

Section **05**

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# Support and Treatment

*'Sometimes that's all you want, you want to get it out of your head and just get it out'*

This resource has been produced by the Consultation and Advocacy Promotion Service and funded by NHS Lothian

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# Resource Overview

## Why is there a Resource?

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The resource has been developed to promote better understanding and support for people with experience of personality disorder diagnosis.

The hope is that the resource can be used in a variety of ways:

- ♦ As a basis for finding out more about personality disorder and what people who have experience of this diagnosis find helpful and unhelpful
- ♦ As a starting point for discussion and reflection amongst staff with an interest in this area
- ♦ As a collaborative tool between service users and workers to discuss their experiences and views and promote a better working relationship

## How does the resource work?

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This resource has been designed so that people using it can **pick out what is most relevant to them at the time and pick and choose what they want to look at.**

The idea is not to **read the resource from cover to cover** (unless you want to!), but to **pull out and use the section and format that is most useful to you at the time.**

The contents of the resource can be used in a variety of ways, as an **individual, in groups or as a training tool.**

Not everyone will identify with everything in the resource, but the hope is that the topics will **provide some insight into the experiences of service users** who have been given a diagnosis of personality disorder and **a starting point for open discussion and understanding.**

## Who is the resource for?

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It is for anyone who has an interest in finding out more about personality disorder, but it is especially aimed at staff who work in this area and people who have lived experience of the diagnosis and want to be able to explain their experiences to others.

## What is the resource?

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It is a collection of information and reflective exercises about the experience of personality disorder diagnosis which has been put together through consultation with people who have personal experience of living with a personality disorder diagnosis.

The resource is written from the point of view of people with lived experience of personality disorder diagnosis and throughout the resource are direct quotes from service users.

The resource has been developed to display information in a variety of ways and to encourage discussion and reflection.

There are sections on:

- ◆ *The Experience of Living with Personality Disorder*
- ◆ *Personality Disorder Diagnosis*
- ◆ *Assumptions and Language*
- ◆ *Support and Treatment*
- ◆ *Attitudes and their Impact*
- ◆ *Living Your Life*
- ◆ *Local and General Resources*

Each section contains:

- ◆ *Section Summary Sheet*
- ◆ *Overviews of Service User Views*
- ◆ *Personal Quotes from Service Users*
- ◆ *Creative Writing or Artwork Contributed by Service Users*
- ◆ *Mind Maps and Word Clouds*
- ◆ *Space to Add Your Own Views and Experiences*
- ◆ *Discussion and Reflection Section*

## SECTION 05 : SUPPORT AND TREATMENT

# Section Outline

<b>Section Summary</b> .....	1
<b>What's Helpful in a Service?</b>	
Approach.....	3
Treatment .....	6
What Did This Mean For Me?.....	8
<b>What's Unhelpful in a Service?</b>	
Approach.....	11
Treatment .....	14
What Did This Mean For Me?.....	15
<b>Peer Support</b>	
Experiences .....	17
<b>Discussion and Reflection Section</b>	
Mind Map and Word Clouds.....	21
How Does This Relate to Me? .....	25
Things to Think About .....	26
Lived Experience .....	29



# IMAGINE....

How would you feel if when you went to get help for a problem you felt supported, understood and equal?

How would you cope if you went to get help and were dismissed, felt judged and were given no information?





**SECTION 05 : SUPPORT AND TREATMENT**

# Section Summary

**What's Helpful in a Service?****Approach:**

- ◆ Just being there
- ◆ Good level of knowledge
- ◆ Equal Relationships
- ◆ Acknowledge what can't be done
- ◆ No Time Pressure
- ◆ Reliable Service
- ◆ Person-Centred

**Treatment:**

- ◆ Good, reliable level of support
- ◆ Focus on your needs
- ◆ Well-trained Staff
- ◆ Coherent Service

**What Did This Mean For Me?:**

- ◆ Acceptance and Acknowledgement
- ◆ It's About Me
- ◆ Feeling Supported
- ◆ Feeling Like You Matter
- ◆ Good Signposting
- ◆ Personal Realisations

*'Where I have had the opportunity and openness from various professionals to develop quality, equal and respectful relationships, my recovery has been made possible.'*

## What's Unhelpful in a Service?

### Approach:

- ◆ Lack of Support
- ◆ Feeling Dismissed
- ◆ Lack of Communication
- ◆ Negative Responses
- ◆ Lack of Information
- ◆ Being Judged

### Treatment:

- ◆ Not Supportive
- ◆ No Coherence or Continuity
- ◆ Invalidation
- ◆ Lack of Explanations or Follow Up
- ◆ Conflicting Information or Views

### What Did This Mean for Me?:

- ◆ Made Things Worse
- ◆ Felt At Fault
- ◆ Fell Through Cracks in Services
- ◆ Negative Impact on Overall Health

*'Should you wait till you're cut down from a tree in your back garden before you can access your help?'*

## Peer Support

Being able to access peer support has been a very helpful experience for some people.

