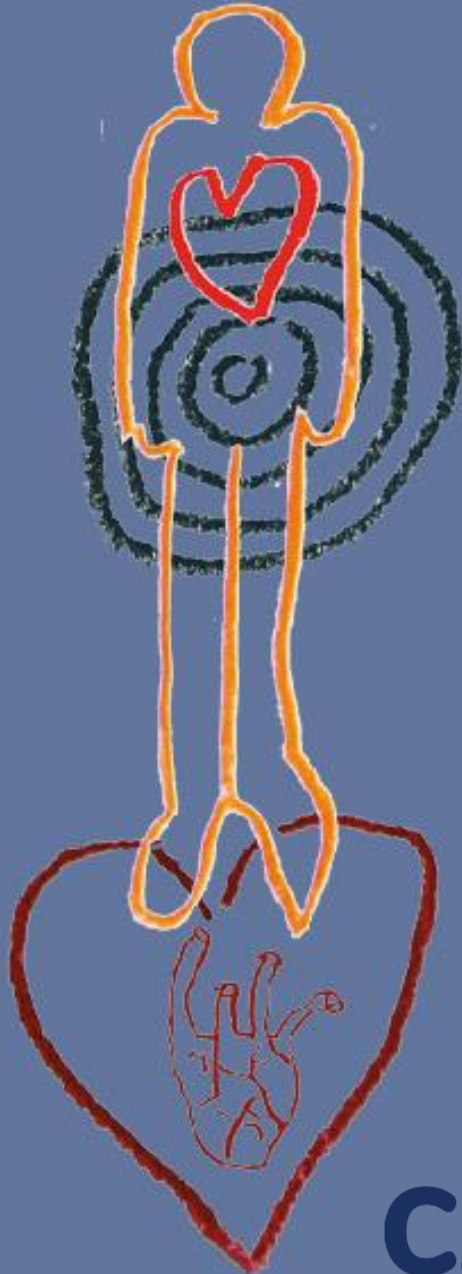


BPD Voices



CAPS

Much More Than A Label

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Introduction



Hello!

We are part of a collective advocacy group called Much More Than A Label. We all have shared experiences of Borderline Personality Disorder (BPD). Collective advocacy is about bringing people who have shared experiences together to make their voices louder and stronger.

This booklet is based on our individual experiences as well as many other experiences. They were brought together through discussions, survey contributions and through the questions we were asked when we delivered Much More Than A Label training. This booklet shares our voices - it does not provide advice.

Throughout this booklet we will use the term BPD. We realise that everyone has different thoughts and feelings about this label (as do we!), and that you might use a different term, such as EUPD (Emotionally Unstable Personality Disorder). We wanted to make it clear to people who might choose to read this booklet what it is about. Hopefully one day there will be a less stigmatising term for people who have a 'personality disorder'.

This booklet is for everyone - including those who may attract a diagnosis of BPD, those who care about them and health professionals.

Throughout the booklet there are reflective spaces for you to use as you wish. You might like to make notes and draw doodles. There are also questions in these spaces for you to consider at your own pace.

We wanted to create this because we have seen plenty of booklets about BPD, but none from the perspective of those with lived experience. We want to raise awareness, reduce stigma and provide reassurance so people have a better understanding and feel less alone.

Our experience is valid.

Your experience is valid.

Thoughts about diagnosis

One person's experience of BPD isn't the same as another person's. Everyone's experience is unique and valid.

BPD is a mental health diagnosis. Some identify with the diagnosis and find it useful. Others feel it's not a valid diagnosis and their experiences would be better explained by a diagnosis of complex trauma. There are whole movements dedicated to this.

"The label is very damaging and the stigma attached to it is unacceptable."

"I spoke to my psychiatrist who explained that sometimes a diagnosis isn't helpful and it is better to treat the symptoms. I told him I would prefer to have a diagnosis so I had something concrete to work with."

"I find the indiscriminate use of this label to excuse poor staff behaviour and standards of care appalling."

