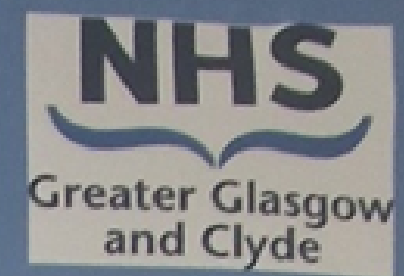


NHS Greater Glasgow and Clyde: BPD Dialogues Group



Borderline and Beyond: Impact of a Lived Experience Information Leaflet



Alison Duncan, Lisa Heenan, Fiona MacNeill, Jamielouise Malone, Jade Cara McNeill, Catherine-Anne Daly, Michelle McBride, Andy Williams

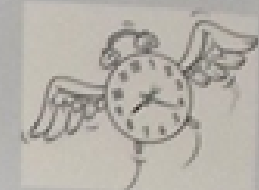
Background: BPD Dialogues is a lived experience group co-facilitated by a mental health engagement charity and NHS Greater Glasgow and Clyde. We launched an information leaflet called 'Borderline and Beyond' in 2022. The leaflet aims to give informed lived experience perspectives on the realities of borderline personality disorder, and to challenge conflicting and stigmatising information available on the internet. The leaflet was developed over two years through a co-production process. It was designed to be accessible, visually appealing and led by real voices of experience. The leaflets have been promoted through staff newsletters, a linked staff training programme and on the Health Board website.

Challenges

We are a small group of volunteers
Many demands on our time
The work depends on everybody's wellness at the time

Oct '23- March '24:

27 hours of work carried out!



Patient and Family Survey (31 Responses)

- 90% found the leaflet helpful or very helpful
- 100% replied that it was important/ very important it was written from Lived Experience
- 93% would definitely recommend this leaflet to a friend
- 81% would not change anything about the leaflet

What People said:

Leaflet outlined how difficult and exhausting the condition is from the point of view of people with lived experience of BPD

The narrative in the leaflet read as frank and honest

It was very good not to have the usual views and info from clinical professionals, which whilst best intentioned often comes across as patronising and very arrogant

Like the 'factoids' and the quotes bring the content to life. Also liked the section on relationships, so real. The balance on highlighting the positives was good to see

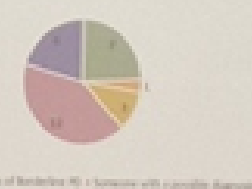
BPD is a misunderstood condition. Having the diagnosis explained in straightforward language, and giving BPD sufferers a voice is really helpful for those close to them

Wish I had been given a leaflet like this when I was diagnosed instead of being told to go online and look it up

Knowing as well that it had been written by people like me, it made it feel a bit more close to home, since a lot of the experiences are 80% to 100% relatable

I thought the gentle tone of voice and use of 'we' throughout might help someone feel less alone with their diagnosis and more importantly their symptoms

Who Responded?



Staff Survey (88 Responses)

- 47% of respondents were AWARE of the Borderline and Beyond leaflet
 - 25% thought the leaflet was VISIBLE/ AVAILABLE in their ward/ CMHT
- We did spot checks, and found the leaflet displayed in 3/10 CMHTs

What Staff Said:

Patients have said how normalising and informative the leaflet is

Patients have discussed how useful this has been to make sense of the diagnosis. Importantly has given hope about treatment options available but also to feel recognised due to it been written from lived experience

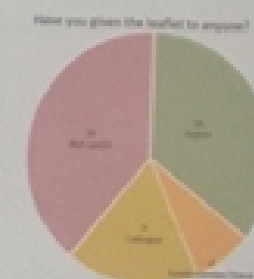
Really informative in an approachable manner. Overall, I think would be really useful as a first introduction to patients or families

I think the wording is a little flippant at times (e.g. mini factoid). The colours of the leaflet also support this image

I would have preferred not to have pink on the pages, as not just females affected

Very informative but long - will people read all through this? The pages with white print are more difficult to read. There are some terms that seem quite complex and wonder if they are needed, but it's a balance with providing enough information for those who would wish to know more. Excellent, thanks for sharing

Maybe more of an explanation as to why BPD may have developed, and that it is different from 'mental illness'



Conclusions and Next Steps:

- Most feedback has been extremely positive
- It is frustrating that despite so much effort, the leaflet is not more visible in clinical areas
- We plan to design a poster with a QR code to access the leaflet on the App
- Based on feedback, we are developing a second Coping Strategies leaflet
- We will retain our colourful informal style, but take on comments to make this easier to read

App and Website:

The leaflet is also now available on the NHS Greater Glasgow and Clyde My Mental Health App and Website.

See the Borderline and Beyond Leaflet here:

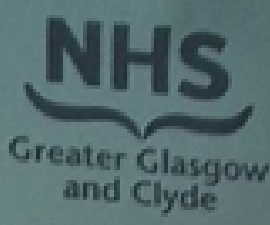
352 Views So far...



