Welcome!

On behalf of the Australian BPD Foundation Ltd I am delighted to introduce the first edition of ‘The BPD Advocate’.

We hope this publication will create understanding and raise awareness of Borderline Personality Disorder (BPD), as well as provide a forum to which anyone with an interest in BPD can contribute.

Furthermore, through publication of this newsletter, the Australian BPD Foundation aims to inform mental health professionals and the community, and help them realise that BPD is an extremely distressing and debilitating mental illness that causes intense emotional pain and suffering to individuals and impacts heavily on family members.

We also intend to show that with access to appropriate evidence-based treatment and support people can and do recover. As such, The BPD Advocate will feature stories from both individual and family perspectives of the rocky and challenging journeys taken by people with BPD and their struggles to recover from this illness.

It is anticipated that increased awareness, knowledge and understanding will encourage mental health professionals to seek the education they need to provide appropriate evidence-based treatment and support for people with BPD as well as their families and carers.

The newsletter, as its name suggests, will take a position of advocacy, and use its voice to influence politicians, national and state government departments, as well as community organisations, to make BPD a priority for mental health service provision.

BPD must not continue to be the ‘Cinderella of mental health’ — it should be given the attention it deserves. Consider the alarming facts: Between 2 - 5% of the population experience BPD, and 10% of those diagnosed will end their life by suicide. Clearly, BPD must be made a priority for mental health service development.

Action is needed now!

Cont...
Welcome (cont...)

As we see it, the key issues that require urgent addressing are as follows:

Education of the mental health workforce so they are equipped to provide the psychological, evidence-based treatments necessary to successfully treat people with BPD

• Implementation of the Clinical Practice Guideline for the Management of BPD (2012)
• Training of first responders (ambulance, police and emergency department staff) to appropriately manage people with BPD
• Training of GPs in appropriate management and referral of people with BPD and their family members
• Adequately funded and resourced education and support groups for families/carers of people with BPD and;
• Research and development of intensive short-term treatment programs for people with BPD.

The Australian BPD Foundation is extremely appreciative of the financial support provided by the Balwyn Rotary Club which has made production of The BPD Advocate possible.

Please help us to make this newsletter active and engaging by contributing. Your views, letters, stories, experiences, poems, book reviews, and research summaries are all welcome.

My hope is that when you see the quarterly BPD Advocate you will grab a cuppa, sit back, put your feet up and settle in for what we hope you'll agree is a good, informative read that advocates for, and gives hope to, those struggling with BPD.

Sincerely,

Julien McDonald
President, Australian BPD Foundation Ltd

MYTHS OR FACTS

“Once you have BPD you'll always have BPD.”

This is not true. We know now that BPD features can subside. A 10-year study by John Gunderson, Professor of Psychiatry at Harvard University, found that BPD has high remission and low relapse rates.

We also have a lot of evidence-based treatments for BPD, like dialectical behavioural therapy, mentalisation-based treatment, and other interpersonal therapies.

What we’re finding is that psycho-social function is something that doesn’t improve or develop as much as symptoms reduce.

As well as continuing to research and improve treatments we need to think about, and focus on, ways of improving people’s quality of life.

How are we going to get people back into life, back into doing what they want to do - working, studying and socialising?

This ‘Myth or Fact’ was supplied by Lee Crothers, a psychotherapist, occupational therapist and founder of the Cognitive Analytic Therapy-informed practice, ‘In Dialogue’, Brunswick, Melbourne.
Janne McMahon, OAM, patron of the Australian BPD Foundation, talks to The BPD Advocate about her twenty years in mental health advocacy and her hopes for the future.

In 1997, eight years after her first husband, Bill, died from leukemia, Janne McMahon, who’d endured mental health issues for most of her adult life, was admitted to the Adelaide Clinic. A mother of two, McMahon was crippled with anxiety, depression and panic attacks — just as she had been in the months before Bill’s death. “I was so sick,” she recalls of those dark times. “Suicide was a very real issue for me even though I had two beautiful kids who I loved dearly.”

Life can turn at the most unexpected of moments and for McMahon, now 68, the first green shoots of her recovery — and the catalyst for her twenty years of tireless work as an advocate for mental health, and Borderline Personality Disorder in particular — began growing in the midst of the darkness.

“While in the Clinic I was invited to provide a patient perspective [in regards to a pilot program being conducted] by Ramsay [Health Care] and the health funds” says McMahon who, by this stage, was married to her current husband Will, who has strongly and tirelessly supported her through her advocacy journey.

She says she couldn’t have done this work for so long without Will’s backing.