"As well as BPD diagnosis trapping you, it leads to people making false assumptions rather than looking at you as a person."

"I finally had a name for the nexus of symptoms I experience... It made sense of SO much. I now treat it more as a useful peg rather than defining label."

"I was relieved when I found out but at the same time very sad. I can understand fully why I have it, it just upsets me because I've always wanted to just be normal. I then realised what is the "normal", I can still be me with knowing that sometimes I may need more help than the significant other but that's ok."



You might think you have other diagnoses that could be considered alongside a BPD diagnosis. You might also feel that a BPD diagnosis isn't the right diagnosis for you and you want to explore this further.

"I have BPD and I also have an eating disorder, anxiety and ADHD. I'd rather have the diagnosis because it really helps me to understand 'okay, that's that part of me, but it's not all of me, it's a part of me'"

"I hate the diagnosis. My friends say they don't think it fits, but I can understand why I have it. No-one has ever sat down and talked to me about how I feel about it though. I feel like if I challenge the diagnosis then that is seen as confirming the diagnosis, so I'm such in a Catch-22 situation."

Here are some tips that we have found helpful for talking to a health professional about diagnosis and misdiagnosis that you might find useful:

- be coherent and clear in what you're saying;
- track your moods/symptoms over time because your moods can change in a pattern and at a different pace;
- if you have someone you trust to go with you to your appointment this can be helpful this might be a family member, a friend, or an advocacy worker (more information about independent advocacy can be found on the back page);
- print things out that you feel are relevant to take with you;
- you can write things down during your appointments and ask for a copy of any reports.

We know it can be hard to talk about this and that you might not have a health professional to talk to.

To find the most recent criteria used by the NHS, visit www.nhs.uk and search for 'borderline personality disorder'.

You can also read more on the [See Me website](http://seemescotland.org).
(seemescotland.org)

What BPD means to us

"To me it's an explanation of the symptoms I face every single day"

"My responses are extreme."

"It means that I'm disordered. It is not a helpful label."

"It means someone who has had one or more traumatic experiences or poor attachment in childhood, when I hear it that someone has likely had a tough time."

"A lot of the time I hate myself."

"It's a negative label that doesn't address my mental health needs."

"I think it is a complex mix of life history, personality, traits, experiences and overwhelming mental pain."

"An unfair label given to people, mainly women, to describe perfectly understandable behaviours that result from trauma and / or emotional distress"

"I struggle to trust people and have romantic relationships."

"I feel empty and sad a lot of the time."

"Things that wouldn't necessarily bother other people can send me into a major low that can take hours sometimes days to get myself out of"

"It makes my relationships super intense and I fear I push people away because of this. I find it difficult to understand and feel alone a lot of the time"

"Belief that I am bad."

"BPD is not a valid diagnosis but is a misogynistic response to emotional disturbance experienced by people (mostly female but sometimes male) who are struggling to survive experiences within our increasingly unequal oppressive sexist racist homophobic transphobic class society."

"Sometimes due to my unpredictable emotions I tend to behave in unpredictable ways."

"I do self-harm and that feels like a compulsion. I get no relief from cutting but it is intensely painful."

"Walking down the street - if someone is walking towards me I can feel quite panicky and want to push through them and bump into them to let them know I'm trying to walk past too. I get really mad about it."

"I can go from 0 - 100 in seconds"

"I feel like I'm the worst person in the world"

"My emotions dictate my life"

"I put myself in risky situations and display many self-destructive behaviours."

"Pseudo-psychotic experiences and dissociation affect cognitive functioning (e.g. memory, attention span, focus)"

Treatment and Support

Treatment and support for BPD can vary, partly because there isn't a 'BPD medication'. It's about treating the symptoms, and because people have such a range of symptoms, there is a big range of treatment and support. Experiences of treatment and support for BPD can also be varied because of what is available in your area. Some people find they get the support they need straight away, but sometimes it can be a struggle to get the support you need because of stigma, the place you live or the health professionals' level of knowledge and expertise. You deserve the right treatment so don't give up on accessing treatment when you need it.

