

Section 02

How Does it Feel...?

*'It's like living life without the rule book
everyone else seems to have'*

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Much More Than A LABEL

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?

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*

SECTION 02 : HOW DOES IT FEEL...?

Section Outline

Section Summary 1

What Does Personality Disorder Feel Like?

'Live a day inside my head' 3

Day-to-Day Life 5

The Emotional Impact 7

The Practical Impact 10

The Long Term Impact 12

The Impact on Relationships 15

Dissociation 17

Self Destruct 19

There Can Be a Positive Side 21

Discussion and Reflection Section

Mind Map and Word Cloud 25

How Does This Relate to Me? 28

Things to Think About 29

Lived Experiences 32

Imagine...

How would you cope if every day you experienced some combination of extreme anxiety, swinging moods, extreme emotions, hyper vigilance, eating issues, alcohol issues, drug issues, difficulty with boundaries and relationships, dissociation, feeling suicidal and urges to self-harm?

SECTION 02 : HOW DOES IT FEEL...?

Section Summary

How does it feel? - 'Live a Day Inside My Head':

- ◆ It affects everything; there are so many things involved it's difficult to know where to start. It has a huge impact on your every day life
- ◆ You don't believe you are a worthy person, or that things can change.

Day to Day Life - 'What the hell's wrong with me?':

- ◆ It makes it hard to function, even though you feel you ought to be able to manage, things are so intense that you can't.
- ◆ It's hard to stay connected to reality, to stay in control and to remember what you've said and done.

Emotional Impact - 'Emotionally you feel all over the place':

- ◆ You struggle to understand and cope with very intense emotions. It's hard to feel in control when you have very strong responses and other people think it's inappropriate.
- ◆ It's very 'in the moment', how you feel can change constantly and you can do things on the spur of the moment.

Practical Impact - 'It's so mentally exhausting':

- ◆ Trying to cope with very strong emotions and your reactions to them and day to day is very hard work.
- ◆ You end up having to put a mask on to cope in public and fall apart in private.

Long Term Impact - 'There's nowhere to be tired of it':

- ◆ There's no let up from how you feel and this can leave you constantly exhausted, confused and vulnerable.
- ◆ Trying to deal with these feelings every day means you will do anything to get a break from them.

Impact on Relationships - 'By relationship I mean any connection with other people':

- ◆ It's hard to sustain relationships when you don't know where you are with yourself. They can end up being very chaotic and intense.
- ◆ You can need constant approval or end up sabotaging the relationships due to how you feel.

Dissociation - 'There's nothing outside my head':

- ◆ As a coping method you can end up becoming dissociated which can be a very distressing and confusing experience.
- ◆ You can become completely disconnected from the world, feeling very detached or unreal and you may not realise it is happening.

Self Destruct - 'I'm disappointed that I'm still alive':

- ◆ Trying to deal with all the intensity, confusion, stress and distress can lead you to do self-destructive things to cope.
- ◆ It can be a way to hurt yourself, ground yourself or even protect yourself from suicide.

The Positive Side - 'A lot of our symptoms can actually have a positive spin':

- ◆ Having such strong emotions can mean that you are more able to empathise with others and have alternative insights about the world.
- ◆ You can also develop a variety of ways of coping and dealing with the challenges of life.

SECTION 02 : HOW DOES IT FEEL...?

What Does Personality Disorder Feel Like?

'Live a day inside my head'

It's incredible intensity, it's inconsistency, it's emotional instability, it's an epic sense of self-loathing, it's pervasive, invasive, ingrained and **it affects everything**.

Just like describing your own personality, describing the experience of personality disorder is something that's very hard to pin down. It can mean many different things to different people; it's complex and to other people it can seem wholly incomprehensible.

You believe that you are some kind of **flawed person**, it's as if you're incapable of liking yourself, incapable of being happy.

When you can't like yourself you **blame yourself for everything**; you don't feel that you deserve to be happy; you want to punish yourself and consciously or unconsciously you can end up sabotaging things that are good for you.

It's also sometimes **impossible to believe that anything can lift you out of this** or change the way you feel, which makes it very hard to believe that other people can help.

There can be **so many different things involved** that it's hard to know where to start - extreme anxiety, swinging moods, extreme emotions, hyper vigilance, eating issues, alcohol, drugs, difficulty with boundaries and relationships, dissociation, feeling suicidal and self-harm to name just a few.

It's also important to remember that there is huge variation due to the criteria used to diagnose personality disorder. One person could be totally different to another with exactly the same diagnosis - after all **we are all individuals**.



*I feel HOLLOW, as if I have no PERSONALITY, SOUL or SUBSTANCE.
I'm a collection of behaviours swirling around a VACUUM.
How can I take up space when I am not even a valid HUMAN BEING*

Day-to-Day Life

'What the hell's wrong with me - I should be able to do all this stuff'

It affects everything whether other people can see it or not. How you feel and what you can do depends entirely on the day, what you can do and achieve can be very inconsistent.

It makes it hard to manage day to day

A lot of the time you can feel like you have to pretend or hide how you really feel. Putting a face on a lot of the time can be very confusing and you can begin to feel like a fraud. You have to put up a social façade to deal with other people and this can be extremely tiring.

