

Section 03

The Diagnosis

*'I'm still the same person I was
before I was diagnosed'*

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!), **www 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?

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?

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*

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Finding Out

IMAGINE...

How would you cope if you found out you had a diagnosis that suggested there was something wrong with you as a person?

How would you feel if you discovered people who were treating you had known about this diagnosis for years and never told you?

How would you manage if you were told this diagnosis, but given no information about it at all?

SECTION 3 : THE DIAGNOSIS

Section Summary

How Did You Find Out About Your Diagnosis?

I was told...

directly by someone treating me

- ◆ My CPN told me
- ◆ My Psychiatrist told me
- ◆ My GP told me
- ◆ A hospital doctor told me

I had to ask...

and sometimes had to really push for information

- ◆ I bounced between my GP, psychiatrist and psychologist asking
- ◆ I was treated for depression for years
- ◆ It was a long drawn out process
- ◆ I asked - I knew it wasn't depression
- ◆ My GP didn't want me to know

No one told me...

it wasn't planned and it was sometimes very distressing

- ◆ It was in a hospital discharge letter
- ◆ It came up in occupational health interview
- ◆ It was in an insurance report
- ◆ I spotted a comment in a letter
- ◆ It was in a report I requested
- ◆ I was told when I woke up in hospital
- ◆ It was on a report for benefits
- ◆ My partner suggested it
- ◆ I worked it out myself
- ◆ Never been told, but saw my notes

Finding Out:

What Was Helpful

- ◆ Useful Starting Point
- ◆ Told about contributing factors
- ◆ Concentration on one diagnosis
- ◆ Hasn't changed my support
- ◆ Accessed Peer Support

What Was Unhelpful

- ◆ No one explained why
- ◆ I had no signposting to information
- ◆ Only got information after I asked
- ◆ Didn't have a chance to ask questions
- ◆ Don't understand how it relates to me
- ◆ Told don't know what to do with you
- ◆ I had been told it was untreatable
- ◆ Given the criteria and sent away

What Was Your Reaction?

Finding out a diagnosis of Personality Disorder can evoke strong emotions and reactions:

Positive Reactions	Negative Reactions
Fits my experiences	Feeling labelled/misunderstood
Makes sense of my situation	Am I dangerous?
Like being given a map	Feels judgemental - the blame is on YOU as a person
I already thought that	Applied because nothing else fits - people don't understand me
At least she told me	Comes as a jolt

When You Get the Diagnosis What Would Be Useful?

Information and Support

- ◆ Someone there when you find out
- ◆ Explain how it relates to you
- ◆ Explain why diagnosis has been made
- ◆ Information about the condition
- ◆ Signposting to reliable information
- ◆ Given information without asking
- ◆ Clear follow up support which will happen very soon

Open Discussion

- ◆ Someone to discuss the diagnosis with
- ◆ Not to have it hidden from you
- ◆ Understand you might be upset and need time to get used to it
- ◆ Right to challenge it if you disagree
- ◆ Diagnosis after proper assessment
- ◆ Information about treatment options and choice about which you want
- ◆ Positive and open attitude to being given diagnosis and moving forward

SECTION 03 : THE DIAGNOSIS

Finding Out About the Diagnosis

How Did You Find Out About Your Diagnosis?

The diagnosis of personality disorder seems to come from different people at different times.

There seems to be a real problem with telling people about their diagnosis.

Very few people had been told about their diagnosis straight away. Many people had to specifically ask what their diagnosis was before anyone would tell them.

I was told...

A few people were directly told about the diagnosis by a professional who was treating them:

- ◆ I was told by my Community Psychiatric Nurse
- ◆ My psychiatrist told me it was clear I had this diagnosis
- ◆ I heard it from my GP
- ◆ I found out from a doctor when I was on a psychiatric ward

I was told by my CPN the very first time I met her; because I had been diagnosed with many different things before she had discussed my case with a doctor

I had to ask...

But many other people had to specifically ask for the information and in some cases really push for an answer:

- ◆ I bounced between my GP, psychiatrist and psychologist asking for a diagnosis
- ◆ I was treated for depression for years
- ◆ I was only told many years after diagnosis
- ◆ It was a long drawn out process
- ◆ I asked as I knew it wasn't depression
- ◆ My GP didn't want me to know

I said to her what do you think I've got and she goes well I don't like labelling people. And I said well if you were to label me and she went on about labelling for a bit longer and I got the thumbscrews out and finally drew it out of her that she thought that I had, well she said I had the classic symptoms of borderline personality disorder I remember a feeling of oh my bloody God, but at least she told me

No one told me...

A large number of people found out in a way that wasn't planned, which some people found very distressing:

- ◆ It was in a hospital discharge letter
- ◆ It came up in an occupational health interview and I didn't know about it
- ◆ It was in an insurance report
- ◆ I read it in my hospital notes
- ◆ I spotted a comment in a GP letter
- ◆ I picked up a report I'd requested from outpatients
- ◆ I was told when I woke up in the Intensive Care Unit
- ◆ I found out the professionals had been using the label for a while
- ◆ When I signed up for benefits it was written on the report
- ◆ I worked it out myself
- ◆ My girlfriend suggested it
- ◆ I have never been told - I am told I am being treated for depression and anxiety

I have never been told about my diagnosis

When You Were Given the Diagnosis...