"I know when I was first diagnosed, I was looking for a medication like a magic cure"

Sometimes, people feel a bit unsure about taking medication for symptoms of BPD. Medication has lots of uses and just because you're on medication now, it doesn't mean you will need it for a long time or need it forever. It can simply be to help you through a crisis.

Some people find that medication helps, but it's not the only option and no one should feel pressured into treatment they are uncomfortable with. If you have

difficulty expressing your views you can contact an advocacy worker.

"I have had a lack of treatment apart from medication. I was told borderlines do not respond to psychological treatment, it was only when my diagnosis was changed to PTSD that I got help."

In our experience, treatment and medication are not the sole route to recovery.

"What I had wasn't good enough – people can be empowered to say no if they feel that is the answer"

"There is no support. While I was labelled with BPD I was confronted with really poor attitudes towards my care. I was seen as a trouble maker and an attention seeker."

Here are some things that we have found helpful in managing BPD. Remember, you're the expert on your condition so it's fine if these don't work for you. It can take time to find what works.

- Support and talking to people is important, whether that's from family, friends, health professionals, advocacy, helplines (some suggested on the back page), support workers or support groups;
- exercise;
- yoga;
- doing nothing;
- listening to music;
- journaling;
- going out for a cup of tea;
- being outdoors.

Reflective space:

What are some things that you do to help yourself feel better?

Things that don't get talked about

Sometimes, there are things about BPD that don't get talked about very often. These include

- public perception;
- gender-based diagnosis;
- resources and funding;
- attachment and relationships;
- masking;
- change;
- and 'recovery'.

Not all of these things will affect everyone who attracts a diagnosis of BPD.

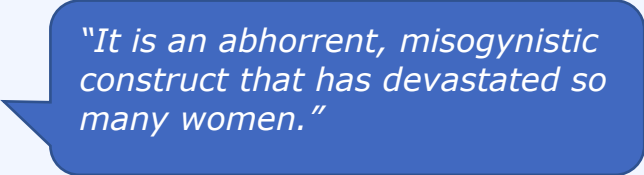
Public perception

The **public perception** of a person with BPD can be negative. If you seem like you're 'functioning' you're not seen as struggling, which isn't necessarily the case. While seeking help people have sometimes experienced being named as manipulative and attention-seeking. These are not acceptable words to describe someone with BPD, but some people refuse to stop using them.

Gender-based diagnosis

BPD is diagnosed in far more women than men. This has led to it being viewed as a discriminatory and oppressive diagnosis by many. The diagnosis can be seen as pathologizing women's emotions and as labelling a normal emotional reaction to an abnormal set of circumstances as a disorder.

Men are more likely to be diagnosed with anti-social personality disorder. Often men feel less able to talk about their feelings and so this may lead to underdiagnosis of BPD.




"It is an abhorrent, misogynistic construct that has devastated so many women."

Resources, funding and barriers to support.

Resources and funding are something that are being more widely reported in recent years, specifically the under-funding and cuts to mental health services. There is a lack of support and services for people with BPD and, and despite independent advocacy from groups like ours, things don't seem to progress or change much.

A lack of resources can also lead to the creation of barriers to accessing support. We have experienced issues around admittance as a hospital patient because of having a diagnosis of BPD. This is because you can be seen as 'attention-seeking' when you're actually in crisis. Maybe this is because the services aren't prepared for what that person needs.

There can be a perception among professionals that people with a BPD diagnosis will 'make each other worse' This means that while people with other diagnoses often have support groups, there is lack of support groups for people with BPD.



"A&E admissions - I felt like I was labelled as just being strange and like they didn't understand my diagnosis."

