

Much More Than A LABEL

A Resource About Personality Disorder By People With Lived Experience

Section **09**

General Information

Information on Diagnosis, Support and Treatment

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

“Much More Than A Label” Copyright © 2011,
The Consultation and Advocacy Promotion Service (CAPS).

CAPS grants permission to reproduce sections of this work for personal and educational use only, in which case CAPS expects to be fully acknowledged as the author of this work. Commercial publication, copying, hiring or lending is prohibited and constitutes a breach of copyright.

Section Cover Photographs © Brenda Carson | Dreamstime.com

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

Produced: July 2011

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.

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 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 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 09 : GENERAL INFORMATION

Section Outline

Information about the following areas can be found in this section:

Service User Led and Focused Information:

Personality Disorder	1
Self Harm.....	3
Dissociation	5
Survivors of Abuse	6
Sexual Assault and Rape Support	8
Domestic Abuse Support.....	8
Advocacy.....	9
Support for Carers	9

Networks, Policy and Training Information:

National Networks	11
Policy and Research.....	11
Training	12

Information Leaflets:

Personality Disorder	13
Borderline Personality Disorder.....	13
Dissociative Disorders.....	14
Grounding	14
Pacing - Managing Energy	15
General.....	15

Treatment Information:

Talking Treatments	17
Cognitive Behaviour Therapy (CBT)	18
Psychotherapy.....	19
Group Psychotherapy.....	20
Cognitive Analytic Therapy (CAT)	21
Dialectical Behaviour Therapy (DBT).....	22
Mentalisation Based Therapy (MBT).....	23
Schema Therapy	24
STEPPS.....	25
Therapeutic Communities	26
Creative Arts Therapies	27

A Few Other Interesting Things:

Useful Books.....	29
Other User Led Resources	30
Myths About Personality Disorder	31
An Open Letter to Those Without Invisible Disability or Chronic Illness	33
The Gorilla In Your House	36
Spoon Theory	38
References/Further Reading List.....	43

General Information

A number of the resources are titled as being about Borderline Personality Disorder, but many of these also have information about other personality disorders as well. There is, unfortunately, currently not a lot of information available about other individual personality disorders.

We hope these resources are useful and can help you find the information that you want.

SECTION 09 : GENERAL INFORMATION

Service User Led and User Focused Information

Personality Disorder

Emergence Plus:

User-led support groups and also provide training.

Formed through the merger of Borderline UK and Personality Plus.

Emergence is a service user-led organisation with the overarching aim of supporting all people affected by personality disorder including service users, carers, family & friends and professionals

We aim to work collaboratively to:

- ◆ Provide support, advice and information
- ◆ Increase public and professional understanding of personality disorder
- ◆ Challenge the associated stigma and social exclusion experienced by individuals affected by this diagnosis
- ◆ Stimulating further health and social policy responses into the prevention and treatment of personality disorder and the reduction of stigma and discrimination

Online Support Groups:

<http://health.groups.yahoo.com/group/BorderlineUK/>

<http://health.groups.yahoo.com/group/managingBPD/>

Website: <http://www.emergenceplus.org.uk/>

BPD World:

User-led organisation providing information, support and advice to those affected by personality disorder. Wide variety of leaflets on personality disorder, management strategies and treatments.

Helpline: 0870 005 3273

Website: <http://www.bpdworld.org/>

DBT Self Help:

This website is a service for people who are seeking information about DBT (Dialectal Behaviour Therapy). This site has been created by PEOPLE WHO HAVE BEEN THROUGH DBT.

Website: <http://www.dbtselfhelp.com/>

BPD Resources:

The purpose of this web site is to provide reliable educational material and direction to family, friends, and relationship partners of individuals affected by borderline personality disorder or borderline personality disorder traits.

Website: <http://www.bpdresources.net>

Soul Self Help:

Website written by someone who has recovered from BPD and delivers training and awareness.

Website: <http://www.soulselfhelp.on.ca/>

Middle Path:

Education and Resources on BPD with information on DBT

Website: <http://www.middle-path.org/>

Positives of BPD:

Emophilia or emophany, a "positive" borderline disorder's view.

Website: <http://www.aapel.org/bdp/BLeophiliaUS.html>

Self Harm

National Self Harm Network:

Online information and support forums and a variety of leaflets to download which can be taken to A&E, as well as distraction and harm minimisation suggestions.

Phone: 0800 622 6000 Open Thursday-Saturday 7pm-11pm, Sunday 6.30pm-10.30pm (including public holidays)

Website: <http://nshn.co.uk/>

The Basement Project:

The Basement Project provides support groups for those who have been abused as children and people who self-harm. These are free to individuals and funded by our work with professionals.

We also provide training, consultation and supervision for workers in community and mental health services. We provide a range of publications offering practical guidance for workers. Our books for service-users offer many creative ideas based on the experience of others who have journeyed through similar difficulties. All are written in an accessible style.

Address: The Basement Project
PO Box 5
Abergavenny
NP7 5XW

Phone: 01873 856524

Website: <http://www.basementproject.co.uk/index.html>

First Signs:

The user-led voluntary organisation, founded by Wedge in 2002, to raise awareness about self-injury and help people who rely on self-injury by providing a safe, friendly message board, ideas for distraction techniques and by inspiring / empowering them to find alternative, healthier coping mechanisms. Our resources include guidance for friends, family, teachers and carers, with downloadable fact sheets. The First Signs Professionals section provides specific resources and articles, together with a unique professionals' message board and details of our popular training package.

Website: <http://www.firstsigns.org.uk/>

Secret Shame:

Self-injury: You are NOT the only one

Website: <http://www.palace.net/~llama/psych/injury.html>

Survivors of Abuse and Self Harm:

SASH provides support to those who find it difficult to communicate face to face or by telephone. We allow those who would rather communicate in writing to do so, to allow them to contact others like themselves.

