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Welcome

The Australian BPD Foundation is proud to introduce our inaugural newsletter. Since our official launch in October last year we have given the Foundation a media presence on Facebook, YouTube, Google+ and Twitter and we hope this newsletter will be yet another way for us to connect with you.

One of the aims of this newsletter is to encourage open dialogue to stimulate discussion and help others to gain a better understanding of the diversity of lived experiences of BPD. Given the varied experiences and the accompanying emotions, there will be times when thoughts and beliefs differ and strong emotions are triggered. It will be important that we all strive to respect each other's points of view even though they may be very different to our own.

We hope this newsletter will provide opportunity for differing views and experiences and discussions to be voiced in a non-judgmental atmosphere of care, consideration and respect. As you will be aware respect and acceptance of difference is so important in creating understanding, support and meaningful communication. There is no black and white or easy answers in this area and so many different ways of looking at the same experience! Articles, feedback and suggestions for future topics are always welcomed. Contact information is provided on the last page. At this stage we plan to publish this newsletter on an occasional basis with more frequent email newsflashes as related to BPD or the work of the Foundation as required.

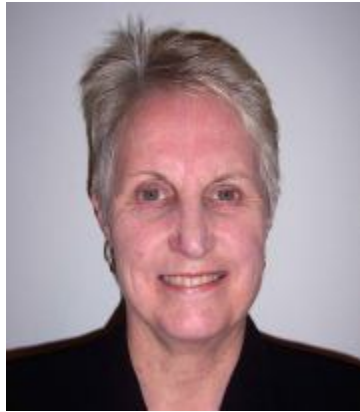
In this newsletter our Patron, Janne McMahon OAM tells us her dream for the Foundation, a carer writes about the 3rd National BPD Awareness Day held in Sydney in 2013, a consumer gives her opinion on whether to tell someone they have BPD or not, a book review and we launch a competition for a name for this newsletter.

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I have a dream.....

by Janne McMahon OAM



2013 marks 50 years since Dr Martin Luther King made his famous speech - 'I have a dream' on August 28th 1963. It accompanied a momentous demonstration representing hope for the equality of African Americans.

As Patron, I too have a dream and this is also about equality, though in a different sense.

I have a dream that people affected by Borderline Personality Disorder will be able to access services designed to meet their needs.

That families are supported and clinicians who choose to treat people with BPD are also supported.

I have a dream that people affected by BPD are treated with respect and that there is no longer discrimination within mental health services based on a diagnosis in Australia in 2013.

I have a dream that people are seen as themselves not a diagnosis and that a robust statewide service (which makes very good economic sense) is established in all Australian jurisdictions based on the Victorian 'Spectrum' Personality Disorder Service together with key aspects of the Project Air initiative.

I have a dream that a National Institute or Centre of Excellence is established to roll out national training, research and data collection.

I have a dream that our Foundation is a strong and well financially supported Foundation that is the one voice for consumers, carers, families and clinicians. That our Foundation is the one tool to lobby governments and that our Foundation is the body to coordinate all future National BPD Awareness Day Conferences.

I have a dream that all of us accept the challenge of raising awareness of BPD. That we all have a task to become the champions for BPD for consumers and carers within our work places, friendships and communities.

Unlike Martin Luther King's call for equality, let it not be that the next 50 years to make a difference.

We are stronger together!

** Janne McMahon OAM has worked within the mental health area as a consumer advocate since 1997. She founded the Private Mental Health Consumer Carer Network (Australia) in 2002 which is a recognised national organisation.*

Janne has appeared before six parliamentary inquiries, is currently and has been a member of a number of Australian Government Committees and Expert Reference Groups including that for Borderline Personality Disorder as well as many other national mental health Reference Groups, Steering Committees, Working Parties and Boards. In 2008 Janne was awarded the Medal of the Order of Australia in recognition of her advocacy work.