“There was a moment for me then, a change in direction. It gave me something to think about, something to do, meetings to attend, and for me it just showed the importance of people with mental illness having something to do. Work, volunteering, whatever it is, something meaningful, something that pulls them out of this black hole.”

Once employed in the banking and real estate industries, McMahon’s ability to empathise with both patient and carer, and her passion to improve their lot, saw her throw herself into a career in advocacy.

In 2002 she had her first big win, founding the Private Mental Health Consumer Carer Network which, last year, attained charitable status and for which she is director and CEO.

Since 2002 she has appeared before ten parliamentary inquiries, contributed to a number of Australian Government committees and national mental health reference groups, and was instrumental in the establishment of the Ministerial Borderline Personality Disorder Expert Advisory Group as well as the NHMRC Clinical Practice Guidelines for the Management of BPD.

On top of that, in 2011, McMahon assisted in the establishment of BPD Awareness Day and during the following year, the establishment of the Australian BPD Foundation.

In 2014 she lobbied successfully for a motion in the Australian Senate and the SA Upper House, acknowledging Borderline Personality Disorder and BPD Awareness Week.

Yet for all these accomplishments McMahon admits there is still so much more that needs to be done to improve the lives of people and carers affected by mental ill health, in particular those affected by BPD — a mental illness which she began to focus on in 2008, the year she was awarded an Order of Australia Medal for services to mental health.

“It seemed to me people with BPD were being treated particularly poorly,” she explains. “People with BPD were, and still are, very often refused access to services because of their diagnosis. That’s terrible and it’s still happening. People are seen as trouble-makers, not as people with a mental illness. They are even derided for taking up time.

“What she has long been lobbying for, and continues to lobby for, is specialised services — something state governments have continued to reject. Moreover, she says, “we need to see de-stigmatising of the diagnosis of BPD and removing
Letters to the Editor

Let us know what matters to you, or what is happening in your local area in the BPD world.

I was lucky enough to be one of the winners of a six-week personal challenge which was held at the gym I attend; Bfirm Personal Training in Berwick. Part of the prize was to “train the trainer”, a prize I decided to offer to someone else who might come up with a much more challenging work out for the trainer than I could.

Then Jarrod, my trainer, thought we should put this prize up for auction instead, and all money raised would go to a charity of my choice. Well I had no hesitation in choosing the Australian BPD Foundation, as our youngest daughter suffers from the serious and complex mental disorder that is BPD. We know first-hand the torment that those with BPD endure and this gave us a great opportunity to be able to support them.

I wasn’t sure just how willing other members of the gym would be, as BPD is still an unknown and misunderstood by many people. But I was so pleased when several members, including Jarrod Matthews and Michael Harold, the owners of Bfirm, either placed a bid in the auction or kindly donated money.

The event was held on Saturday, April 22nd, and Jarrod was put through his paces for one hour by the three winners of the auction. I have to say they really made the most of their opportunity to “turn the tables” and he was certainly put under pressure to perform.

The money raised through this fundraiser was the fantastic amount of $1,540, but we were even able to take it a step further when my husband, Graham, kindly donated a further $1,000. He is the editor of the newsletter for the Mustang Owners Club of Victoria and every year he donates the amount he is paid for this position to a different charity, so this year he very kindly decided to support this fundraiser, bringing the total amount to $2,540.

I would like to take this opportunity to thank Jarrod, Michael and all of the Bfirm crew, and of course my husband, Graham, for all of their support.

Sandra Bell

Thank you from the Foundation Sandra, for your initiative and valuable contribution helping us continue our work. Editor.
BPD Awareness Week

In 2014 the Australian Senate declared the first week of October as BPD Awareness Week.

The aim of this week is to promote understanding of Borderline Personality Disorder in the community and to work towards better treatment options and quality of life for those affected by the disorder.

A number of clinical and not-for-profit organisations with an interest in BPD are collaborating to raise community awareness of BPD and the need for access to evidence-based treatment, expanding early diagnosis, and family education to promote resiliency and positive recovery for everyone impacted by BPD.

This year the Australian BPD Foundation is coordinating the BPD Awareness Collaboration group comprised of:

- Australian BPD Foundation including the NSW, SA & Victorian Branches
- BPD Awareness ACT
- BPD Community
- Fenix Borderline Network WA
- Guy Ellies, Volunteer Project Coordinator 2016 BPD Awareness Week
- Helping Minds WA
- Mental Health Carers BSW
- Mental Illness Fellowship Australia
- Mind Australia Limited
- NEA-BPD (National Education Alliance for BPD (Aust) and ‘Family Connections’
- NEAMI National
- Orygen, the National Centre of Excellence in Youth Mental Health (Vic)
- Private Mental Health Consumer Carer Network (Australia)
- Project Air Strategy for Personality Disorders (NSW)
- SANE Australia
- Spectrum Personality Disorder Service for Victoria

It is great to see the group constantly expanding! We are building on the excellent foundation established in 2016 and look forward to building the momentum in 2017.