Attachment and relationships

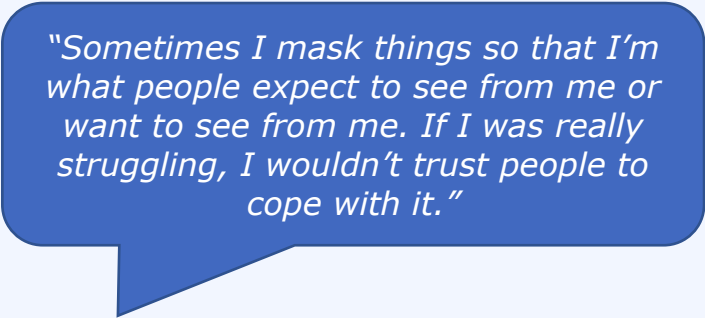
These can be difficult. Some people can become very attached to someone and they might have a favourite person or someone who feels particularly safe. For some people this can be because they didn't feel attached to and/or safe with anyone in their early lives and childhood, or the adults in their lives weren't

emotionally available and they need to compensate for this.

If you feel attached to someone, and you want to tell them and feel comfortable to do so, it's important to be honest with them and explain the context of BPD.

If someone with a BPD diagnosis tells you that they feel attached to you it is important to give considered thought to your reaction and try to be understanding.

Masking



"Sometimes I mask things so that I'm what people expect to see from me or want to see from me. If I was really struggling, I wouldn't trust people to cope with it."

Relationships and **masking** can also be difficult. Masking can look like presenting different versions of yourself in order to fit in, be liked, or to not be a burden which might not match up with how you're feeling inside. Masking can be linked to a fractured sense of self or identity or a fear of abandonment. It can be easier to play a role than to be yourself in a particular

environment. Trying to work out what someone wants from you can be very tiring:

Recovery

"Sometimes I mask things so that I'm what people expect to see from me or want to see from me. If I was really struggling, I wouldn't trust people to cope with it."

'Recovery' and BPD are not fully understood. Recovery is not a uniform process, but lots of people do manage to achieve remission from BPD. Some people worry about how even positive changes could affect their stability and they might be concerned that good things are going to disappear. You might also feel like you don't deserve something good to happen.

Remember that recovery is possible and that you are

"Recovery can be scary, when you finally get the help you need you don't want to lose it because you are a little better"

deserving.

"Recovery is a road not a destination."

"Recovery to me means support put in place."

"Recovery shouldn't be imposed by services and it should be self-defined."

"It's this broken ladder to climb up – it isn't an easy walk uphill. It's someone clutching on as they climb something that is unstable."

Reflective space:

What depictions of people with BPD have you seen in the media? Are they more positive or negative?

What do you think are some things that affect you because of a BPD diagnosis, but aren't talked about?

Stigma

Have you ever noticed people making assumptions about how you will behave and treating you differently because of it?

Have you ever been made to feel like there's something inherently wrong with you?

Have you ever struggled to access treatment or felt like you don't deserve support?

These are just a few examples of what stigma could look like.

"In my experience there's a lot of stigma around the choices people are making that are coping strategies associated with distress, for example addiction and risk-taking. There is a stigma because people are seen as difficult because they are engaging in behaviours that people don't 'approve' of or 'agree' with, instead of judging the behaviour you could ask 'what can we do to reduce the distress?'"

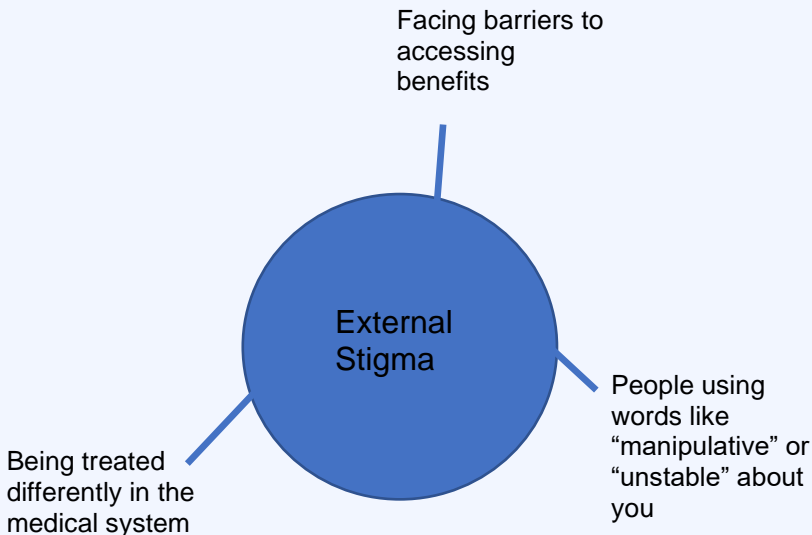
Reflective space:

What's your personal view of BPD? How do you experience stigma?