NHS Greater Glasgow and Clyde: BPD Dialogues Group



In Conversation with BPD Dialogues: Borderline and Beyond



Amy Holder, Fiona Macneill, Jamielouise Malone, Joan McBride, Alison Duncan, Lisa Heenan, Jade Cara Mcneill, Catherine-Anne Daly, Andrea Williams

The Borderline Personality Disorder Implementation Steering Group was formed in February 2019. The steering group was tasked with the development of services for people with a diagnosis of BPD as part of the NHS Greater Glasgow and Clyde 5-year Mental Health Strategy.

From the first Steering Group meeting, it was agreed as a priority to involve people with lived experience in the development and design of the BPD pathway. The group reviewed different models of lived experience engagement and co-production from across the UK. Links were then made with third sector organisation the Mental Health Network, and a partnership was agreed whereby MHN hosts the BPD Dialogues group, with direct links to the BPD Steering Group.

The first meeting of the group took place in February 2020. 8 people with lived experience attended. The next meetings were cancelled due to COVID-19, then reconvened on Zoom from June 2020. The group decided its own name (BPD Dialogues), terms of reference and priorities for action.

What do you like about coming to the BPD Dialogues group?

I enjoy hearing and sharing stories with other sufferers of BPD. It's our own little escape space where we won't be judged as we all have similar issues that we can discuss and help each other navigate safely through. I will have experienced things with BPD that others haven't & vice versa so it helps in this aspect too.

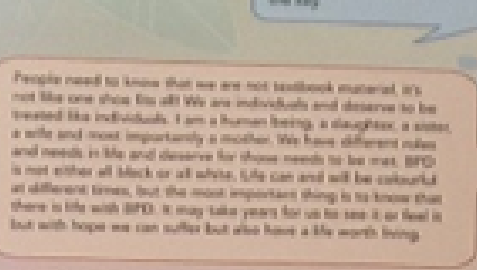
I like coming to the group as I can use my experience to help others. It helps me feel less alone as this diagnosis can be very isolating.



What would you like people to know about BPD?

I am an experienced borderline of 15+ years and I used to believe that was it. I couldn't get better, that I was stuck in my own prison with my distorted thoughts and morbid dysphoria but with the right therapy, awareness, understanding and medication it can be a beautiful thing once controlled. It doesn't have to define your life. Things improve and do get better, you just have to believe and, most importantly, have hope. Remember, you hold the key.

People need to know that we are not textbook material. It's not like one shoe fits all. We are individuals and deserve to be treated like individuals. I am a human being, a daughter, a sister, a wife and most importantly a mother. We have different rules and needs in life and deserve for those needs to be met. BPD is not either all black or all white, life can and will be colourful at different times, but the most important thing is to know that there is a life with BPD. It may take years for us to see it or feel it but with hope we can suffer but also have a life worth living.



What do you think needs to change to improve BPD services?

Information sharing and best practice. Where to get hold of information when you need it. School leavers and health centres need more information for young people. It doesn't have to be after the diagnosis that people learn about this. It could be for a best friend or family member. This could be what saves someone's life.

We need more training for professionals, so they have the right information about us. More steps to take away the stigma associated with BPD. Working alongside the group so we can improve things together.

Not one size fits all



Snippet 1 from Leaflet: How does BPD develop?

Most experts agree that BPD develops due to a combination of genetic and environmental causes. That means it is a mix of 'nature' and 'nurture'. The mixture of causes might be very different from person to person. Many people with BPD have had stressful experiences in their early life, such as abuse or traumatic life events. This can be subtle, for example: feeling unsupported, invalidated or emotionally neglected. Not everyone who has a diagnosis of BPD has a history of trauma, and not everyone who experiences trauma goes on to have BPD.

Creating the Leaflet: The Process

July 2020
• BPD Dialogues group agreed that writing a leaflet from a lived experience perspective was a priority

August 2020
• Review of existing leaflets by MHN, NHS Greater Glasgow and Clyde and Royal College of Psychiatrists

February 2021
• Monthly or more frequent meetings over 18 months to generate and agree content by a process of discussion and review. Much material to consider. Many low disagreements - all resolved through discussion

February 2021
• I felt not agreed
• Not reviewed through "Open to All" NHS process to ensure accessibility

March 2021
• Lengthy design process via Medical Illustrations dept
• BPD Dialogues Group had final control over layout, images, fonts and colours

October 2021
• Leaflet printed and distributed to all MHN Teams in NHS GGC
• Advertised through BPD Steering Group Newsletter, and staff Care Brief

February 2022
• Electronic version of leaflet on NHS GGC MyHealth App
• Plans to video accessibility on NHS GGC public website and through GPs

What went well?

I liked the methodology, focusing on one section at a time over several meetings to make sure it was good. We sometimes decided that certain things were better suited to a different section and held onto them. Once we'd written it all, we reviewed it all in one and tweaked it. We printed it in the order we wrote it.

