



Much More Than A LABEL

A Resource About Personality Disorder By People With Lived Experience

Section **01**

Much More Than a Label

*A resource about personality disorder
by people with lived experience*

AN INTRODUCTION

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

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Contact:

Naomi Salisbury, Development Worker

CAPS – The Consultation and Advocacy Promotion Service

5 Cadzow Place, Edinburgh, EH7 5SN

0131 538 7177

www.capsadvocacy.org

naomi@capsadvocacy.org

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 01 : AN INTRODUCTION - MUCH MORE THAN A LABEL

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SECTION 01 : AN INTRODUCTION - MUCH MORE THAN A LABEL

About the Resource

Acknowledgements

Over forty people contacted the project and over thirty contributed their views and experiences. I would like to acknowledge how incredibly grateful and honoured I am to have these contributions from so many different people and how much each individual contribution to the project is valued.

Without people being willing to come forward and take part there would be no resource, and there was a strong sense amongst the participants that if talking about their own experiences would help others then that made it worthwhile.

I would like to thank the following people:

Paul Campbell
Ewan Law
Vicky Wood
Craig McAdam
Beki Scott
Kirsty McGuinness

And also to acknowledge and credit the many other valued participants who preferred to remain anonymous.

I would also like to thank CAPS and NHS Lothian, especially Keith Maloney and Linda Irvine, who took a chance on this project and gave it their full backing.

The project volunteers who have been invaluable.

The Edinburgh BPD Social Group who have been very enthusiastic about the project from the beginning and been a real source of inspiration.

Anne O'Donnell of CAPS Management Committee who took the time to review and give extremely helpful feedback.

Fran Holton who got me started down this road.

Gaurav I think we are even on the thesis front now!

And finally, almost everyone I have discussed the project with – the response has been overwhelmingly positive and I can only hope the resource does the participants justice!

It has been a pleasure to work on the project and continue to see it develop, change and grow. We have been able to develop information and training sessions, a short film and other resources and I look forward to continuing to develop the project.

Naomi Salisbury

CAPS – The Consultation and
Advocacy Promotion Service

March 2011

About the Project and the Resource



About the Personality Disorder Project

The Personality Disorder Project is a collective advocacy project which was set up to consult with people in the Lothian area who have experience of personality disorder. The project initially ran from April to October 2009, was hosted by The Consultation and Advocacy Promotion Service (CAPS) and funded by NHS Lothian. NHS Lothian have since provided further funding to continue and develop the project.

The aim of the project is to give people with a diagnosis of personality disorder a voice; to talk to people with experience of personality disorder diagnosis; to find out about their experiences of the condition and using services and to find out what was helpful and unhelpful.

The project was commissioned by the Lothian Psychological Intervention Network (LPIN) Group for People who may attract a diagnosis of personality disorder. The group has been holding yearly seminars since 2006 to share information about personality disorder in the Lothian area. The idea of a resource aimed at staff but written by service users was first suggested in 2007 and over time the potential scope of the project grew. In 2008 NHS Lothian agreed to fund a collective advocacy project hosted by CAPS and this began in April 2009.

Why Personality Disorder?

The 2001 National Institute for Mental Health report Personality Disorder: No Longer a Diagnosis of Exclusion¹ reflected the views of service users and carers. The document reported that personality disorder is the most stigmatised mental disorder by both the public and professionals.

People with a diagnosis of personality disorder have been described the 'patients psychiatrists dislike' and people felt that they were seen as their label which caused problems when receiving treatment.

The Hear Me! Survey² carried out by See Me in 2006 indicated that stigma is particularly high for personality disorder in comparison with other mental health conditions. People with a diagnosis of personality disorder had the highest stigma experience overall, of 94%, where 81% was the average for people who had experienced stigma due to their mental health condition.

¹ http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4009546

² <http://www.seemescotland.org.uk/2006-results>

In addition to this 51% of people with a personality disorder diagnosis had experienced stigma in mental health/other health services, while the average for those with mental health conditions was 24% overall.