If you were to change the name for BPD, what would you change it to?

External stigma

People with BPD can encounter stigma in the medical system, when accessing benefits, in their families and social circles, and while simply navigating their day to day lives.



Many people who have a diagnosis of BPD find that they encounter stigma when they are navigating the healthcare system. Some people's experience is that medical professionals treat them differently because of their diagnosis or they experience "diagnostic overshadowing" where any medical issue is seen through the lens of BPD or attributed to BPD.

Although it's easy to feel helpless when you're navigating the healthcare system it's important to know that you are not alone. You have rights and these can be protected in lots of different ways.

These include:

- having honest conversations with your doctor, disagreeing with them or challenging their views if they are stigmatising;
- requesting a change of doctor if you feel uncomfortable with yours;
- complaining to the NHS;
- speaking to your elected representatives or the Ombudsman;
- finding more information from the Mental Welfare Commission (www.mwscot.org.uk);
- bringing a trusted friend or family member with you to appointments;
- asking for independent individual advocacy;
- and taking part in independent collective advocacy.

Internalised stigma

If you repeatedly experience people saying negative things about you just because you have BPD, it is difficult not to internalise some of that. Understanding external stigma goes a long way to beginning to understand the causes of internalised stigma.



It can also be difficult to understand the effects that having a mental illness like BPD has on other parts of your life without stigmatising yourself or your behaviour. For example, some people with BPD find it hard to focus on a task; it can be easy to get angry and frustrated at yourself rather than understanding this holistically as part of having BPD.

Members of our group have found that concentrating on not seeing yourself as less valuable because of your diagnosis can help in addressing internalised stigma. It's important to recognise that all your actions come from what you've experienced in life. Many people with BPD see their diagnosis as a result of trauma they have experienced. Reminding yourself of this context can be helpful in tackling internalised stigma.

Tackling stigma

Sometimes tackling stigma can be made even more difficult because of the stigma that already exists. Tropes around BPD, for example that people with the diagnosis are “dramatic” or “overly emotional” can mean that the act of standing up for yourself can become a stick to beat you with.

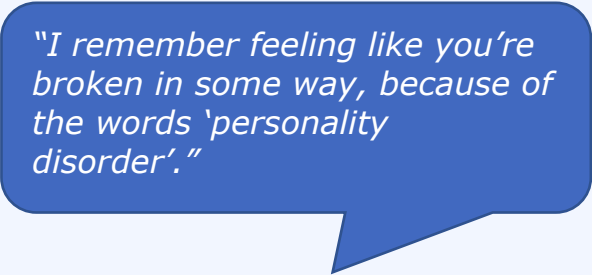
You don't have an obligation or a duty to tackle stigma. It can sometimes feel as though it is your responsibility to “fix” stigma immediately when you experience it. The person being subjected to stigma doesn't hold the whole responsibility for changing the world and the way mental health is perceived.

Is the term BPD stigmatising?

Any mental health diagnosis can attract stigma, but BPD/EUPD can be especially so because the words “personality disorder” can feel more blaming towards

the person, as though it's someone's personality that is the problem. Everyone is different and some people find the terms BPD and EUPD helpful. For others these terms can feel damaging and distressing.

Symptoms of BPD are shared with other diagnoses. Some people feel their symptoms and traits more closely align with CPTSD, autism etc. It's important that people feel that they can have conversations about this



"I remember feeling like you're broken in some way, because of the words 'personality disorder'."

with health professionals, family members and friends.