*"I have a dream...
equality
respect
accessibility"*

*"Accept challenge
of raising
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Consumer Perspective: "Please tell me my diagnosis" (Name withheld by request)

I want to share with you my story of being diagnosed with borderline personality disorder. I share my story in the hope of reaching out to those living with BPD and of course their families and their friends. I want to let you know that you are not alone. Most importantly, I want to plead with health professionals to please reconsider telling your patients if you believe they have a diagnosis of BPD and they have not already been told. I am hearing all too frequently stories of people who are not being told of their diagnosis until they lose their families, their minds and sometimes their lives.



I was never actually told of my diagnosis of BPD until I read it in my file one day.

For 16 long years I had always just been told that I had depression and an eating disorder. I had been in an out of psych hospitals, on every psychiatric medication you can imagine and had stretched the emotional and financial boundaries of my family beyond belief. No one, including myself could understand why I was not getting better.



Three years ago, things really came to a head. As a psychiatrist would say, complex family issues arose and I subsequently made a very serious suicide attempt. I was admitted to a large public hospital where they saved my life. I was interviewed by psychiatrists and told them what I knew to be true: that I had depression and an eating disorder.

One night, the nurse left my file on my bed. So, of course I read it. There in my file were details of a conversation one of the Doctors had with my psychiatrist of five years. The notes said depression, eating disorder and what the? BPD....no, no no...they must mean BED for binge eating disorder right? Not Borderline Personality Disorder. My heart sank, I kind of already knew this is what I had. I suspected something was wrong with me, but I could never put my finger on it. At that moment, as I lay in that hospital bed I had confirmation that I was psychiatric scum.

Upon being discharged from the hospital I was too scared to tell my Mum that I had BPD. I thought she would kick me out of the house. I honestly thought it meant I was a bad and evil person. When I finally plucked up the courage to tell my Mum, she wasn't surprised, hugged me and told me it was ok. I asked her if she wanted me to move out. She told me to stop being ridiculous. She cried and told me that I am never, ever to make an attempt on my life again and how can she help me get happy. I told her I had Googled, that people with BPD should do something called DBT. She asked me to do it. I didn't have the strength to do it for me, but I did have the strength to do it for Mum. I felt so bad for what I had put her through.

"...you are not alone"

"....I suspected something was wrong with me but could never put my finger on it"

"....made no difference to my psychiatrist...made a big difference to me"

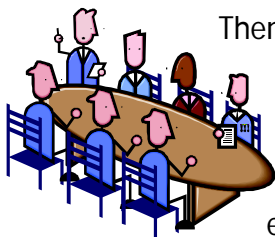
"...how could I trust a Doctor that did not have trust in my strength to fight an illness and work with me openly and honestly?"

"Let us know that we are not bad and that there is hope for us..."

"Help us to make an informed decision"

Before finding out about DBT, I need to ask my regular psychiatrist if this BPD thing really was true. Did I have Borderline Personality Disorder as I had read in my file? He said 'yes'. He went on to say he had never told me this before as he felt it would make little difference to me and he had been treating my BPD with medication anyway. He said he had known for years. I was so angry. It may have made no difference to my psychiatrist, but it certainly would have made a lot of difference to me and my family. It would have made a lot of difference to me deciding if I wanted to keep seeing him each week. It would have made a lot of difference to my decision to keep going into hospital or try DBT instead.

I ended up 'firing' my psychiatrist, not because he diagnosed me with Borderline Personality Disorder, but because he did not tell me I had this disorder. How could I trust a doctor that did not have trust in my strength to fight an illness and work with me openly and honestly as I had done with him?



Then began my two year journey of DBT, I hated it for the most part, but I started to get better. I am still not 'cured' by any means but I am a lot better than I used to be. I have an understanding of when I am being 'borderline'. This is my way of saying: 'I am experiencing intensity of emotion that I can't quite control as well as I would like right now'. I also undertook a DBT program that focussed on binge eating, which I found really helpful.

I feel my Mum has also benefited from my diagnosis. As awful as it is for her to have a daughter with BPD, I see a different sort of inner peace in her. Finally she knows what is wrong with her daughter. She knows why she has a daughter who feels things so deeply and why her daughter has not been getting better for all those years. It was because she was not given the opportunity to access the right treatment for BPD.