I have to work to constantly stimulate my own brain, to concentrate on 'reality', speak to people and keep doing these things until maybe, possibly I might stay attached to the world

It's hard to remember things; it can be hard to hold down a job. It has a severe effect on your outward apparent abilities.

A lot of the time I can't remember what I've said. Because if you're stressed, although I come across as quite calm a lot of times in my head the whole conversation is going on and I can't actually remember what I've said

You know some of the things you're doing are unreasonable, but there's almost complete lack of control not to act on your impulses. It's hard to feel like you're in control when you don't understand what's going on yourself.

When I was struggling with extremely intense emotions, my brain was so taken over I couldn't even work out how to make a cup of tea

Your quality of life is terrible; you can feel like you have no life.

I know I'm able to get up, get dressed and do stuff and I seem to be fairly functioning, but to be honest a big part of my quality of life is really, really shit...



The Emotional Impact

'Emotionally you feel all over the place'

It's hard to explain your emotions to other people when you struggle to understand them yourself. When you have extremely strong responses to seemingly small events it's difficult to feel in control or that you are able to freely express yourself in case people think your reaction is inappropriate. When you are constantly told you are not doing the right thing it becomes very hard to trust yourself and also other people. This in turn can mean you end up becoming very defensive and hyper vigilant to others' feelings, expressions and body language.

I guess it's just you constantly feel like you're trying to manage stuff, keep everything under with its lid on, not like explode at the slightest thing that's not worth exploding over

It's hard to explain just quite how much of an impact your emotions can have on your life.

There are times when I have good days, and times when I have totally crap days and when I have crap days nobody wants to be around me

'Borderline Personality Disorder is counter-intuitive'

Emotional experiences are incredibly intense, and constantly changing.

My moods swing incredibly quickly, I can be speaking to a friend and be pretty jovial to being within the next five minutes absolutely suicidal

'It's very in the moment'

When you're in a certain mood it's almost impossible to remember that you've ever felt any different, where you are seems like all there is.

I suppose there's just that rollercoaster isn't there, kind of one minute you can feel fine and quite content and the next minute you can think like there's absolutely and utterly no point to any of it...And I could actually just chuck myself off something on the spur of the moment



not see

not see
liquid eyes in rock
crystal blue-clear
water runs deep

not feel
tender glance of sun
warm yellow glaze
rock stands bathed

no smell nor taste
sweat drips sweet
grass tastes salt
see me here

silent, marble on rock
water drips from eyes
ripples in sand to the sea

I see you
but dimly
through crystal-rock.
salt sting eyes--I cry.

leti hawthorn

The Practical Impact

'It's so mentally exhausting processing every little thing and rationalising it out'

Every little thing can provoke a strong emotional response and either this needs to be processed which is an exhausting process, or if it's not expressed the emotion stays and comes out in other ways.

My planned or intended argument does not happen, but the stress that it caused, surfaces and lives on

Emotions can swing in minutes from desperate adulation to destructive hate and everything in between.

There are good days and bad days, but there's no let up from the extreme emotions.

I think the moods and the relationships are probably the worst ones, because all of that's so chaotic, it just kind of leaves me feeling like I don't know whether I'm coming or going, what do I do, my goals and all that change so frequently...I just can't focus on something, I think something's a good idea, then I get well or I get ill...

'I can do things with one 'hat' on that I can't do with the other. It doesn't make sense'

What you know and what you experience can be two different things.

