

### Section 06

# Attitudes

*'The Label is a barrier to getting involved  
with understanding what it means'*

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?

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?

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 06 : ATTITUDES

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# Imagine...

How would you feel if when you went to get help you were met with positive and accepting attitudes?

How would you cope if you went to get help and were met with negative and assumptive attitudes?





**SECTION 06 : ATTITUDES**

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# Section Summary

**What's Helpful?****Attitudes which are:****Validating**

- ◆ Validate how you feel and respond
- ◆ Validate you being there
- ◆ Validate your experiences even if they don't share them
- ◆ Challenging without judging you

**Accepting**

- ◆ Accepting of you as you are
- ◆ Accepting your coping strategies
- ◆ Accepting you can be in good and bad places
- ◆ Accepting you expressing your feelings
- ◆ Treating you as an equal

**Positive**

- ◆ Positive about the diagnosis
- ◆ Positive about you
- ◆ Positive about your situation
- ◆ Positive body language and approach

**Holistic**

- ◆ Recognising the need for practical AND emotional support and offering
- ◆ Recognition of you as a an individual

**Knowledgeable**

- ◆ Good level of knowledge and understanding
- ◆ Able to explain the diagnosis and what's happening
- ◆ Support you to gain insight

**What's the impact?**

- ◆ You feel like someone cares
- ◆ You feel accepted as you are

## What's Unhelpful?

### Attitudes which are:

#### Assumptive

- ◆ Assuming things about people without getting to know them
- ◆ Assumptions made based on the diagnosis rather than the actual person
- ◆ Assumptions that you are manipulative
- ◆ Assumptions which are actually untrue

#### Conflicting

- ◆ Mixed messages between and within services
- ◆ Told to do things which are contradictory
- ◆ Told to do things by someone who has very little knowledge
- ◆ People putting their own interpretations on your experiences and needs

#### Negative

- ◆ Refused treatment
- ◆ Faced with patronising, unwelcoming, standoffish and even hostile and punitive attitudes
- ◆ Leave you feeling invalidated, misunderstood and disempowered

### Why are they Unhelpful?

- ◆ It reinforces all the bad things you already believe about yourself and puts you off seeking help

### What's the impact?

- ◆ You can tell even if someone is trying to hide it
- ◆ Attitudes follow the diagnosis – this is upsetting and confusing

## Friends and Family Attitudes

Positive	Negative
Still see you as the same person	Blaming the disorder for everything
Being gentle, kind and caring	Treat you like you're fragile and keep things from you
Continuing to trust you	Don't let you explain things
Reassuring you	Dismissing your problems
Accepting it as part of you	Avoid all discussion



## SECTION 06 : ATTITUDES

# Professional Attitudes

## What's Helpful?

### Attitude is everything!

#### Validation

When your emotions and responses seem very different to people around you one of the most important things you can receive is validation of how you feel and respond. Validation of you getting help and being with the person you are working with is part of that.

*You know what just being like nice, you know the people that have made me feel so much better at times when I've been really crap have been like a nurse that's put her hand on your shoulder or something like that or just been you'll be alright or just like smiled at you... just kind of validate you being there*

#### Acceptance

#### 'It's real to me!'

Acceptance of you as the person you are, where you are, rather than blaming you is also hugely important. Accepting that there is a need for certain behaviours and that this is the way you've learnt to cope rather than just saying stop. Accepting that you can be in good and bad places, and that this can vary a lot and letting you express your feelings is very important.

*To have that as being OK, 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*

## Being Positive

When people are positive, supportive and understanding, they give you hope. It can be as simple as chatting to you, putting a hand on your shoulder, giving you a smile or just being nice to you. Not making assumptions or stigmatising and recognising that you can do good work together gives you hope.

## Holistic

It is important to have support that is holistic and where you can get practical help and recognition of the day to day issues you have.