SASH also provides a half yearly newsletter, by the survivor, for the survivor. For those who would like to share their views, thoughts and feelings through poetry, photos and stories. Their courage and words will offer comfort and hope to others.

Address: SASH
20 Lackmore Road
Enfield
Middlesex
EN1 4PB

Email: sashpen@aol.com

Website: <http://sashpen.webs.com/>

Bristol Women's Crisis Centre:

BCSW is a collectively run charity set up in 1986 to respond to the needs of women in emotional distress. They have a particular focus on self-injury and provide a national helpline for women in crisis. They offer any woman who calls a chance to talk through her feelings in confidence, without fear of being judged or dismissed. They also support self-help groups, offer training and publish a wide range of literature

Address: P.O. Box 654
Bristol
BS99 1XH

Helpline: 0117 925 1119

Opening Times: Fri and Sat evenings 9pm - 12.30am
Sundays 6pm-9pm

Email: bcsw@btconnect.com

Website: www.selfinjurysupport.org.uk

Dissociation

Mosaic Minds:

Mosaic Minds is a primarily internet based organization by a group of dissociative survivors of childhood trauma and their loved ones. It seeks to provide an online clearinghouse of information for those whose lives are impacted by the more extreme form of dissociation called "Dissociative Identity Disorder" (DID).

Website: <http://www.mosaicminds.org/>

Dissociation World:

Part of BPD World. Has information and online forums about dissociation.

Website: <http://www.dissociation-world.org.uk/>

First Person Plural:

Small UK wide charity led by abuse survivors with first hand experience of complex dissociative distress.

Address: PO BOX 2537
Wolverhampton
WV4 4ZL

Website: <http://www.firstpersonplural.org.uk/>

Survivors of Abuse

Survivor Scotland:

The Survivor Scotland website has been developed to improve the lives of survivors of childhood sexual abuse. For the first time, people have access to a wide range of material about abuse, all in one place. It is a networking resource for a wide variety of interested people, and it gives useful links to other websites that may also be helpful.

Address: Adult Care and Support Change Team
Scottish Government Health Department
Room 2ER
St Andrew's House
Edinburgh
EH1 3DG

Email: survivorscotlandfeedback@scotland.gsi.gov.uk

Website: <http://www.survivorscotland.org.uk/>

National Association for People Abused in Childhood:

NAPAC is the National Association for People Abused in Childhood. We are a registered charity, based in the UK, providing support and information for people abused in childhood

Freephone

Support Line: 0800 085 3330

If our 0800 number allows you to leave a message please ignore it as this is a fault that we are currently working on - we apologise to those of you who have already left messages and have been expecting a call back.

Address: NAPAC
42 Curtain Road
London
EC2A 3NH

Website: <http://www.napac.org.uk/>

Survivors UK:

Provides information, support and counselling for men who have been raped or sexually abused.

Address: UK National Helpline
Office Number: 0207 404 6234
Ground Floor
34 Great James Street
LONDON
WC1N 3HB

Opening Times: 7pm-10pm Mon/Tue/Thu

Email: info@survivorsuk.org

Website: <http://www.survivorsuk.org/>

Trauma Counselling Line Scotland:

Confidential telephone counselling for men who have experienced any form of abuse.

Phone: 08088 020406

Open: Monday – Wednesday 5pm – 7pm
Thursday and Friday 11am – 2pm

Website: <http://bit.ly/fwPTK1>

Sexual Assault and Rape Support

Rape Crisis Scotland:

Provides a national rape crisis helpline for anyone affected by sexual violence, no matter when or how it happened. The helpline is open from 6pm to midnight, 7 days a week, and offers free and confidential initial and crisis support and information and can also put you in touch with local rape crisis centres or other services.

Helpline: 08088 01 03 02

Address: 1st Floor
Tara House
46 Bath Street
GLASGOW
G2 1HG

Phone: 0141 331 4180

Email: info@rapecrisisscotland.org.uk

Website: <http://www.rapecrisisscotland.org.uk/index.htm>

Domestic Abuse Support

Scottish Domestic Abuse

For help and information

Freephone: 0800 027 1234 in absolute confidence

Opening Times: 24 hours a day, seven days a week

Website: www.domesticabuse.co.uk/

Advocacy

Scottish Independent Advocacy Alliance:

The Scottish Independent Advocacy Alliance (SIAA) promotes, supports and defends the principles and practice of independent advocacy across Scotland. The website includes a directory of independent advocacy providers across Scotland.

Address: 69a George Street
Edinburgh EH2 2JG

Phone: 0131 260 5380

Website: www.siaa.org.uk

Support for Carers

Carers 4 PD:

A voluntary service dedicated to providing information, support and advocacy for carers of people diagnosed with a Personality Disorder. It is staffed by volunteer carers who have a great deal of experience in caring for people diagnosed with Borderline Personality Disorder

Email: info@carers4pd.co.uk

Website: <http://www.carers4pd.co.uk/default.html>

Anything to Stop the Pain:

Website and email support group is the home of about 300 members and serves to share strategies and tools with which the members can live a more peaceful life with someone with BPD.

Website: <http://www.anythingtostopthepain.com/>

Free E-Books: 4x4 e-book: <http://bit.ly/dZqVV1>

Five Common Mistakes Made By Supporters of People with BPD - <http://scr.bi/h3RMti>

SECTION 09 : GENERAL INFORMATION

Networks, Policy and Training Information

National Networks

Scottish Personality Disorder Network:

A network database across Scotland of people from different professional backgrounds and users and carers to help each other progress work locally and nationally around personality disorder.

