

UNDERSTANDING BORDERLINE PERSONALITY DISORDER (rev 2018)

Hi, my name is Sue Sibbald and I was given the diagnosis of Borderline Personality Disorder (BPD)* eight years ago. Some people find the diagnosis really helpful because it helps them make sense of what has happened to them. Others find it a difficult diagnosis to receive for a number of reasons and sometimes prefer the description of emotional sensitivity to describe what they experience. Some people feel that understanding things based on what has happened to them and how it has affected their day to day living is more useful than a diagnosis. Whatever you think about these issues is ok.

I now work for Sheffield Health and Social Care (NHS Foundation Trust) training staff and people with a diagnosis of BPD or think they may meet the criteria (I also work with people who see themselves as emotionally sensitive). This leaflet is for anyone who has a diagnosis of BPD or wants to find out more because for example, they think they might have this condition or know someone who might have.

The first thing you need to know is that you are **not** alone with this diagnosis. It is estimated 1-2% of the population have BPD and with the right help, and support do lead happy lives. I like to think I'm just a bit different to other people, but that has so many positives.

Personally I'm very creative, love getting out and doing things, and the fact I am spontaneous, means I get to do lots of exciting things. I believe if we manage our lives by learning about what BPD is and use skills like the ones taught in Dialectical Behavioural Therapy (DBT)* which I will talk about later, things can become so much easier. Of course we have 'ups and downs' like everyone does in life, but it can become more manageable.

I have to point out now that I know I am giving you lots of information, please don't feel you have to do it all at once. Some many of us tend to 'overdo' things and rush to do too much and then get overwhelmed and give up. It has taken me eight years to get through the things I am going to tell you about. Maybe just watch the video I mention later to begin with, or choose a book to read. Take things *slowly* and at your own pace. You may find other things you find really helpful; this isn't a definitive list. Also wherever I think I might be using some jargon, I put a * and have written an explanation at the end of this leaflet.



You might have been given a copy of the *NICE guidelines for BPD. These guidelines are written to help you understand the diagnosis. If you haven't got one, you might be able to pick one up from your *CMHT reception or find them on line on the NICE website www.NICE.org.uk (you can go online at your local library if you do not have internet access at home). When I was diagnosed I read the guidelines and they didn't make too much sense, so I will just give you quick rundown of how it feels for me.

Remember though we are all different, so my experience won't necessarily be like yours.

Here's what it's like for me:



One of the main features for me is that if I feel people are abandoning or rejecting me and I become really upset. For example, if I know I may never see someone again, or I can even feel bad if someone doesn't return a text really quickly. This can lead me into difficulties in making friends, as the pain for me perceiving them leaving can feel too much to bear. It can lead me to self harm, if it becomes too overwhelming. So I have generally kept people at a

distance, as it feels like too much of a risk to let people come close. On occasions in the past when I have had a close friend, I thought they were wonderful, and I would do absolutely anything for them, but if I perceived they were going to leave me or they do something I see as hurting me, I hate them with a passion. It can be like I see things in extremes* sometimes as if there is no middle ground (e.g. I either love them or hate them). I am making friends now, it's still quite difficult, but I am getting there.

I also find it hard sometimes getting in touch with my feelings and feel empty inside, when I am with a person for any length of time I often take on their identity and try to become like them; this is called identity disturbance*. I have found *mindfulness does help with this (naming and describing feelings and becoming more aware of who I am).

Some people are quite impulsive around sex, spending, substance abuse, driving dangerously and/or binge eating. I'd say for me it's not one of my areas of concern, but when I was younger I did take drugs. I have an impulsive side to my nature, but it's mainly under control. However, this may be something you need to work on.

One thing I find really tiring is one minute I'm feeling fairly OK and then I may get *triggered by an event or something I think about and I feel like I can't move, I have to go to hide in bed because the emotional pain is so bad. This can happen several times in a day and when you're out and about, you have to hide it and it may come out as anger later, or just an overwhelming feeling of exhaustion.

Another area of concern for me is feeling sometimes like I want to harm myself. Some days I can think about suicide or self harm a great deal, it's constantly on my mind, other days hardly at all. Sometimes I have self harmed, but this is better for me as I use DBT skills to help.