The financial support provided so generously by Mind Australia Limited, NEAMI National, Project Air Strategy for Personality Disorders NSW, and Spectrum Personality Disorder Service for Victoria has enabled us to contract The PR Collaborative to undertake a public relations and media campaign for BPD Awareness Week.

The BPD Awareness Week Collaboration group is also extremely appreciative of the pro bono support that Titan Digital www.titandigital.com.au have kindly offered to continue to manage the website they developed for BPD Awareness Week in 2016.

GET INVOLVED!

Your participation by contributing your thoughts and views via the website will strengthen efforts to raise awareness of BPD. Check out www.bpdawareness.com.au and get involved!!

EVENTS

What events would you like to see happening in your local area to raise awareness?

Plan now. Email your ideas to bpdawarenessweek@gmail.com

MIND MUSEUM

Please upload your ‘expression of emotion’ (in any art form) onto Instagram at www.instagram.com/bpdawarenessweek

Tag it as #bpdawarenessaustralia and it will automatically be showcased in the Mind Museum of the BPD Awareness website.
News - NDIS

My husband, Todd, has struggled with mental illness from childhood. Diagnosed with Borderline Personality Disorder, anxiety, depression, bipolar 2 and post-traumatic stress disorder, he has tried for many years to get well but has never been able to access the right services to meet his needs. Too often services would put him in the ‘too hard basket’.

In January he was granted an NDIS package.

Being able to be in control of the services he uses has empowered Todd and he has been able to put the supports in place that he needs to get well, and life for both of us is improving.

Having the best kind of support tailored to his needs has saved his life.

Things are still up and down, but the breaks in between episodes are getting longer and less intense. Todd is engaging in the community and is developing a sense of accomplishment. His self-confidence is slowly improving.

We decided to write our story together as we felt it was important to help others in their journey.

Applying for the NDIS is not easy (or quick) when you have a psychosocial disability and face a rather invalidating, frustrating and traumatic experience.

Getting the support you need is vital; counsellors can help in this.

Our first step was to contact the NDIA and get the first lot of forms sent out.

We considered the questions and answered them ourselves before we made an appointment with our long-time, non-judgmental and compassionate GP who understands Todd’s complex needs and the impact of BPD on our lives.

We repeated the process when the NDIA sent us another form asking for further evidence.

Finally, Todd was accepted on the NDIS and the case manager made an appointment to meet us.

The case manager was compassionate and empathic at the assessment meeting. She asked what Todd’s life was like on a day-to-day basis.

She asked the same of me, his wife and carer.

She asked him to tell her what the last 30 days had been like.

As she heard, it had been a tough time for Todd with hospital admissions after suicide attempts and self-harm incidents, which saw him withdraw from the wider world and struggle to stay alive each day.

Hearing that, she asked him what supports would assist both of us and improve our lives so affected by psychosocial disability.

Finally, she asked him to determine what his goals would be under the NDIS plan and what services he would need to achieve these goals.

A few weeks later we met again and Todd’s NDIS plan was outlined to us.

There were supports included, primarily for Todd, although I was given access to counselling sessions.

Once his plan was approved we accessed a plan manager and a support coordinator.

We also sought the services Todd had been granted: a DBT group, weekly therapy with a psychologist/mental health social worker, weekly art therapy, a drop-in art group for people with mental illness, and support workers to mentor him and help him engage in the community.

This is the first year of Todd’s plan and we are still working out what can and can’t be included.

The NDIS, (you may have heard), is in a constant state of flux, with everyone feeling frustrated. Scare campaigns suggest that the NDIS will run out of money, etc. I am not here to talk about that. I can say, however, that for the first time ever, Todd is accessing appropriate services to meet his support needs.

It’s only early but things are improving and we are not living in constant crisis.

There is hope of recovery.
TIPS

Get support for yourself during the NDIS process.

For people with a mental illness, with or without a psychosocial disability, the application process can be traumatic and upsetting.

It is hard having to prove you have a psychosocial disability, especially as we don’t all have a shared understanding of what that means.

Be patient and learn to cope with continual change, otherwise the NDIS will do your head in.

You also need to accept that the process takes time and there can be lots of back and forth. It’s definitely not a quick process.

Have documented reports, supporting evidence and NDIS access forms, information on the behaviours that cause difficulty in your, or your loved one’s, life.