What was helpful?

- ◆ It was a useful starting point
- ◆ I was told about the factors that might have contributed
- ◆ There is now a concentration on one diagnosis
- ◆ It hasn't changed the support I receive
- ◆ I've been able to access peer support

What was unhelpful?

- ◆ No one explained why I was given the diagnosis
- ◆ I had no direction and ended up finding scary information on the internet
- ◆ I only got information after I asked for it
- ◆ I was given the criteria and sent away
- ◆ I got leaflets on emotion, but no specific information
- ◆ I didn't have a chance to ask questions
- ◆ I had been told it was untreatable
- ◆ I don't understand how it relates to me
- ◆ I was told they didn't know what to do with me



leti hawthorn

What Was Your Reaction?

A diagnosis of personality disorder is not something most people are expecting to hear and can evoke very strong reactions and emotions.

Does that mean you're telling me my entire personality is flawed?

There can be positive reactions, feeling that it fits your experience and makes sense of your situation.

But there can also be negative reactions, feeling your stomach sinking, feeling labelled and misunderstood. The diagnosis can feel really judgemental, and it can come as a jolt and can leave you wondering if you are dangerous. It can be a horrible and upsetting thing to hear and you can feel it's your own fault, and also that if you get upset it's your own fault, and it can seem like something shameful. You can just feel utterly gob smacked.

It can also leave you totally and utterly confused to be given a diagnosis of personality disorder. It can feel like it's a label that has been applied because nothing else fits, as a cop out or because the member of staff doesn't understand what is going on for you.

It just feels like saying that there's something wrong with YOU, cos it's your personality, it feels a bit like putting the blame on you for being this misformed character rather than you're having an illness or whatever

It can feel as though it's a question of not fitting tick boxes for other diagnoses or leave you wondering what's so special about this diagnosis when you've been given many other ones. If you don't agree with the diagnosis it can feel as though it is set in stone if you try to challenge it.

It can be a very daunting experience even to go to the appointment, and very difficult to be left with a label and no information or support.

I've never told anybody ever, all my life been really good, got a really good social façade, it was completely hidden, completely hidden from my husband, anybody that knows me would never guess. And then you're sitting in a room telling complete strangers something that you've never even said out loud ever in your life, and I came away and I think after about a week or so I just felt what did I get out of doing that, I felt really, really shit

When You Get the Diagnosis...

What would be useful?

Information and Support:

- ◆ Somebody with you when you find out
- ◆ An explanation of how it relates to you
- ◆ An explanation of why this diagnosis has been made
- ◆ Information about the condition
- ◆ Signposting to reliable information
- ◆ To be given information straight away without having to ask for it
- ◆ Follow up support given as soon as possible

It would have been nice if somebody had sat down and talked to me, instead of giving me a blurb ten minutes before I have to go back to work, and I have to go back to work and keep my head straight

Open Discussion:

- ◆ Somebody to discuss the diagnosis with
- ◆ Not to have it hidden from you
- ◆ An understanding that it might be upsetting to hear and you'll need time to get used to it
- ◆ The right to challenge it if you don't think it's right
- ◆ To be diagnosed after a proper assessment
- ◆ To be told all about the different treatments available and given the option of which you prefer
- ◆ A positive and open attitude to being given the diagnosis and moving forward with it

I'd have liked to find out with somebody there, and to be able to go what does this mean and so what happens now, even if what happens now is we don't know, we'll have to develop that over time

SECTION 03 : THE DIAGNOSIS

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.