- ◆ Helpful not to feel so alone
- ◆ Colossal Validation
- ◆ Feeling that I'm not that different
- ◆ Quite reassuring, because everyone's quite normal
- ◆ There are lovely, bright, intelligent people with similar experiences

## SECTION 05 : SUPPORT AND TREATMENT

# What's Helpful in a Service?

### Approach:

#### Just Being There

- ◆ Listening
- ◆ Validation

*People accepting that what you say is real, even if it's real to you. It feels to me there's a difference between someone saying yeah well look at this objectively and actually there's another way of looking at this and saying no you don't feel that....Yes I do, no you don't, Oh OK I'm not allowed to...*

*With my support worker at the Edinburgh self harm project that was so important for us to talk about that and for her to have a really good understanding of what it means*

#### Good Level of Knowledge

- ◆ Observant
- ◆ Well-informed

#### Equal

- ◆ Objective
- ◆ Flexible
- ◆ Compromise from both sides
- ◆ Two-way

*We'll come to a compromise. I've sort of said to her sometimes I am unrealistic about stuff and that's when we discuss stuff and compromise and I said to her that I need to be able to tell you that you're being unrealistic, and I feel so far she's taken that on board*

## Acknowledge What Can't Be Done

- ◆ Admitting limitations
- ◆ Managing expectations

## No Time Pressure

- ◆ Relaxed
- ◆ Seen over time
- ◆ Open-ended
- ◆ No rush to discharge

*I think everyone with this diagnosis should receive talking therapy and DBT as standard rather than having to fight to get anything*

*I think it's understanding it, I think it's acceptance, and I think it's like an empowering attitude – it's not like yeah you've got BPD, you're going to be a nightmare, you're never going to get over these things, you're always going to feel like this, behave like this, instead it's like OK, you have learnt these behaviours because of these experiences and these are the ways you now think about things and just trying to understand it and I guess as soon as you're aware of something you can start to like change it or work it out more, So OK I've learnt to see things like this, because of this and actually I don't want to continue being like this so at least I have some understanding of where it's come from, and I can rationalise it*

## Reliable Service

- ◆ Diagnosis carries treatment with it
- ◆ Reasonable waiting lists
- ◆ Continuity

## Person-Centred

- ◆ Empowering
- ◆ Accepting
- ◆ Showing an interest
- ◆ Seeing you holistically





## Treatment:

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### A Good, Reliable Level of Support

- ◆ Support when you can't function
- ◆ Therapy and practical support together
- ◆ Hospital when needed
- ◆ Regular support
- ◆ Alternative ways of expressing yourself
- ◆ Good crisis support
- ◆ Somewhere safe and quiet to go

*Understanding the context of my life experiences and supporting me through my understanding of them and personal development and growth*

*It's just understanding that the way people behave or think is because somehow their experiences have led them to that, working that out and breaking that down and changing it*

### Focus on Your Needs

- ◆ Time taken to explain diagnosis
- ◆ Focus on behaviour AND feelings
- ◆ Not taking away control

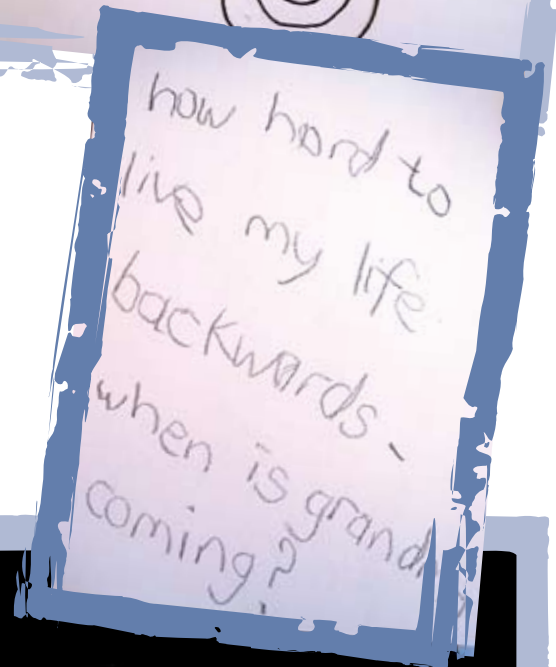
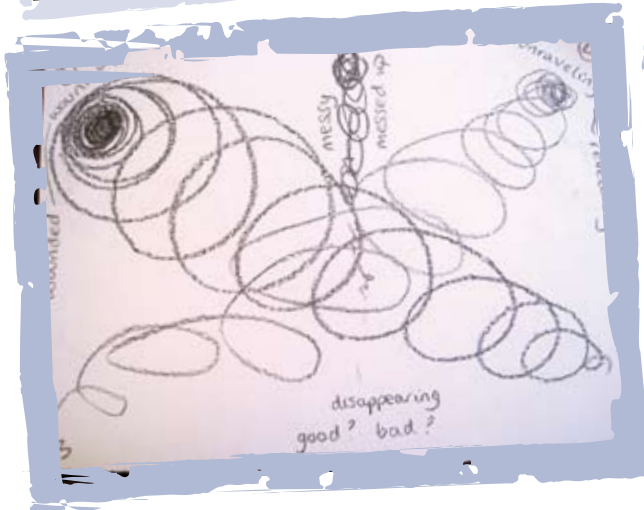
### Well-trained and Coherent