So, now comes my plea. If you are a health professional with a client with BPD and you have not told them of their diagnosis, please reconsider.

People with BPD are stronger than you think. Trust us, the way we have shown you trust; work with us the way we have worked with you. Let us know that we are not bad and that there is hope for us. That is all we really need to hear.

Help us make an informed decision on the treatment we now wish to access, even if that no longer involves your care.

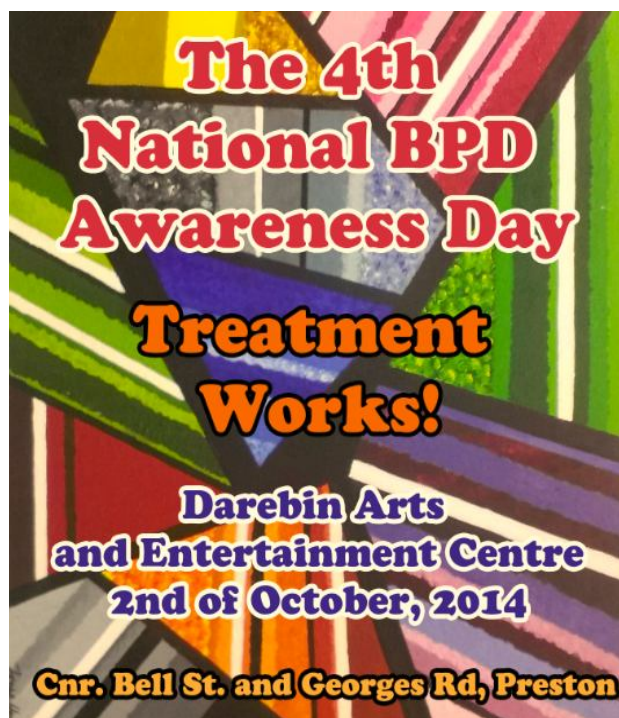
Give us printed information on BPD so that we don't google the terrible things that are on the internet about us. Please go through the printed information with us so that we understand what you are trying to tell us.

If you tell us our diagnosis and we get mad at you for you little a while, trust that we will come back to you. We will value that you trusted us enough to be honest enough with us. If we take a little longer to come back, maybe mail us a copy of this article to let us know you care and that we are not alone.

*I would like to dedicate this article to a dear friend of mine who passed away and suffered from BPD



4th National BPD Awareness Day 2nd October 2014



Building on the successes of the previous years' National BPD Awareness Days planning is well underway for the 4th National BPD Awareness Day to be held on the 2nd October 2014.

Confirmed keynote speakers include:

Dr. Roy Krawitz: Roy is a New Zealand psychiatrist and Honorary Clinical Senior Lecturer (Auckland University) specializing for the last 25 years in working with people with borderline personality disorder (BPD) and in dialectical behaviour

therapy (DBT) (therapist, trainer) over the last 10 years. Roy has authored 5 books on BPD and published research of the effectiveness of his therapy, his generalist BPD training and of the DBT service he works in. Waikato District Health Board is a New Zealand public health service that has supported BPD treatment with a full comprehensive DBT service since 2000. A book review of one of Roy's books follows later in this newsletter

Ms. Catherine Bennett has travelled the BPD road that led her past fourteen suicide attempts and eight years of intensive therapy; she now regards herself as fully recovered from BPD and is studying a Bachelor's Degree in Psychology at Deakin University, and is writing a detailed book about her journey. Catherine is passionate advocate for raising awareness of this disorder and the effectiveness of appropriate treatment. She regards herself as a survivor of both BPD and Complex Post Traumatic Stress Disorder. Catherine will speak about *Relapse and Recovery*.

A variety of workshops will also be run during the day.

Please keep the day free – we would love to see you.

Psychiatrist
specialising in
BPD, author,
researcher &
trainer

*Relapse and
Recovery*

Workshops

Competition: Searching for a name for our newsletter.