Specific mental health diagnoses are not guaranteed to be considered to cause a psychosocial disability.

Focus on the impacts of the mental illness on daily life, rather than focusing on the illness itself.

Talk to others if you can find them that have been through the process. Ask them what they found important to focus on

Make sure counselling is included for carers.

Find a good support coordinator. Ask them what level of experience they have with psychosocial disability, how many clients they have, and whether they understand the complexities of mental illness and comorbidities.

Do they understand the diagnosis you or the person you care for has? Do they have experience in supporting people with this illness?

Good luck on your journey!

Natalie and Todd

This is an edited extract. The full version can be found on the Australian BPD Foundation website: http://bpdfoundation.org.au/news.php?newsid=9

Psychosocial disability is the term used to describe disabilities that may arise from mental health issues.

Whilst not everyone who has a mental health issue will experience psychosocial disability, those that do can experience severe effects and social disadvantage.

People with a significant disability that is likely to be permanent may qualify for NDIS support.

Recovery is about achieving an optimal state of personal, social and emotional wellbeing, as defined by each individual, whilst living with or recovering from a mental health condition.
Lived Experience

James*, 21, recently gained insights into his triggers with the help of DBT

“Long before I was diagnosed with BPD I always had a lot of self-loathing and anxiety about not fitting in, partly due to my confusion at the time about my sexuality. Besides that, when I was 13 I was first diagnosed with depression and panic disorder and put on antidepressants.

Then, when I was 17, when the HSC [Higher School Certificate] started to get serious, I was diagnosed with OCD and medicated for that at quite a high dose. High school was really hard. I felt I had to make an impression on everybody. With my teachers I wanted to be more than just another student. I've had this ongoing theme of rejection and abandonment for a long time. To this day it's what I struggle with the most.

I can come across as emotionally manipulative, particularly in relationships with friends and with potential [romantic] partners. I want too much too soon, and I get distraught at the smallest things, like people not replying to my texts, like things not going as planned. Distance is perceived as rejection. They say, ‘What’s your problem? You’re crazy, get over it!’ So it’s extremely hard to sustain any relationship. I feel like I’m never going to have a healthy relationship.

Social media is a big trigger and not a good tool for me. I have OCD as well and the accessibility that social media gives me to people, and to see what they’re doing, is dangerous. So if I don’t get a reply from someone and I know they are online I assume they’re ignoring me and I get into a spiral of self-hate and self-harming behavior, like drinking, cutting myself, or overdosing on prescription pills. These are drastic measures to numb the pain. I just can’t manage my emotions.

When I was 17 I started self-harming. Around that time I realised one cut was quite deep and needed attention. So I drove myself to a medical centre but it was closed. I broke down in the car park and called [a telephone help line]. The lady I spoke to made this cringing noise, and said she couldn’t understand how anyone could do that to themselves, that it was disgusting. So I then drove myself to Manly Hospital where I got stitches. They called my parents and told them I’d self-harmed. I’d previously hidden my behaviour from my parents. So it was really hard for Dad to grasp — he was closed off to those sorts of things. But since then he’s become an amazing support; he’s learnt everything he can about BPD. But at the time they just didn’t know what they could do to help. They felt hopeless.

I’ve been admitted to psychiatric hospitals three times, in February most recently.

It was in October 2015, when I started seeing a new psychiatrist, that I was diagnosed me with BPD. After the appointment I went home, looked at the nine traits of BPD in the DSM [Diagnostic and Statistical Manual of Mental Disorders] and thought I’d never read something that described my personality so perfectly.

8
There has been ongoing debate around the use of the term ‘Borderline Personality Disorder’
Many people feel that the name needs to change, whilst others feel that the thinking around the name needs to change.
We hope to bring you more about this in future editions. Write to us with your thoughts.

Labels

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Carers’ Corner

Bridget* knows she can’t control Emily*, 18, or her daughter’s feelings, but she can validate them.

My daughter, Emily — who I’ve been on my own with since she was six weeks old — started displaying symptoms of BPD when she was about 13 or 14.

Over the course of many years, until we finally got a diagnosis, she got progressively worse. She is not at all aggressive but she is a significant self-harmer and has suicidal ideation. She’s had numerous admissions.

I am a registered nurse and I work with adolescents in a school. As such I had high expectations of myself as a carer but there have been times through the years that I’ve been unable to cope. I would say I was close to a nervous breakdown on two occasions. The public health system couldn’t help and Emily continued to be sent home to me leaving me on suicide watch, which I felt was totally ridiculous. And in all the years I was going through CAMHS [Child and Adolescent Mental Health Services] I was never directed to any support services for carers. Their priority was Emily. I don’t know whether they thought that because I was a nurse I would be okay, or that I could find help on my own.