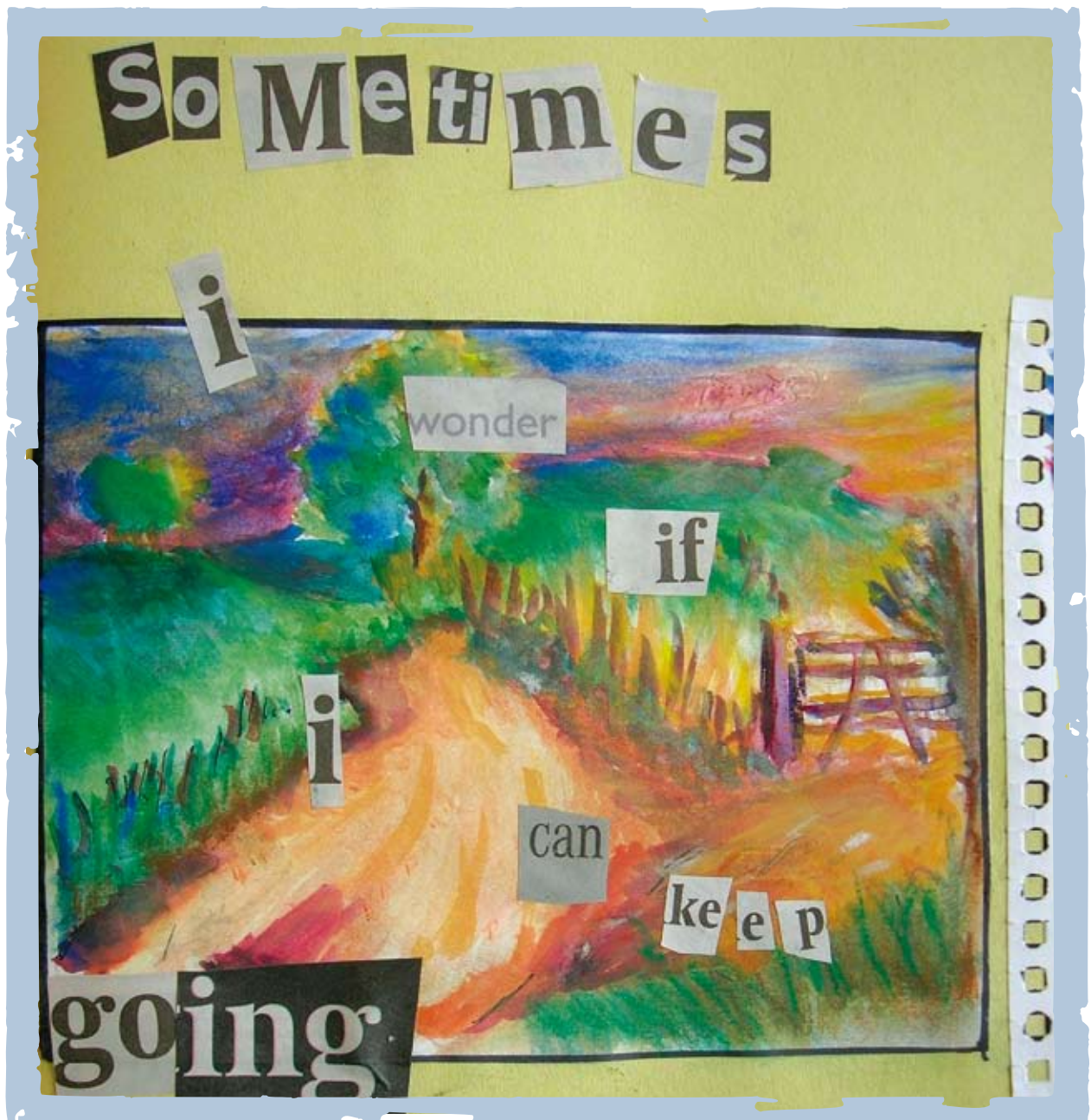
It can be like being two different people, and you can switch from one state to the other in a moment.

Keeping Up Appearances: Constantly 'putting a face on' to the outside world or acting is exhausting; for example coping through a meet up and then collapsing in suicidal tears when behind your own closed door

It's as if there are parts of you that are not grown up, as if you've missed out on something somewhere and you have to learn it as an adult. You have to learn how to experience and deal with emotions.

Having to learn how to experience quite a lot of emotions, having to learn a lot of really basic mental abilities that people take for granted

Ultimately you can spend most of the time feeling that you are a complete fraud.



The Long Term Impact

'Sometimes you just get tired of it, there's nowhere to be tired of it.'

Dealing with these emotions is extremely draining, there's no let up from being happy and smiley, and ultimately it wears you down and you just can't deal with it all the time.

You try to keep a lid on it and not to explode, even though every little thing needs to be mentally processed

You constantly have to manage stress and anxiety and this has an enormous impact on your life.

The stuff that goes on in your head is so draining; it means I can't necessarily do as much as I want to do... it wears you down