We all learned how different each of our experiences were from diagnosis to treatment. None of us had the same journey. Each of us completely different. On the other side of that, it was helpful for us to understand how difficult it is for medical teams and the challenges they may face around diagnosis because it is so individual.

NHS leaflets are full of big medical words and terms that I don't understand. It's also smaller print and a font that's hard to read. Creating something on a coloured background with simple words in a bigger clearer font was life changing. It was filled with quotes and images that didn't feel clinical. It filled me with joy, we had something eye catching that was created by people with real life experiences of the diagnosis. Not your standard statistics and jargon that didn't apply to me and made us all the same. It came from people who know exactly how the condition affects you.

It was eye opening, fulfilling, and gave me a great sense of achievement. I loved every moment of it. There were differences of opinions but it's important to see everyone's views.

What challenges did you have to overcome?

There were challenges. For example, getting everyone's opinions on board and trying to make it non-medical. It was hard to decide what to include and exclude. The leaflet has turned out quite lengthy, but it's all great content. There wasn't anything which wasn't important. We could have written a book!

Trying to get the wording right, so our points came across properly. Having our views reflected in a productive manner. Also, having to compress all the information we had, as we had so much.

It was a longer process than we thought, but that's because we wanted to get it right.

Snippet 2 from Leaflet: How people react to getting a diagnosis

Everyone reacts differently to getting a diagnosis:

- It can be a relief to find that there is a recognised condition with a name, and that there are other people with similar symptoms. It can be hopeful to know that treatments are available
- It can be confusing if things are not discussed or explained clearly
- Sometimes people can feel upset or angry, as they feel this is a negative or stigmatising diagnosis

All reactions are valid, and there should be time to discuss your feelings about it with your doctor or other mental health professional.

What's a common myth about BPD?

There seems to be a myth that you cannot treat BPD. To be honest, I probably once believed this after two unsuccessful cycles of DBT. Thankfully the third cycle changed my life and every day I wake up armed with effective skills to battle anything that BPD throws at me.

That we are all attention seekers, we overreact and take things the wrong way, have split personalities, we're out of control, crazy, dangerous, time-wasters.

There is an assumption that everyone is the same: emotional, unstable. We all have different reactions to different triggers. You see it with different physical health professionals. Other problems are downplayed and palmed off as your BPD. We're not taken seriously when it matters for your physical health.

That we don't care, when in reality we can care too much, we just express it differently.

What coping skills do you find most useful?

Probably distraction - something creative. I like jigsaws. I count the pieces and take a systematic approach. It takes you away from your head to rethink things and not react immediately.

Usually, I always start by just grounding myself. I tend to use the STOP skill where I physically stop what I am doing if safe to do so, I then attend to my breathing using paced breathing. I can do this anywhere.

I've created my own coping mechanisms as the ones currently used by the Community Mental Health Teams aren't accessible or useful at all for me. Along with the visual stress I also suffer from chronic pain/fatigue and mobility issues. I have mobility aids in the house and use aids outside as well. So being told to go for a walk, when I physically can't get into one is like a kick in the teeth. I use a variety of craft materials to help me cope. Using different materials helps with a range of feelings. For example, I draw/paint something nice when I'm upset or scrunching up paper when I'm angry.

Self-compassion, staying in control, using 54321 (touch, smell, hear, see & taste), bringing the word STOP down on my rapid thoughts mentally.

What skills and values must healthcare professionals have when working alongside you?

I think healthcare professionals need more understanding and training on the actual diagnosis of BPD and the various traits each individual may have or present. They need to be more compassionate, demonstrate empathy and listen to the individual's current experiences. Validate our current emotional state, taking it seriously, noting verbal and non-verbal communications.

Those supporting us must be kind, compassionate, understanding, and patient. Actually listen to us. Involve us in our care plan and treatment. Ask our opinion. Get to know us as individuals. Not assume things. Don't make us feel like an inconvenience. Have a positive relationship with us.

Sit down and speak to the person, find out about them. Always introduce yourself and get their perspective before getting someone else's notes up. Forget their medical history for now. Listen to what they're saying.

Snippet 3 from Leaflet: There can be some positives too

People with a diagnosis of BPD can be very good at relating to other people and their emotions. This means we can be empathic and sensitive, and more understanding of others.

We can have more intense feelings than most other people - when we care, we really care!

This also means we can be much more approachable (on a good day), and easy to talk to.

Having strong emotions can also mean that we can feel passionate about things, and really notice little details that others might miss.

People with a diagnosis of BPD have often had to be more resourceful and resilient than they realise and can become more resilient with the right therapy. This does not mean a person always feels that they can cope with a situation, even if they have faced it before - it always depends on the circumstances at the time. Some people with a BPD diagnosis are highly creative and original in many different areas, like art, writing, singing or poetry.





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