Website: <http://www.scottishpersonalitydisorder.org/>

Personality Disorder Programme:

This website provides information, resources and learning opportunities on Personality Disorder (PD) as well as supporting the development of the National Personality Disorder Programme.

Website: <http://www.personalitydisorder.org.uk/>

Policy and Research

Personality Disorder in Scotland: Demanding patients or deserving people?

Delivering improved care: A discussion paper

http://bit.ly/aberdeen_uni

No Longer a Diagnosis of Exclusion:

This document provides information for Trusts about the Government's intentions for the delivery of personality disorder services within general mental health and forensic settings.

Website: http://bit.ly/NHS_personality_disorder

NICE Guidelines:

Borderline Personality Disorder: Treatment and Management

<http://www.nice.org.uk/guidance/CG78>

Antisocial Personality Disorder: Treatment and Management

<http://www.nice.org.uk/guidance/CG77>

Personality Disorder Institute:

Research Institute based in Nottingham

http://bit.ly/institute_mh

Training

Knowledge and Understanding Frameworks:

Training course on personality disorder being run by the Department of Health and the Open University.

Website: <http://www.personalitydisorder.org.uk/training/kuf/>

SECTION 09 : GENERAL INFORMATION

Information Leaflets

General Information on Personality Disorder, Dissociation and Pacing.
These leaflets are all available on request from the relevant organisations.

Personality Disorder Leaflets

Personality Disorders:

http://bit.ly/royal_college_psychiatrists
- Royal College of Psychiatrists

Understanding Personality Disorder:

http://bit.ly/mind_pd
- MIND

Personality Disorder:

http://bit.ly/mental_health_foundation
- Mental Health Foundation

What is Personality Disorder?:

http://bit.ly/rethink_pd
- Rethink

Borderline Personality Disorder Leaflets

Understanding Borderline Personality Disorder:

http://bit.ly/mind_bpd
- MIND

An Introduction to BPD:

http://bit.ly/borderline_uk
- Borderline UK

What is BPD?:

<http://www.bpdworld.org/leaflets-a-downloads>
- BPD World

Borderline Personality Disorder:

<http://www.patient.co.uk/doctor/Borderline-Personality-Disorder.htm>
- Patient UK

What is Borderline Personality Disorder?:

<http://www.abdn.ac.uk/~wmm075/uploads/files/leaflet.pdf>
- Scottish Personality Disorder Network

Dissociative Disorders Leaflets

Understanding Dissociative Disorders:

<http://bit.ly/kJSSbi> - MIND

Dissociation and Dissociation Disorders - Frequently Asked Questions:

<http://www.isst-d.org/education/faq-dissociation.htm>
- International Society for the Study of Trauma and Dissociation

Information Leaflets on Grounding

Grounding can be a useful technique to use when you are very anxious or can feel yourself becoming dissociated

Grounding Exercises:

http://bit.ly/thriving_now
- Thriving Now

Grounding Handout:

http://bit.ly/dr_patti_levin
- Dr Patti Levin

Grounding:

http://bit.ly/grounding_ipcommunications
- IP Communications from Seeking Safety:
A Treatment Manual for PTSD and Substance Abuse

Information Leaflets on Pacing

The concept behind pacing is that if you manage your energy wisely it will gradually increase. Pacing can bring structure to the day and give you back a sense of control. A lot of people taking part in the project reported that they got very tired very easily, and although these booklets are aimed at people with ME, the information can be useful for others who need to manage their energy levels - see also The Spoon Theory at the end of this section.

Pacing:

<http://bit.ly/koXZbL>
- Action for ME

Pacing for ME and CFS: A guide for patients:

<http://www.wames.org.uk/pacingweb.pdf>
- Welsh Association of ME and CFS support

General Self Help Leaflets

Centre for Clinical Interventions:

Online modules and worksheets around a variety of mental health issues.

Website: <http://www.cci.health.wa.gov.au/>

Get Self Help:

Massive range of self help worksheets and ideas developed by a clinical psychologist.

Website: <http://www.getselfhelp.co.uk/>

SECTION 09 : GENERAL INFORMATION

Treatment Information

Below is information about some of the therapeutic treatments which are available. This is not an exhaustive list, and there may be many other forms of support which people with a personality disorder diagnosis find help. This section aims to provide information about each type of treatment listed so you can be better informed about them.

Talking Treatments

There are different types, but they are all 'talking treatments' in which you talk with another person. It can help you to overcome:

- ◆ stress
- ◆ emotional problems
- ◆ relationship problems
- ◆ troublesome habits
- ◆ problems such as hearing voices.

Leaflets on Talking Treatments:**Understanding Talking Treatments:**

http://bit.ly/mind_talking_treatments
- Mind

Talking Therapies:

http://bit.ly/mhf_talking_therapies
- Mental Health Foundation

Types of Talking Treatment:

http://bit.ly/rethink_talking_treatments
- Rethink

Cognitive Behaviour Therapy (CBT)

CBT is a way of talking about:

- ◆ How you think about yourself, the world and other people
- ◆ How what you do affects your thoughts and feelings.

CBT can help you to change how you think (“Cognitive”) and what you do (“Behaviour”). These changes can help you to feel better.

Unlike some of the other talking treatments, it focuses on the “here and now” problems and difficulties. Instead of focussing on the causes of your distress or symptoms in the past, it looks for ways to improve your state of mind now.