Feeling angry was another feature for me, it came in sudden waves crashing over me and then it's gone. For me it is mainly triggered by my feelings of abandonment or frustration if things aren't perfect. Some people get into physical fights. I found recognising my emotions and being self compassionate towards myself has helped me with anger.

Finally (which can be quite frightening) are the occasional visual hallucinations and paranoid feelings I get when I am really stressed. I sometimes *dissociate which is a feeling like I am unconnected to things or when you've arrived somewhere and can't remember how you got there. We all do it to some extent or another, and it can last a short or long time. For me it's linked to my feelings and thoughts around my childhood and it is another survival strategy I have developed.

Just remember you may not have all of these experiences, you may only have a few and that's ok; we are all different and have had different lives. You may have other experiences or feelings and that is ok too. For example, some people can feel times when they have a desperate emptiness or yearning inside, that nothing seems to help or they can state shift* where they move from feeling or being very different at different times – if this is really strong, it can sometimes be like they are separate people. Also people can often feel like they are 'stuck' and the same things keep happening, whatever they try to do differently, or they may feel that they don't deserve to have a better life.

One thing many people who experience BPD struggle with is their ability to stop and think about themselves and what's happening – there are loads of different ways this can affect us. It can be like a 'merry go round' that they can't get off (the same things happen again and again) and then it can be hard to reflect on things, step out of situations and feelings. It can seem difficult to recognise what is going on in our own head or feelings or other people's (some people call this struggling to mentalise). This can make it hard for us to change things that we do that might not be good for us. *Mentalisation Based Therapy is a therapy created which helps people to learn how to understand what others and ourselves are thinking and feeling. Sometimes we think we know what others are thinking and feeling, but we can get it wrong and I find it is good to check things out with people.

Traumatic experiences: What happened to you? (rather than what's wrong with you)

Many people given a diagnosis of BPD have had one or more traumatic experiences, often starting in early life (up to 73%, but NOT everyone with the BPD diagnosis). Trauma can include being neglected as a child, losing a parent, abuse of any kind, poor physical health, having a parent who isn't well (physically and/or mentally), parents separating and many more. For some children with emotional sensitivity the trauma can be that they experienced invalidating parents e.g. saying "be strong", "don't be dramatic" or letting you know what you do isn't good enough. I have found that being more accepting of my past unhelpful experiences has enabled me to move on with my life. It wasn't easy because what happened was wrong and I didn't deserve it, but instead of staying stuck and miserable, I found moving on led me to live a life where I am more content.

Helping Recovery

Here are some more links that I have found useful over time and I found talking to other people who have BPD really helpful. I met people to begin with *on line and now have gone on to meet some of them in real life.

I realise not everyone is a friend of *Social Media and that's ok, but to those of you who are, you may wish to check the following out:



This is a really good *Facebook and *Twitter person to follow Debbie at www.healingfrombpd.org - she has lots of videos and *blogs about BPD and you can find out how she no longer meets the

criteria for BPD as she uses DBT skills to help herself manage the condition. You can learn a lot from Debbie about DBT and talk with some people who follow her, she is American and lots of British people follow her.

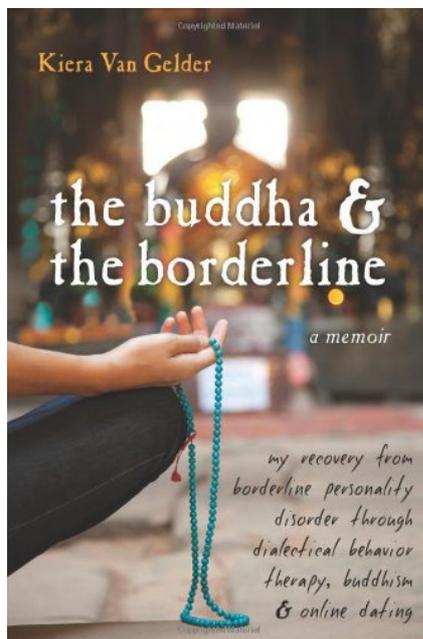
Dialectical Behavioural Therapy (DBT) was created by Dr Marsha Linehan (Professor of Psychology and Psychiatry) who herself has BPD. The basic premise behind it is that you have to accept who you are, but at the same time be willing to change. You learn four set of skills that basically help you manage your life better. These are Distress Tolerance, Mindfulness, Emotional Regulation and Interpersonal Effectiveness. There are lots of skills under each heading. I have taught myself these skills over the years and they have made a massive difference for me.

