

Welcome to the first edition of the BPD Foundation Newsletter for 2015

Experience of a Dialectical Behavioural Therapy participant

(Not all DBT programs are the same)

Almost 4 years ago I found out that I had Borderline Personality Disorder. Dr Google told me that DBT was what I needed to do. I promptly asked my psychiatrist to refer me to this DBT thing.

My psychiatrist explained that DBT was called Dialectical Behavioural Therapy and was a program developed by Dr Marsha Linehan. He said it was specially developed for people with BPD and that I could participate in the program as part of a group or do the program with a psychologist one on one. I asked my psychiatrist what he thought. He recommended doing DBT one on one and gave me the name and number of someone he said was 'good'.



We now enter the Sergeant Major period. Yes, that's what I called my first DBT therapist behind her back. She was so strict. Sergeant Major had a whiteboard in her room and gave me a form which contained all these concepts in grid form that I didn't understand. She seemed to look down on me and to be honest she scared the crap out of me.

Sergeant Major explained that the piece of paper was called a Diary Card and that I was to fill it out each day. It contained things like my urge to commit suicide, binge eat or self harm out of ten each day. It also contained check boxes of when I used skills that she had taught me. I was told that we couldn't start a session without my diary card and that if I didn't bring it each week we couldn't really do an effective session.

I lasted with Sergeant Major for about a year. My

Editor's note: Research now shows us that 'good clinical care' in addition to a variety of therapy programs eg DBT, ACT, Mentalisation, CBT are equally valuable in treatment of BPD. It is important that if one form of treatment is not suiting you to give another a try

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Mum paid a fortune for the sessions and I felt incredibly bad for causing her financial strain. To be honest, I think what I learnt with Sergeant Major was how to not look borderline. I was told what was acceptable behavior, what wasn't, how my behaviours can push people away and how my expression of emotions can also push people away.

I became a robot. I was behaving in all the right ways, but inside, I was dying. I was in so much emotional pain and devastated by past losses and trauma that I felt the pain would kill me. I was told by my psychologist that I was not allowed to talk about my trauma, losses or pain until I had learnt the DBT skills. This really pissed me off. I left Sergeant Major and told her I couldn't see her due to work commitments clashing with her availability. This was a lie.

Now we enter the 'Suck It Up Academy'. This is the name I gave the private DBT centre where I was about to spend a year of my life. I attended twice a week as an outpatient. I was not impressed about learning the skills all over again, but I needed to finish DBT. Surely if I can show I've learnt all the DBT skills someone will listen to my pain? Won't they?

No, they never listened to my pain. I tried so hard to look cured in the hope that they would listen to my pain but they just didn't want to hear it.

Once again I was pissed off with DBT. I went and worked with a different psychologist to work on my pain. Problem was, by the time I was given the opportunity to talk about my pain and trauma, I couldn't find the words. They were buried so deep that I didn't know how to access them.

Now we enter the life changing experience stage. I hurt my back, lost a career I worked really hard to get and became acutely suicidal. I ended up in a private psychiatric hospital where I was treated as a person, as me. But OMG, who am I? I buried her so deep.

With the help of a new psychiatrist, new meds, great nurses I started to become me. I didn't care if

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I looked borderline. I just wanted to be me. To find out who that was. To be real with people and to recover. I was now determined to give DBT one last crack.

I started DBT for a third time as a day patient where I had recently been admitted. It was here that I was introduced to Miss M. Miss M was to be my DBT therapist. There was no way in hell that this therapist was getting into my head. I was soon to discover that Miss M had other plans.



DBT with Miss M was very different to what I had experienced before. At our first session she explained to the group that we would be doing trauma informed and experiential DBT. She started off by teaching us about parts of the brain called the amygdala and the neocortex. Had I just walked into a psychology course?

Miss M explained how a person can develop BPD and all the ways we can be invalidated as a child.