Leaflets on CBT:

Cognitive Behavioural Therapy (CBT):

<http://www.patient.co.uk/pdf/pilsL664.pdf>
- Patient UK

Cognitive Behavioural Therapy (CBT):

http://bit.ly/cbt_royalcollege
- Royal College of Psychiatrists

Making Sense of Cognitive Behaviour Therapy:

http://bit.ly/mind_cbt
- Mind

Psychotherapy

Psychotherapy gives you a regular time to think - and talk - about the feelings you have about yourself and other people (especially your family and those you are close to). You discuss:

- ◆ what's happening in your life at the moment - how you do things and the part you play in things going right or wrong for you
- ◆ what has happened in the past
- ◆ how the past can affect how you are feeling, thinking and behaving right now.

Leaflets on Psychotherapy:

Making Sense of Psychotherapy and Psychoanalysis:

http://bit.ly/mind_psychotherapy
- Mind

Psychodynamic Therapy:

<http://bit.ly/ieG2wa>
- NHS Oxford and Buckinghamshire

Psychotherapies:

http://bit.ly/psychotherapies_royalcollege
- Royal College of Psychiatrists

Group Psychotherapy

In group psychotherapy patients discuss things in a group environment with the psychotherapist controlling and facilitating. The group setting is particularly good for focusing on relationship problems. The group setting provides a safe area to practice new behaviours which will hopefully lead to a lasting change.

Leaflets on Group Psychotherapy:

Group Psychotherapy:

<http://www.patient.co.uk/doctor/Group-Psychotherapy.htm>
- Patient UK

Group Analytic Therapy:

<http://bit.ly/iU7OeU>
- NHS Oxford and Buckinghamshire

Cognitive Analytic Therapy (CAT)

Cognitive Analytic Therapy involves a therapist and a client working together to look at what has hindered changes in the past, in order to understand better how to move forward in the present. Questions like 'Why do I always end up feeling like this?' become more answerable.

Useful Websites about Cognitive Analytical Therapy:

Association of Cognitive Analytic Therapists Online:

<http://www.acat.me.uk/>

Leaflets on Cognitive Analytic Therapy:

Cognitive Analytic Therapy:

<http://www.psychotherapy.slam.nhs.uk/Default.aspx?tabid=528>
– NHS South London and Maudsley

Cognitive Analytic Therapy:

<http://bit.ly/iue3Eg>
– NHS Oxford and Buckinghamshire

Dialectical Behaviour Therapy (DBT)

DBT is based on a model suggesting that both the cause and the maintenance of BPD are rooted in biological disorder combined with environmental disorder. The emotional difficulties individuals with BPD face consist of two factors, emotional vulnerability plus deficits in skills needed to regulate emotions.

The treatment consists of individual support as well as a skills group looking at the following four modules:

- ◆ Mindfulness
- ◆ Distress Tolerance
- ◆ Interpersonal Effectiveness
- ◆ Emotion Regulation

Useful Websites on Dialectical Behaviour Therapy:

DBT Resources for Professionals

<http://behavioraltech.org/>

Leaflets on Dialectical Behaviour Therapy:

Dialectical Behaviour Therapy:

http://bit.ly/mind_dialect

- Mind

Dialectical Behaviour Therapy:

<http://www.bpdworld.org/leaflets-a-downloads>

- BPD World

Dialectical Behaviour Therapy:

http://bit.ly/NHSDevon_dialect

- NHS Devon

Dialectical Behaviour Therapy Frequently Asked Questions:

http://www.behavioraltech.com/downloads/dbtFaq_Cons.pdf

- Behavioural Tech

Mentalization Based Therapy (MBT)

MBT is a type of psychotherapy created to treat people with borderline personality disorder. It's also been found to be useful for people with other types of mental illness. As the name suggests, it centres on the concept of 'mentalization'. Mentalization is simply about recognising what's going on in our own heads and what might be going on in other people's heads.

MBT is intended both to help you to sharpen up your ability to mentalize and to be willing to use it, especially when you're feeling intense emotions.

Useful Websites on Mentalization Based Therapy:

User View of Mentalization Based Therapy:

<http://www.mentalising.com/mentalisation-based-therapy.html>

Information from University College London:

<http://bit.ly/mentalisation>

Schema Therapy

Schema therapy integrates elements of cognitive therapy, behaviour therapy, object relations, and gestalt therapy into one unified, systematic approach to treatment.

Schema Modes are the moment-to-moment emotional states and coping responses that we all experience. Often your schema modes are triggered by life situations that you are oversensitive to (our “emotional buttons”). Many schema modes lead you to overreact to situations, or to act in ways that end up hurting you. The goals of Schema Therapy are: to help patients to stop using maladaptive coping styles and thus get back in touch with their core feelings; to heal their early schemas; to learn how to flip out of self-defeating schema modes as quickly as possible; and eventually to get their emotional needs met in everyday life

Useful Websites on Schema Therapy:

All about Schema Therapy:

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

Overview of Schema Therapy:

http://www.cognitivetherapy.me.uk/schema_therapy.htm

A Client’s Guide to Schema Therapy:

<http://www.davidbricker.com/clientsguideSchemaTherapy.pdf>

Systems Training for Emotional Predictability and Problem Solving (STEPPS)

The goal is to provide the person with BPD, other professionals treating them, and closely allied friends and family members with a common language to communicate clearly about the disorder and the skills used to manage it. Clients learn specific emotion and behaviour management skills. Key professionals, friends, and family members whom clients identify as part of their “reinforcement team,” learn to reinforce and support the newly learned skills.

The training is composed of three steps:

Step 1 - Awareness of Illness

Step 2 - Emotion Management Skills Training

Step 3 - Behaviour Management Skills Training

Useful Websites on STEPPS:

University of Iowa STEPPS Program:

http://bit.ly/iowa_steps

STEPPS for BPD:

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

Sussex Partnership Presentation on STEPPS at SPDN:

http://bit.ly/spdn_steps

Therapeutic Communities

Therapeutic Communities (TCs) are 'psychologically informed planned environments' - they are places where the social relationships, structure of the day and different activities together are all deliberately designed to help people's health and well-being.