- ◆ Robust workers
- ◆ Variety and choice
- ◆ Good relationships
- ◆ Everyone singing from the same hymn sheet

*Having support from people not scared of my emotions whilst at the same time able to help me work my way through them and regain control. I feel the need to say that the emotions I am referring to are distress not aggression and anger*



leti hawthorn



## What Did This Mean For Me?:

### Acceptance and Acknowledgement

- ◆ Coping skills acknowledged
- ◆ Allowed to just be
- ◆ Able to express myself

*Everyone else seems to blame you for all of this stuff... You know you shouldn't be this angry, you shouldn't do this, but they'll just be like yeah you're angry you know so shout about it, tell us about it, it's better than like you know bleeding it out, you know shout it out*

*She was quite empowering, she'd look at different symptoms and she'd ask me to go away and read about my different symptoms*

### It's About Me

- ◆ Person-centred - not others' expectations
- ◆ Collaborative care plan
- ◆ Discussion
- ◆ Asked me to go away and read up on it

### Feeling Supported

- ◆ Someone to be there for me
- ◆ Broader understanding
- ◆ Felt like they understood

*In order for me to recover I needed to know what I could do, rather than just being instructed without any actual explanation of why or more to the point why is it better to act in one way than another*



## Feeling Like You Matter

- ◆ Touching base
- ◆ Treated like a human being
- ◆ Don't feel like a burden in therapy
- ◆ Others as mirrors to look into in group therapy

*Instead of having just one mirror to look into, which individual psychotherapy would offer, group psychotherapy offers you several mirrors with which to reflect yourself and that's what it does, it's great and one of the good things about having people who have experienced some of the things that you have experienced, you can ask them questions about them, when really what you're looking for are answers about yourself*

*I have respect for my CPN because she is clearly trying to support me and I know it must be a stupidly stressful job and she has answered my constant questioning!*

## Feeling Informed

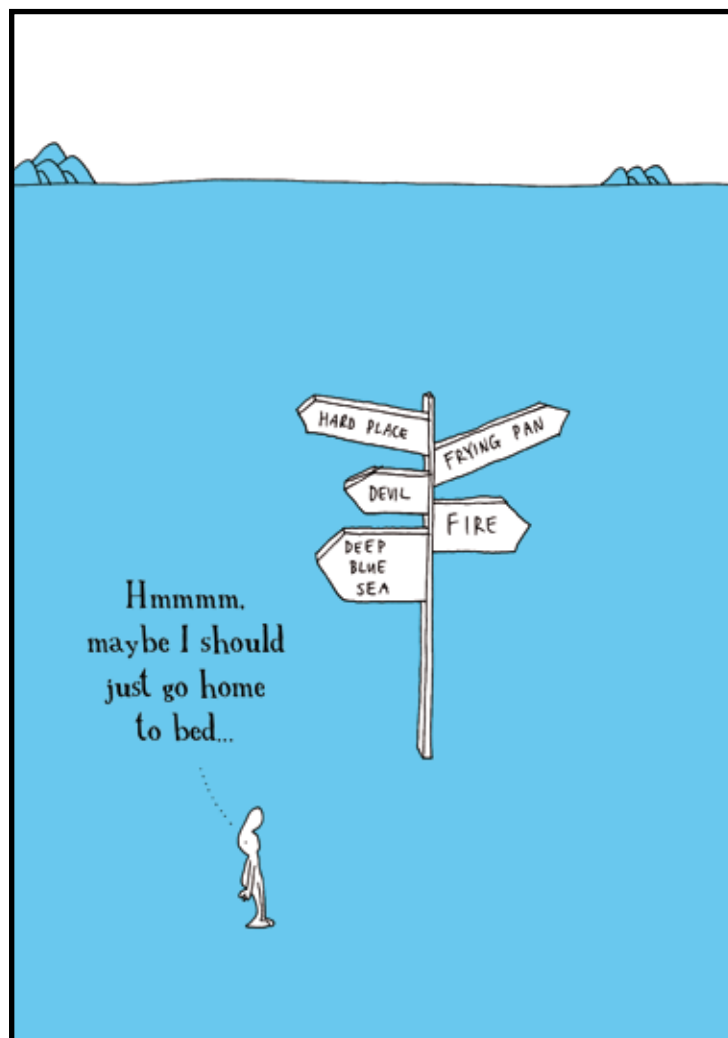
- ◆ Directed to useful information
- ◆ Financial support
- ◆ Help with benefits

## Personal Realisations

- ◆ Peer support
- ◆ Eureka moments
- ◆ Able to stop blaming myself

*I thought I was fully self aware and it turns out I had completely missed this whole other level of process*