These examples of invalidation hit me hard, Miss M was explaining my childhood without even knowing it yet. I found myself experiencing grief over my childhood and intense emotions. These emotions were so strong that for the first few weeks of DBT I did a runner each lunch time and went home. I knew Miss M wouldn't want to hear about my pain and I didn't want her to get too close. I knew I would probably be in trouble, but I chose to run.

Just like clockwork, Miss M called me each time I did a runner. Instead of being yelled at, I was met with concern. Miss M actually wanted to hear about my pain and encouraged me to share that pain with the group. She also wanted to check if I was OK. This was a foreign concept to me. Did this therapist actually really care about me? Wow.

Miss M had started to work her way in to my world. As I started to trust her and the group I started to learn about myself. I discovered my strengths and the areas I needed to work on. This was an incredibly uncomfortable experience. It was like having a mirror put up to my face and in that mirror I could see my flaws.

Over nine months we did a lot of processing and learnt the DBT skills. I was so relieved to not have the DBT skills shoved down my

throat military style as was done at the Suck It Up Academy. I was ecstatic that there were no diary cards.

During DBT I strengthened the relationships and friendships I wanted to keep and I ended two very significant relationships in my life. This hurt like hell but was crucial for my wellbeing.

I found the strength to stand up for things that I strongly believed in. I could see compassion for myself for the first time and understood just that little more about my BPD.

DBT was not all smooth sailing. I have to admit that I was not a model patient. I veered off track a number of times. Each time this happened, Miss M did not fix things for me, but she explained to me and explored with me how I could fix them myself. She also explored with me how I could do things differently next time. I really appreciated this as I never felt like I was in trouble. I felt I had someone on my side who would help me, even if I did stuff up and even if I got angry with them.

Yes that's right. I have been very angry with Miss M at times. When I told her how angry I was, she never retaliated, she just listened and wanted to understand. I even got an apology from Miss M on two occasions. Throughout my extensive psych history, I have never had an apology from a therapist. I didn't know that therapists like Miss M existed.

Somehow, Miss M broke through my walls. I developed an attachment with Miss M which was to become one of the most healing aspects of my journey. Miss M genuinely cared about me which in turn helped me to care about myself.

I need to also acknowledge the team of people who helped me during my journey through DBT. There is my psychiatrist, who I think is pretty cool. We have a relationship based on honesty and trust. I have contracts with my psychiatrist which helps me feel safe, it doesn't feel threatening, it feels containing. There is Miss A my art therapist. Miss A is also pretty cool. She has been with me since I got admitted to hospital. She just accepts me as I am. I constantly tell her that I don't understand how this art therapy works and she just smiles at me. We both know it is working for me and I guess in time I will come to understand. I can now explain my trauma to therapists and I can finally get my words out. Miss A accepted me on my very bad days and embraced my happy days. I love how she gently suggests we have some "quiet space to

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process the art work" when I'm being a chatterbox. This is a frequent occurrence.

If you are considering DBT, I want to let you know that they are definitely not all the same. If one DBT centre does not fit for you, try another. It does not mean there is something wrong with you, it just means that the style of DBT that the centre is using may not be right for you. I often wonder what Marsha Linehan would think of practitioners doing DBT in such different ways? I may even send her a copy of this article.

I will forever be grateful to Miss A, my psychiatrist and my DBT group for believing in me when I couldn't believe in myself. For helping to show me the way when I've veered off track and for giving me the gift of a journey towards recovery.

I graduate from DBT today. This is a sentence I never thought I'd say. The only way I know how to express my gratitude to Miss M is by dedicating this article to her.

Thank you Miss M.

Name withheld by request

New Family Connections Program

A recent graduate of the program said, '*I left the program with the ability to generate within myself a sense of peace, and a sense of hope – invaluable!*'

For families with a relative with borderline personality disorder, the twin feelings of feeling vilified and self-vilification/guilt are common. Often heard refrains include, '*Did I cause it?*' or '*Did I exacerbate it?*'

Family members explain feelings of isolation in dealing with their relative's struggles. Equally difficult is experiencing the judgement of friends and family members.