Coping Mechanisms

Some people find that their ways of coping with BPD can be stigmatised. It's important to recognise that these methods may be people's only way of coping with their distress. People with BPD might manage their distress through self-harm and other ways that can appear self-destructive to others. They could be experiencing really intense emotions and not know what to do with them. You can find information about support services for self-harm on the back page.

Tips for friends and family members

If you have a family member, friend or colleague who has shared their BPD diagnosis with you, remember that they are still the same person. The diagnosis *does not* change who they are.



It's important to recognise that this person felt safe sharing with you. Talking about mental health issues can be difficult and it's important to understand that. Be there for the person; the conversation is dictated by them, not you.

Here are some things that we would want you to consider:

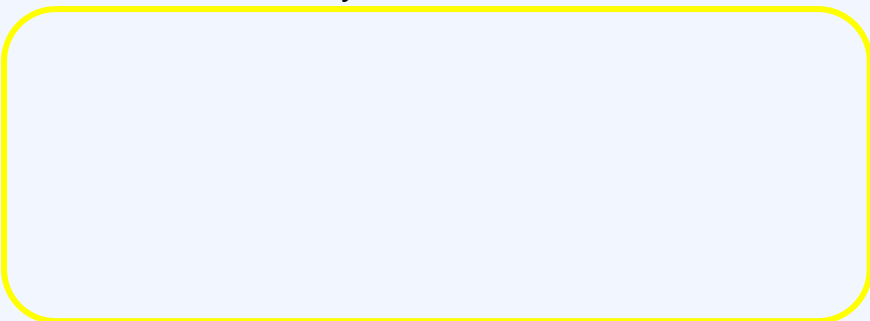
- listen, don't assume;

- be patient;
- be open-minded and open-hearted;
- hear what the person is saying rather than relying on google or information you find in books;
- you shouldn't judge the person or make them feel any pressure;
- if they don't want to discuss at length or answer your questions that's OK;
- be supportive;
- challenge harmful stereotypes;
- allow space;
- you don't have to 'fix' anything;
- they are the same person they were before the diagnosis.

What BPD means to me

We prefer to look at the personal experiences of people with BPD, rather than the label and cultural associations of BPD.

We've spoken a lot about our experiences of BPD. Here's some space to write or draw your thoughts about what BPD means to you:



What's next?

You might not feel ready to think about what's next. If you don't, don't worry, that's okay. But it's important to know there are things you can do if, and when, you feel ready.

Get involved

You might be interested in finding out about independent advocacy. We are the Much More Than A Label collective advocacy group from CAPS Independent Advocacy. Collective advocacy is where a group of people who are all facing a common problem and have had similar experiences get together to work on specific issues and have their voices heard. You can find further information about advocacy organisations on the last page of this booklet.

Here are some quotes from people with lived experience of BPD:

"Having a meaningful job that helped others, gave me a sense of identity"

"I'm living day to day – some days are good, some days are harder"

Reflective space:

What are your thoughts and feelings? What is one thing you have taken from this booklet that might help in the future?

Advocacy organisations:

- CAPS Independent Advocacy provide individual advocacy and collective advocacy across the Lothians, including the personality disorder project 'Much More Than A Label' who created this booklet. To get involved and find out more head to www.capsadvocacy.org or call 0131 273 5116
- www.siaa.org.uk/find-advocate/ you can search for independent advocacy organisations in your area

Not all services are for everyone, and different people have different experiences. It's important to find support that works for you. Don't give up, there is support for you out there and you are more than deserving of the right support.

The below services are all freephone and 24/7:

- Samaritans call 116 123 if you need someone to talk to
- Shout text SHOUT to 85258 if you're struggling to cope and want to talk with someone by text
- Edinburgh Crisis Centre 0808 801 0414 for emotional and practical support

Other services that you may find useful:

- Self-injury support 0808 800 8088 for women affected by self-injury, open Tuesday, Wednesday and Thursday 7 – 9.30pm

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