*A balance and support and treatment that includes a better understanding for the user about what their condition is and what they can do to help themselves. Sometimes it feels like you are being instructed in what is the correct way to live rather than explaining it in terms of why it may be you act out in certain ways and why this is damaging to you*



## SECTION 05 : SUPPORT AND TREATMENT

# What's Unhelpful in a Service?

### Approach:

#### Lack of Support

- ◆ No standard approach
- ◆ Being told to distract yourself

*They tell you to do colouring in or do a jigsaw or something. But you can't concentrate. So it's hard, it's hard to put things together when you can't concentrate*

*Should you wait until you're cut down from a tree in your back garden and then you can access your help?*

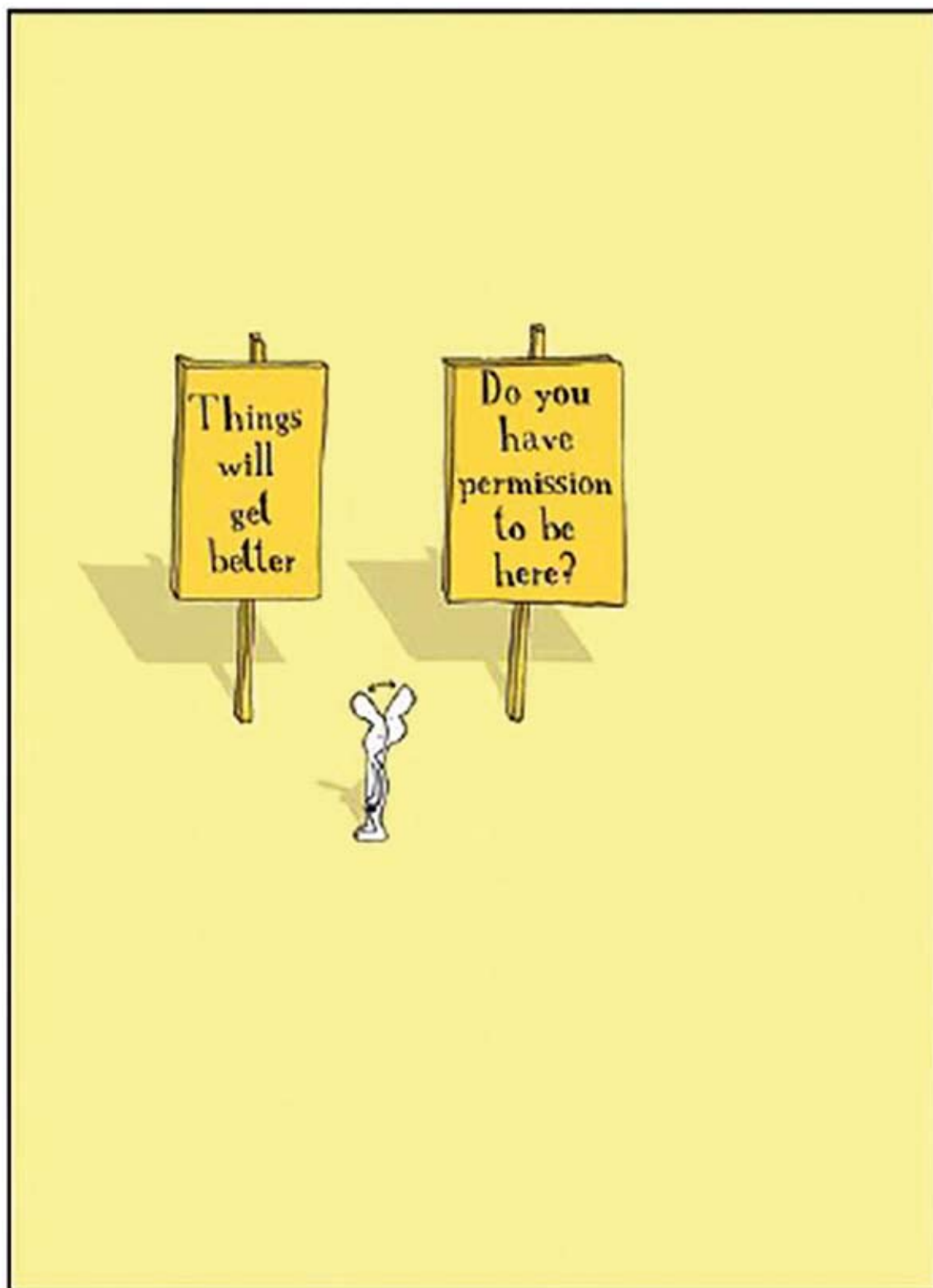
#### Feeling Dismissed

- ◆ Told you're 'high functioning' - which seems to mean you must be OK
- ◆ Told to go private
- ◆ Needing to seek out support

#### Lack of Communication

- ◆ Communication breakdown
- ◆ Not proactive
- ◆ Expecting change with no support
- ◆ Thinking you shouldn't know about diagnosis
- ◆ Not telling you about the diagnosis
- ◆ No information