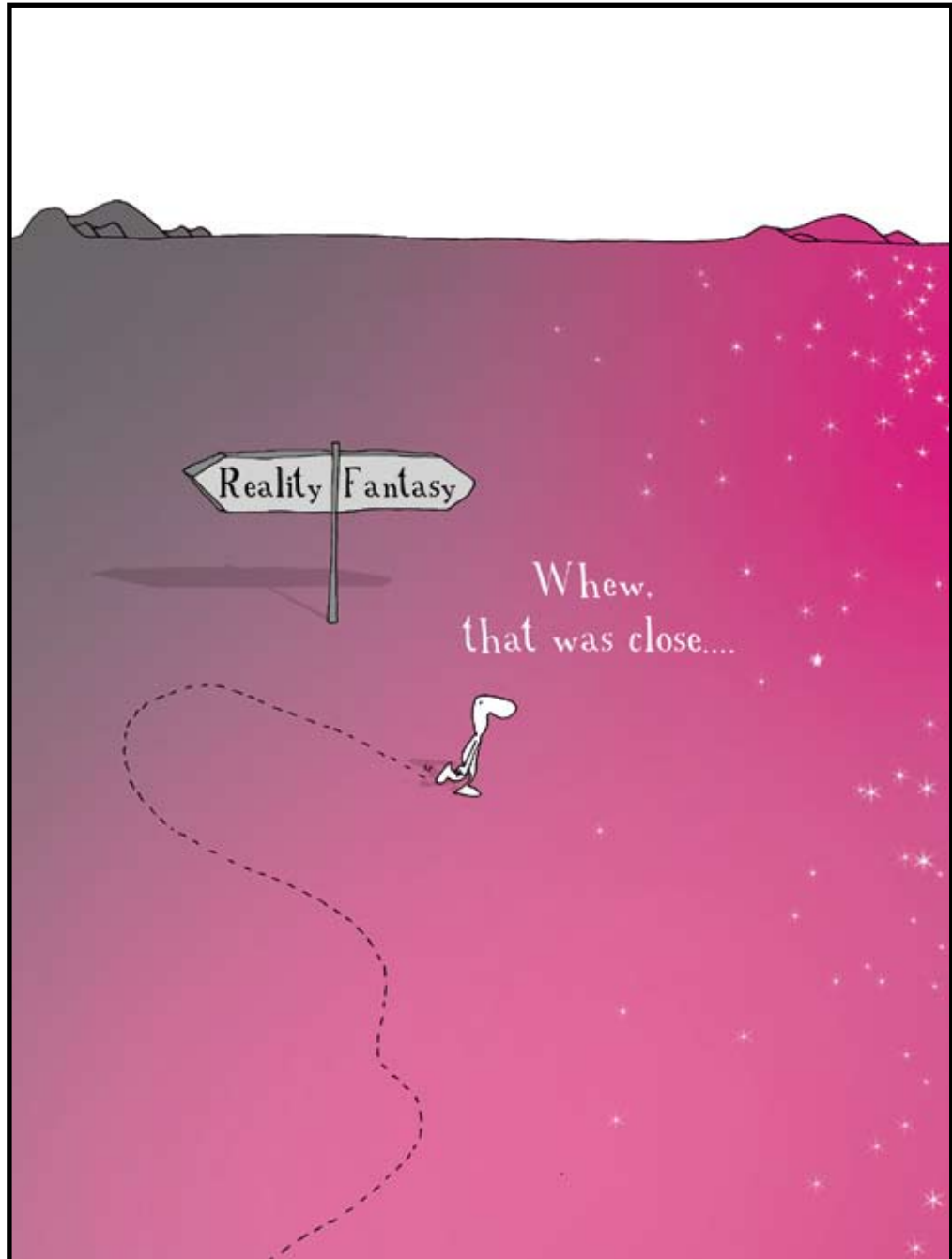
There's nowhere to go when you're tired of dealing with the inside of your own head and your own reactions to the world around you.

There is no let up and being hyper vigilant of everyone and everything around you just makes it worse.

Despite feeling such intense emotions you still feel detached from the world around you, empty and lonely.

When it gets really bad you can start to hide from the world, start to dissociate, your sleep patterns go, you can't focus - every part of you just needs a break.

I lock the doors and take to my bed



ISOLATION

I get up in the morning and stand on the
scales,
I look at myself and I've gone off the rails,
Whatever I try everything fails.

I try to keep busy during the day,
I feel so useless whatever I say,
and get so angry but there's no affray.

I get on my bike and go for a ride,
but this is a reason to go away and hide,
I can't keep putting things to the side.

I try and get out and feel frustrated,
I can't fit in and feel deflated,
I get very anxious as I'm not elated.

I get home at night and feel so miserable,
I have a drink and I'm not so vulnerable,
otherwise I may get a knife and do the
unspeakable.

I feel so lonely especially at night,
The whole day just hasn't been right,
Whatever I've done can't go out of sight.

I feel so pathetic when I go to bed,
but then I think at least I'm not dead,
after all it's all in my head.

This is my life I know it's not real,
how can it have any appeal
I know for a fact I've had a raw deal.

B. Nelson

The Impact on Relationships

'By a relationship I mean any connection with other people'

Not really knowing where you are with yourself has a huge impact on your relationships with other people.

It means you have to keep a part of yourself hidden. You might not have many friends and the ones you do have need to be more accepting.

It means you're not sure how to deal with relationships, you can have poor and chaotic relationships and you keep messing them up.

I can't maintain steady relationships; they're all so chaotic and intense

There's a desperate need to be accepted, to feel attractive, and yet this intensity causes anxiety and stress and means boundaries are pushed