Association of Therapeutic Communities:

<http://www.therapeuticcommunities.org/>

Therapeutic Communities in Scotland:

Lothlorien:

Based on the therapeutic community model, which includes principles of collective responsibility and empowerment. Central to the life of the community is the daily meeting, where we plan work and other activities, and attempt to address issues of living together as a group in an open way.

Contact: Brendan Hickey, (Manager)
Phone: 01644 440602
Email: lothlorien1@btopenworld.com
Website: <http://www.lothlorien.tc/>

Garden Villa Therapeutic Community:

This is a service for people who have difficulty in forming and maintaining relationships, with disorders of eating, with some forms of depression. We offer a wide ranging programme based upon psychotherapy in group settings.

Garden Villa

Leaflet: www.abdn.ac.uk/~wmm075/uploads/files/TC_Leaflet.doc
Address: Upper Garden Villa
Royal Cornhill Hospital
Aberdeen
AB25 2ZH
Contact: Linda Treliving
Phone: 01224 557397 (secretary)
Website: http://bit.ly/aberdeencity_contact

Creative Arts Therapies

Creative arts therapies are a way of using the arts - for example, music, painting, clay, dance, voice, or drama - to express yourself in a therapeutic environment with a trained therapist. Arts therapists help their clients to express themselves and to make sense of what they have created in the context of their life experience and their state of mind.

Useful Websites on Creative Arts Therapies:

British Association of Art Therapists:

<http://www.baat.org/>

British Society of Music Therapists:

<http://www.bsmt.org/>

Association for Dance Movement Therapy UK:

<http://www.admt.org.uk/>

Leaflets on Arts Therapies:

Arts Therapies

http://bit.ly/mind_art
- Mind

Creative Therapies:

http://bit.ly/devon_creative_therapies
- NHS Devon

SECTION 09 : GENERAL INFORMATION

A Few Other Interesting Things

Useful Books

Useful Books Recommended by People with Lived Experience
of Personality Disorder

Managing Intense Emotions and Overcoming Self-Destructive Habits
by Lorraine Bell

The Borderline Personality Disorder Survival Guide
by Alex Chapman

Voices Beyond the Border: Living with BPD
edited by Vicky Cox and Lucy Robinson

Man's Search for Meaning
by Victor Frankl

Borderline Personality Disorder Demystified
by Robert O. Friedel

Borderline Personality Disorder (The Facts)
by Roy Kravitz and Wendy Jackson

Skills Training Manual for Treating Borderline Personality Disorder
by Marsha Linehan

The Power of Now
by Eckhart Tolle

The Lost Art of Being Happy
by Tony Wilkinson

Other User Led Resources

Borderline Personality Disorder Information Pack - Highland Users Group

For more
information

contact: Highland Users Group
Highland Community Care Forum,
Highland House,
20 Longman Road,
Inverness IV1 1RY

Phone: 01463 723560

Fax: 01463 718818

Email: hug@hccf.org.uk

Website: <http://www.hug.uk.net/>

Service User Involvement in Personality Disorder Services - Resource Pack for Service Users and Staff - Thames Valley Initiative

Website: <http://www.exclusionlink.co.uk/assets/RegionalSUPack.pdf>

The Hurt Yourself Less Workbook - National Self Harm Network

Website: <http://www.nshn.co.uk/>

Myths About Personality Disorder

“Personality disorder is not treatable”

This was once believed to be true but there is more and more evidence emerging that people can and do learn to manage BPD or recover from it. There are a number of treatments which have been shown to help as well as personal understanding and insight. The issues may have taken a long time to build up, so treatment is generally quite long-term. It is really important for people who are diagnosed with a PD to know that it is treatable and to have hope.

“A person with this disorder can just stop it all if they just try hard enough”

A lot of the time someone diagnosed with a PD is struggling to understand their experiences and deal with other people’s often negative reactions to them. It is very difficult to remain in control of experiences you don’t understand. Most people diagnosed with a PD do not feel in control of what they are doing all the time and need support to understand what is happening. In a way it’s like suggesting you could speak Chinese with no lessons if you just tried hard enough - how would you even begin?

“You have a problem with your personality; therefore you are a flawed person”

Often the way someone behaves is due to the way they have learnt to cope with the experiences they have had. These coping strategies may not be socially acceptable or may be very self-destructive, but they are not who the person is. People who are diagnosed with a PD come in all shapes and sizes, just like the rest of the population. Their views, feelings and likes and dislikes are just as valid as anyone else’s. Feeling that other people think you are a bad person through and through only adds to the stigma and distress of this diagnosis.

“BPD means you almost have a personality or almost have a personality disorder”

The term ‘borderline’ comes from the description of the condition being on the border between psychosis and neurosis (anxiety or depression). It is considered a condition in its own right, not a description of a half-formed personality or a bit of a problem. Symptoms of BPD are wide ranging and are just as severe and disabling as with any other condition. It is not possible to almost have a personality or a disorder, either you do or you don’t.

“People with PD are just manipulative, “bad” and hurt other people on purpose”

People diagnosed with a PD are often desperately trying to make sense of the world around them and trying to have some control over what is happening to them emotionally. When you are in the grip of very intense emotions that feel intolerable, it is very easy to act without thinking or in desperation, but there is normally not a deliberate plan to manoeuvre others, more a deep-seated need to get some support in any way you can. Manipulative normally implies that someone is emotionally skilful, whereas people diagnosed with a PD often feel like they have no emotional control or skill.