Two other useful websites if you want to learn skills is www.dbtselfhelp.com and www.ilovedbt.com. They have everything on there you need to know about DBT, descriptions of the skills and *diarycards for you to start logging your everyday use of them.

I have personally found this *app you can download to be really helpful for learning DBT it's called 'diarycard', if you have an Ipad or Iphone you can download it from the app store. You can learn all the skills and log them, if you get stuck; Debbie has done a video you can find on *YouTube which shows you how to use it.

Another useful app is VIRTUAL HOPEBOX which is free on android and iphone. This is a bit like 'a self sooth kit' and is good to use if you are feeling overwhelmed. You can add photos, music, do puzzles or words searches and mindfulness practice. It is easy to use and is great to distract and be mindful with.

For those of you who like to read, there are some powerful autobiographies which I will list below:



This autobiography looks at the period up to Kiera's diagnosis and through to her recovery through DBT and Buddhism. It sheds light on her private struggle to become more compassionate to herself and is essential reading for those who want to understand what recovery means.

GIRL IN NEED OF A TOURNIQUET - MERRI LISA JOHNSON

This is Merri Lisa's account of how BPD affected her life and relationships caused by events from the past. She uses quotes from poems and song lyrics to tell her story of her recovery

through therapy. We see inside her turbulent mind as she tries to discover who she is and what she wants from life.

LOUD IN THE HOUSE OF MYSELF - STACY PERSHALL

This book is an account of the author's experience of living with BPD, bipolar, bulimia and anorexia. She had an unconventional childhood, wants to become a belly dancer, streamed her suicide attempt live on the Internet and uses tattoos and DBT as part of her recovery.

GET ME OUT OF HERE MY RECOVERY FROM BORDERLINE PERSONALITY DISORDER - RACHEL REILAND

Rachel is a married mother of three and an accountant. She tells her story of her life with BPD anorexia, promiscuity, impulsiveness, suicide attempts, hospitalization, intensive anger and how she recovers through therapy and the support of family and friends.

MY ALIEN SELF MY JOURNEY BACK TO MYSELF - AMANDA GREEN

Amanda was born in the UK to a mum with catatonic schizophrenia, travelled the world to places such as Japan, Thailand and Australia and finally got a diagnosis of BPD.

She began to recover when she came across CBT and found this really helpful. Her aim in writing this book was to share her story to beat the stigma around mental health.

BEYOND BORDERLINE –TRUE STORIES OF RECOVERY FROM BORDERLINE PERSONALITY DISORDER EDITED BY JOHN G GUNDERSON AND PERRY HOFFMAN

This powerful compilation of stories reveals the deeply personal firsthand perspectives of people who have the label Borderline Personality Disorder and explores the numerous ways in which this disorder has affected their lives and how they move forward on their path towards discovering how to live with BPD.

The following books are more factual:

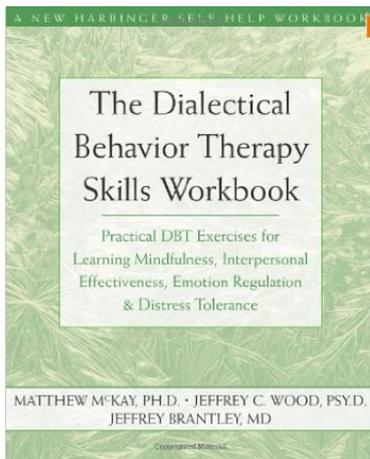
UNDERSTAND YOUR BORDERLINE PERSONALITY DISORDER - CHRIS HEALY

This book offers basic information about BPD and is interactive so that people can explore their own attitudes or concerns about the diagnosis. It's organised into sessions so a worker could help someone go through the book. It talks about psychotherapeutic interventions that might be helpful and how to manage day to day.