The Mental Health Act (Care and Treatment) (Scotland) 2003 Section 328³ defines “mental disorder” as meaning any mental illness, personality disorder or learning disability however caused or manifested. This means that under the principles of the Act a diagnosis of personality disorder cannot exclude someone from receiving support and treatment, which has happened in the past.

NHS Lothian committed in their 2005-2010 Joint Mental Health and Well-Being Strategy for Lothian to build on existing good practice in the area of personality disorder, as well as ensure that a diagnosis of personality disorder did not exclude access to services. The 2011-2016 draft strategy ‘A Sense of Belonging’ continues to build on these aims.

The last few years have also seen the development of Integrated Care Pathways (ICPs) for mental health including personality disorder.

When the Lothian Psychological Intervention Network (LPIN) group for people who may attract a diagnosis of personality disorder began to work on the Integrated Care Pathway (ICP) for personality disorder it became clear that although legislation might have changed, services and information about personality disorder were still not readily available. Service users often found that there was a lack of information on the condition and that staff did not want or know how to support them.

It was suggested that a resource pack for staff be put together by people who have experience of personality disorder diagnosis and this grew into a wider consultation and ongoing collective advocacy project.

³ <http://www.legislation.gov.uk/asp/2003/13/section/328>

What is Collective Advocacy?

Collective Advocacy is one form of independent advocacy which exists in Scotland and is defined as a right for mental health services users under the Mental Health Act (Care and Treatment) (Scotland) 2003. Everyone who uses mental health services has a right to independent advocacy.

Independent advocacy supports people to have their voice heard and have as much control over their lives as possible. It is provided by organisations who are separate and independent from other types of services and is based on four principles:

- ◆ Putting the Service User First
- ◆ Accessibility
- ◆ Accountability
- ◆ Freedom from Conflict of Interest

Collective advocacy is when a group of people come together over common issues, to support each other and campaign on issues that are important to them.

More information can be found here:

<http://siaa.org.uk/images/leaflets/Guide-to-collective-or-group-advocacy.pdf>

Why Do a Consultation?

Studies indicate the prevalence of personality disorder is about 10-13% of the adult population in the community (No Longer a Diagnosis of Exclusion, NIMHE, 2003). The adult population of NHS Lothian area at the last census in 2001 was 634,394 (General Register Office for Scotland (2003) Census 2001)⁴. This means that an estimated 82,471 adults in Lothian may meet the criteria to be diagnosed with a personality disorder.

The number of people who the diagnosis could affect is so large, that it would not be possible to know people's views and opinions without doing some sort of consultation and actually asking them.

⁴ <http://www.gro-scotland.gov.uk/census/censushm/index.html>

What Happened Next?

The project was hosted by the Consultation and Advocacy Promotion Service (CAPS) and aimed to consult with service users who had experience of personality disorder diagnosis about their views on the condition and the services they had received.

We set up face to face interviews and a paper and online survey to allow people to feedback in the way that most suited them. We sent publicity about the project to a variety of organisations in Edinburgh and the Lothians and recruited two volunteers with lived experience of a personality disorder diagnosis to help with the project.

The response to the project was very positive with a number of people coming forward to be interviewed and fill out questionnaires. Those who took part were keen to share their experiences in order to help and better inform others who are either working in the area or have a diagnosis of personality disorder themselves.

The contributions were then written up into this resource and all participants were invited to comment on the resource before the final version was produced.

The project has continued to work with people with lived experience of the diagnosis of personality disorder to develop training delivered by service users and workers, an exhibition, a short film and a reference group made up of people with a diagnosis of personality disorder. The project has recently been awarded a national best practice award for service user participation and influence at the Mental Welfare Commission's Principles Into Practice Awards 2011. For more information about the project please contact Naomi Salisbury, Development Worker on 0131 538 7177 or naomi@capsadvocacy.org

Introduction to the Resource

This resource has been developed with input from a variety of people who live in the NHS Lothian area and have either been diagnosed with or feel they meet the criteria for a personality disorder diagnosis.