*Even though I 'seem' alright, I am still struggling and though I am struggling, I can still do a lot*

## Knowledgeable

It is also important to work with people who have a good level of knowledge and understanding so that they can explain the diagnosis, explain what's happening and why, support you to gain insight and challenge you without judging you. It's really quite basic – wanting to be treated as an equal and a human being.

*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 and I'm able to treat myself with the help of these other people and that I'm moving on, she challenges me well, but without judging me, that attitude I think is absolutely bang on*

## What is the impact of these attitudes?

Makes you feel someone cares

## Why are they helpful?

You feel accepted as you are

## Passing on Information to Other Professionals

It is really important to remember that, if mental health professionals have found the diagnosis of personality disorder difficult to understand at times, when the diagnosis is used to non-specialist professionals or non-professionals they may not have much or any understanding of the diagnosis. This may lead them to make assumptions or leap to conclusions that were not intended. It is more helpful to outline the problems and issues someone has rather than just providing a label.

## Carrots



## What's Unhelpful?

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### Attitude is still everything!

One of the biggest problems for people with a personality disorder diagnosis is the attitudes of other people. This can often be from professionals and people who are treating them. Stigma can come from people who really should know better. Many people find that when their diagnosis became one of personality disorder, attitudes towards them changed.

### Assumptions

Something which happens frequently is people seeing the label of personality disorder and making assumptions about someone without getting to know them. You can encounter attitudes that range from patronising, unwelcoming and standoffish to hostile and punitive. Responses from professionals seem to be filtered through assumptions about the diagnosis, body language can be hostile and staff do not try to understand. All of your behaviour and responses can be pathologised and misunderstood.

*The therapist said it was unusual my wanting to see the paper work too. She just put it down to my condition*

Assumptions about people can have very big consequences. You can be accused of lying because information has not been passed on correctly, you can be told that you should not work with vulnerable people by someone who has never met you. You can be ridiculed and treated badly, and people assume that you will be manipulative.

When people have these attitudes towards you, you can tell and then you begin to feel judged, dismissed and that you are seen as frustrating.

You can feel degraded and misunderstood by these attitudes. An interest in what is happening and asking questions can mean you are labelled as combative or having a problem with authority.



*I requested a psychiatrist appointment myself, but had the most upsetting and hostile interaction with a 'trainee' (one year placement person) where he stone walled me (when I asked for clarification on him saying there was no drug treatment for bpd he just kept repeating the same answer), and was dismissive of my issues. I only recently read his full report and was devastated by it. He also ridiculed me having presented at the royal ed emergency team with visual disturbances and extreme anxiety when the emergency team were actually understanding of my fears and presentation considering a strong family history. I feel like I am "in prison" now with a bpd diagnosis, am not being listened to or taken seriously*

## Conflicting Information

Conflicting information and mixed messages can also be very confusing. You can be told you are not engaging with treatment, but never given a choice about whether you wanted it or what type of treatment you were offered. You can be told it is all down to you and you can control the things that are happening, but at the same time not be trusted to make your own decisions.

*Nobody wants to know because it's borderline personality disorder – BPD – Something I can control apparently according to CPN and Consultant Psychiatrists*

You can be told what you ought to do by someone who has very little information or knowledge about the subject, and who gets information wrong rather than admit they are not sure. Also you might not even know about the diagnosis and can't understand why people have this attitude towards you or how best to respond.

You can be told you are not ill enough for treatment, but also be assumed to be violent and dangerous. You can find what you said being ignored and people putting their own interpretation on things, and focusing on the issues they think are important rather than what you think is important.

## A Long Way Down -Nick Hornby

"A man who wants to die feels angry and full of life and desperate, and tired and exhausted, all at the same time; he wants to fight everyone, and he wants to curl up in a ball and hide in a cupboard somewhere. He wants to say sorry to everyone, and he wants them to know just how badly they have let him down."



## Negative Attitudes

People might refuse to engage with you or refuse to treat you based on your diagnosis, they might shout at you, tell you to go away, act like you're a waste of space, not consult you about treatment, intimidate you, or even tell you to go and kill yourself.