*I couldn't look after myself at that time, I couldn't be by myself for a minute, I was really unwell and to think that anything was going to change when they hadn't put any change in place...*



### Negative Responses

- ◆ Lack of choice
- ◆ Service restricted to certain people
- ◆ Barred from services
- ◆ Not explaining treatment
- ◆ Cancelling appointments
- ◆ Endless waiting lists
- ◆ Feeling you are seen as a waste of time
- ◆ Being told you're not normal
- ◆ Assuming physical health problems are related to mental health

*I'm only allowed to speak to one person, I'm not allowed to speak to anyone else, something to do with my care plan... I've got to wait till he comes in, so if I've got a crisis I'm not allowed to talk to anyone but him. So I've got to keep my crisis on hold until he comes in*

*I've had lots and lots of difficult encounters in A&E following episodes of self-harm where I've been treated like a second rate citizen and been made to feel worthless!*

*I'm frightened to mention physical health problems in case they are dismissed as mental health*



## Treatment:

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### Lack of Support

- ◆ Treatment more about numbers than people
- ◆ Short, infrequent appointments
- ◆ Lack of interaction
- ◆ Not explaining treatment
- ◆ Inexperienced/unconfident therapist or worker
- ◆ No follow up
- ◆ Not told about available help or other services
- ◆ Therapy too difficult without other support

*They'll make up their own story and tell me what's going on for me and twist it and it's not the case...It makes me angry and frustrated. Sometimes I just walk out or ask them to leave*

### No Coherence or Continuity

- ◆ Being turned away
- ◆ Discharge after serious events with no help
- ◆ Lack of crisis support
- ◆ Service user tells professional about available treatment
- ◆ Conflicting advice
- ◆ Services bickering with you left in the middle

*Everything negative that I believed about myself... All that was totally reaffirmed, that I was as awful and terrible and pathetic a person as I believed*

## Invalidation

- ◆ Denying feelings
- ◆ Decisions made for you
- ◆ Deciding what my problems are
- ◆ Your own insight and coping abilities not acknowledged

*Saw a CPN a few times and he seemed to decide what my problems were for me and what the solutions should be. Another one who didn't really listen to me or consider what I know about myself*

## What Did This Mean For Me?:

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### Made Things Worse

- ◆ Stress
- ◆ Felt out of control after therapy
- ◆ Emotions escalating - not even left on a level
- ◆ Felt backed into a specific response
- ◆ Felt manipulated by the situation

*I've just gone from being a fully functioning human being who held down a full-time job to having to get someone else to write a letter for me and it felt like being forced into becoming dependent, which didn't really help very much*

## Feeling at Fault

- ◆ No acknowledgement of personal change
- ◆ No recognition of my efforts
- ◆ Having to explain yourself
- ◆ Made to feel 'difficult'
- ◆ Dismissed as attention seeking

## Falling Through the Cracks

- ◆ Passed around services
- ◆ Falling into service gaps
- ◆ No input

## Impact on Overall Health

- ◆ Having physical illness dismissed
- ◆ Afraid to bring up physical problems

*I've got some quite serious medical conditions, and I was kind of not laughed off, but told that it was stress or something related to my mental health condition... And you just think I'm going to end up dying from some physical condition because people are just fobbing me off with anti-depressants and anti-psychotics and stuff*



## SECTION 05 : SUPPORT AND TREATMENT

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# Peer Support

### Experiences

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Being able to access peer support on the internet and in person has been a very helpful experience for a number of people.

*Being part of the BPD group has been massively helpful to not feel so alone, and see that there are lovely, bright, intelligent people with similar experiences*

*The thing that has been particularly useful is peer support, is actually sitting next to people who appear relatively normal, who aren't howling at the moon, but who share certain personality traits I guess. They're funny, witty, charming folk, yet they experience some of the things that I do and it's that validation which is absolutely colossal, it's probably the biggest thing in all of this. It's feeling that I'm not that different to everybody, because I think any mental health problem is very isolating, and having that was great*

*I am now going to a self harm support group at the Royal Edinburgh which I'm finding very helpful*

*The best support I've found actually is this group, the Edinburgh group, and the Edinburgh website, that's been the best thing, cos like I say on the first meeting I don't know what I was looking for, a bunch of I don't know, loonies, what do a bunch of BPDers look like? It was only when I sat there in the cafe thinking I have no idea what I'm looking for...And that was a quite reassuring because everybody's quite normal...*

Although some people have been warned to avoid this type of group, which felt like an invalidating response.

*I felt disempowered as well, because she didn't credit me with my own ability, my own self-determination*

### FURTHER INFORMATION:

There is information about these groups and other local and national support in the information section at the end of the resource.





**SECTION 05 : SUPPORT AND TREATMENT**

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# Discussion and Reflection Section

**Mind Map and Word Clouds**

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The following pages contain a Mind Map and Word Clouds which give a summary of some of the experiences that have been described in this section.

These have been included to give an alternative view of people's experiences and a visual representation of the descriptions in this section.

The Mind Map was created by brainstorming around a main topic and splitting it into smaller areas before adding specific experiences. There are also some quotes included in the Mind Map which sum up people's experiences.