This is **your** newsletter and we are asking our members to think of an appropriate name for this newsletter. Please email your thoughts/ideas to admin@bpdfoundation.org.au.

Suggestions so far include: "*Border Lines*" "*Pathways ...to understanding BPD*"

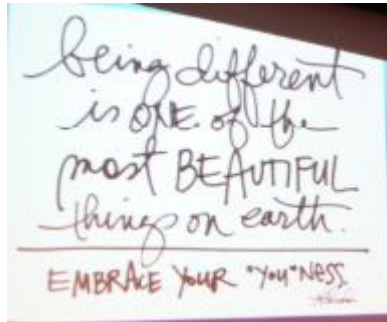
A panel of members will judge the entries and the person with the winning entry will be offered free admission* to the 4th National BPD Awareness day to be held on 2nd October 2014.

* travel not included

A carer reflection on the 3rd National BPD Awareness Day held in Sydney October 2013

Thanks to support from ARAFMI NSW, I attended the Friday sessions of this Sydney conference. We heard from Prof John Allen, the Chief Psychiatrist for NSW, that BPD affects 5 to 13% of Australians, and that 50% of people who have a mental illness also have an overlap with BPD. So these BPD Awareness Days are indeed important not only to those of us involved in the area of BPD, but also to those involved with any other mental illness.

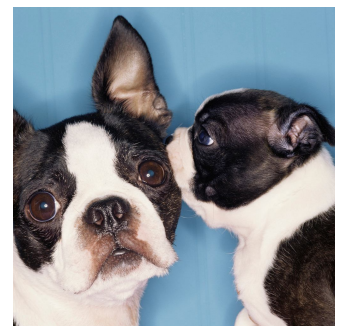
*Janelles's message
"being different is
one of the most
BEAUTIFUL things
on earth.
EMBRACE YOUR
'YOU' ness"*



Janelle Abbott was the first speaker and gave an emotional account of what it felt like to have BPD, or as she likes to call it, HSS, Highly Sensitive Souls. She spoke of the shame and despair that many people with BPD, sorry, HSS, felt, the fear that people would leave her, because she saw herself as an evil, bad person. She longed to end her life, yet had a love of life. The pain of her feelings and emotions was

felt by all of us, and certainly reduced me to tears. She asked that those of us who cared for someone with HSS, listened to them, but without judgement. Consumers need someone to care and understand how hard life is for them, and that they are doing the best they can and to validate this. In her words "The pain of BPD can be crippling; chaos is all we know." And yet, despite her sad story, it truly was a celebration of Recovery. She has worked hard learning DBT skills, and now works with adult mental health consumers, teaching them the benefits of exercise and nutrition, and is a peer mentor for young people experiencing psychosis.

Janelle's sister, Renae spoke next and told us about Janelle's journey with mental illness, and how it affected her as her sister. It was a difficult time for all in the family, and Renae coped by detaching herself to preserve her life. Her message to professionals was, as was Janelle's, to listen, really listen to the person with BPD, to validate the person, and to educate everyone to prevent BPD from developing. Her message to families was to not judge.



Jenny Learmont who is a carer, spoke about how carers are often forgotten by the system. Carers need to look after themselves in order to help their family member. Most importantly, there should be no more blame of carers for having caused the illness. Carers need love, hope and support to enable them to continue their caring role.

This was also the theme of Eileen McDonald's session. She asked that the system use carers, rather than abuse them. Once again listening was seen as being important. She asked that clinicians listen to carers and hear them! Carers are mostly treated as difficulties or obstacles by hospital staff. There is usually trauma care for the consumer but nothing for carers, who can be very

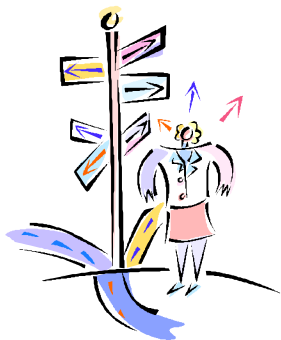
*"....really listen to
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".....prognosis for Recovery from BPD is better than that for any other major psychotic illness."