*it was definitely assumptions, she knew hardly anything about me, I'd met her maybe once or twice*

All of these things just reaffirm all of your negative beliefs about yourself. They leave you feeling invalidated, misunderstood and disempowered.

### What is the impact of these attitudes?

You can tell even if someone is trying to hide it.

Attitudes towards you change with your diagnosis, which is upsetting and confusing.

### Why are they unhelpful?

It reinforces everything bad you already believe about yourself and puts you off seeking help.

## ego

I am who I am  
not who I was  
or yet might be  
but who I am  
and I'll fight for every part of me  
and tackle all adversity  
I am who I am  
so give me space

I am who I am  
not a shadow like I used to be  
but a fully human entity  
who's fought so hard to be just me  
I am who I am  
I cannot lie

I am who I am  
not the child you knew as me  
but who I am  
I've used so many masks, deceptions  
to hold my head high in the streets  
now I am who I am  
the **mask** is me

I am who I am  
and I'm sorry for who I was  
or tried to be  
but now for once I feel at one with me  
I'm strong and stubborn, the real me  
I am who I am  
I cannot turn round

I am who I am  
I'm shouting now  
I'm me, one woman  
who loves  
and hurts  
and fights  
to be the person I've been looking for  
myself where no deception lies  
and I know you can't accept that now  
you think I'm trying to fool once more  
but I am who I am  
that's all I know

## alter ego

Run and hide  
find a figure to admire  
leave the mirrors empty  
take  
the path  
without  
a sign  
ignore the one that might belong

Run and hide  
from everything that threatens you  
from all you fear might draw you in  
Just flee from home  
and keep on running  
run and hide

*No, I'm staying here  
the mirror's facing me  
my path is now seducing me  
I cannot run, just stand and breathe*

**leti hawthorn**

**SECTION 06 : ATTITUDES**

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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.

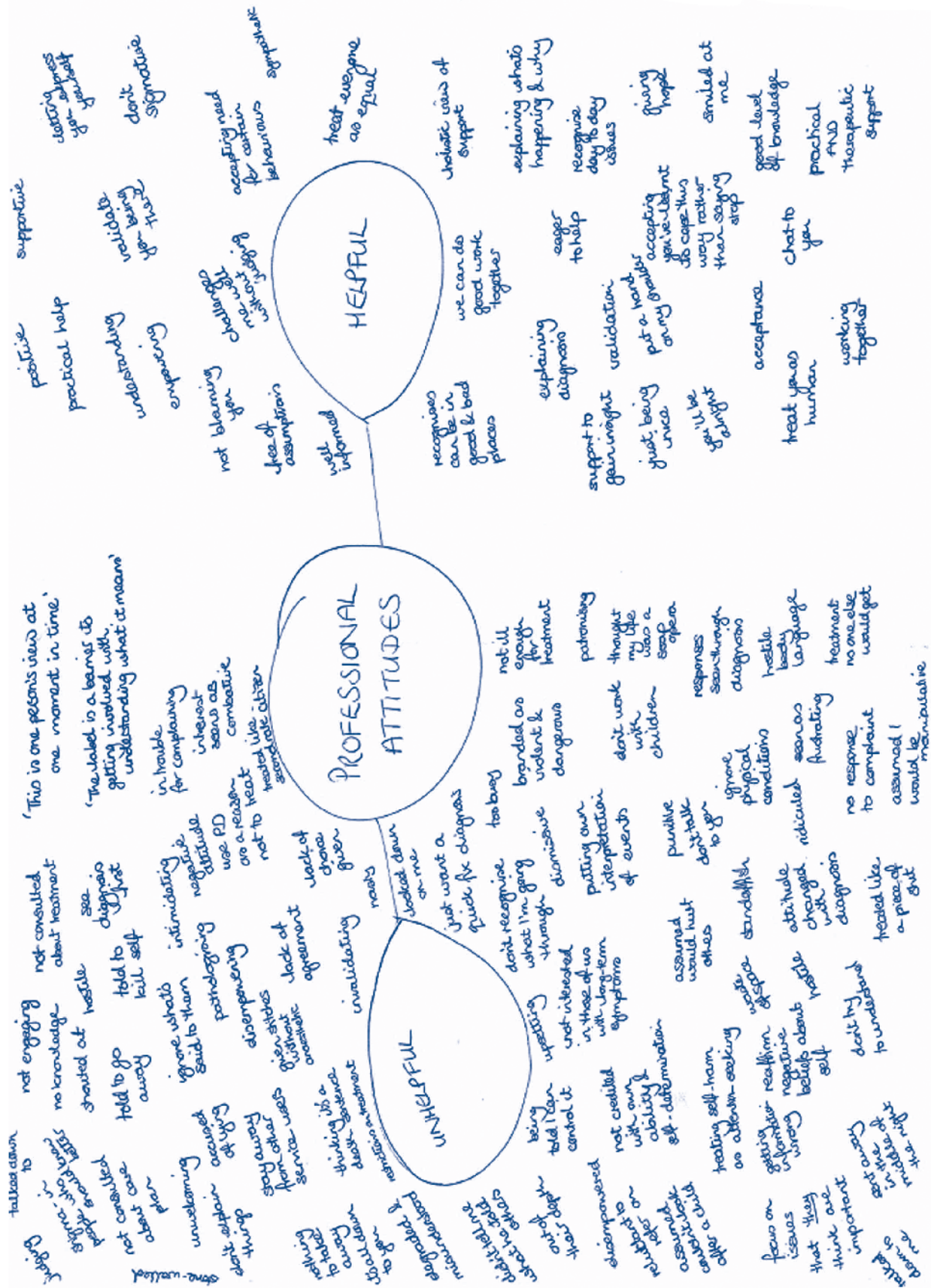
The Mind Map was created by brainstorming around a main topic and splitting it into smaller areas before adding specific experiences. There are also some quotes included in the Mind Map which sum up people's experiences.