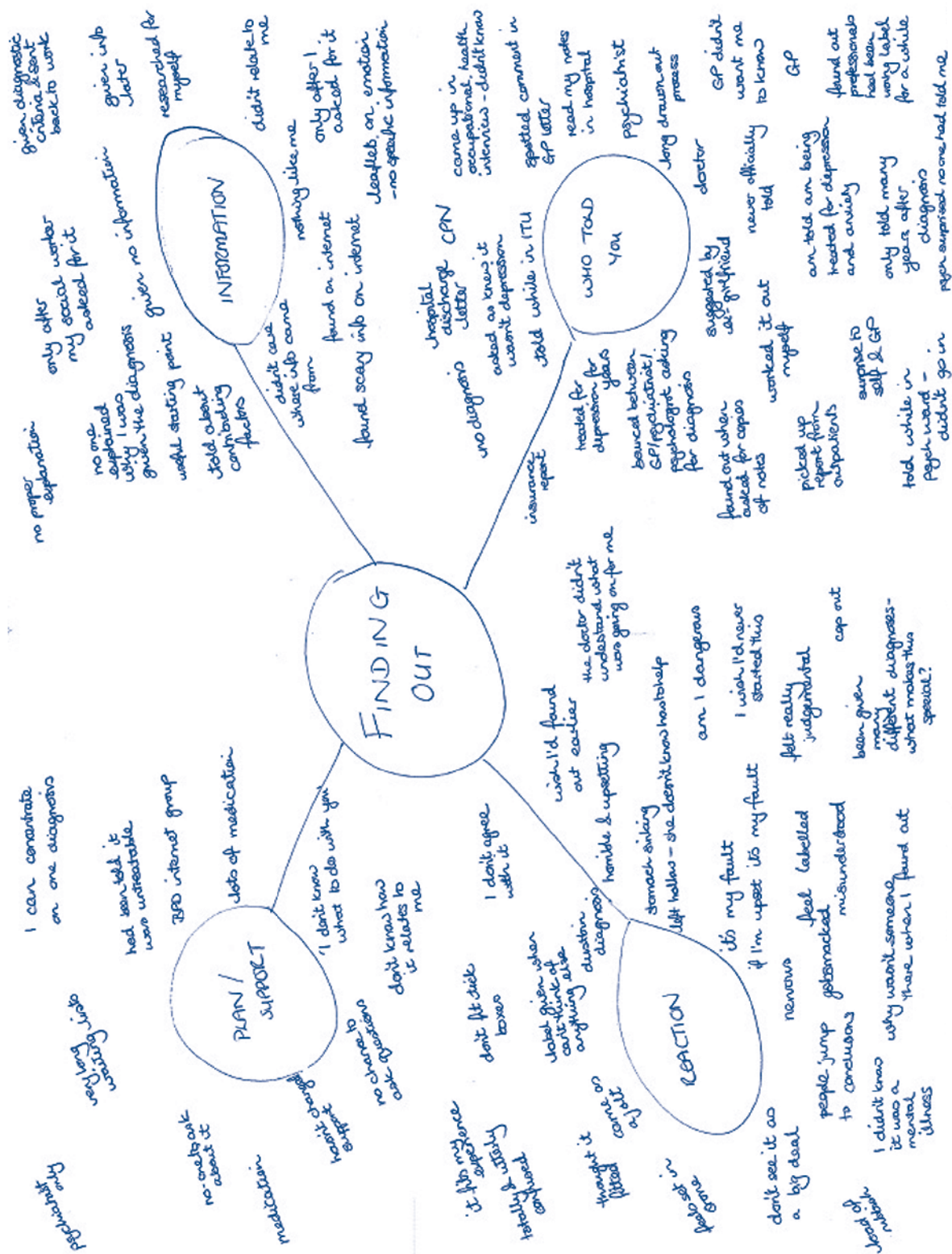
These have been included to give an alternative view of people's experiences and a visual representation of the descriptions in this section.

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 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.



ashamed
 defective rubbish
 miserable no information tangible
 it fitted me stereotyped misunderstood
 betrayed peace of mind judgemental hollow
 dustbin diagnosis horrible
 starting point
sense out of chaos
 labelled flawed person
 gobsmacked explanation
shocked
assumptions
 applying rationality
 implications
 not just mad reassuring sense of self
 confused set in stone upsetting scary
 upsetting

How Does This Relate to Me?

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:

How do you feel after reading about people's experiences of finding out about their personality disorder diagnosis?

Was there anything in their descriptions or experiences which surprised you or you didn't expect?

How do you think you would like to find out about a diagnosis like this? What would you find helpful or unhelpful?

Service users said the things that it would be useful to have information, support and open discussion when they were given a personality disorder diagnosis. How can workers make sure these are available?

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.

P9 - Dew on a Spiders Web

Dew caught in a cobweb on a gate leading into a cemetery. There is such fragility, threads are broken yet somehow the web stays connected to the metalwork. There is death beyond and also peace. The web is used to trap and kill prey for the spider yet it also catches dew which sits jewel-like, reflecting the sunlight...

Lived Experience

Each of the following quotes are different people's personal experience of finding out they had a diagnosis of personality disorder.

For each person's experience there is a 'Finding Out' Section and a 'Reaction' Section.

Have a look at the 'Finding Out' sections and think about or discuss the positives and negatives of each situation.

Then read the 'Reaction' sections to see how this experience impacted on each person.

For each experience think about:

- ◆ Why do you think the person had this experience and reacted in the way they did?
- ◆ What impact do you think this experience would have on their relationships with the professionals they are working with?
- ◆ Do you think reading about these experiences will have any impact on your practice?

ONE - Finding Out:

She got a book off the shelf and she went through the diagnostic criteria, she just read them out to me and then it was time to go because the session was up

ONE - Reaction:

So I stumbled off back to work, and googled it, as you do and the first thing that you come across is some totally crap website that says you're all dangerous and everybody that's anywhere near you should leave and get themselves out and get the children out because these are manipulative, self-centred, horrible people. So you sit there and think that's nice - I've seen the psychiatrist and the therapist and they both think I'm this horrible manipulative person

TWO - Finding Out:

Initially people didn't tell me and hedged around the subject. After reports were written for occupational health and a finance company there were phrases of personality disorder and borderline personality. I asked outright and again, people wavered around not telling me. A change of psychiatrist and she told me outright, got the ICD-10 off the shelf and showed me that this was me

TWO - Reaction:

Emotionally unstable personality - borderline type, sounds very technical really but I suppose it needs to. For me, actually being given a firm diagnosis was like being given a map of a strange city.