It was wonderful to see that there are many clinicians who value families' involvement in the journey to a more fulfilling life. The Family Connections Program offers education, skills and understanding that will empower family members and help to improve their relationships.

A comment by a participant at the recent family connections training in Melbourne 2-3 May

Stigma is reported widely amongst the BPD community. This phenomenon is perhaps best illustrated by the example of family members being told, '*I don't accept BPDs in my practice,*' or '*We don't want those patients in our hospital!*'

To help address these issues, NEA.BPDAust has introduced the evidence based **Family Connections Program** designed to support family members and help them understand the disorder and the chaos that often exists, the impact of the illness on their relative and themselves and to teach skills to improve the quality of their lives.

Family Connections is a 12-week, manualised, free, community based program run by Australian clinicians and family members who have received specialist

Leader training. Specifically it provides information on the latest research, coping skills (drawn from DBT), and support. Co-developed and maintained by Professor Alan Fruzzetti and Dr Perry Hoffman, the program has been running in the US for over a decade and has over 1,000 families on its waiting list.

Three research studies point to its effectiveness in significantly reducing family member experience of burden, grief and depression and significantly improving family member experience of mastery and empowerment.

The **Australian Family Connections Program** is now available in Melbourne and areas of regional Victoria. Families in Perth and Adelaide will be able to access the program from July this year. Additional information and registration for the program can be found in the 'For Families' section of the NEA.BPDAust website at www.bpdaustralia.com



Hocking-fellowship Brings BPD into Spotlight

In May, 2014 I was the recipient of the Inaugural SANE Australia Barbara Hocking Fellowship. This enabled me to travel overseas to research and study Borderline Personality Disorder focussed services, programs and organisations. I have a recovered lived experience of BPD and now work as a peer support worker. There are almost no programs and services for people with BPD, except for DBT programs run by clinical psychologists. My intent is to create community and peer based programs and services in Australia.

My first stopover was Washington DC where I attended the National Alliance for Mental Illness (NAMI) conference and was part of the National Education Alliance for BPD (NEA-BPD) gang. NEA-BPD run a twelve week program led by trained group leaders called Family Connections where parents, carers, siblings and spouses learn education, skills training and support for their loved one with BPD. My next stop was in New York where I attended a weekend Family Survival Skills course called the TARA Method run by Valerie Porr, who has written the best, most comprehensive book for families of people with BPD called Overcoming Personality Disorder, a Family Guide for Healing and Change. I was privileged to be allowed to sit in and observe for the two days. Valerie emphasises that there is an over-arching biological and genetic inherited component of BPD and that parents; especially the mothers, are not to blame. These two services are for family members, the following services are for consumers.

After New York, I flew to England where I was invited to visit The Haven Project in Colchester. The Haven Project is a crisis/safe house for people with BPD who are registered users. They have crisis and respite beds, a 24/7 crisis line and taxi vouchers for people who are in crisis to have a safe journey to the house. The Haven also has DBT skills groups, creative writing groups, addiction workshops, healthy living, friendship group, welfare rights and arts and crafts, among many other services on offer. I then visited Suffolk Waves, which is a day-therapy drop-in service running twice a week in Ipswich and Bury St. Edmunds. Services include one on one counselling, Life Skills program including, How to Survive Christmas, yoga, dance, drama, music (special funding is dependent on these) and informal

support groups.

Then onto Wicklow, Ireland to participate in a five day Mindfulness Based Stress Reduction course based on Jon Kabat-Zinn's teachings. This was held in the hotel function room with 92 people from 27 countries. We all sat on a yoga mat and meditated, including standing, sitting, lying and walking meditation, as well as conducted self body scans, self massage and yoga. The teachers checked in after each session to see how we were doing as sometimes intrusive thoughts and flashbacks can occur. There were several silent sessions and one 24 hour silent period we were not allowed to talk with anyone. This was all very confronting and several times I wanted to leave, and I was not alone, that is quite a common feeling. I persevered and I am glad I did because since that time I have been able to become more mindful more easily.

