

The Humpty Dumpty Definition



'A retired psychiatrist I asked to help me when I was first diagnosed with personality disorder (PD) told me that he likened PD to a scene in Lewis Carroll's 'Alice Through the Looking Glass'. He referred to the concept of PD as being like a 'Humpty Dumpty' word. When Alice challenges Humpty Dumpty on what he means and his use of language, he replies '...when I use a word, it means just what I choose it to mean, neither more nor less!' So PD, he explained to me, means precisely what a psychiatrist says it means, neither more or less.'

Andrew H Smith

Borderline Personality Disorder: the diagnosis that breeds prejudice

Let me introduce myself; I am a timewaster, an attention seeker, I'm manipulative, argumentative, a difficult patient and I'm not really ill. Maybe I should have simply told you that I have a diagnosis of borderline personality disorder (BPD). You may, however, be one of the few people who are prepared to reserve judgement until we meet.

Over the last ten years, I have met many professionals who have given me a chance to show my better side, take responsibility and move forward. However, sadly there have been far too many who have been blinded by the

diagnosis and failed to see the person in front of them. Too often they concentrate on the fact that people are difficult to treat, generally unresponsive to medication and that hospitalisation is rarely the answer and can even be detrimental. What they frequently miss is the fact that many people with this diagnosis also suffer very distressing bouts of anxiety and depression which can make life very painful and normal functioning impossible.

I, along with many of my fellow sufferers, have had great difficulty in the past expressing what I feel verbally and, at times, I have sought attention by other means. If I

had been able to cry when feeling depressed or shake when anxious I am sure I would have received a sympathetic response. Instead I have been sent away, told to go and lie down or offered medication when what I really needed was to express my feelings in a safe environment.

I have learned a lot about my diagnosis, symptoms and behaviour and am not the same person that I was 10 years ago when I was first diagnosed. Unfortunately, I still carry the BPD burden with me. All I can hope for is for people to recognise that individuals with this diagnosis can get better and change, even if, from



time to time, there are relapses. All I ask of people when they hear the diagnosis is to refrain from making judgement until they meet me. If they treat me fairly and with respect then they invariably receive the same. If I am treated as trouble from the start it can become a self fulfilling prophecy as I battle against attitudes based on stereotypes. It's not good for me and it's no fun for the professionals either. I believe that good therapy comes from sufferers and professionals working in partnership but both sides need to be willing.

Em Jones

Hope for the future



In 2003, the Department of Health highlighted the nationwide lack of services for people with personality disorder

and published the landmark report, 'Personality disorder: No longer a diagnosis of exclusion'. As a result, the profile of personality disorder has been raised significantly, and a number of pilot sites were set up around the country to develop new approaches to personality disorder. In Hertfordshire, we have identified new funding to develop a specialist service and are working with service users, carers and staff to design it from the ground up. To do this,

we aim to bring together the most successful ideas from pilot projects up and down the country in order to meet the unique needs of Hertfordshire.

The new service will cover the whole of the county and will be accessible to anyone suffering significant difficulties as a result of a personality disorder, whether formally diagnosed or not.

Our plan is to create a team that can work in partnership with existing services across Hertfordshire to improve the treatment and support offered to people with personality disorder and their carers. The

team will provide an expert consultation service, assessments and specialist treatment, as well as training in conjunction with service users to improve health and social care services. The overall aim is to improve the experience of people with personality disorders whatever services they come into contact with, ultimately enabling them to manage their conditions and lead a more fulfilling life.

Mark Knowles

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The official definitions

The Department of Health acknowledges that health professionals have not always agreed how best to identify personality disorders in its report *'Personality disorder: No longer a diagnosis of exclusion'*. Currently, the World Health Organisation and the American Psychiatric Association have each produced a definition. The report finds the American definition useful. People with a diagnosis of personality disorder often have more than one personality disorder and the definition includes clusters. The report summarises the definition 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.