These books are specifically about DBT:

DBT SKILLS TRAINING HANDOUTS AND WORKSHEETS SECOND EDITION –MARSHA LINEHAN

This book has 255 user friendly handouts and worksheets and is an essential resource for learning DBT.



THE DIALECTICAL SKILLS WORKBOOK - MATTHEW MCKAY AND JEFFREY C WOOD

This easy to use workbook teaches you the four core skills in a straightforward step by step guide. I find this book really helpful there are lots of things you can practice. This is a really good book to buy if you want to learn about DBT.

THE EMOTIONALLY SENSITIVE PERSON, FINDING PEACE WHEN YOUR EMOTIONS OVERWHELM YOU – KARYN D HALL

In this book Karyn teaches you how to stay in the present moment, how to identify emotional triggers and develop a healthy identity using cognitive behavioural and mindfulness skills. The skills used help you manage and take charge of overwhelming emotions

These books are for **parents, carers, other halves, friends**, but I found them good reading too. Perhaps if you felt people need to understand you a bit better it could help to ask them if they want to read one of these books:

LOVING SOMEONE WITH BORDERLINE PERSONALITY DISORDER - SHARI Y MANNING

This book gives family and friends of people with a diagnosis of BPD valuable skills for helping themselves and those they care about. A good guide and teaches you how to validate a very important skill. I found this book very useful for me too.

OVERCOMING BORDERLINE PERSONALITY DISORDER A FAMILY GUIDE - VALERIE PORR

It looks at helping the family as a whole in how to decrease the collective stress of living together with someone who is particularly emotional. It teaches some DBT and MBT skills and looks at not blaming the person with BPD but giving hope that change is possible.

THE POWER OF VALIDATION- ARMING YOUR CHILD AGAINST BULLYING PEER PRESSURE ADDICTION SELF HARM AND OUT OF CONTROL EMOTIONS- KARYN HALL AND MELISSA COOK

Validation is the recognition and acceptance that a person's feelings and thoughts are true and real for him or her regardless of whether or not those feelings make logical sense. This is a must read book for parents and teachers of young children and most definitely an essential read for those who value rewarding relationships and make kids feel like they matter.

If you are interested in mindfulness (a skill which is part of DBT and many people use in the UK these days to help with stress), here are some interesting books:

FINDING PEACE IN A FRANTIC WORLD - DR DANNY PENMAN AND PROFF MARK WILLIAMS

This book teaches you about mindfulness and gives you a few simple but powerful ways to practice mindfulness that you can use in everyday life. These can help with stress, anxiety, unhappiness. The book has an eight week plan on how to get started with mindfulness, using different forms of meditation.

MINDFULNESS FOR BORDERLINE PERSONALITY DISORDER: – BLAISE A AGUIRE AND GILLIAN GALEN

In this book you will learn the basics of mindfulness and try out exercises to help you practice. There are some stories from people with BPD which may give you some understanding. This helps you gain control over your symptoms.

There are also two apps you may find useful for Mindfulness Headspace which teaches mindfulness in ten sessions ten minutes a day. It is free but if you want to use it more they will charge after that. The other is Insight Timer which is free and has loads of meditation and you can see on a map where people are meditating around the world.



A video which I found so useful is 'Back from the Edge' made by Marsha Linehan, the creator of DBT. It has people with BPD explaining about their lives and also parents and carers tell their stories too. It really helped me understand more about BPD. You may find parts a little triggering so either watch it with someone or just be in a good frame of mind when you do. You can just search

for it on *YouTube . It's 45 minutes long and is so helpful, maybe a good place to start.

Other useful websites are:

www.emergenceplus.org.uk. This is a Personality Disorder site linked to training.

www.mind.org.uk. Mind charities site with some information about BPD

www.nice.org.uk/cg78. You can read the NICE guidelines here.

www.getsomeheadspace.com. This is an online mindfulness programme you can also download an app.

www.sheffieldmentalhealth.org.uk On this website there is a section on self help and there are numerous self help groups listed. The website is run by Sheffield Flourish

www.sheffieldflourish.co.uk Grow your skills, dreams and networks with a mental health friendly community of kind and interesting local people.

www.nowmattersnow.org This is a website if you to use if you are feeling overwhelmed it has videos showing you how to use skills on how to cope. It is American so the telephone help lines are not applicable.