The Word Clouds were created by typing a jumble of words related to a specific topic. The words which are repeated most often come out in a larger font to represent their relative importance.

The Mind Map and Word Cloud try to represent a cross section of the experiences of the people who took part in the project and all of them may not relate directly to everyone.

There is information in the introduction section about how to create your own Mind Maps and Word Clouds.







inconsistent  
no information  
passed around  
huge waiting lists  
bickering explaining yourself  
conflicting advice barred deciding my problems  
coping not acknowledged  
not interacting  
no coherence  
restrictions denying feelings  
not supportive  
no follow up  
invalidating no choice  
dismissed



## How Does This Relate to Me?

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This page has been included for you to add your own views and feelings on this section, and anything else you want.

## Things to Think About

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In this section service users identified a number of things they find helpful and unhelpful when receiving support and treatment.

Is there anything you could you do specifically around each of these areas in your own work?

What might be ways that people think they are giving these things but not quite hitting the target? For example - trying hard to be reassuring, but in doing dismissing the person's experiences and being invalidating.

What might be the reasons staff do react in ways that service users find unhelpful? Do you think there is anything that might help staff to react in a more helpful way?

How could you explain the limits of what can be offered?

## Artwork in this Section:

Have a look at the artwork in this section.

What do you think the creator was trying to express in the picture?

How do you think the creator might have felt at the time?

Some contributors have written an explanation about their artwork.

### P5 Neglected Plant and Blooming Crocuses

The picture of the plant at Unit is to show how with BPD you are sensitive to the smallest signs of rejection...the fact that the plant is not well cared for used to really upset me. The crocuses are happy flowers getting good treatment!

### P7 Recurring Nightmare

At a dream workshop i shared a recurring nightmare from childhood, which lingers in me now. It's always black-and-white, always big balls chasing me round and round in a circle getting bigger and bigger, faster and faster. The facilitator asked what i might be able to do to change what happens. Gradually i got the image of balls of wool unravelling rather than being wound up so i worked this out through a series of illustrations, the last one of which was what was left having done the unravelling. When i got home that day i found a card which was LOVE being knitted in red wool. That's what i need to do - take the hurt, take the damage and make something beautiful with it...

### P10 Signpost

I was ready to grasp and run with anything, but no-one there to give direction, and I couldn't work out the path myself.

### P12 Things Will Get Better

A glimpse of hope, but would I be allowed it? I was referred for a therapy that even the referral letter said I couldn't attend around work, but told if I didn't accept it the CMHT would discharge me. When I met someone to discuss it, I was told that the waiting list was closed due to over-demand - "Do you have permission to be here?"

## **P13 Empty Parking Spaces**

Even tiny changes can knock you off course. When I came to the unit and found the parking spaces were empty I thought no one was there and I had been abandoned, when they had moved the parking to another place. This picture is also a symbol of the very strong and intense emotions you have - every time I see the empty spaces now I get those overwhelming feelings again and have to deal with them.

## **P19 Blessed are the Cracked**

I first saw this quote on a fridge magnet. It seemed really appropriate for the project - a resource by people with lived experience. But it's also true for me - when I first discovered I'd been given the diagnosis, it risked my career & my identity & I was told I was now 'severe and enduring' and 'this is how things will be'. It was involvement in the peer support group that showed me people living successful lives despite the label, & that I learned there was treatment. They let in light/hope.

## Lived Experience

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### What does it really mean?

There are a lot of words and phrases such as validation, acceptance and communication that sound great on paper but can be very hard to describe.

So what do these terms actually mean in practice?

The following pages each identify an area that people with experience of personality disorder find very important when receiving support and treatment.

Firstly think about how you would define each term and then think about or discuss what each of these terms mean in practice.

Have you come across people who would define the terms differently?

What problems might you face if a service user and worker have different definitions of these terms? How could you make sure you are working from the same definition?

Underneath each term there are some personal experiences and some do's and don'ts. Have you changed your view about what each term means after reading these experiences and why?

## Holistic:

**"Support based on mutual respect and person-centred, understanding the context of my life experiences and supporting me through my understanding of them and personal development and growth"**

**"Having support from people not scared of my emotions whilst at the same time able to help me work my way through them and regain control"**

**"In an ideal world it would be I think if someone presents or if someone's diagnosed with something like this then I feel they should be getting regular support at least from a CPN or support worker"**

What Helps	What Doesn't Help
<ul style="list-style-type: none"> <li>◆ Person-centred-about what I need</li> <li>◆ Alternative ways to express yourself</li> <li>◆ Therapy AND practical support to keep going in between</li> <li>◆ Help with finances and benefits</li> <li>◆ Medication/hospital if needed</li> </ul>	<ul style="list-style-type: none"> <li>◆ Feeling out of control after therapy appointments with nowhere to take it</li> <li>◆ Seen as a label, not a person</li> <li>◆ Told no help because you're 'high functioning'</li> <li>◆ Treatment more about numbers than people</li> <li>◆ Services bickering about your treatment</li> </ul>