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.











## 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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What do you think is the impact of both positive and negative attitudes in both the short-term and the long-term?

How do you think these attitudes arise?

What are the different reasons for both positive and negative attitudes?

Do you think negative attitudes in this area are a problem?  
If so, what can you do about them?

Do you think there are different things that individuals and services as a whole can do?

## Artwork in this Section:

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Have a look at the artwork/poetry in this section.

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

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

Some contributors have written an explanation about their artwork.

### P7 Carrots

Seems to say the way to understand people is to try and see the world from their point of view

### P10 A Long Way Down

An illustration.

### P12 ego and alter ego

A poem.

## Lived Experience

---

This section looks at some of the problems related to negative attitudes and tries to address them.

Look at the title of each table and think about/discuss how negative attitudes could have an impact in each of these areas.

Then look at the issues which have arisen for service users and think about/discuss how you could tackle these issues and best support someone dealing with them.

Can you think of any other issues that you think might arise and how you would try to deal with them?

After the discussion consider if this exercise has made you reconsider some areas of your practice. If so, which ones and why?

## Assumptions

## What Issues Can Arise from Negative Assumptions?

- ◆ Not responding or not responding quickly to treatment can sometimes be seen as failure and not trying hard enough
- ◆ The attitude that personality disorders are untreatable or not 'a real illness' is out-dated and wrong, but some people still seem to believe this
- ◆ After so long you get to know yourself and your illness, this sometimes isn't acknowledged when you say you need help or something isn't working
- ◆ It's difficult to make any comments, complaints or suggestions when you are sometimes seen as manipulative, attention-seeking or dramatic – it's hard to believe you are being taken seriously

## What Could Help?

This image shows a full page of primary-ruled notebook paper. It features ten sets of horizontal lines across the page. Each set consists of three lines: a solid top line, a dashed middle line, and a solid bottom line. The lines are evenly spaced and extend from the left margin to the right edge of the page. There is no handwriting or other markings on the paper.

## What Problems with Consistency Could Arise from Negative Attitudes?

- ## What Could Help?