Cluster A (the 'odd or eccentric' types): paranoid, schizoid, and schizotypal personality disorder

Cluster B : (the 'dramatic, emotional or erratic' types): histrionic, narcissistic, antisocial and borderline personality disorders

Cluster C : (the 'anxious and fearful' types): obsessive-compulsive, avoidant and dependent

Getting the diagnosis

By accident

I found out by accident when I saw my medical notes on my GP's computer screen. All I was ever really told was 'it was about the way I think' and that I would grow out of it. Being told that personality disorder isn't really a mental illness just made me feel like I didn't really belong anywhere. Without any real information about what the diagnosis meant was extremely damaging to me and, of course, my self-destructive behaviour and self-loathing escalated which was met with the attitude that I was acting out. This just confused me all the more. **Dawn Pritchard**

Being copied in

I was copied into a letter from my GP to my employer explaining my absence from work and that's how I discovered I had borderline personality disorder. **S Westwood**

Unbelievably, I received my diagnosis by post in the form of a copy of a letter sent from my consultant to my GP. I had recently become homeless, my marriage had broken down and I was



separated from my partner and young son. I had been staying at a homeless person's hostel, living in a small room with five other men who liked to wear their trainers for a minimum of 25 hours a day. I had developed adhesive spondylitis causing my shoulder to

Feelings about the label

- **'I hate it. Professionals have judged me based purely on the diagnosis which has a bad reputation.'**
- **'I cannot describe the dread and anguish that being told you have a personality disorder causes. First, disbelief, shock, fear, then anger. It puts you on the wrong side of every disagreement. The very fact I disagree with the label is confirmation of my disorder: Catch 22.'**
- **'It's a negative and very dangerous term, overused and not at all helpful.'**
- **'There now seems to be a need to show that I am not just attention seeking if I feel ill and that I'm not treating hospital as a hotel.'**
- **'Relief at first. Instead of multiple problems it could be put under one name. Then later offended by it.'**
- **'Relief to have something diagnosed after 20 years of 'alcoholism' due to my condition.'**

freeze up and my neck to lock. I didn't sleep for longer than an hour or so for three months. I was also suffering from tendonitis and the side-effects of all the medication I was taking. I was exhausted, stressed and depressed and revisiting old nightmares. After being re-housed and able to have visits from my son, excellent cortisone treatment and several months of rest in my own space, I was feeling much better and considerably more optimistic about my future. Except I now have a permanent diagnosis of personality disorder which will be on my records forever. **Andrew H Smith**

Being told positively

As someone who had allowed a previous diagnosis of schizophrenia to overwhelm me, I was determined, when presented with my current diagnosis of dependant personality disorder, that I would define it and not allow it to define who I am. My psychiatrist advised me to use it as a means by which to make sense of my past and present but not to allow it to adversely determine the person I had become and could develop into. As a consequence of being raised by inadequate parents within a dysfunctional family, I went on to try and resolve the lack of security and attention that I had experienced by attaching myself inappropriately to individuals, environments and addictions. I hoped for these attachments to compensate for that which had been denied me in my formative years.

This knowledge and insight has allowed me to lead my life in a better informed manner. I now recognise when circumstances extract an unwanted response from me. This affords me the opportunity to engage my newfound insight and revise my response.

It is my belief that, with the appropriate support I have received and a change in mindset, individuals can be optimistic about living a life beyond the perceived limits of a diagnosis of personality disorder. **Chris Munt**



Recovery is possible!

- Never give up hope! Recovery to me means keeping my flat clean, visiting my friends and going out. It's being a service user trainer and sharing my knowledge and experience in the hope it will help people understand more.
- Recovery doesn't mean going back to how you were before. You go on to a 'new found' place in the world.
- It is possible to find a way to live with it. I don't know if you can recover from being you! For me, the key has been accepting and owning the BPD aspects of myself.
- Living and working independently. Acceptance and beating stigma.
- Recovery means disputing the diagnosis and seeking alternative means of support to deal with the traumas such as physical and sexual abuse or post traumatic stress disorder that have led to self harming and addictive behaviours.

What has helped to recover?

- Doing Viewpoint 'Presentation Skills' course, writing a book on my experiences, 'Suicide Junkie' published by Chipmunka, and building a relationship with my wife, who has the same diagnosis, and supporting each other. A healthy relationship is a healthy mind. **S Westwood**
- Recovery for me began when my shrink asked me to give a name to this detached, self-destructive, confused part of me. I called it Fred: Fragile, Repressed, Emotional, Detached. By accepting Fred as being part of me, I am beginning to connect with Fred, rather than battle.
- A trusted, respected support worker
- Medication
- Viewpoint – a sense of achievement and belonging
- Education
- People believing in me
- Self help through AA and the Lister Day Hospital (now closed)
- Therapies: Transactional Analysis, anger management, assertiveness, art, pottery, relaxation, meditation, exercise,
- Peer support and creativity



Artwork by Sue

What types of services are needed?