The resource is written from the point of view of people with experience of personality disorder diagnosis, and is a piece of collective advocacy.

Participants included people with Borderline Personality Disorder, Avoidant Personality Disorder, Paranoid Personality Disorder, Schizoid Personality Disorder, Dissociative Identity Disorder and Personality Disorder Not Otherwise Specified.

Some people who took part did not agree with their diagnosis and felt it did not reflect their experiences, did not relate to them or was a result of professionals trying to fit them into categories or not fully understanding what was happening for them.

The majority of participants had been diagnosed with Borderline Personality Disorder which reflects the fact that more people are diagnosed with Borderline Personality Disorder than other personality disorders.

Therefore the content of the resource reflects the experiences of those who contributed and the diagnoses they have been given.

It is also common to meet the criteria for more than one personality disorder, so some people involved in the project had been diagnosed with a number of personality disorders.

The resource covers people's experiences of life with personality disorder diagnosis, how they found out about the diagnosis, and what they find helpful and unhelpful in support and treatment and the attitudes of others.

Everyone's experiences and views are different and the resource tries to represent the variety of opinions and experiences of the project participants. Not everyone will have the experiences described here, but we have tried to cover the most common ones the participants talked about.

The resource is not meant to be a definitive view of personality disorder, but a tool which gives an insight into people's experiences and is a starting point for better support and understanding for people with a diagnosis of personality disorder.

About the Resource

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

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

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 workers and service users to discuss their experiences and views and promote a better working relationship

The resource is written from the point of view of people with experience of personality disorder diagnosis and throughout the resource are direct quotes in speech bubbles from people who took part in the project.

The contents of the resource can be used in a variety of ways, for individual reflection, group discussion and as a training tool.

Not everyone will identify with everything in the resource, but the hope is that the topics will provide a starting point for open discussion and understanding.

Layout of the Resource

The resource is divided into different sections on a number of topics. Each section has a number of different parts which display the information in a variety of ways and introduce topics for discussion:

Written Word:

A description of the topic using personal experiences and quotes to describe experiences and views

Quotes:

Personal experiences or views relating to the topic

Mind Map:

A visual diagram of the topic broken down into different areas, to give a broader view of thoughts, feelings and experiences

Word Cloud:

A quick overview and visual representation of the words people taking part in the project associated with the topic

Resources:

Discussion points around the topic with personal experiences and examples

Creative Writing and Artwork:

Artwork or writing relating to the section, provided or suggested by people who took part in the project

Personalising the Resource

We hope that this resource can be used not just as a training tool but also for individuals to better express their experiences and needs to others.

The resource has been designed so that it can be personalised and used individually.

At the end of each section there is space to add personal views on your experiences and what you find helpful and unhelpful.

However, there is no need to stick to this suggestion - the hope is that you would add whatever information you feel is useful in whatever form suits you best.

Mind Maps and Word Clouds

In each section as well as written descriptions there are mind maps and/or word clouds which give different visual representations of people's views and feelings.

Some people taking part in the project suggested that these could be useful tools to explain your feelings to others or to express them for yourself.

Both mind maps and word clouds can be made using programmes which can be downloaded from the internet and we have listed them here in case you find them useful.

- ◆ Mind Maps can be made using software which can be downloaded at:
<http://www.xmind.net>

This software allows you to make mind maps with a variety of layouts, colours and pictures.

- ◆ Word Clouds can be made by using:

<http://www.wordle.net>

This site allows you to create word clouds, change the colours and font and either print the word cloud or save it as a PDF file.

Creative Writing and Artwork

A number of service users who contributed their experiences to the project also contributed creative writing and artwork they had done or poems, quotes and pictures that meant something to them and these have been used to illustrate the resource.

"I use art to express how I feel when I have no words and am intensely distressed. It calms me down and provides a connection to my therapy sessions and my art therapist, where we can discuss the images and what I'd felt. This was more helpful to me in crisis than anything else I'd tried, or has been suggested"

The creative writing and pictures have been used in sections where they are relevant and explanations or information about them are included in the discussion and reflection section. The aim of including creative writing and artwork is to show different ways of expressing people's experiences and to provide another opportunity for discussion.