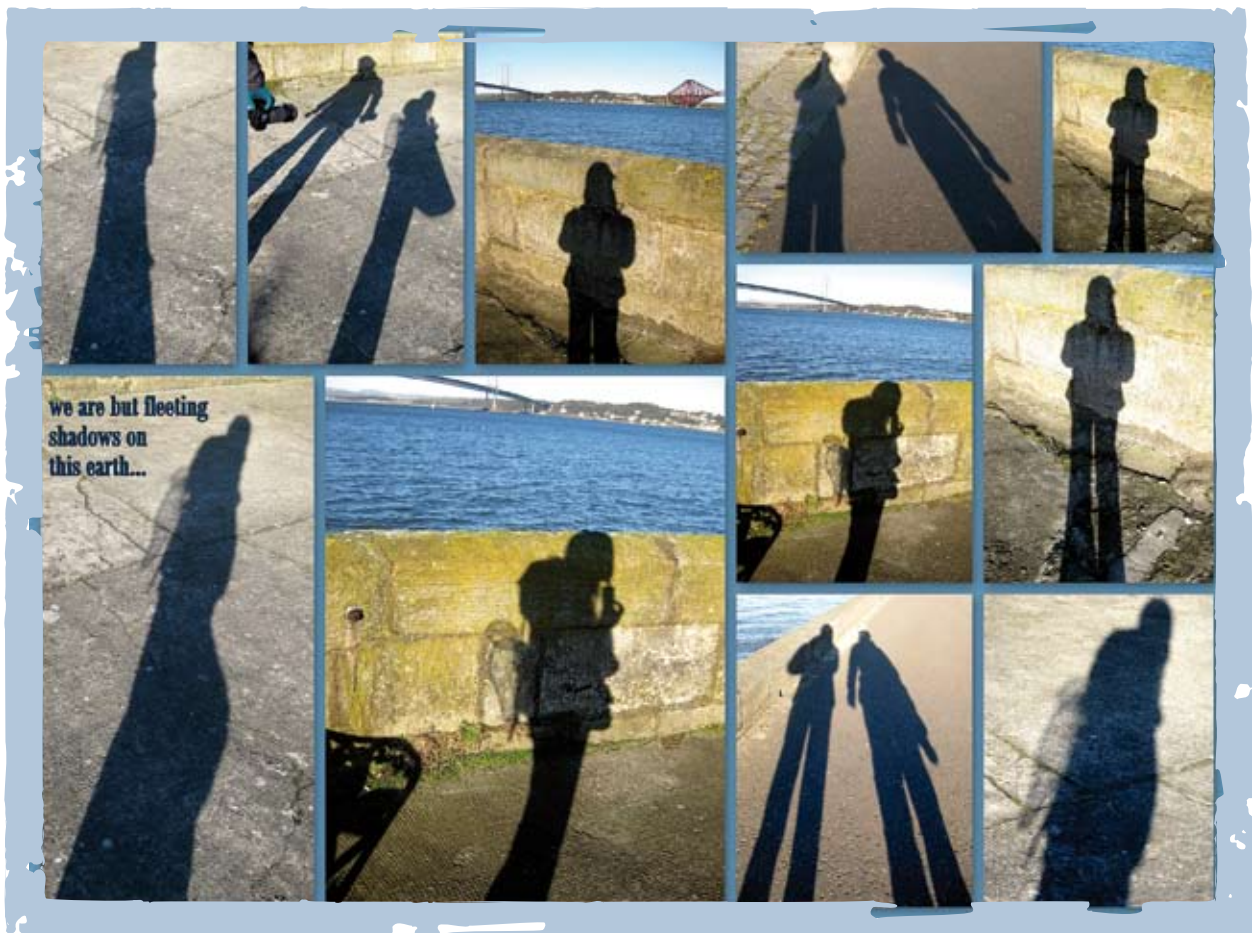
Every single action and word that comes out of my mouth is still to a large extent desperately attempting to get acceptance, I need some positive response to absolutely every single little interaction and if there's not even the tiniest grain of that to get to instantly it's just a massive emotional slide straight away... And then it's like this backwards and forwards and that's because you didn't get a smile when you said something

Relationships can end up in a push and shove situation, veering between feeling suffocated and feeling abandoned.

Maintaining friendships for a decent length of time or not trying to sabotage everything that's good - for me that's one of the main things. I do just end up literally sabotaging every good friendship that I make and it's really quite annoying

Sometimes it means you just give up on relationships altogether.

It affects my ability to have relationships I don't really have anyone who is 'close' to me because I constantly think anyone who does get to know the 'real me' will run a mile



leti hawthorn

Dissociation

'Three days is a long time to think that you're the only entity in the world'

Dissociation is when you feel or become disconnected from the world around you. This can happen in a variety of different ways and may mean you are unable to interact with people around you, experience situations differently from others or are unable to remember what happened.

Dissociation can happen in a number of different ways including memory loss, depersonalisation where you feel you are unreal; de-realisation where you feel the world around you is unreal; identity confusion and also identity alteration.

Experiences like this can have a huge impact on your life, especially if you are constantly trying to deal with feeling unreal or cannot remember events that other people can.

Dealing with constant stress can cause you to dissociate and become disconnected from reality. This can be extremely distressing and confusing as you may not realise what you are doing or even remember it later.

Dissociation I find extremely difficult to cope with in the sense that it is an automatic reaction and a behaviour I need to control - I met someone I hadn't seen in a couple of years and she told me about a whole day out we had – I had no recollection of it