A SAFETY PLAN

Something I find helpful is having a safety plan. This is designed to help you when you are in a crisis and if you make one for yourself, you can use it when you get overwhelmed. It can include different strategies that can help, phone numbers of helplines or friends you can call who may help as well as ways you find helpful for distracting yourself from bad stuff. Personally I find playing “angry birds” is a good distraction or doing a word search on Virtual Hopebox. You may like to listen to music, watch a movie or get outside, it is about what you find helps you. Some people like it to include reasons for keeping going such as photos of loved ones. You may want to keep it somewhere safe or carry it with you so you can refer to it if you need to.

A good place to look at how to make a safety plan is on the website www.connectingwithpeople.org. On there is a link ‘Feeling overwhelmed helping you stay safe’. This leaflet helps you think about what to do if you are in crisis and what to include in a safety plan.

I wish you well with your recovery journey:

I have gathered this information over time; I taught myself everything and am a big believer in self help and having some support along the way. I want to encourage you to help yourself more too if you can. I just thought it was a struggle when I was first diagnosed and I wish I had some of this information to help me make sense of things.

It takes time, be kind and gentle with yourself, but it does get better if you work hard at your recovery.

I want to finish with a few ideas I have gathered together around recovery. For me it's been about teaching myself, reading books, learning DBT skills, talking to others with my diagnosis via social media and in real life, looking after myself, going to the gym, gardening taking meds, meditation/mindfulness, my family and learning that life can be fun.

Dr Rachel Perkins (Clinical Psychologist) is someone who has written and spoken widely about recovery and social inclusion for people with mental health conditions, and she is herself a service user. I want to share with you some of her ideas:

She says you need to find meaning in what is happening when you are first diagnosed and also a new sense of self and purpose. For me, it was around discovering what I liked in life what brings meaning to me; the things I speak about above. There’s something important about trying to develop your own direction and discover for yourself (rather than rely on others to do it for you as this doesn’t work). It is possible to recover a meaningful valued and satisfying life.

Recovery isn't about getting cured, it's about learning to live with the problems we have. I like to talk about discovering what helps me. It's also a deep personal journey of growing within and beyond what has happened to you. You need three elements to help you along the way HOPE, OPPORTUNITY AND CONTROL. I think that the people who support us can help us foster hope, assist us to take back control and access opportunities.

We can also work ourselves to achieve these goals. Some days it can be REALLY hard, but for me it's been worth it, slowly getting my life back, beginning to find real meaning and enjoyment in my life. For some people this can be like starting their lives for the very first time.

So what's going to happen next...?

I want to encourage you to have a go at some of the things I have suggested, at your own pace. You can achieve a lot by being determined to help yourself. You may be in touch with mental health services and if so, you may want to attend the education course that is run in SHSC to understand more about BPD and learn some coping skills. That's maybe all you need to do, but you may feel that learning some DBT skills is a way forward or you may decide therapy is needed. You may not use mental health services and this is okay too; for some people there can be much better ways to get help. A skill that's really helpful is mindfulness* (it's a key skill of DBT) and has helped me so much, it's what I learnt first. You can access mindfulness training through tapes and books, on line (including through videos on You Tube) . You might have to try a few things until you find exercises that you like. You can practice meditation at Sheffield Buddhist Centre and they do run courses to help you learn, and they teach you about Buddhism at the same time. They don't charge for courses, but ask for a donation. I mentioned previously Headspace, which you can access via the internet or download the app, this is free for ten days then you can pay a few pounds a month. It teaches you mindfulness via video clips with guided meditations and is easy to do at home.

There is also a great Peer support group run by Sheffield Health and Social Care Trust called Sunrise it meets every second Wednesday of the month for people who use mental health services with any diagnosis, there are also local groups that run from the two CMHT'S so you could find out more about that.

I hope you have found this information useful, I am sure you can find other resources that may help you in your recovery, I think it's really empowering helping yourself, I really feel like I have accomplished something and have met some wonderful people along the way. I wish you all the best in finding your own way to help manage your daily life, I am still learning too; it takes time and you need some patience.



Glossary *

APP Is a software application designed to work on smartphones or tablets. You can download from the Apple store.