“Everyone who has BPD has been abused”

There is a high correlation with childhood sexual abuse and being diagnosed with BPD, which has led some people to argue that it is a complex form of Post-Traumatic Stress Disorder. Many people who are diagnosed with BPD have backgrounds where there has been a lot of stress and trauma, but not everyone has been abused. It can be hard for people to understand why someone who has not been abused can develop these issues, but the reasons behind BPD are not currently fully understood. No history of abuse does not mean that someone is suffering less or is experiencing less distress.

“Everyone who self harms has BPD”

There is a belief that everyone who self harms has BPD or ends up diagnosed with BPD, but in fact it is not necessary to self harm to be given a BPD diagnosis and self harm alone does not indicate that someone has all of the other issues that are associated with BPD. It is important to consider all aspects of a person, and not just focus on self harm.

An Open Letter to Those Without Invisible Disability or Chronic Illness

Invisible Disability Or Chronic Illness

By Ricky Buchanan on May 10, 2009

Having an invisible disability (ID) and/or invisible chronic illness (ICI) means that many things change. Just because you can't see the changes doesn't mean they aren't real. Most people don't understand much about these disabilities/diseases and their effects, and of those that think they know, many are actually misinformed. In the spirit of informing those who wish to understand ...

... These are the things that I would like you to understand about me before you judge me...

Please understand that being disabled/sick doesn't mean I'm not still a human being. I have to spend most of my day being very careful what I do, and if you visit I might not seem like much fun to be with, but I'm still me stuck inside this body. I still worry about school and work and my family and friends, and most of the time I'd still like to hear you talk about yours too.

Please understand the difference between "happy" and "healthy". When you've got the flu you probably feel miserable with it, but I've been sick for years. I can't be miserable all the time, in fact I work hard at not being miserable. So if you're talking to me and I sound happy, it means I'm happy. That's all. I may be tired. I may be in pain. I may be sicker than ever. Please, don't say, "Oh, you're sounding better!" I am not sounding better, I am sounding happy. If you want to comment on that, you're welcome.

Please understand that being able to stand up for five minutes, doesn't necessarily mean that I can stand up for ten minutes, or an hour. It's quite likely that doing that five minutes has exhausted my resources and I'll need to recover - imagine an athlete after a race. They couldn't repeat that feat right away either.

Please repeat the above paragraph substituting, "sitting up", "walking", "thinking", "being sociable" and so on ... it applies to everything that I do.

Please understand that the effects of chronic illnesses and many disabilities are variable. It's quite possible (for me, it's common) that one day I am able to walk to the bathroom and back, while the next day I'll have trouble sitting up. Please don't attack me when I'm worse by saying, "But you did it before!" If you want me to do something, ask if I can and I'll tell you.

Similarly, my illness/disability may vary suddenly, meaning I may need to cancel an invitation at the last minute, if this happens please do not take it personally.

Please understand that "getting out and doing things" does not make me feel better, and can often make me worse. Chronic illnesses/disabilities may cause a secondary/reactive depression (wouldn't you get depressed if you were stuck in bed 23 hours a day for years on end?) but they are not caused by depression. Telling me that I need some fresh air and exercise is not correct and probably not appreciated - if I could possibly do it that, I would.

Please understand that if I say I have to sit down/lie down/take these pills now, that I do have to do it right now - it can't be put off or forgotten just because I'm doing something else more exciting. Illnesses and disabilities do not forgive their victims easily.

Please understand that I can't spend all of my energy trying to get well from my incurable chronic illness/disability. With a short-term illness like the flu, you can afford to put life on hold for a week or two while you get well. But an important part of having a chronic illness or disability is coming to the realization that you have to spend energy on having a life while you're sick/disabled. This doesn't mean I'm not trying to get better. It doesn't mean I've given up. It's just how life is when you're dealing with a chronic illness/disability.

If you want to suggest a cure to me, please don't. It's not because I don't appreciate the thought; and it's not because I don't want to get well. It's because I have had almost every single one of my friends suggest one at one point or another. At first I tried them all, but then I realized that I was using up so much energy trying things that I was making myself sicker, not better. If there was something that cured, or even helped, all people with a certain illness or disability then we'd know about it. This is not a drug-company conspiracy, there is worldwide networking (both on and off the Internet) between people with similar and different chronic illnesses and disabilities; if something worked we would know about it.

If after reading that, you still want to suggest a cure, then do it if you must. Preferably in writing and accompanied by the scientific papers that prove it works. But don't expect me to rush out and try it. I might not even reply. If I haven't had it or something like it suggested before, and it sounds reasonable, I'll probably take what you said and discuss it with my doctor.

Please understand that getting better from an illness can be very slow. And getting better from an invisible disability might not happen at all. People with chronic illnesses have so many systems in their bodies out of equilibrium, and functioning wrongly, that it may take a long time to sort everything out, if it ever happens.

I depend on you - people who are able-bodied - for many things.

But most importantly, I need you to understand me

(c) <http://notdoneliving.net/openletter/id>

The Gorilla in Your House

With thanks to everyone over at Ouch.

Acquiring a disability is a bit like getting home to find there's a gorilla in your house. You contact the approved and official channels to get rid of infestations of wild animals (in this case, the NHS) and they umm and aah and suck air in through their teeth before saying something roughly equivalent to "what you've got 'ere, mate, is a gorilla, and there ain't really a lot what we can do about them, see..." before sending you back home to the gorilla's waiting arms.

The gorilla in your house will cause problems in every part of your life. Your spouse may decide that (s) he can't deal with the gorilla, and leave. Your boss may get upset that you've brought the gorilla to work with you and it's disrupting your colleagues, who don't know how to deal with gorillas. You're arriving for work wearing a suit the gorilla has slept on. Some days you don't turn up at all because at the last minute, the gorilla has decided to barricade you into the bathroom or sit on you so you can't get out of bed. Your friends will get cheesed off because when you see them - which isn't often, because they don't want to come to your house for fear of the gorilla and the gorilla won't always let you out - your only topic of conversation is this darn gorilla and the devastation it is causing.