[illegible]

# Communication

## What Problems with Communication Could Arise from Negative Attitudes?

- ◆ If you don't know what's going on it's very difficult to participate in your treatment, management or recovery
- ◆ Sometimes it seems there has to be 'action' on self harm and suicidal feelings – isn't asking for help beforehand responsible?
- ◆ Dissociation can cause real and very awkward problems and make it hard to remember what's been discussed
- ◆ You can be very good at masking and covering up and you can find it hard to drop that mask and be honest about how you are
- ◆ Seeming OK doesn't mean being OK

## What Could Help?

[illegible]

## What Problems with the Need for things to be Taken at Face Value Could Arise from Negative Attitudes?

- ◆ Reactions can seem totally out of proportion, but it doesn't mean they're not happening or real – give us a chance to explain rather than dismissing or invalidating it – just because it's small to one person doesn't mean it isn't a big deal to someone else
- ◆ People are often able to achieve insight – this has to be recognised – that we have it, but that in itself it is not enough to make everything change
- ◆ Need to be taken seriously and not get the impression you are being a 'waste of time' or 'drain on services'
- ◆ 'Acting out' is generally born of acute, constant and very intense frustration and desperation – not a desire to get attention

[illegible]



# Intensity

## What Problems Could Arise from Negative Attitudes when Dealing with Very Intense Experiences?

- ◆ Emotions are very intense and immediate, overwhelming and frequently seemingly senseless to others
- ◆ It can be very hard to regulate how you feel or calm yourself down
- ◆ It can be very frightening experiencing your own reactions and feelings and the reactions of others
- ◆ Intense emotions can take a long time to calm down again – in that period almost anything to 'make it stop' seems reasonable and afterwards it can be almost impossible to remember why
- ◆ Things can change incredibly quickly – fine to actively suicidal in hours or even minutes

## What Could Help?

This image shows a full page of blank primary-ruled paper. It features ten sets of horizontal lines across the page. Each set consists of a solid top blue line, a dashed middle blue line, and a solid bottom blue line, providing a guide for letter height and placement. The background is white, and there are no margins or other markings present.

## What Problems Could Arise from Negative Attitudes When there's a Need for Encouragement?

- ◆ You can end up very isolated socially and find it hard to see a way out
- ◆ Need encouragement of self-management – and that this can be achieved
- ◆ Constantly question yourself and the way you do everything – this is exhausting
- ◆ It can be difficult identifying appropriate emotions sometimes or feeling that you have a 'right' to feel them – especially after lots of input about controlling them

[illegible]

# Relentlessness

## What Problems Could Arise from Negative Attitudes When Feeling Overwhelmed by Relentless Feelings and Emotions?

- ◆ It's constant, it never lets up – imagine constantly having a buzzing radio in your head
- ◆ Chronic emptiness is almost impossible to describe and very hard to live with – nothing you do is any different or makes any difference
- ◆ You never know what's the best thing to do – to help yourself and to 'please' services

## What Could Help?

[illegible]

## What Problems with Sensitivity Could Arise from Negative Attitudes?

- ◆ You can be very perceptive, so even if someone is not actively saying negative things it can come across – these perceptions shouldn't always be dismissed as paranoia
- ◆ You can be very sensitive to rejection – this can be something as small as not returning a call or text or even not putting the 'xxx' at the end of a text
- ◆ You can be very impulsive/compulsive – lacking in boundaries at that moment in time – and it feels like there IS no control – maybe there's not
- ◆ You can get caught in black and white thinking – your last interaction with someone is definitive – your opinions and feelings towards others change constantly

[illegible]

# Individuality

## What Problems with Individuality Could Arise from Negative Attitudes?

- ◆ We are all individuals – it is very difficult to deal with others' assumptions based on 'criteria' or other perceived wisdom
- ◆ It is important to consider everyone holistically and that you have other areas to your life and are not just this annoying, no-hope patient
- ◆ You can get stuck in a Catch 22 situation – a good period means you are discharged from services with no support and going down again means waiting for re-referral. Trying to keep these services in the interim can be seen as exaggerating your condition or trying to get attention – as can returning to the service in a crisis