Creative Writing and Artwork has been provided by:

B. Nelson

Grace

Karen Sutherland

Leti Hawthorn

Natalie

Tamsin

We would also like to acknowledge very kind permission from:

Harold's Planet to use some of their cartoons

<http://www.haroldsplanet.com/>

Karen Sutherland for the main cover illustration

Penguin Group (UK) for the use of the Nick Hornby quote

Personality and Personality Disorder



We continue to shape our personality all our life.

Albert Camus

**Personality is far too complex a thing to be trussed up in
a conceptual straight-jacket.**

Gordon Allport

SECTION 01 : MUCH MORE THAN A LABEL

Personality and Personality Disorder

What is Personality?

It is very hard to find a straightforward definition of what personality actually is.

But without a definition of personality how can we talk about personality disorder?

In *The Science of Personality* Lawrence A. Pervin says, 'Personality is the complex organisation of cognitions, affects, and behaviours that gives direction and pattern (coherence) to the person's life. Like the body, personality consists of both structures and processes and reflects both nature (genes) and nurture (experience). In addition, personality includes the effects of the past, including memories of the past, as well as constructions of the present and future.' (p447)

He also says that, 'Research suggests that environment is important in shaping personality, but one important part of the environment, the family, does not affect all children in the family in the same way... The interaction between nature and nurture is such that simple answers to complex questions are impossible. There is never gene without environment or environment without gene; that is, we must always be aware of the nature and nurture of personality.' (p180)

So personality is not straight-forward or easy to describe - how can you capture easily what makes a person who they are?

What is Meant by Personality Disorder?

There are two main resources which describe and classify personality disorder; the International Classification of Disease 10 (ICD 10), and the American Diagnostic Statistical Manual IV (DSM IV). However, these are clinical descriptions and do not necessarily explain what the every day experience of personality disorder diagnosis is like.

They describe personality disorder in the following ways:

The International Classification of Mental and Behavioural Disorders (ICD-10) (World Health Organisation 1992)

This defines a personality disorder as: 'a severe disturbance in the character, logical condition and behavioural tendencies of the individual, usually involving several areas of the personality, and nearly always associated with considerable personal and social disruption'.

The Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) (American Psychiatric Association 1994)

This defines a personality disorder as: 'an enduring pattern of inner experience and behaviour that deviates markedly from the expectations of the individual's culture, is pervasive and inflexible, has an onset in adolescence or early adulthood, is stable over time, and leads to distress or impairment'

There are nine categories of ICD-10 personality disorder and ten categories of DSM-IV personality disorder. The classification scheme means that people are rarely diagnosed with or meet the criteria for just one personality disorder.

The DSM clustering system groups the subcategories of DSM-IV personality disorder into three broad 'clusters': Cluster A, B and C.

Diagnostic and Statistical Manual IV Personality Disorder Clusters

Cluster A - 'Suspicious':

- ◆ **Paranoid**
May be suspicious of other people and feel that others are being nasty. Sensitive to rejection and tend to hold grudges.
- ◆ **Schizoid**
Don't have strong emotions, don't like contact with other people and prefer own company. Have a rich fantasy world.
- ◆ **Schizotypal**
Have odd ideas and difficulties with thinking. Other people see them as eccentric. May see or hear strange things

Cluster B - 'Emotional and Impulsive':

- ◆ **Antisocial**
Don't care about the feelings of others, get easily frustrated, fight, commit crimes and find it hard to have close relationships. Do things on the spur of the moment, don't feel guilty and don't learn from unpleasant experiences.
- ◆ **Borderline, or Emotionally Unstable**
Do things without thinking, find it hard to control emotions, and feel empty. Feel bad about themselves and often self-harm. Make relationships quickly, but easily lose them. Can also feel paranoid or depressed and, when stressed, may hear noises or voices.
- ◆ **Histrionic**
Over-dramatise events and tend to be self-centred. Emotions are strong, but change quickly. Worry a lot about appearance and crave excitement.
- ◆ **Narcissistic**
Feel very important and dream of success, power and status. Crave attention, tend to exploit others and ask for favours that aren't returned.