## Acceptance:

**"Please LISTEN and do NOT judge me"**

**"I think it's understanding it, I think it's acceptance, and I think it's like an empowering attitude-it's not like yeah you've got BPD, you're going to be a nightmare, you're never going to get over these things, you're always going to feel like this, behave like this, instead it's like OK, you have learnt these behaviours because of these experiences-it's just understanding that the way people behave or think is because of somehow their experiences have led them to that, working that out and breaking that down and changing it"**

What Helps	What Doesn't Help
<ul style="list-style-type: none"> <li>◆ I'm allowed just to 'be'</li> <li>◆ I felt like they understood</li> <li>◆ Support for the issues you're having, not the label</li> <li>◆ Accepting the need for some behaviours</li> <li>◆ Accepting you've learnt to cope this way rather than just saying stop</li> </ul>	<ul style="list-style-type: none"> <li>◆ Made to feel 'difficult'</li> <li>◆ Denying my feelings</li> <li>◆ Being told you're 'not normal'</li> <li>◆ Barred or restricted from services</li> <li>◆ Being looked down on or patronised</li> <li>◆ Attitude towards me changed with diagnosis</li> </ul>

# Taking Responsibility:

“Not blaming you, everyone else seems to blame you for all of this stuff. You know you shouldn’t be this angry, you shouldn’t do this”

“Instead of seeing it like this behaviour has to stop it’s wrong it’s not the way that we’re socialised to present ourselves, OK so this something that you’ve learnt to do or a way to cope or whatever it is and then accepting that as it is and wanting to change it and giving the person hope”

“I did have a suicide attempt, but for four or five days before that I’d been saying I’m feeling suicidal and been told by the assessment team that I needed seeing as an emergency first thing the next day and didn’t hear anything. But then when I saw the psychiatrist ten days later, and I was told I had been impulsive”

What Helps	What Doesn’t Help
<ul style="list-style-type: none"> <li>♦ Accepting you’ve learnt to cope this way and helping you understand it</li> <li>♦ Challenging when you have the strength to respond to it</li> <li>♦ Support to gain insight and two-way discussion</li> <li>♦ Focus on behaviour AND feelings</li> <li>♦ Everyone following through on crisis plans so you know support is there</li> <li>♦ Validating your feelings as well as challenging them</li> </ul>	<ul style="list-style-type: none"> <li>♦ Just being told ‘take responsibility’ with no discussion</li> <li>♦ Everything done on the terms of staff and the service</li> <li>♦ Removing responsibility and then informing you when you should take it back</li> <li>♦ Using ‘taking responsibility’ as a reason not to give any support</li> <li>♦ Being told to ‘take responsibility’ when in crisis and too distressed to think straight</li> </ul>



## Peer Support:

**"Sitting next to people who appear relatively normal...who share certain personality traits. They're funny, witty, charming folk yet they experience some of the things that I do and it's that validation which is absolutely colossal"**

**"Being part of BPD group has been massively helpful to not feel so alone, and see that there are lovely, bright, intelligent people with similar experiences"**

**"It's a cool group, people just sharing experience and talking about what's helped for them and what hasn't helped, but in a sort of informal way"**

What Helps	What Doesn't Help
<ul style="list-style-type: none"> <li>◆ It's extremely validating</li> <li>◆ I couldn't tell who the group was to start with-they all looked normal</li> <li>◆ We can share information about what's out there and what we've found helpful</li> <li>◆ It's helped me gain more insight</li> <li>◆ It gives me hope</li> </ul>	<ul style="list-style-type: none"> <li>◆ Told meeting others with the same diagnosis will make you worse</li> <li>◆ Told you will meet some very ill and manipulative people</li> <li>◆ Felt like I wasn't credited with my own ability and self-determination</li> <li>◆ 'You're alright-it's the rest of them that are the problem...'What does this say about me?</li> </ul>

### FURTHER INFORMATION:

There are both local and national peer support services which are listed in the information section at the end of the resource.

## Time:

**"The fact that it's open-ended is really useful, so there's no fear of it ending early or finishing at a time when I don't feel ready"**

**"I said to her it would be useful to have monthly or six weekly appointments just to touch base, make sure I've got my meds so I don't run out, and see how things are going. And she's fine, she's like if you need to contact me during the week just give me a call"**

What Helps	What Doesn't Help
<ul style="list-style-type: none"> <li>◆ Flexible</li> <li>◆ Seen over time</li> <li>◆ No rush to discharge</li> <li>◆ Relaxed approach</li> <li>◆ Open-ended</li> <li>◆ Seen within a specific time limit</li> <li>◆ Explanation of timescales at the beginning</li> </ul>	<ul style="list-style-type: none"> <li>◆ Short, infrequent appointments</li> <li>◆ Endless waiting lists</li> <li>◆ Having to wait for years</li> <li>◆ Passed around services</li> <li>◆ People not contacting you when they said they would</li> </ul>