## What Could Help?

[illegible]



# Friends and Family Attitudes

I feel like most people understand  
the symptoms, but not how it feels





**SECTION 06 : ATTITUDES**

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# Friends and Family Attitudes

**What Can Be Helpful From Others Around You?**

---

**Attitude is still everything!**

*You're still the person you were yesterday*

It's very helpful when other people can see beyond the diagnosis, and can use it as a tool to better understand you or go and seek out information. Being gentle, caring and patient can go a long way to helping as well as letting you say when you feel under the weather. Trying to understand, accepting it as part of who you are, continuing to demonstrate trust in you, reassuring you that you are doing well and continuing honesty are all helpful and supportive attitudes.

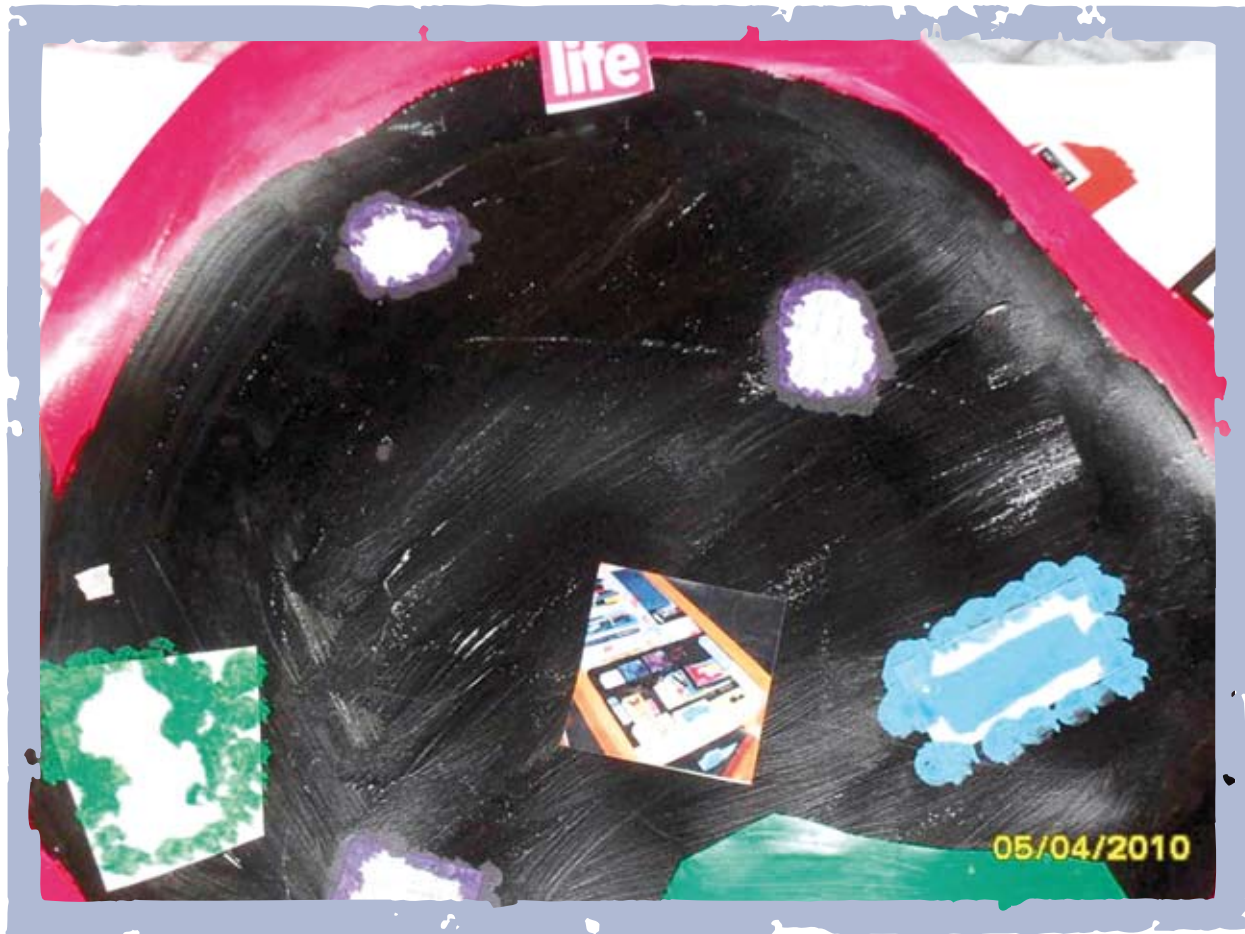
*I had so many stupid reactions I don't want to try any more*