Cluster C - 'Anxious':

◆ Obsessive-Compulsive (Anankastic)

Perfectionist, worry about detail and are perhaps rigid. Cautious and find it hard to make decisions. Have high moral standards, tend to judge other people and worry about doing the wrong thing. Sensitive to criticism and may have obsessional thoughts and behaviours.

◆ Avoidant (aka Anxious/Avoidant)

Very anxious and tense; worry a lot, feel insecure and inferior. Want to be liked and accepted and are sensitive to criticism.

◆ Dependent

Rely on others to make decisions and do what others want them to do. Find it hard to cope with daily tasks, feel hopeless and incompetent and easily feel abandoned by others.

These descriptions are only an overview of the different personality disorder diagnoses. Diagnosis is made on the basis of different traits which individuals can display. Many people have these traits, but for some people they become difficult to deal with. However, a label or diagnosis may not say as much about a person as the experiences they have.

More Information

There are a number of leaflets and websites available which give information about personality disorder. For a full list please look at the general information section which has information and links to these resources.



leti hawthorn

Why Do People Develop These Issues?

No one knows for sure but research suggests that there are a variety of different areas involved including:

Biological Factors such as inheritance and temperament

'Research suggests that inheritance and environment each account for fifty percent of the difference in personality traits between patients.'
(Jang & Vernon, 2001)

'Temperament' can be defined as biological variability in emotional responsiveness, fixed by genetic factors.' (Alwin, 2006 in Personality Disorder and Community Mental Health Teams: A Practitioner's Guide)

Neuroanatomical and Biochemical Factors

'There seem to be some aspects of personality disorder that have developed because of problems with the structure of the brain. However, it is unclear whether the brain has been like this since birth or has been affected by life experiences.' (Alwin, 2006)

Psychological Factors - Childhood Abuse/ Mistreatment

'There is evidence of a high degree of psychological and social dysfunction in the families of patients who develop personality disorder.' (Alwin, 2006)

There is also a fairly high incidence of experience of abuse or neglect in people who are diagnosed with personality disorder. However, not everyone has experienced this and abuse or mistreatment in childhood does not automatically mean that someone will go on to be diagnosed with a personality disorder.