"....need to get all consumers, carers and clinicians working together on the same platform."

traumatised by coping with the self harm of their loved one. She asked that carers be in a full partnership with everyone involved with caring for their family member.

As a carer I was extremely pleased that this was backed up by both Dr Sathya Rao and Prof Brin Greyner.



Dr Rao started his talk by telling us that the prognosis for Recovery from BPD is better than that for any other major psychotic illness. With psychotherapy there is improvement in all areas of symptoms of BPD in 12 months, and it takes about 2 years to settle complex cases. People with BPD generally get well and stay well. No one model of psychotherapy is better than another!

However discrimination, rejection and labelling by many in the mental health system still persists. Many mental health staff are still only managing the illness, rather than treating it. The system often only reacts, (to crises) rather than being proactive. Dr Rao outlined his dream model for treating BPD: Prevention, early intervention, containment, stabilisation, remission, and recovery.

His model would consist of setting up a BPD Clinic where anyone could walk in with a GP referral for assessment and psychotherapy. There would be a Complex Client clinic, a Recovery Clinic and 24 hour telephone and online support for clinicians, patients and family members. Families and carers would get education about BPD, as well as support.

The challenges are that there is still a lot of stigma associated with BPD, and treatment is grossly under-resourced. There needs to be an increase in awareness about BPD, and we need to influence and educate policy makers for more funding. The National BPD Guidelines need to be implemented and there must be better training for all. Dr Rao said there was need to get all consumers, carers and clinicians working together on the same platform. We need a National Training Focus. A modified Spectrum model for the whole country would cost \$22 million. That is \$1 for each person in Australia.



Prof Greyner started by saying that family carers are the key to helping consumers with BPD and so they need help themselves to know how best to do this. The best treatment for BPD is psychological therapy, not medication. Young people with emerging symptoms should be assessed for possible BPD.

Prof Greyner suggested a step-down model of treatment. When someone was in crisis they needed a quick response, but as they improved, treatment could step down. It was important that people in crisis should be offered an appointment within 1 to 3 days of the crisis. There is no alternative to providing good treatment. Even though it costs to do therapy, there is a much higher cost for doing nothing.

*"...not alone
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*"Recovery for
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*"...a book for
anyone who is
involved with, and
cares about,
someone with a
BPD diagnosis."*

Assoc. Prof. Chris Willcox spoke about the consumer perspective on treatment. Most consumers said the stigma surrounding the diagnosis of BPD was not good. Most accepted the diagnosis and described relief that they were not alone and that "there was finally something that explained everything." It is felt that Mental health services are the stigmatisers.

Consumers said police and ambulance workers had limited understanding of Mental health and BPD, as did GP's. Consumers felt not listened to by health professionals.

Many went to hospital, not because they wanted to, but because they felt unsafe in the community.

Nursing staff often made them feel they were not wanted there. Being non-judgemental was most important to consumers, as was also showing kindness. People want to improve; the lives they are living now are truly terrible.

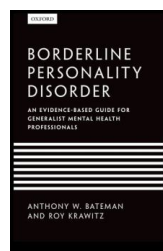


Thinking back on all I heard, it truly was a celebration, in that Recovery for people was is only possible but very probable. But for me, as a mother, the best celebration was that at long last parents were no longer seen as having caused the illness, and therefore being the "enemy". It is now acknowledged, that if we are included in the treating partnership with the consumer and clinician we can play a valuable role.

Judy Burke is a Carer and with her husband facilitates the Sanctuary Carer Support Group in S.A.

Book Review

"Borderline Personality Disorder - An evidence based guide for generalist mental health professionals" by Anthony Bateman and Roy Krawitz (2013)



This is a book that, in my opinion as a carer of a daughter diagnosed with BPD, should be on every GP's bookshelf. It should also be read by nurses, and any health workers supporting someone with BPD, and although it is written with these people in mind, there is one chapter in particular which is specifically for carers. In other words, it is a book for anyone who is involved with, and cares about, someone with a BPD diagnosis.