BLOGS A Blog is part of a website such as Wordpress or it can stand alone; an individual or a company post articles or information. I post information on my blog about me and Borderline Personality Disorder. You can search for a blog by a topic on Google.

BPD Borderline Personality Disorder also known as Emotionally Unstable Personality Disorder, - or Emotional Regulation Disorder; but I like the words “Emotionally Sensitive People”.

CMHT Community mental health teams are made up of health and social care staff such as social workers, psychiatrists, occupational therapist and mental health nurses. They provide support to people with mental health needs who live in the community.

DIARYCARD A diarycard used in DBT has two sides to it, the first side lists all of the DBT skills and each day you mark off which of the DBT skills you have used that day. Its purpose is to remind you of the skills each day and to track how you are getting on with them. You can choose to practise certain skills on one day or you may be using some because of certain situations that arise.

The other side of a card is about observing any urges or feelings you may be having so you can track them.

I find my diarycard has been really helpful also in remembering the skills and learning them.

FACEBOOK is a free social networking website where you can keep in contact with family and friends or work colleagues. You can create a profile about yourself, upload videos or photos and send messages.

IDENTITY DISTURBANCE Is when you have sudden changes in self image for example change in plans about you career, your sexuality or types of friends you have. It can sometimes feel like you have no sense of who you are at all and then we can take on the character of people that we meet.

MBT Mentalisation Based Therapy is a therapy specifically designed for people with BPD. Its focus is about helping us to differentiate our own thoughts and feelings from those people around us. I often assume I know what others are thinking, when I could be totally wrong, it's about learning not to try and guess, but to check out with others, that way I have found it saves a lot of heartache.

MINDFULNESS Mindfulness comes from an ancient Buddhist practice and is a simple idea but not religious. It means paying attention in a particular way, on purpose, in the moment and not judging as you do it such as doing one things at a time. This can help us with acceptance and awareness. Mindfulness is one of the four key skills for DBT (called ‘Wise Mind’ in DBT). You can be mindful of your breath just paying attention to breathing.

Your mind may wander and that's ok, but you can bring it back to the breath. You can even ‘wash up’ mindfully just paying close attention to the job not thinking about other things.

NICE (National Institute for Health and Care Excellence) is a public body which is part of the Department of Health which writes guidelines including those about the appropriate treatment and care for people with specific illnesses, diseases or conditions.

SOCIAL MEDIA Social Media refers to interactions between people in which they share create or exchange information in virtual communities and networks. Such sites include Facebook or Twitter

STEP (Short-term Education Programme) is part of SHSC and provides services for adults under 65. It supports people with enduring mental health problems. They provide group education courses run by recovery workers. You need to be referred by a GP or a worker from within your CMHT.

STATE SHIFTING This can be like you seem as if your state of mind can be very different at different times e.g. in different situations or with different people. These 'states' can feel like they take over such as feeling 'completely overwhelmed and vulnerable', or 'completely angry and maybe ranting', or being 'the perfect carer for other people'. If you experience this, you can then shift to another state either suddenly or gradually triggered by something happening. It can be like you have no control of this and sometimes it can be like you don't remember the other state/s properly.

THINKING/ACTING AS IF IN EXTREMES (sometimes called black and white thinking) means that someone can think or act as if everything is an extreme like someone is 'all good' or 'all bad' and there is no middle ground. We may view one person for example in our family as all good and then another as all bad. This can also relate to feelings about ourselves where we feel we are 'amazing' one minute and then the next 'all bad'. These feelings usually change dependent on things that are happening in our lives.

TRIGGERING A trigger for someone with BPD is caused by an event that makes your symptoms worse. Most, though not all, triggers happen around relationships or mention of harming yourself. If I get triggered I find my thoughts often spiral out of control and so my symptoms become worse such as beginning to have urges to self harm.

Often you may find on social media site (Twitter or Facebook) people use TW which means trigger warning. This means they are going to all about something potentially triggering such as self harm or past abuse.

TWITTER is an information network where you send messages made up of 140 characters. You can follow friends, celebrities or people with a diagnosis of Personality Disorder.

YOUTUBE is a video sharing website, where you can upload videos for public or private viewing.