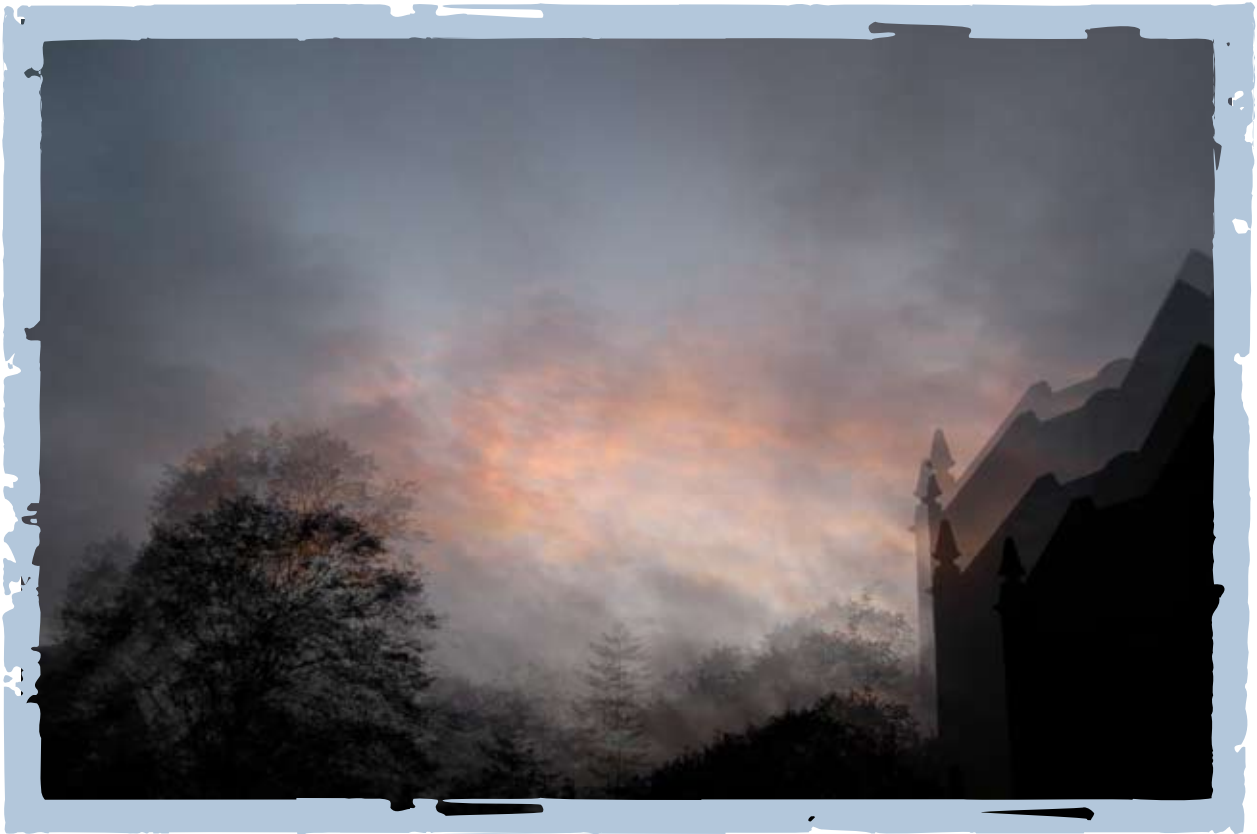
You can end up feeling very cut off and detached from the world and very unreal.

The dissociation - I can vanish off for three days, mentally where I believe that there's nothing outside my head. And three days is a long time to think that...you're the only entity in the world...Emotionally I can be detached, sometimes it feels like I've never been anything else

It can be extremely difficult to describe or even recognise this experience, and it can have an enormous impact on your ability to deal with day to day life.

FURTHER INFORMATION:

More information on dissociation and support can be found in the general resources section



leti hawthorn

Self Destruct

'I'm disappointed that I'm still alive'

Somehow you have to try and deal with all the intensity, feeling of unreality and confusion, and extreme levels of stress and anxiety and that's where self destructive behaviour can come in. This can include self harming, sabotaging things in your life, isolating yourself, neglecting yourself and suicide attempts to name a few.

The biggest impact of Borderline Personality Disorder that continues to affect me is without doubt my self hatred. I have reached indifference which is further than I have come in my life before

Constant impulses to harm yourself are very hard to ignore.

People always imagine folk building up to suicide... I get there very quickly, find myself with my head in a noose, thinking this is a very good day to die. Incredibly intense, and I think probably the best way I can describe it is like Tourette's...the compulsion to do it is incredible, it's almost unstoppable