The authors are the well known Psychiatrist and Mentalisation expert Dr. Anthony Bateman, and unknown to me, but possibly not to clinicians, New Zealander Dr. Roy Krawitz.

The book gives an outline of basic information about BPD, and importantly how to communicate the diagnosis to the consumer. The causes of BPD are discussed, and although the authors acknowledge that there may have been

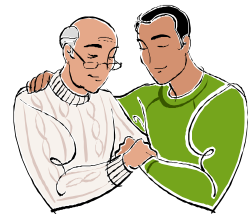
"We (carers) struggle enormously with the burden of association and hope that clinicians will see us for who we are: concerned, and often struggling, parents who are not abusers."

"...clinicians need the backup of other clinicians to support their work"

trauma, sexual or other abuse as a child, they also focus strongly on the biological causes, such as "sluggish serotonin system" and altered brain activity.

They note also that, as babies or children, people diagnosed with BPD may have been highly emotional and/or highly sensitive, which could then have meant that the quality of parenting for these children was a "poor fit". Since many parents are still blamed by many in the mental health system for having caused BPD in their children, this is refreshing information for those carers who are desperately trying to understand, and help, their son or daughter, yet are all lumped in together. As one carer in the book is quoted, "We struggle enormously with the burden of association and hope that clinicians will see us for who we are: concerned, and often struggling, parents who are not abusers."

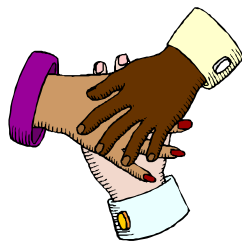
There are chapters on different methods of care, such as generalist psychiatric management, structured clinical management, good clinical care and supportive psychotherapy, comparing the effectiveness of each. This is the first book that I have read which suggests that clinicians working with people with BPD should do so with compassion and empathy, which is very refreshing, having heard from other carers, and experienced firsthand, the disdain with which some clinicians treat these consumers.



While it is recognised that inpatient treatment is generally not recommended as a treatment of choice for BPD, one chapter focuses on when this may be necessary eg acute risk of suicide or imminent danger from risky behaviour. Similarly the authors discuss when medication should be prescribed, and which of these has shown to be effective and for how long they should be prescribed.

Supporting someone with BPD can often be emotionally difficult work, and there is an important chapter on how the team of people doing this can themselves be supported. This recognises that clinicians need the backup of other clinicians to support their work, particularly with high risk BPD patients.

As a carer, I found it enlightening that these two professionals not only recognise the importance of including the family caring for someone with BPD, but in fact suggest that it is very important that families are given information about BPD, (providing the consumer agrees, which in most cases in their experience they do). As Bateman and Krawitz point out, clinicians spend at best one hour a week with the patient, whereas families are there, generally, 24/7.



Without relevant information, the consumer simply returns to the same environment, which may have contributed to the emotional upheavals. Carers need information about BPD itself, and about the various therapies that might be used by the treating team, so they can then support the treatment. Carers

“... they stress that carers be made aware of a non-blaming theory of the causes of BPD, as many parents already suffer from huge guilt.”

also need to be provided with education about validation, which the authors say is one of the most important skills carers need to learn to help their family member.

The authors talk about acknowledging the grief that parents experience and the importance of validating this, as well as the huge challenges families and friends live with. Once again they stress that carers be made aware of a non-blaming theory of the causes of BPD, as many parents already suffer from huge guilt. At the end of this particular chapter, there is an excellent handout with information for families, which clinicians are encouraged to photocopy and give to them.

Throughout the book there are many vignettes and comments both from consumers and carers, taken from actual cases of both Bateman's and Krawitz's practices, and this gives the book a sense of real life situations.

This book is not only a must for inclusion on every clinician's bookshelf, but it would be very useful in NGO libraries, to be available for staff, as well as families of those with BPD, to read.

Judy Burke and her husband are carers and facilitate the Sanctuary Carer Support Group in S.A.

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