It might take time but knowing where I was I could work my way through it. Before that I felt lost, that people were being dishonest and not open with me and yet expecting that in return

THREE - Finding Out:

I went through major trauma and my best friend died. I struggled to cope and used cutting and bulimia as expressing how I felt. No psychiatrist was interested in the trauma I had suffered but I got labelled borderline personality disorder due to how I coped

THREE - Reaction:

Despite my coping mechanisms changing for the better but my mental health getting worse I am still diagnosed as only BPD. Only my hallucinations and false images and memory are getting too much to bear but the consultant says I'm still BPD even although I am totally different from the girl diagnosed with BPD 2 years ago.

I feel I was misdiagnosed and it was a quick fix diagnoses to get me out their way. Diagnosed BPD once and it's a lifetime label forget everything as it seems

FOUR – Finding Out:

I was not told I have a diagnosis of BPD. I found out when I asked to have copies of all my psych notes going back from the age of 16

FOUR – Reaction:

It was noted in there by a psychiatrist who I feel did not understand what was going on for me. I do not agree with what was put and I don't feel I fit the criteria of any of it. The diagnosis I felt was a cop out as a result of the mixture of symptoms that didn't fit their tick boxes and therefore didn't know what else to call it

FIVE – Finding Out:

I wasn't actually told I just sort of read it...Cos I had a sneaky peek (at my notes) and I read it, I wasn't actually told. I had treatment for years and years, but I was always told it was depression or anxiety; I was never given a big label. But I was actually; just not told about it

FIVE - Reaction:

I already thought that so it didn't really matter to me, but that point I was kind of wondering...I'm pissed off, because the thing is they've never mentioned it to me, so what's the point in me mentioning it to them?

SIX - Finding Out:

I wasn't told. I found officially because I read it in a report that was written to my occupational health department and I'd asked to see a copy, so it was written with the full knowledge that I'd see it. But it wasn't what I was expecting to see when I went to pick up this report

SIX - Reaction:

It came as a real jolt to read it, I'd had psychotherapy before and someone had said about borderline traits, but I'd been told specifically they didn't think I'd got BPD...Suddenly it was like I thought I'd been dealing with depression and suddenly it was like you've got this flawed character. It was all a much bigger thing and longer term and nobody to ask

What does the Diagnosis Mean to You?

IMAGINE...

How would you feel if someone gave you a diagnosis that helped you make sense of your experiences and identify with others who had the same experiences?

How would you cope if you found that this diagnosis had been kept from you for years, although staff had known about it?

How would you manage if you found that this diagnosis changed the way that people responded to you in a negative way?

SECTION 3 : THE DIAGNOSIS

Section Summary

The Label...

The label itself carries a lot of different meanings for different people:

- ◆ Just another word for my problems
- ◆ Makes me feel everything about me is flawed
- ◆ Not exactly empowering
- ◆ Makes you sound hysterical
- ◆ Makes you sound on the edge of being dangerous
- ◆ Implies you're defective as a person
- ◆ Doesn't tell you what to expect
- ◆ You can end up being seen as a label rather than a person
- ◆ It doesn't change who you are as a person

Diagnosis - The Good...

'I'm not just willfully being a pain in the arse'

- ◆ It can be a relief to understand there is a reason
- ◆ Everything that has happened starts to make some sense
- ◆ Beneficial to know
- ◆ Reassuring to understand what's happening and why
- ◆ Gives you something tangible to work with
- ◆ It's a good starting point to find out information
- ◆ It lets you have a better understanding and awareness of yourself
- ◆ Helps you put your experiences in a context
- ◆ Gives you peace of mind and validation
- ◆ You can identify with others
- ◆ You can start to make sense of things and learn to cope

Diagnosis - The Good...

- ◆ Doesn't mean you live up to it, but you can be less harsh on yourself on bad days
- ◆ You need to know to start to recover

People Want to Know!

- ◆ Understanding about how your experiences can have such an impact on you can help you to understand why things are the way they are now
- ◆ Some people felt that the diagnosis might have been kept from them in order to protect them from stigma and the negative connotations of personality disorder
- ◆ Not telling people can lead to a lot of confusion on their part, and cause problems in working with services and staff
- ◆ Finding out later that a diagnosis has been kept from you can be very upsetting, make you question the trust and relationships you have with staff and reinforce your feelings of not being good enough or worthy
- ◆ Knowing gives you the empowerment that comes from getting your own understanding of yourself

Diagnosis - The Bad and the Ugly...

There can be a huge impact on how you feel about yourself:

- ◆ It challenged my sense of self
- ◆ Assumptions were made about me
- ◆ Left feeling defective and flawed
- ◆ Ashamed to tell anyone

There are other negatives about the diagnosis as well:

- ◆ Find it isn't acknowledged as an illness
- ◆ Blocked from services
- ◆ Staff had little time for me being emotional
- ◆ A big fear of being judged and treated badly
- ◆ Feeling stereotyped by professionals
- ◆ Blamed for your illness
- ◆ Not listened to
- ◆ Asking questions is seen as a symptom
- ◆ Being patronised
- ◆ Once diagnosed it's set in stone and you can't question it
- ◆ Other explanations don't seem to be considered any more

SECTION 3 : THE DIAGNOSIS

What Does the Diagnosis Mean to You?