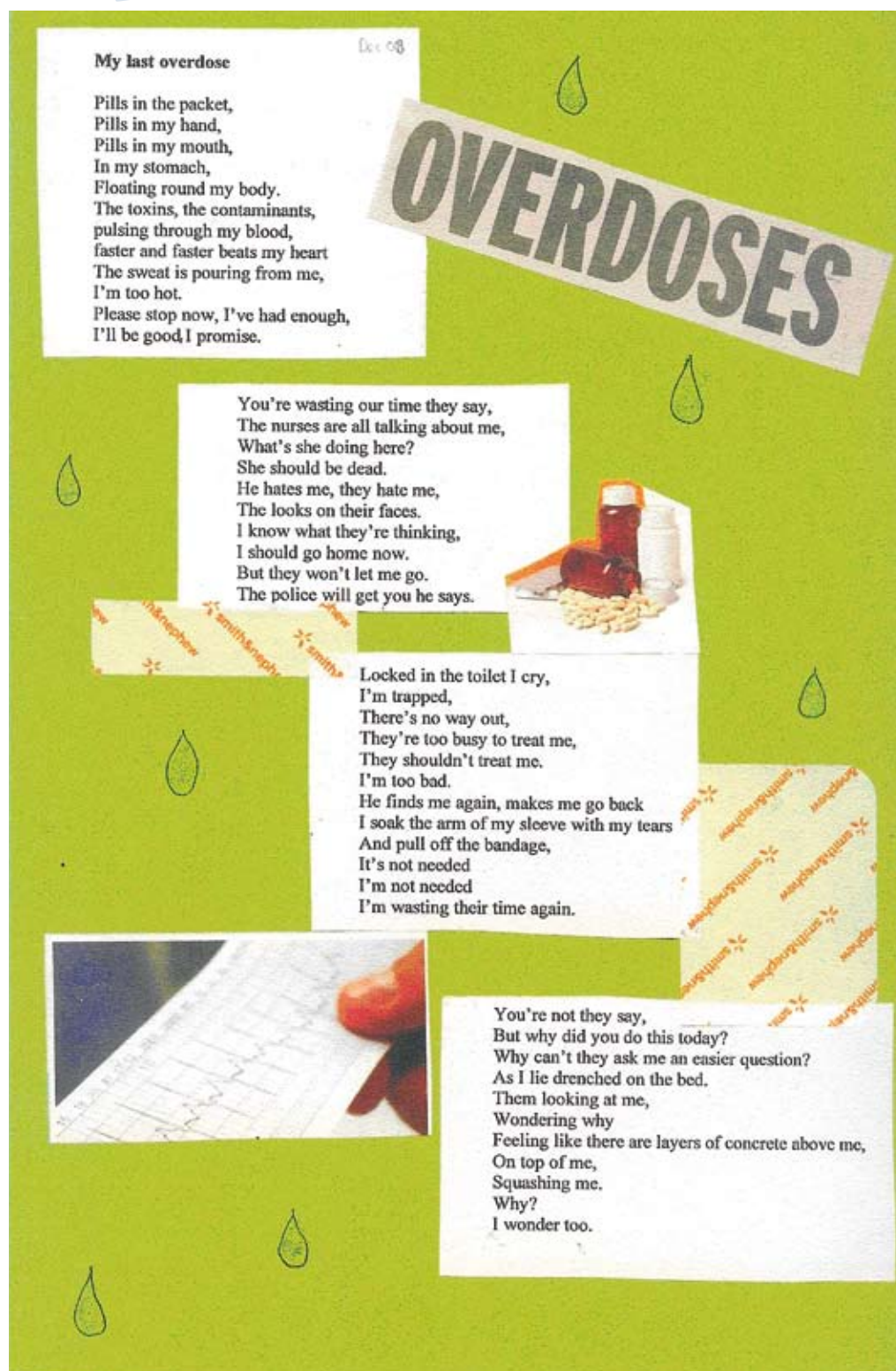
'Every day I wake up and have to persuade myself there is a reason to be alive'

Harming yourself can be a way to avoid suicide, or to punish yourself.

The level of harm you inflict on yourself is not a measure of how distressed you are

It's a vicious circle.

I cannot keep on going the way I've been going. I know for a fact inside my own head, there is a day when I'm going to snap and I am not going to make it



FURTHER INFORMATION:

More information on self harm and support can be found in the general resources section

There Can Be a Positive Side

'The strength we have as individuals'

It can seem that it's all negative, but some people also pointed out the positive side of their experiences.

We are all terribly 'emotionally sensitive' as we are told! I don't think it is as simple as saying that and that sucks because I view it as also having the ability (when well!) to empathise with people, to be moved by art or music, to use it to find a way to relate to people when you feel so incredibly isolated

Having a different view of the world can give you alternative insights.

What you've learned and how you understand the world can also mean you have developed a variety of ways to deal with life and inner strength.

A lot of our symptoms can actually have a positive spin. Never mind the fact that the strength we have as individuals to come through not only our disorders which we live with but our personal backgrounds is to our credit



leti hawthorn

"These are people who have had in general difficult lives and they've gone against a lot of adversity, and they're actually people rich with ways of coping with life"

Lisa Edwards, Community Psychiatric Nurse and Founding Member of Moray BPD Support Group in a pod cast for the Mental Welfare Commission

http://bit.ly/Principles_into_practice

I'm a Survivor

remove shutters
draw back curtains
rip off netting
that's the easy bit...
now roll up sleeves
brush down cobwebs
get to work with sponge,
hot water, soap and elbow grease.

no light through shutters
curtains block all but brightest of moons and suns
netting obscures all detail
but the dirt and grime
the insistent cobwebs and bird splats
they are the real cause, the true reason
why I cannot see out and you cannot see in.

change the water
now take scrunched-up newspaper (Guardian or Independent?)
add vinegar to the bucket
and begin to remove the smears from the glass.

the sun is revealed
as the wind pushes the clouds along
and that perfect window
shows its many imperfections

unlock, lift out panes
(this is hard work - the frames
have been painted so they are
stuck to the surround)
and finally,
breathless and perspiring
the entirety of what is beyond the window is revealed
and light pours into the room.

leti hawthorn



leti hawthorn

SECTION 02 : HOW DOES IT FEEL...?

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.