## Communication:

**"Where I have had the opportunity and openness from various professionals – social workers, support workers to develop quality, equal and respectful relationships my recovery has been made possible"**

**"We can be normal, polite, functioning kind of relatively normal looking, we don't have to look like this or act like that to have this diagnosis. It's always about assumptions"**

**"My GP admits to not knowing stuff, but that's fine, I'd rather that than get the wrong information, but it's not as in, 'Oh I don't know', it's 'I'll try and find out' or 'That's interesting', so it feels quite two way which again makes me feel I'm being treated a bit more like a human being as well"**

What Helps	What Doesn't Help
<ul style="list-style-type: none"> <li>◆ Being told what's going on</li> <li>◆ Continuity between people you're seeing</li> <li>◆ Discussion about treatment and support</li> <li>◆ Openness and honesty from both sides</li> <li>◆ Listening not assuming</li> </ul>	<ul style="list-style-type: none"> <li>◆ Lack of communication</li> <li>◆ Breakdown in communication between services</li> <li>◆ No contact at all</li> <li>◆ No engagement or interaction</li> <li>◆ Not returning calls or responding to letters</li> <li>◆ Making assumptions</li> </ul>

## Information and Explanation:

**"The doctor explained to me that the things that have happened to me have changed me so much"**

**"If this means getting to the bottom of things and actually deal with and actually get things on track for good, rather than a cycle of depression every three years, then that's good"**

**"It helped me make sense of myself and before I couldn't"**

**"With my support worker it was so important for us to talk about that and for her to have a good understanding of what it means"**

What Helps	What Doesn't Help
<ul style="list-style-type: none"> <li>◆ Time taken to explain the diagnosis</li> <li>◆ Broader understanding of my situation and how I got here</li> <li>◆ Biology-environment-genetics explained</li> <li>◆ I was able to stop blaming myself</li> <li>◆ Useful, accessible resources</li> <li>◆ Able to admit service limitations</li> </ul>	<ul style="list-style-type: none"> <li>◆ Not telling me about the diagnosis or giving me information</li> <li>◆ Not explaining treatment</li> <li>◆ Having to tell the staff what treatment is available</li> <li>◆ Not told about other help</li> <li>◆ Passed around services</li> <li>◆ Inexperienced staff</li> </ul>

## Supportive:

"We'll come to a compromise. I've sort of said to her sometimes I am unrealistic, about stuff and that's when we discuss stuff and compromise and I said to her that I need to be able to tell you that you're being unrealistic, and I feel so far she's taken that on board"

"She was quite empowering, she'd look at different symptoms and she'd ask me to go away and read about my different symptoms"

"The psychotherapist I'm working with just now her attitude is bang on I think she recognises that I can be in a bad place sometimes, recognises I can be in a good place sometimes, and we can do some good work and that this is treatable"

What Helps	What Doesn't Help
<ul style="list-style-type: none"> <li>◆ Compromise from both sides</li> <li>◆ Treated like a human being</li> <li>◆ Showing an interest in me</li> <li>◆ Focus on feelings AND behaviour</li> <li>◆ Empowering</li> <li>◆ Not taking away control</li> </ul>	<ul style="list-style-type: none"> <li>◆ Told I am in control without showing me how</li> <li>◆ Expecting change with no support</li> <li>◆ Cancelling appointments</li> <li>◆ Discharged after serious self harm with no follow up</li> <li>◆ Feeling blamed</li> <li>◆ Trying to reassure but dismissing my feelings</li> </ul>

## Validation:

"The fact that they are just there, and you don't necessarily have to get yourself out the house and go down...when I'm having a am I over reacting, is this just me, am I having a crisis...and when someone says do you want to come and have a chat you think OK so one somebody's listened, it's not quite legitimate, but you feel like someone does agree it's a crisis"

"I think it improved my relationship with her tenfold, she obviously accepted that my life is a bit shit and it can be helped by biting myself"

"People accepting what you say is real, even if it's real to you. It feels to me that there's a difference between someone saying yeah well look at this objectively and actually there's another way of looking at this and saying no you don't feel that... Yes I do... No you don't... Oh OK I'm not allowed to"

What Helps	What Doesn't Help
<ul style="list-style-type: none"> <li>◆ Acknowledgement of what you've already tried to do to help yourself</li> <li>◆ Acknowledging the difficulties I'm having and why</li> <li>◆ My insight and experience are acknowledged</li> <li>◆ Coping skills acknowledged</li> <li>◆ Just listening</li> </ul>	<ul style="list-style-type: none"> <li>◆ Having to explain yourself</li> <li>◆ Dismissed</li> <li>◆ No acknowledgement of personal change</li> <li>◆ Denying my feelings</li> <li>◆ Deciding what my problems are for me</li> <li>◆ Scared into a specific response</li> </ul>

## Notes

This image shows a full page of a document template designed for handwriting practice. It consists of approximately 28 evenly spaced, horizontal blue dashed lines extending across the entire width of the page. The background is plain white, providing a clear guide for letter height and placement. There are no margins, text, or other markings present.



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