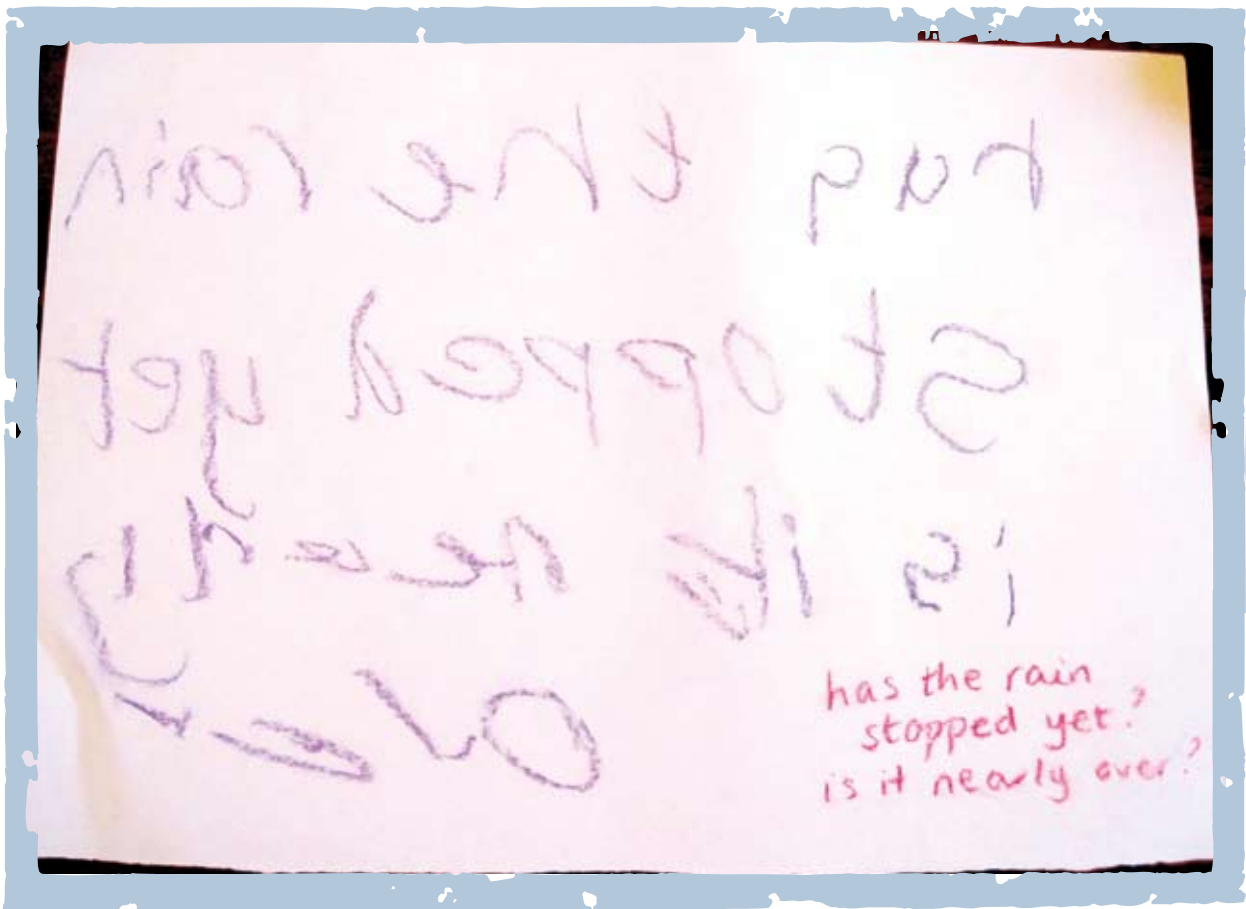
Marsha Linehan, who developed Dialectical Behaviour Therapy for treating people with a diagnosis of borderline personality disorder, talks about the experience of an invalidating environment. This is where someone grows up in a situation where their needs and feelings are not taken at face value. Linehan also describes people who have a diagnosis of borderline personality disorder as having the emotional equivalent of 'third degree burns'.

The experience of personality disorder diagnosis has also been described as being like a swan swimming along serenely on top of the water while paddling frantically underneath to keep going.

People learn from their experiences so it is likely there will be a reason for someone to have learned to respond in a certain way, however irrational it may seem to other people.

No two people are the same, and everyone will have very individual reasons for being the person that they are. Everyone's experience is unique to them, whether or not others had the same experience. It is important to see and accept someone as they are, as well as understand there may be many contributing factors to the person they are today.