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 the experiences of people who have been given a personality disorder diagnosis?

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

Think of a time when you have had a very intense emotional experience. How do you think you would cope if this experience had not come to an end?

How in control do you think you would feel if you were constantly experiencing strong emotions and high levels of stress and distress all of the time?

How do you think you would cope if you experienced dissociation?

Was there anything in this section that helped you to understand why people end up harming themselves or doing other self-destructive things?

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.

P4 I Feel Hollow

An illustration.

P6 Divided

One side looks not too bad, I am alone up a hill, isolated but I am also 'swimming' quite happily in the sea. The other side there are fireworks and chaos, where I cling to control.

P8 Anger, Sadness and Pain – Just the title. That's it.

P9 not see – A poem.

P11 Sometimes I Don't Know If I Can Keep Going – A collage.

P13 Reality and Fantasy

Sometimes reality hurts so much that disappearing to a fantasy world where you can feel safe is the only option (in my case the 'safe' corner of my flat with teddy bear and iPod cocooned from the rest of the world, or dissociating).

P14 Isolation

A poem.

P16 Fleeting Shadows

Here I am long-legged and I have wings - perfect! My girlfriend appears in some of the images, I am alone in others. That's how I am, sometimes able to be present, other times disconnecting, disappearing...

P18 Double Exposure

I walk home from college and usually take photos as I go. When I get home I upload the images on to Picasa and play with them, often getting absorbed for ages. On this occasion I superimposed several images of the same scene which I'd taken. The trees and buildings and sunset-shaded clouds can be seen but it is difficult to focus, there is a jarring, a visual disturbance...

P20 Overdoses

A collage.

P22 Beauty in Brokenness

I dropped something in the kitchen and it fell on to the side where I had left this saucer. The woman who made it has retired to Greece now. I was very sad. But instead of getting upset or angry I let the broken saucer sit in the kitchen for a few days. Then the crocuses started coming out in the garden. I took the broken saucer outside and used it to frame the crocuses. This collage is called 'Beauty in Brokenness'

P23 remove shutters

The image shows three of the phases described in the text below. I made the triptych at a creative listening workshop at the Bield, near Perth and then described the process to the others in the workshop, working it out as I revealed the layers.

The more you look the more you will see - not because there is more there to be seen but because you are ready, you have opened your eyes, your heart and your spirit to see that statue you never noticed, the inscription on a wall, the detail in stained glass window are brought into focus, the scales drop from your eyes and you see the truth.

P24 Message in a Bottle

A collage.

Lived Experiences

The following quotes are taken from personal experiences of people who have a diagnosis of personality disorder.

Have a look at each quote and think about how these experiences, thoughts and feelings might affect someone on a in each of the areas which have been described in this section:

- ◆ **Day to Day Life**
- ◆ **Emotionally**
- ◆ **On a Practical Level**
- ◆ **In the Long Term**
- ◆ **In Relationships**
- ◆ **Ways of Coping**
- ◆ **Positives**

Lived Experience - A Distressing Experience

We may not fit definable boundaries, but that doesn't mean something real which affects our lives isn't happening and it is an extremely distressing experience and is long term - you might get over it, you might not. The disorder is difficult enough to cope with, never mind the lack of information, support and general fear people have of you

Lived Experience - Feeling Purposeless

Purposeless. There's no purpose. There's no purpose to yourself, no purpose to what you do... You just wish you weren't here; you just didn't exist and you can't look to the future and think that'll be interesting and that'll be interesting, you just think oh god I don't want to be here another ten years still feeling crap...you know if there was a big on off switch and you could just go 'Off', just flick it – it'd be brilliant

Lived Experience - Making a Cup of Tea

I am a bit better now at being like OK I feel really angry with this person, has this person really done something wrong, no this person's just not made me a cup of tea. It doesn't mean she hates me, it doesn't mean she's never going to talk to me again, so stop being a bitch, go over and just bite your tongue and say, you know I'm sorry for being really arsy with you for the last two weeks, it's because you didn't make me a cup of tea which is really stupid, but it's because of this and explain it. And I am getting a bit better at doing that, but it's really hard because still in my head I'm like, no it means she hates me, take the hint, never talk to her again, behave awfully towards her so she hates you too

Lived Experience - Chaos Theory

It means being incapable of liking yourself at all in any respect. Swerving from desperate adulation and really needing positivity from someone to really, really destructive kind of hate...

On-off desire to cause harm to yourself emotionally or physically... Almost complete lack of impulse control and for me an almost complete inability to be happy at all, to feel any real kind of happiness... Having to learn how to experience quite a lot of emotions, having to learn a lot of really basic mental abilities that people take for granted

Lived Experience - Needing Defence

I was defensive because at various stages I couldn't sleep, when I did sleep I had nightmares I would wake up screaming from. I was in a car with a friend as we were passing a bus I could see it smashing into us and people wondered why I was suicidal! Or why I would be so aggressive well I was trying to make sense of what was real and what wasn't

This image shows a full page of a document template designed for handwriting practice or general writing. It consists of approximately 20 evenly spaced, horizontal blue dashed lines running 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.