There are three major approaches to the gorilla in your house. One is to ignore it and hope it goes away. This is unlikely to work. A 300-lb gorilla will sleep where he likes, and if that's on top of you, it will have an effect on you.

Another is to try and force the gorilla out, wrestling constantly with it, spending all your time fighting it. This is often a losing battle. Some choose to give all their money to people who will come and wave crystals at the gorilla, from a safe distance of course. This also tends to be a losing battle. However, every so often, one in a hundred gorillas will get bored and wander off.

The crystal-wavers and gorilla-wrestlers will claim victory, and tell the media that it's a massive breakthrough in gorilla-control, and that the 99 other gorilla-wrestlers just aren't doing it right due to sloppy thinking or lack of commitment. The 99 other gorilla-wrestlers won't have the time or energy to argue.

I have known people spend the best years of their life and tens of thousands of pounds trying to force their gorillas to go away. The tragedy is that even if it does wander off for a while, they won't get their pre-gorilla lives back. They'll be older, skint, exhausted, and constantly afraid that the gorilla may well come back.

The third way to deal with the gorilla in your house is to accept it, tame it, and make it part of your life. Figure out a way to calm your gorilla down. Teach it how to sit still until you are able to take it places with you without it making a scene. Find out how to equip your home with gorilla-friendly furnishings and appliances. Negotiate with your boss about ways to accommodate, or even make use of, your gorilla. Meet other people who live with gorillas and enjoy having something in common, and share gorilla-taming tips.

People get really upset about this and throw around accusations of "giving up" and "not even trying". They even suggest that you enjoy having a gorilla around because of the attention it gets you (while ignoring the massive pile of steaming gorilla-turds in your bedroom every morning and night, not to mention your weekly bill for bananas). The best way to deal with these people is to smile and remind yourself that one day, they too will have a gorilla in their house.

(c) <http://batsgirl.blogspot.com/2008/04/gorilla-in-your-house.html>

The Spoon Theory

by Christine Miserandino

My best friend and I were in the diner, talking. As usual, it was very late and we were eating French fries with gravy. Like normal girls our age, we spent a lot of time in the diner while in college, and most of the time we spent talking about boys, music or trivial things, that seemed very important at the time. We never got serious about anything in particular and spent most of our time laughing.

As I went to take some of my medicine with a snack as I usually did, she watched me with an awkward kind of stare, instead of continuing the conversation. She then asked me out of the blue what it felt like to have Lupus and be sick. I was shocked not only because she asked the random question, but also because I assumed she knew all there was to know about Lupus. She came to doctors with me, she saw me walk with a cane, and throw up in the bathroom. She had seen me cry in pain, what else was there to know?

I started to ramble on about pills, and aches and pains, but she kept pursuing, and didn't seem satisfied with my answers. I was a little surprised as being my roommate in college and friend for years; I thought she already knew the medical definition of Lupus. Then she looked at me with a face every sick person knows well, the face of pure curiosity about something no one healthy can truly understand. She asked what it felt like, not physically, but what it felt like to be me, to be sick.

As I tried to gain my composure, I glanced around the table for help or guidance, or at least stall for time to think. I was trying to find the right words. How do I answer a question I never was able to answer for myself? How do I explain every detail of every day being effected, and give the emotions a sick person goes through with clarity. I could have given up, cracked a joke like I usually do, and changed the subject, but I remember thinking if I don't try to explain this, how could I ever expect her to understand. If I can't explain this to my best friend, how could I explain my world to anyone else? I had to at least try.

At that moment, the spoon theory was born. I quickly grabbed every spoon on the table; hell I grabbed spoons off of the other tables. I looked at her in the eyes and said "Here you go, you have Lupus". She looked at me slightly confused, as anyone would when they are being handed a bouquet of spoons. The cold metal spoons clanked in my hands, as I grouped them together and shoved them into her hands.

I explained that the difference in being sick and being healthy is having to make choices or to consciously think about things when the rest of the world doesn't have to. The healthy have the luxury of a life without choices, a gift most people take for granted.

Most people start the day with unlimited amount of possibilities, and energy to do whatever they desire, especially young people. For the most part, they do not need to worry about the effects of their actions. So for my explanation, I used spoons to convey this point. I wanted something for her to actually hold, for me to then take away, since most people who get sick feel a "loss" of a life they once knew. If I was in control of taking away the spoons, then she would know what it feels like to have someone or something else, in this case Lupus, being in control.

She grabbed the spoons with excitement. She didn't understand what I was doing, but she is always up for a good time, so I guess she thought I was cracking a joke of some kind like I usually do when talking about touchy topics. Little did she know how serious I would become?

I asked her to count her spoons. She asked why, and I explained that when you are healthy you expect to have a never-ending supply of "spoons". But when you have to now plan your day, you need to know exactly how many "spoons" you are starting with. It doesn't guarantee that you might not lose some along the way, but at least it helps to know where you are starting. She counted out 12 spoons. She laughed and said she wanted more. I said no, and I knew right away that this little game would work, when she looked disappointed, and we hadn't even started yet. I've wanted more "spoons" for years and haven't found a way yet to get more, why should she? I also told her to always be conscious of how many she had, and not to drop them because she can never forget she has Lupus.