When friends and family avoid discussing things it can be lonely, invalidating and frustrating. Not wanting to know, or look at information and withdrawing support aren't helpful responses.

People see you're upset and blame the disorder rather than think of it as a normal reaction. People treat you as if you're really fragile and keep information from you.

Being judged, patronised or not allowed to explain what's happening, feels very dismissive.

*He's never given me time to sit and explain what's going on inside my head (partner)... He turned around and said it's all inside your head, there's nothing the matter with you*



**SECTION 06 : ATTITUDES**

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# Discussion and Reflection Section

**Mind Map and Word Cloud**

---

The following pages contain a Mind Map and a Word Cloud 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.

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The Word Cloud was 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.

seek out information  
think you're fragile  
patronising  
showing trust  
accepting you trying to understand  
patient blame the disorder  
see beyond diagnosis reassuring  
avoiding discussion judging  
gentle withdrawing caring

## Helpful

- 'Don't kill yourself or I'll kick your head in'
- Think of me saying 'DON'T!'
- Have been able to keep career/registration
- Quick response
- Nice, but unaware - check up, do their best
- Reassurance - pointing out better than was - congratulating
- Looking at information
- Trying to understand
- Able to say when feeling mentally under the weather
- Sought out information
- See beyond the diagnosis
- Diagnosis useful to explain to others
- Caring - being gentle, patient, generally looked after
- 'You're still the person you were yesterday'
- Continued trust eg. babysitting
- Part of who you are

## Unhelpful

- Can't live with family
- People withdrawing support
- Lack of information/understanding
- Avoid discussion - lonely/invalidating/frustrating
- Don't want to know
- Don't look at information
- 'Had so many stupid reactions, don't want to try any more'
- Treated like really fragile - not told about things like family illness
- People see you're upset and blame the disorder rather than normal reactions
- Something physical would be easy to talk about
- Feel have put people through a lot with behaviour in the past
- People don't want to know
- Again lack of interest
- Scared of what they might see
- Don't accept what happened
- Judgemental - freak/weirdo
- Don't listen/change the story
- Don't believe in condition/missing writing
- Patronising 'I'm really sorry'
- Don't allow to explain
- Feel dismissed by lack of understanding

## OTHERS' ATTITUDES

- 'don't know how much of it is me not wanting to talk to people'
- don't want to talk about suicidal ideation to close relatives/friends
- people on internet: they understand & are not going to freak out
- other people w/ mlt issues understand to a degree
- 'I feel like most people understand the symptoms, but not how it actually feels'



## **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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How can people with a personality disorder diagnosis be supported to explain the situation to those close to them?

How could you help friends and family/carers to better understand the situation and support the person while looking after themselves?

## Artwork in this Section:

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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.

### **P34 My Island.**

My life – Included is my 'safe home', everything organised, writing, books to read, a swimming pool, parks, sounds nice but its surrounded by darkness...



Notes

Handwriting practice lines consisting of 20 horizontal dotted lines.

## This image shows a full page of a document template designed for handwriting practice or general writing. 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 contrast for the lines. There are no margins, text, or other markings present on the page.

Notes

Handwriting practice lines consisting of 20 horizontal dotted lines.

