talk to my PO. She had softened towards me since our initial meeting and I looked forward to seeing her each week.

We spoke about any issues I was having but equally, we discussed her and her personal life. ‘Enough about you, did I tell you about what I did last weekend?’, she would say. I liked talking to her. She was funny, intelligent and interesting. She also seemed to care about me. We discussed my issues with attachment, a common symptom of BPD, and she seemed to understand what a serious problem it was for me. The feelings can become so intense that some people become obsessed and even resort to stalking. I hadn’t, but I understood how easy it could be to reach that stage. We talked about anything and everything, and we laughed, a lot. I was becoming attached to her, and she knew it. She asked if I wanted a different PO; I declined. The best way of curtailing this type of attachment is to have no contact with the subject. However, the one with the attachment will not break the contact because they yearn for that person’s attention. The following comment is a good example of the feelings some people, including myself, frequently experience. It may sound extreme, but unfortunately, for many it is reality.

They’re like my drug. Whenever I get their attention, I’m happy for a while. But when I don’t, it’s like the world’s falling apart and I don’t know what to do. Jordie W. (themightyt.com)

Half way through my probation period I was told by a senior officer that I would now only need to see my PO every two weeks. I had been doing well and the concerns of supervising me, exhibited at the beginning, seemed to have lessened. This should have been good news. It wasn't; I was devastated. I started to think of the time when I wouldn't be able to see her, and I couldn't bear it. I thought of the railway track and how much I wanted to end my life. I don't know how I managed the drive home. I felt numb, yet desperate.

Once home, I couldn't settle. I sent an email to the PO, complaining about never getting any help from CMHS. She phoned me, but I didn't answer. I knew I wouldn't be able to talk because I was crying so much. She asked the police to carry out a safe and well check, but they refused. Over the weekend, I sent more emails to my PO, threatening anyone she might send to my door. I wasn't serious, but I needed to do or say something extreme so that I could calm down. On the Monday, I was arrested and charged with malicious communication. I pleaded guilty. The police said they had a statement from my PO to say she was upset at receiving the emails. The magistrate was sympathetic to my feelings but said he couldn't allow anyone to send vitriolic comments to a PO. He sentenced me to 6 weeks in prison.

While in the cell awaiting transport, my PO came to see me. She told me that her manager had recalled me to prison to serve the rest of my initial sentence, another six months. She also said she had not made a statement and was neither angry or upset at my emails. She thought the whole saga was 'sad'. Despite the fact that I would have to serve another six months in prison, I was happy that she was not angry with me.

After my release, despite the emails, and perhaps proving that she had not been upset by them, the same PO continued to supervise me for the seven months extended probation I had been given. I was still attached to her and grateful that I would be seeing her every week. Our relationship went back to the way it was before my arrest and one day, she broke down in tears, apologising for what had happened. Looking back, I don't know if she had genuinely wanted to help me or had encouraged my attachment. She gave me a lot of information about herself but when I then tried to probe further, she said it was inappropriate. Either way, the thought of not seeing her was more than I could bear. I said it was ok, I didn't blame her, and it was true. How could I blame her for being kind?

I have heard that the whole of the probation service is to be re-nationalised. Despite my problems, I welcome this news wholeheartedly. Having heard the horror stories from the private sector, I am grateful to have been with the National Probation Service. Knowing that someone was there for me (despite my 'issues') meant a lot.

I do question, however, why probation officers (and possibly police and prison officers?) do not have the kind of awareness training that warns them about attachments, so that they can set boundaries. Individuals with BPD can be extremely vulnerable and prone to overplay the smallest act of kindness shown to them. One in ten people with BPD end their own lives. I was very nearly part of this statistic.

Name withheld

It is important to note, that not all people with BPD experience attachment issues, and of those that do, only a small number will feel the emotions as extremely as the person in this example.

My Favourite Person

by Laura

I didn't know what having a 'favourite person' meant, until I attended the BPD group in Chesterfield. I did not know what was wrong with me at the time. I discussed my feelings with a few people close to me. But none of them could relate or understand why I felt this way. I have written this account so that others may feel less alone, and to give people a general insight into how debilitating it can be.

The first time I saw my FP, I was in my early twenties. The only way I can describe it was that it felt like love at first sight., despite the fact that no romantic or sexual feelings were involved. There was that instant connection and the moment felt special. I remember it like it was yesterday. He was/is younger than me, which suited me because I have always been immature for my age. In the beginning, I was there for him a lot. He was suffering from teenage angst and depression, triggered by a break-up. I suspected he had a bit of a crush on me but nothing ever came of it, because it was his friendship that I craved. I also knew, deep down, that if we were in a relationship I would lose the friendship that was so special to me.

I supported him with his troubles and I remember him sending me a Christmas card, thanking me for my emotional support. In the early days, there were definitely times when he became too needy and I felt that I wanted to distance myself, but I didn't. We spent many blissfully happy evenings together, chatting, listening to music and watching films. We were both suffering with depression at the time and became a good support for each other.

Eventually, I felt that my life began to revolve around him. I religiously listened to his radio show and I would talk about him to others constantly. Even when I moved away, we would meet up regularly. I lived for our meet-ups. He was there for me after break-ups from abusive relationships. I didn't have many friends and didn't feel close to my family. He became my world. He would make me happier than anyone else ever could. No-one could ever make me laugh as hard. I felt he was the one constant in my life.

But then, he wasn't there for me as much. He began to distance himself from me. I panicked, terrified of losing him and so foolishly (I thought) told him he wasn't being a supportive friend since my mental health had worsened. I said things like 'I was always there for you'. I would phone him and he would make it clear it wasn't convenient. He wouldn't talk to me because he was out and busy with his friends. He had also got a serious girlfriend by this point. I became seriously jealous because she was taking attention away from me. I had never met her but I began to feel that I hated her.

I became more suicidal, self-harmed and used alcohol to numb the pain. Everything felt pointless without him. I was desperate to save our friendship. I invited him round to my house and he stopped overnight. But something was different; everything had changed. He was cold towards me and I remember that he didn't even bring his possessions in from his car. I was devastated, and I blamed myself completely. Eventually, he arranged to visit me again. I was beside myself with excitement. It would be just like old times!

But he cancelled on me last minute. I was heartbroken and began a painful grieving process. It was physically painful at times. I cried more than I thought was possible. I had entangled myself so much into his life that I felt I completely lost my identity. It wasn't until he was gone, leaving a gaping hole in my life, that I realised how intense my feelings were. I feel it is a common theme in my life that people move on and grow up and I'm always stuck in the same place emotionally. Things can never go back to the way they were because people change. I don't.

He is so happy without me. I was so desperate to feel some connection with him again that I slept with someone he used to be friends with. Eventually, I decided I needed to stay distant from my FP. I didn't want what I saw as his 'personal life' rubbing in my face. I couldn't stand the thought that he could be happy without me. I fantasised that he would turn up at my door miserable and begging for things to go back to the way they were. What bothers me the most now is how ecstatic and manic I felt in his company. I'm worried I'll never feel those dizzying heights again. What if I never feel that happy again?

Supported by…

Public Health

North Derbyshire CCG

Derbyshire County Council

Derbyshire Dales District Council

Foundation Derbyshire

Derbyshire Recovery and Peer Support Service

Derbyshire Voluntary Action

Lloyds Bank

We welcome ex-offenders, and are proud to be a member of…

CLINKS

supporting voluntary organisations that work with offenders and their families