Atlanta, Georgia was the next stop where I attended an International Peer Support conference. I met some wonderful people there and discovered that many people with disabilities have service dogs for companions. These dogs are allowed in hotels and on planes. These canine companions have made a huge difference in relief from loneliness and isolation for people.

Victoria, BC, Canada was next on my itinerary and I attended a very well structured weekly BPD consumer support group attended by about twenty people. It was wonderful to sit in with people who share my illness and think the same way I do, including all the dark thoughts I have. Very validating and connecting. The BPD Society of BC, Victoria also runs an informal DBT skills group once a week. My final stop was San Francisco where I attended a workshop on Personality and its Implication for Psychotherapy run by Nancy McWilliams.

I have been back in Perth for six months and am starting to implement everything I learned overseas. There is a weekly regular BPD consumer support group at the mental health organisation I work for. I am starting to have meetings and forums as to how the Haven Project in WA will look like. I was in Melbourne in April, 2015, helping SANE Australia with BPD web content, forum input, media interviews as well as talking to staff about how BPD affects the person diagnosed and their families. Jack Heath, CEO and I made a video urging people to apply for the 2015 Hocking Fellowship which is now up on the SANE Australia you tube channel.

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The Hocking Fellowship is not unlike that other fellowship, the one undertaken by the adventurers in The Hobbit and Lord of the Rings. The discovery is not just in where you travel and who you saw, and what you did, but how it affects you personally. The journey undertaken over the past twelve months from application to final report and post fellowship work has changed the way I see myself, what I didn't know I was capable of doing, and how I now have a global perspective of BPD. The Hocking Fellowship is truly the gift that keeps on giving.

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An article from Sonia Neale the inaugural recipient of the SANE Australia Barbara Hocking Fellowship. Sonia is our consumer representative on the Board of the BPD Foundation. Sonia lives in Western Australia. Sonia's full report can be found at:

www.sane.org/news-comment-2015/1413-hocking-fellowship-brings-bpd-into-spotlight.

[Applications are now open for the Hocking Fellowship 2015 to Australians, like Sonia, who are active in the mental health field and want to help improve treatment and support for those affected by mental illness. See details and application form at www.sane.org/projects/hocking-fellowship]

Book Review

Mindfulness for Borderline Personality Disorder is a must-read for any Borderline Personality Disorder (BPD) sufferer.

In this book, the authors Blaise Aguirre and Gillian Galen explore how mindfulness — the essential strategy in Dialectical Behaviour Therapy (DBT), developed by psychologist Marsha Linehan — can open the doors to genuine healing.

Written in clear terms and using a non-judgmental stance, it is a practical guide with chapters broken up into take-home mindfulness lessons for the reader.

Mindfulness for Borderline Personality Disorder is a simple, yet effectively written book with personal accounts of those with BPD. These accounts delve into intensity of emotion, suicidal ideation, remorse, loneliness and feelings of worthlessness, while also giving practical advice to help with these feelings.

The authors examine mindfulness and how it can help those suffering from BPD, teaching the reader of the importance of strengthening their practice.

The book provides helpful instructions on how to set up a formal mindfulness practice as well as how to practice mindfulness in daily life.

Mindfulness for Borderline Personality Disorder is an essential companion to Linehan, Marsha **Skills Training Manual for Treating Borderline Personality Disorder**.

Borderline Personality Disorder: Open Letter to Emergency Department and Hospital Based Staff

by Sonia Neale

People with a diagnosis of BPD are often accused of manipulation and splitting in psychiatric settings. A quick Google search reveals that manipulation is the action of manipulating someone in a clever or unscrupulous way, the skilful handling, controlling or using of something or someone, to manage or influence skilfully, especially in an unfair manner, to manipulate people's feelings. I have never felt skilful, clever, influential or in control in an emergency department or hospital setting yet I have been accused of manipulation and splitting.

What I do feel is shame, shame, shame and more shame, along with confusion and fear. I feel physically sick and unsafe. My body is burning internally. Shame causes the amygdala in our brain to produce a cocktail of poisonous chemicals. We are burning from the inside out. Invalidating our feelings is like throwing petrol onto an already fierce raging fire.