I asked her to list off the tasks of her day, including the most simple. As, she rattled off daily chores, or just fun things to do; I explained how each one would cost her a spoon. When she jumped right into getting ready for work as her first task of the morning, I cut her off and took away a spoon. I practically jumped down her throat. I said " No! You don't just get up. You have to crack open your eyes, and then realize you are late. You didn't sleep well the night before. You have to crawl out of bed, and then you have to make your self something to eat before you can do anything else, because if you don't, you can't take your medicine, and if you don't take your medicine you might as well give up all your spoons for today and tomorrow too." I quickly took away a spoon and she realized she hasn't even gotten dressed yet. Showering cost her spoon,

just for washing her hair and shaving her legs. Reaching high and low that early in the morning could actually cost more than one spoon, but I figured I would give her a break; I didn't want to scare her right away. Getting dressed was worth another spoon. I stopped her and broke down every task to show her how every little detail needs to be thought about. You cannot simply just throw clothes on when you are sick. I explained that I have to see what clothes I can physically put on, if my hands hurt that day buttons are out of the question. If I have bruises that day, I need to wear long sleeves, and if I have a fever I need a sweater to stay warm and so on. If my hair is falling out I need to spend more time to look presentable, and then you need to factor in another 5 minutes for feeling badly that it took you 2 hours to do all this.

I think she was starting to understand when she theoretically didn't even get to work, and she was left with 6 spoons. I then explained to her that she needed to choose the rest of her day wisely, since when your "spoons" are gone, they are gone. Sometimes you can borrow against tomorrow's "spoons", but just think how hard tomorrow will be with less "spoons". I also needed to explain that a person who is sick always lives with the looming thought that tomorrow may be the day that a cold comes, or an infection, or any number of things that could be very dangerous. So you do not want to run low on "spoons", because you never know when you truly will need them. I didn't want to depress her, but I needed to be realistic, and unfortunately being prepared for the worst is part of a real day for me.

We went through the rest of the day, and she slowly learned that skipping lunch would cost her a spoon, as well as standing on a train, or even typing at her computer too long. She was forced to make choices and think about things differently. Hypothetically, she had to choose not to run errands, so that she could eat dinner that night.

When we got to the end of her pretend day, she said she was hungry. I summarized that she had to eat dinner but she only had one spoon left. If she cooked, she wouldn't have enough energy to clean the pots. If she went out for dinner, she might be too tired to drive home safely. Then I also explained, that I didn't even bother to add into this game, that she was so nauseous, that cooking was probably out of the question anyway. So she decided to make soup, it was easy. I then said it is only 7pm, you have the rest of the night but maybe end up with one spoon, so you can do something fun, or clean your apartment, or do chores, but you can't do it all.

I rarely see her emotional, so when I saw her upset I knew maybe I was getting through to her. I didn't want my friend to be upset, but at the same time I was happy to think finally maybe someone understood me a little bit. She had tears in her eyes and asked quietly "Christine, How do you do it? Do you really do this everyday?" I explained that some days were worse than others; some days I have more spoons than most. But I can never make it go away and I can't forget about it, I always have to think about it. I handed her a spoon I had been holding in reserve. I said simply, "I have learned to live life with an extra spoon in my pocket, in reserve. You need to always be prepared."

Its hard, the hardest thing I ever had to learn is to slow down, and not do everything. I fight this to this day. I hate feeling left out, having to choose to stay home, or to not get things done that I want to. I wanted her to feel that frustration. I wanted her to understand, that everything everyone else does comes so easy, but for me it is one hundred little jobs in one. I need to think about the weather, my temperature that day, and the whole day's plans before I can attack any one given thing. When other people can simply do things, I have to attack it and make a plan like I am strategizing a war. It is in that lifestyle, the difference between being sick and healthy. It is the beautiful ability to not think and just do. I miss that freedom. I miss never having to count "spoons".

After we were emotional and talked about this for a little while longer, I sensed she was sad. Maybe she finally understood. Maybe she realized that she never could truly and honestly say she understands. But at least now she might not complain so much when I can't go out for dinner some nights, or when I never seem to make it to her house and she always has to drive to mine. I gave her a hug when we walked out of the diner. I had the one spoon in my hand and I said "Don't worry. I see this as a blessing. I have been forced to think about everything I do. Do you know how many spoons people waste everyday? I don't have room for wasted time, or wasted "spoons" and I chose to spend this time with you."

Ever since this night, I have used the spoon theory to explain my life to many people. In fact, my family and friends refer to spoons all the time. It has been a code word for what I can and cannot do. Once people understand the spoon theory they seem to understand me better, but I also think they live their life a little differently too. I think it isn't just good for understanding Lupus, but anyone dealing with any disability or illness. Hopefully, they don't take so much for granted or their life in general. I give a piece of myself, in every sense of the word when I do anything.

It has become an inside joke. I have become famous for saying to people jokingly that they should feel special when I spend time with them, because they have one of my “spoons”.

© Christine Miserandino

(c) http://bit.ly/spoon_theory

References/Further Reading List

The Science of Personality, 2nd Ed., Lawrence A. Pervin, 2003, OUP

It's a Difficult Life to Lead - Supporting People with personality disorder: service user and provider perspectives,

Iain Ferguson, Aileen Barclay and Kirsten Stalker, University of Stirling, 2003

Personality Disorder and Community Mental Health Teams:
A Practitioner's Guide,

Edited by M.J. Sampson, R.A. McCubbin and P. Tyrer, 2006, John Wiley and Sons

Chapters can be found at:

<http://www.personalitydisorder.org.uk/resources/index.php>

Articles by Heather Castillo at:

<http://www.thehavenproject.org.uk/Research.html>

Dissociation: What is it and why is it important?

Jon Stone Practical Neurology 2006; 6:308-313

<http://pn.bmjournals.com/cgi/content/extract/6/5/308>

CAPS
independent
advocacy
The Consultation & Advocacy
Promotion Service

NHS
Lothian