The Label...

No diagnosis is pretty, but a diagnosis of personality disorder has a much larger impact than just words on a page.

The diagnosis is just another label for the problems I have lived with for twenty odd years

It has significance for each person as an individual as well as an impact on how they are viewed by others. It feels very negative, it's not exactly empowering and can sound like you're hysterical or on the edge of being dangerous. There's an implication that there's something wrong with your personality, and that you're defective as a person.

I don't like the wording of the diagnosis to say a personality disorder makes me feel that my personality and all my likes and dislikes as a human are flawed in some way

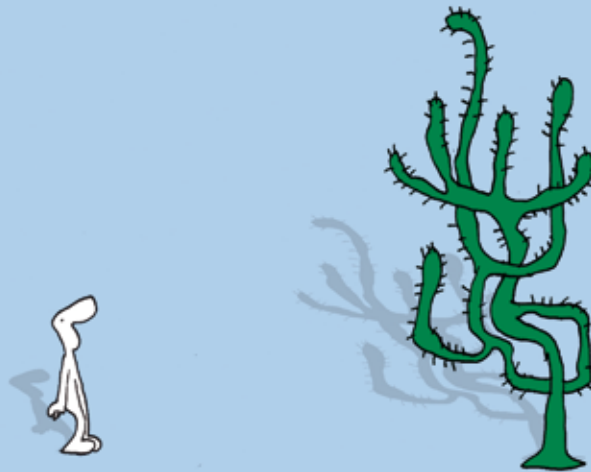
It doesn't tell you what to expect, and you can end up being seen as a label rather than a person.

But being given a label doesn't change who you are as a person.

I'm still the same person the day I'm diagnosed as I was the day before

Normality is relative.

For example, relative
to that cactus
I am perfectly normal....



Diagnosis - The Good...

It can be a relief to understand that there is a reason for the way you are and that everything that has happened does make some sense together.

I'm not some sort of scary psychotic bitch

It gives me a little candle that says you're not just a dickhead. And it gave me a springboard for applying rationality to my thought processes and behaviour

I'm not just willfully being a pain in the arse

It was like reading about every feeling I ever had

A lot of people who have a personality disorder diagnosis, have either not been told about the diagnosis at all, or have only been told years after the diagnosis was made or after asking to be told what was wrong with them. Although the wording of the diagnosis isn't pretty, no diagnosis is pretty, and knowing about your diagnosis has a lot of benefits.

*It was like being given a map of a strange city.
It might take time but knowing where I was
I could work my way through it*

Understanding what's happening and why is very reassuring. Receiving a proper diagnosis can be a relief as it's tangible and gives you a starting point. It allows you to concentrate on one diagnosis and read about it. Knowing your diagnosis lets you have a better understanding and awareness of what's happening for you. It helps to understand that everything's not arbitrary, not all random and unexplainable and that everything fits together.

I understand myself better

Knowing the diagnosis can help you to put your experiences into a context as well.

The things that have happened to me have changed me so much

Having a diagnosis and being able to get information about it gives you peace of mind and validation. It's not just you this is happening to, you can identify with other people. You can begin to apply rationality to what's happening and can seek specific support and work on specific problems. You can start to make sense of yourself and put sense on top of chaos. You can discuss this with people working with you and begin to get to the bottom of things, deal with things and learn to cope.

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

Just because a diagnosis is written down doesn't mean you'll start living up to it. If you have been given the diagnosis you already have the problems associated with it. It also means you can stop being so harsh on yourself and give yourself credit on the bad days. You need to know to start to recover.

It doesn't excuse my behaviour; it allows me not to beat myself up about it

It's useful to know your diagnosis and to be able to reflect on it.

It can feel less lonely, even though just having the diagnosis doesn't change anything.

Just when the caterpillar thought the world was over, it became a butterfly



Protection?

I wonder if the "truth" was kept from me for my own good

Some people felt that they hadn't been told about the diagnosis by people who felt they were looking out for them, and were worried about the impact of the negative connotations of the diagnosis.

My old CPN didn't want me to know that about myself in case I lived up to the diagnosis. and make things worse for myself; and also to have all the opportunities that everybody else can get

It may not seem reasonable, but there is a reason

When I saw the words I thought that meant I was crazy and thought I was someone else, but the doctor explained to me that she wrote that because the things that have happened to me have changed me so much

It can be very helpful to know what the problem is so that you can begin to make sense of your experiences.

I now feel I have been having a normal response to traumatic events - rather than feeling profoundly "not normal" and "diseased"

Information about how traumatic experiences can impact on you can help you to understand why you might be where you are now.

Just when he began to feel
like he might fit in,
Harold realised he was left-shadowed.



People Want to Know!