Imagine a grizzly bear bounding into emergency and bailing you up against a wall and someone in charge expects, no, demands, that you sing "The Star-Spangled Banner." How many of you would be able to do that with adrenaline and cortisol screaming around your brain and body?

When my amygdala is in charge of my body, and my pre-frontal cortex is in hiding, I am operating on fight/flight and freeze. I am falling down a deep, black bottomless pit. When I am well, I can manipulate, that is, I can plan ahead in a clever and skilful manner and I am in control. My brain is cold and analytical. People with antisocial personality disorders have cold amygdala which is why they can con people out of their life savings. People with BPD have boiling hot amygdala and would find writing their name a challenge.

When we are in the middle of a BPD amygdala meltdown we regress to a very young age and swearing is part of this regressed condition. We use primitive forbidden language as nouns, verbs and adjectives because we do not know how to cleverly and skilfully manipulate language to

get our emotional needs met. At this point we are almost pre-verbal. Swearing can help expel the feeling that we are burning up inside. It dampens and discharges the toxic chemicals. It feels cathartic. I feel for the person receiving this torrent of cathartic emotions. I have been on the receiving end of this a few times. I feel for the emergency and psychiatric staff. This is part of the devaluation process consistent with the nine BPD symptoms; please separate the person from the behaviour. Effective training helps people understand why this happens. Please do not take this devaluation, regression and lack of language skills personally.

A BPD meltdown with all its colourful language in the moment is a life-threatening experience for us. Let me repeat that. We are experiencing an out of body, near death experience. We are paranoid and dissociated, also criterion for a BPD diagnosis. Again please do not be surprised when we walk through that door displaying all nine symptoms in the moment. We are doing what we are supposed to do, according to the DSM V.

The DSM V was written for a reason, it is the psychiatrist's bible, and one that is always referred to. The DSM V clearly states the idealisation/devaluation process as part of the nine symptom range, so why do hospital staff show disgust and revulsion when we assign you as good or bad?

An extremely clever group of professors got their pre-frontal cortices together and created the nine symptoms from people's observable behaviour which ironically is sometimes used as exclusion criteria for admission to a hospital. Go figure!

Another article by Sonia Neale <http://blogs.psychcentral.com/being-borderline/2015/01/borderline-personality-disorder-open-letter-to-emergency-department-and-hospital-based-staff/>

"When you understand, you cannot help but love. You cannot get angry. To develop understanding, you have to practice looking....with eyes of compassion. When you understand, you love. And when you love, you naturally act in way(s) that can relieve the suffering of people."

Thich Nhat Hahn (Buddhist Monk)

Watershed event!

First in Australia

The Congress of the USA made a declaration in 2008 acknowledging the month of May as BPD Awareness Month. We can now advise that Australia has also done something very similar!

On 1st October, 2014 Senators Penny Wright (Australian Greens) and Jan McLucas (ALP) co-sponsored a motion to the Senate of the Australian Parliament, declaring the first week of October of each year as BPD Awareness Week. The BPD community acknowledges that Senators Wright and McLucas are the first politicians in Australia to assist in a practical sense in recognising Borderline Personality Disorder. This is a first for any parliament in Australia where a disease or illness has been acknowledged in such a manner.

As you will read, the Foundation, together with our Patron Janne McMahon and supporters Dr Martha Kent from South Australia and Professor Andrew Chanen from the HYPE Program (Helping Young People Early) at Oxygen in Victoria, were instrumental in getting support for this initiative.