- Very caring and competent members of staff who give me a chance, who don't treat me as trouble from the moment I meet them and who give me the opportunity to just be myself.
- Being given the diagnosis and plenty of information about it in a sensitive and understanding way rather than by accident and in a manner which fosters hope not abandonment.
- Continued changes in the perception of mental health.
- 24 hour helpline and/or support in person, particularly at night, weekends and Bank Holidays.
- Calming music when you're kept on hold on the phone.
- Somewhere to go when in crisis with staff who have good training/background in working with people with PD.
- A safe place to express myself.
- A place like The Haven Project in Colchester offering day services, support and treatment in the community including residential respite care.
- Support groups.
- I need to lose the passion I have for self neglect and the desire to stay ill.
- Recognition that what is seen as acting out is very probably a tried and tested coping strategy that has enabled me to survive so far.
- Access to choice of therapeutic styles.
- More opportunities to do sport.

My arms and legs are severely scarred through self harming which stops me wearing swimsuits and vest tops which are the only practical sports wear to do athletics. A group for people with scars and injuries, however caused, to do sport without being stared at and stigmatised would really help me mentally as well as physically.

- Need consistency from service providers.
Staff you know well may sometimes give you leeway, such as thirty minutes unescorted leave instead of ten as stated in the care plan. Staff who don't know you will stick to the rules which can lead to arguments or being set up for rejection. It can also lead to tension between staff members.
- Services where the term PD is not one of exclusion.
- Services which no longer recognise PD as a viable diagnosis and expunge the label from my records.
- Alcohol services need to understand dual diagnosis of PD. They only see the alcohol side as detrimental.

ARE YOU A CURRENT OR PAST USER OF MENTAL HEALTH SERVICES IN HERTFORDSHIRE?

Would you like to help improve mental health services in the county? Then Viewpoint would like to hear from you.

Viewpoint exists to empower and support people who use or have used mental health services to be part of the decision making process. We do this by bringing together interested groups and individuals to get involved in the development, provision and monitoring of mental health services. We offer support, training and travel expenses to Viewpoint meetings.

To join Viewpoint, please fill out the slip on the back page and return to us

Viewpoint is a registered charity number 1105423

See me not my diagnosis

- If you work in mental health or have a diagnosis of PD yourself, you will come to see beyond this bogus, negative and limiting diagnosis and look instead to the individual behind the label to see their integrity as a person worthy of care and concern.



- I do have Borderline Personality Disorder but I also have so much more in my life. I have great friends, I have a passion for reading, I have a loving family. I have a future even if at times I can't see it. Through my work with Viewpoint as a service user trainer, I have the chance to use my skills to teach others about various aspects of mental health.

Can you help me?

When I want your help
 I'll make you laugh
 I'll fight with you
 I'll chat with you
 I'll run from you
 But I won't even whisper
 the continuous words inside my head
 'I'm scared.
 Please help me.'

Em Jones

Service users' views count!

Help create better personality disorder services!



This special edition of the Viewpoint newsletter explains to service providers how damaging it is to be excluded from help by a label and what needs to happen to make life better. Many thanks to Viewpoint news gatherer, Andrew H Smith, who designed a questionnaire to collate people's views which are reflected here. If you would like to make your views count, contact Jacqui Deakin at Viewpoint on **01707 328014** and she will pass your views onto Chris Munt, Viewpoint Vice-Chair, who sits on the Implementation Group of the team designing the new services.



'Now is the Time' support group Ware

Have you been given a diagnosis of personality disorder and/or are driven to harm yourself to feel better?

If you live in South East Herts, there is a group for YOU in Ware held every Tuesday afternoon. The purpose of the meeting is to have a support/therapy group to enable positive change. It is a safe place to share experiences, practice helpful techniques and to receive and provide support. This group is open ended and is by referral and assessment only. **Self** referrals are welcome.

To find out more, call **01920 486748** and leave a message on the answer phone. Kate will call you back.

If you would like more information about Viewpoint, contact us on **01707 328014**, or complete the reply slip below and send in an envelope with no need of stamps to Viewpoint, **FREEPOST NAT8850**, Welwyn Garden City, Herts, AL7 1BR.

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