I remember a feeling of oh my bloody God, but at least she told me

For some people it's hard to shake the feeling that if they had known about the diagnosis earlier then their lives might have been very different. With more understanding and insight into their situation they might have made very different choices.

I wish I'd found out earlier

Having the diagnosis kept from you can be counterproductive and even harmful and doesn't help with a positive working relationship with those treating you.

Before I felt lost, that people were being dishonest and not open with me and yet expecting that in return

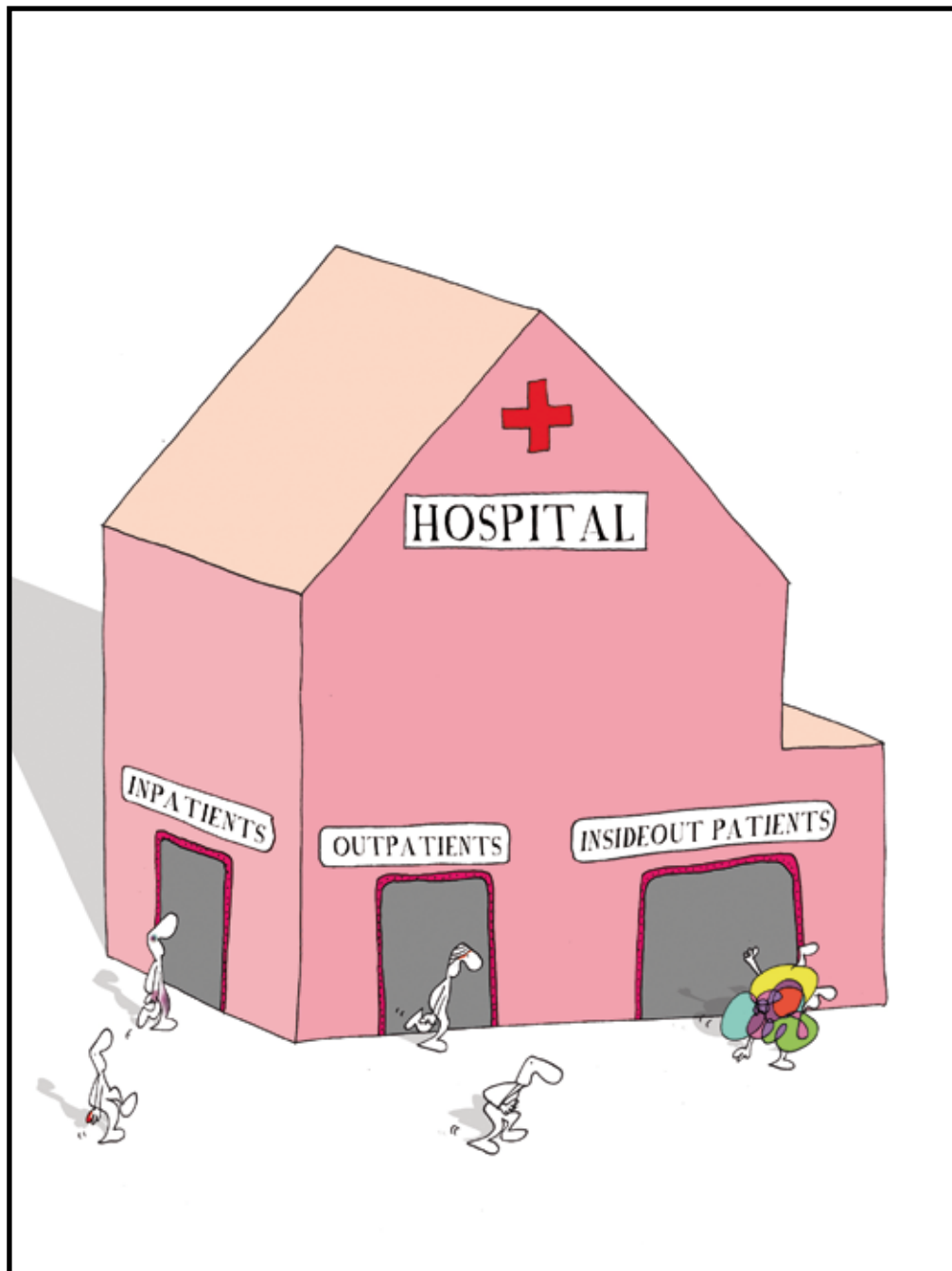
Having a diagnosis kept from you can lead to a lot of confusion and questions about your relationships with staff. And finding out that you have been given a certain diagnosis a long time ago, and everyone involved in your care knew except you can be very upsetting.

You begin to look back and wonder if people treated you and made decisions about you based on information you had no idea about, which is very unsettling.

It's hard to be sure of a collaborative working relationship with people treating you if you can't be sure they are telling you the truth.

It also sort of reinforces some of the like, well, just the fact that people are doing things not quite behind your back, but it reinforces a lot of the not being good enough or not quite fitting

If you don't get told your diagnosis you don't get the empowerment that comes with getting your own understanding of yourself, the condition and where you are now.



Diagnosis - The Bad and The Ugly

Being given a personality disorder diagnosis has enormous implications a lot of which can come from other people's responses to the diagnosis. You can feel labelled and that the diagnosis has negative connotations.