Here is the motion from Hansard 1 October, 2014:

Borderline Personality Disorder Awareness Week

Senator WRIGHT (South Australia) (15:43):

I, and also on behalf of Senator McLucas, move:

That the Senate —

(a) notes that:

(i) at any one point in time, between 1 and 4 per cent of the general population experiences Borderline Personality Disorder (BPD),

(ii) the disorder can be characterised by overwhelming emotions, relationship problems, impulsive and risk-taking behaviour and a fragile sense of self,

(iii) a history of trauma, abuse or deprivation is common among those with the disorder,

(iv) despite its prevalence, enormous public health costs and devastating toll on individuals and families, recovery from BPD is possible,

(v) BPD is a leading cause of suicide, with an estimated 10 per cent of individuals with this diagnosis taking their own lives, and

(vi) an increased understanding of BPD is required among health professionals and the general public by promoting education, research, funding, early detection, and effective treatments; and

(b) acknowledges That the Australian BPD Foundation, through ongoing advocacy from Ms Janne McMahon OAM, Dr Martha Kent and Associate Professor Andrew Chanen, has declared the first week of October each year as Borderline Personality Disorder Awareness Week with the aim of promoting understanding of the disorder in the community and working towards better treatment options and quality of life for those affected by the disorder.

Question agreed to.

We can also advise that following strong lobbying over a lengthy period, the upper house in South Australia's Parliament, the Legislative Council also passed the same motion with the addition of the need to establish a Statewide Specialised BPD Service (Unit). The motion was co-sponsored by Hon Tammy Franks MLC (SA Greens) and Hon Kelly Vincent MLC (Dignity for Disability) on Wednesday 19th November, 2014. This motion attracted strong support from the cross bench members including SA Liberals, Family First and an independent. The content of the motion was the same but included an additional clause in support of a statewide specialised borderline personality disorder service (unit) for South Australia be established. Unfortunately the South Australian Labor Government so far has opposed the establishment of this service. Subsequently, a petition has been organised by Ms Franks' Office following a request from a consumer.

If you wish to do something positive for raising awareness of BPD, you can add your weight to this important task, simply by going to the online petition:

<http://chn.ge/1topkvR>

Can you imagine what might actually happen across Australia if the parliaments in every state and territory adopted the same motion! Something to think about! **Janne McMahon**

from Janne McMahon



I wanted to give my thoughts on the most recent 4th National BPD Awareness Conference held in Melbourne on 2nd October, 2014.

I was inspired by the speakers, especially Catherine and Fred who gave us all wonderful insights into their life's journeys. I was inspired

by just being in a warm and welcoming BPD community where hope, recovery and acceptance was the norm. I was inspired by the strength and courage shown by the presenters in the breakout sessions.

The Australian BPD Foundation is in my view leading the awareness and acceptability of having a diagnosis or supporting someone with the BPD diagnosis around Australia and boy, do we still need to get the message across. It is our task to inspire others by taking the awareness and acceptability to our work mates, our families and our communities.

BPD.....What works! was aptly named for the focus of this year's Conference. There are now several recognised treatments on offer that have proved to be effective. We heard that at the Conference.

I am always inspired by the work of the Foundation and I take great pride in being a Patron. Let's all work together to continue these Conferences and awareness raising that people can and do recover.

Let's inspire others as others have inspired us!

Janne McMahon

The Australian BPD Foundation invites you to the 5th Annual National Borderline Personality Disorder Conference 2015 to be held at the Flinders University, Bedford Park, South Australia on the 2nd October 2015.

We are anticipating a very lively, positive and productive day. An excellent line-up of national speakers will present key note addresses and workshops throughout the day. These include

- **A/Prof Dr Andrew Chanen:** President International Society for the Study Personality Disorders & Medical Director Orygen The National Centre of Excellence in Youth Mental Health;
- **Prof Brin Grenyer:** Director of Project Air Strategy for Personality Disorders in NSW;
- **Sonia Neale:** Peer Support Worker and recipient of the Inaugural Barbara Hocking Fellowship;
- **Catherine Bennett** BPD Survivor
- **Cathy Kezelman AM:** Director of ASCA (Adults Surviving Child Abuse)

5th Annual National Borderline Personality Disorder Conference 2015. 'New Directions – New Opportunities' Adelaide - Friday 2nd October, 2015

Some funding is available to help cover travel/accommodation expenses for rural and interstate delegates.

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