I feel I have been having a normal reaction to abnormal circumstances



leti hawthorn

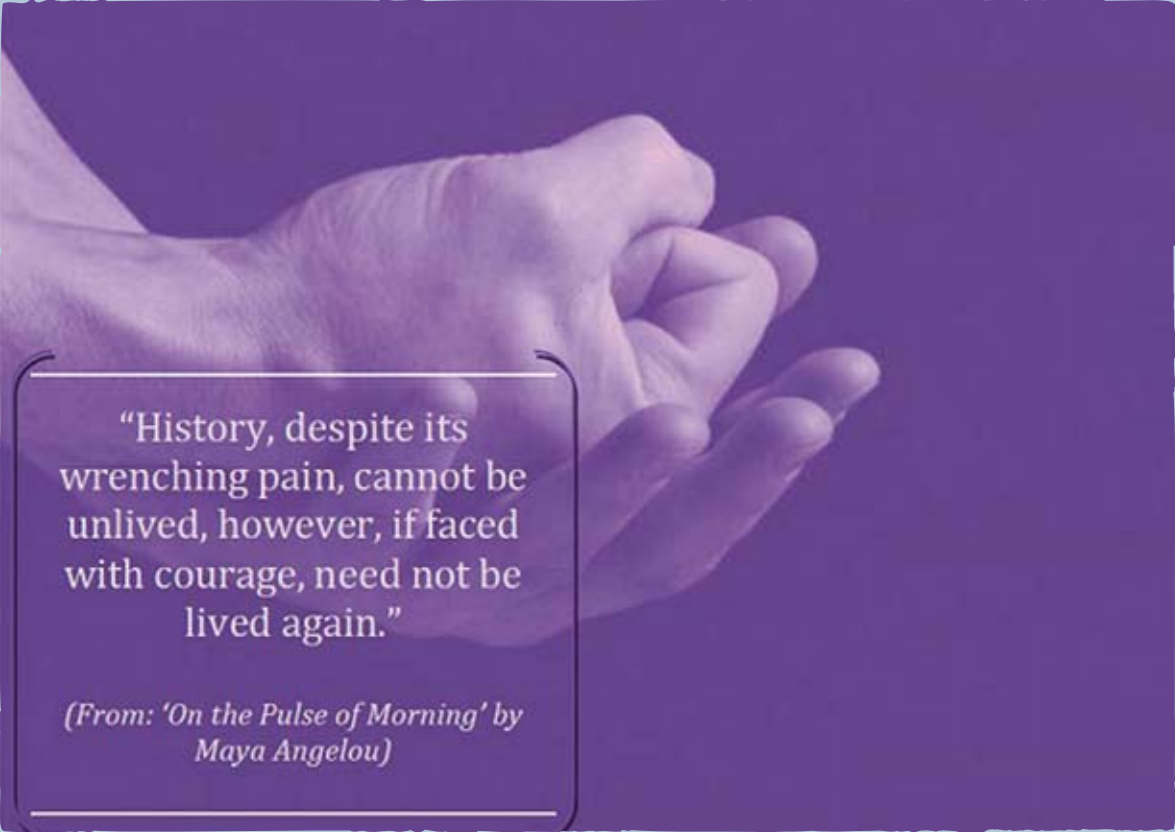
The Sum of Your Experiences?

People who took part in the Personality Disorder Project were:

mothers; friends; professionals; partners; brothers; graduates; god-parents; babysitters; fathers; employees; athletes; aunts; mental health trainers; volunteers; students; sisters; teachers; artists; writers; uncles; spouses

But they had also experienced:

bereavement; domestic violence; eating disorders; alcoholism; ridicule; sexual abuse; adoption of children; physical neglect; physical abuse; self harm; humiliation; suicide attempts; divorce; emotional abuse; homelessness; job loss; bullying; terror; sexual assault; emotional neglect; severe dissociation



“History, despite its wrenching pain, cannot be unlived, however, if faced with courage, need not be lived again.”

(From: 'On the Pulse of Morning' by Maya Angelou)

Artwork in this section

Have a look at the artwork in this section.

What do you think the creator was trying to express?

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

Some contributors have written an explanation about their work.

P21 - Distorted Collage

I am fascinated by shadows, the shadow-self I try to avoid, the shadow shape I make which I can like much more than my real shape or dislike immensely as in this case where, because of the bag on my back and the coat I was wearing, I look bizarre, lumpy, as the collage says distorted

P23 - Is It Over Yet?

Writing with my left hand, not knowing what was going to come through this hand. This is my child-self, abused by my grandfather

P24 - History

This came up on a 'random quotes' webpage and hit me as so true. How can one sentence say so much? This needs to be one of my goals - I like the fact it doesn't deny past trauma/suffering, whilst saying it's possible to move on. She also acknowledges the courage it takes to make this step.

Notes

A series of horizontal dotted lines for taking notes, spanning the width of the page below the 'Notes' header.

Notes

A series of horizontal dotted lines for taking notes.

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