I suspected I was labelled with BPD as some NHS professionals had little time for me being emotional and I was forever being blocked to psychology that I had been asking for, for years

People have preconceptions and can be very judgemental. This can lead to a fear of being judged.

There was a big fear that people were going to judge me and treat me badly and that getting proper services was going to be a bit of a chore

It can mean you are stereotyped by professionals, not listened to, blamed for your illness and seen as a social pariah. Asking questions about it can mean you are told you have a problem with authority.

I have met many professionals who are quite patronising when they learn I have Borderline. Believing I'm only playing up for attention when I'm really needing help

The concept of personality disorder can challenge your sense about who you are and you find that assumptions are made about you.

I was being told about a 'disorder' that challenged my actually sense of self

It leaves you with the feeling that you are defective, a flawed character and that all of your likes and dislikes are also flawed.

Personality disorder makes me feel that my personality and all my likes and dislikes as a human are flawed in some way

You can feel ashamed to tell anyone, as well as wishing it was more widely recognised and acknowledged as a serious illness.

I feel ashamed to tell anyone or them to find out

'Set in Stone'

A problem with the Personality Disorder diagnosis seems to be that once it has been written down other explanations or diagnoses don't seem to be considered any more.

Diagnosed BPD once and it's a lifetime label forget everything as it seems

For some people the diagnosis doesn't make sense and other conditions seem to better describe their experiences.

It doesn't relate to me

Your opinion doesn't seem to matter even if the diagnosis doesn't actually make sense to you.

I am different from the girl who was diagnosed

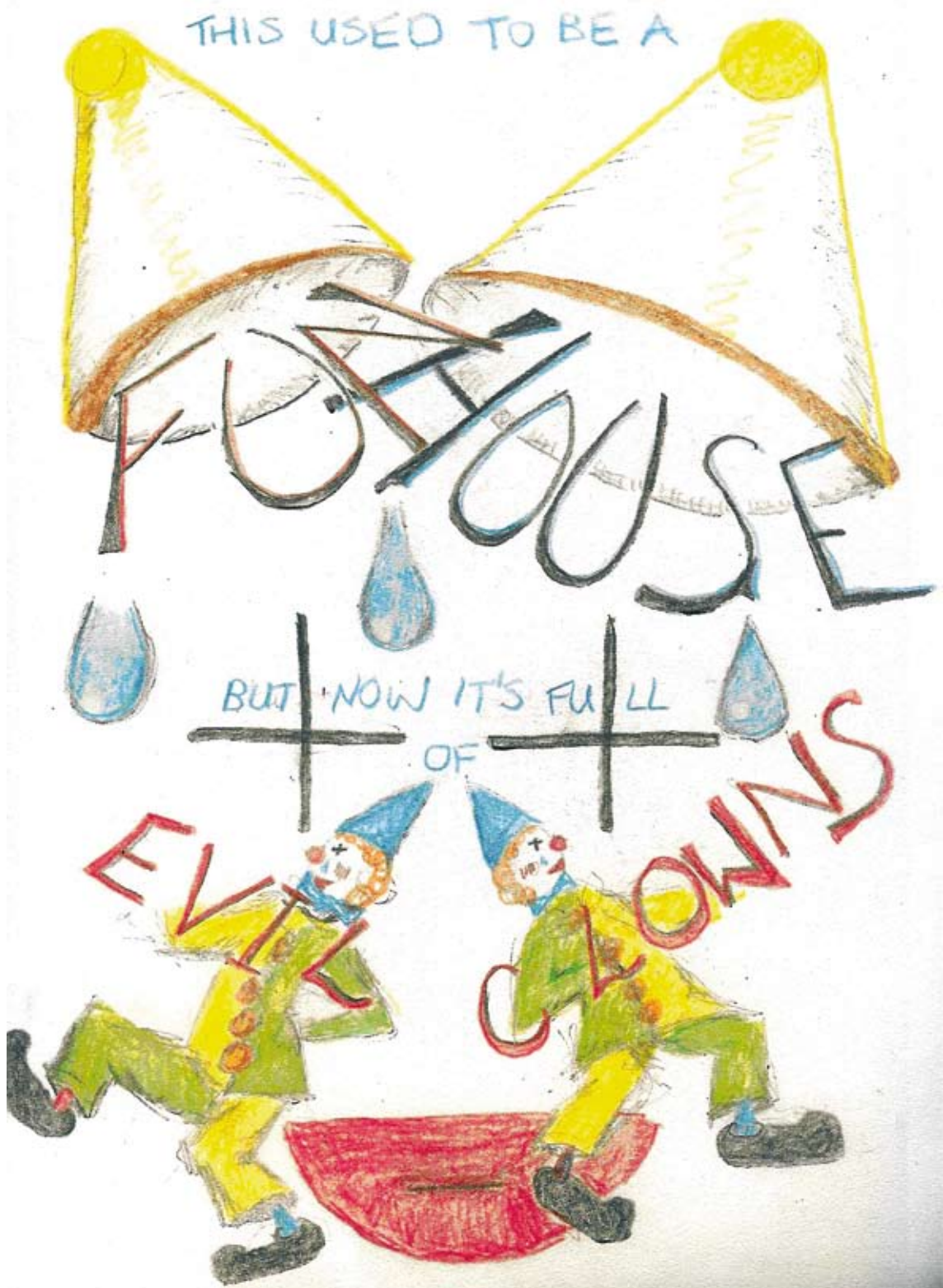
It is important to have the diagnosis explained properly to you, in terms of how it relates to you and why you have been given the diagnosis.

It is also important to be able to ask to have the diagnosis reconsidered at the time or in the future without the request being seen as part of the condition.

They made a diagnosis and they think that's it

Some people feel that the label should be scrapped as a diagnosis, and the focus should be on their experiences and how best to understand their lives.

I fundamentally do not agree that there is any such disease as BPD and wish to see it removed from the DSM. I find that people want me to use the label to provide a context to understand people's behaviour whilst I believe that is fundamentally a wrong starting point



MOTHER

You tried to change him but put him down,
He changed his ways but you would frown,
He took no more and decided to drown.

He left us all in that big place,
All because you were on his case,
In the end he couldn't take the pace.

My brother tried but couldn't cope,
You made me think he'd turned to dope,
After listening I lost all hope.

After that I stayed in my shell,
I thought my brother was in a cell,
The next few years were absolute hell.

From then on you turned on me,
Why, oh why could you not see,
What you were doing to me.

We left the town that made you sad,
You didn't know I felt so bad,
You'd finally turned your back on Dad.

I was no longer your wee boy,
No longer that small bundle of joy
With you I became really quite coy.

I'd had enough so went away,
With my mother I had no say,
I'd live to fight another day.

My first few years were full of good,
In that time on my own I stood,
But eventually it affected my mood.

I really had a very good job,
but people saw me as a knob,
All I did was sack the mob.

The doctor told me to lose some weight,
but this was simply to open the gate,
to what, in fact, was my fate.

I worked so hard I lost the plot,
As a result it burst the clot,
And out it came that little tot.

From then on it wasn't me,
Many people could obviously see,
That I just wasn't full of glee.

I then, myself, wanted to kill,
So I took pill after pill,
And ended up in that awful mill.

Eventually I had to go back,
But understanding there was a lack,
Most of the time I couldn't hack.

I decided one day I had to quit,
Finally I left that awful pit,
I wouldn't even miss it a bit.

With my mother all love has gone,
This is the beginning of a new dawn,
And I hope from this no bad will spawn.

B Nelson

SECTION 03 : THE DIAGNOSIS

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.

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 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.

still the same person
 tangible identification
 empowering relief
 there is a reason ashamed
 understand myself defective
 reassurance
 less lonely
 validation
 beneficial
 flawed
 negative
 connotations
 just another label
 set in stone
 negative

How Does This Relate to Me?

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

The experience of being given the diagnosis of personality disorder raised a number of issues which could have an impact on service users.

These included not being told about their diagnosis, feeling they are seen as a flawed person, feeling judged and not being able to challenge the diagnosis.

Why do you think these issues might arise?

How do you think these issues might make the person who has been given the diagnosis feel?

Why do you think so many people have not been told about their personality disorder diagnosis and what do you think is the impact of service users not being told, for both service users and staff?

Artwork in this Section:

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.

P38 Normality

This arrived in my inbox shortly after discovering my diagnosis. After 35+ years of having friends & a career despite life frequently being a struggle someone had judged that I "didn't conform to societal norms". Who had decided what was normal? And did that mean if I lived somewhere else I wouldn't have BPD?

P41 Caterpillar

I was given the diagnosis in the aftermath of hitting rock bottom and attempting suicide. Avoiding having to reach that point would have been great, but it was also the place from which I could either give up, or fight to grow. It reminds me of the caterpillar/butterfly story in the front of "Stories of Changing Lives" (about service users moving into the community from long stay hospital - available from the Patients' Council at the Royal Edinburgh Hospital) - where squeezing out of the chrysalis is what makes for stronger wings - "A butterfly's lesson".

P43 Left Shadowed

I had to come to terms with the fact I was considered 'different' and a misfit.

P45 Inside Out Patients

Just appealed, but notice which patients are the most colourful!

P49 Pink - Funhouse

This song kept playing in my head and seemed to reflect how at one time things had seemed okay, but now my head was being made a mess of by these “evil clowns”.

P50 Mother

A poem.

Lived Experience

Have a look at the following issues which were raised by service users and discuss/think about how they might affect the relationships between service users and professionals.

Problems with the diagnosis are more to do with other people's responses to the diagnosis than you knowing about it

You find out you had been given a label or diagnosis years ago and no one had told you

You realise that staff had been working with and reacting to information that you knew nothing about

Once you've been given the diagnosis it seems to be 'set in stone'

You're left with the feeling that you are a flawed character and this reflects on every aspect of you and your life

There is a lot of stigma and many negative connotations attached to the diagnosis

Notes

[illegible]

[illegible]

Notes

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