But I was exhausted through lack of sleep. Emily had never completed a full week at school and I was constantly terrified that she was going to die. I would go to bed every night planning her funeral.

Maintaining a normal living, financial situation, and work life was nearly impossible. It was like I was suffering post-traumatic stress. I was doubting every decision at home and work. I felt like I had been a failure as a wife, as a mother, as a nurse. Fortunately I had a fantastic boss who was incredibly supportive and gave me almost a term of compassionate leave.

At one stage, when it felt like I had come to the point of complete collapse, my relatives, who are in Perth, stepped up to help. I felt incredibly guilty, but I took Emily to Perth and left her there for nearly three months so I could have a break. It wasn’t until then that I finally got some sleep, got grounded, and could see things a little bit more clearly. That’s when I sought out support services, support groups, and got some respite. I found out about all the things that were available to me.

Before that my response to Emily was to try and control her; at a time when adolescents try so hard to become independent. And as she became more unwell I’d pull her in even harder, literally demanding to know where she was every five minutes.

I remember cornering her in the car one day, saying ‘For God’s sake tell me what the hell is going on!’ It is probably the most damaging thing I could’ve done to her. She still remembers it, getting trapped in the car with her mad mother! She said she didn’t know why she did what she did but that she didn’t want to talk about it, especially with me. In hindsight she couldn’t articulate it, but I think she didn’t want to impose more worries on me. She felt very responsible for me, which is a very sad thing because that shouldn’t be the way it works. I think we both tried to do the best for the other person but only made things worse.

At the moment Emily is an inpatient at a private mental health clinic in Melbourne. They have adjusted her medication for depression and she said she’s feeling so much happier.

We’ve still got the BPD but we’re now looking at more of a BPD individual rather than a depressed, anxious, suicidal BPD girl. Which is actually quite nice.

Me? I am surprisingly good. Emily and I communicate really well. I say ‘What can I do differently that is not going to make you feel smothered if you’re feeling suicidal?’

I think I’ve learnt that I can’t control her or her feelings, only validate them. Understanding that validation is by no means agreeing that her feelings are rational but they are just as real (rational or not) for her.

That was a light bulb moment I’ve had. I can only change my behavior to continue my own sense of normality. Realising this has made things better between her and me.

* Names have been changed
Clinicians Rethinking BPD

Research at Monash University is trialling new approaches to BPD.

In a recent meeting of the Victorian Mental Health Professionals Victorian BPD Network, Monash University professor of psychiatry Jayashri Kulkarni discussed her ongoing studies into “novel and potentially promising” pharmaceutical treatments using glutamate-modulating drugs that could benefit those with BPD.

Professor Kulkarni believes there is an urgent need for a new approach to treating people with BPD due to the expense of psychological therapies and the current lack of effective medication.

In reference to her current research, Professor Kulkarni told the gathering that glutamate, a neurotransmitter, modulates the excitability of nerves within our brains.

Normally the system tightly controls itself but the balance can be disrupted in times of trauma leading to emotional distress, hypersensitivity and difficulty in managing emotions.

“Altered glutamate signalling appears to be a key event in the pathophysiology of BPD,” she said.

New drugs could, she believes, “allow the neurotransmitter systems [in people with BPD] to calm down enough to allow the concepts and the work that’s being done in psychotherapy to hit home.”

Professor Kulkarni believes the ineffectiveness of current medication contributes to the stigma associated with BPD.

“Medication usage in BPD is a disaster,” she said. “You can almost make the diagnosis [of BPD] by the fact that if a client has an anti-psychotic prescribed, an anti-depressant, a mood stabilizer, a benzodiazepine, she's got this condition pretty much.”

“It’s a real problem because every one of those medications has a side effect, a big one.

Nobody seems to be good at taking people off drugs.

We seem to be really good at laying on another layer upon another layer.”

“Of course when the drugs don’t work that’s another huge stigma. Often what happens is the patient will say I can’t take that anti-depressant, it makes me feel nauseated, and so on, it then comes back to bite her [with judgments from health professionals]: ‘Oh look, she’s just such a pain, she’s being manipulative. Everything we try she refuses. We can’t treat her.’ That adds to the therapeutic nihilism that goes on and on.”

The research group Professor Kulkarni directs at the Monash Alfred Psychiatry Research Centre is dedicated to discovering new treatments, new understanding and new services for people with a range of mental illnesses.

A video of Professor Kulkarni’s presentation can be found on the Australian BPD Foundation website: http://bpdfoundation.org.au/mhpn-victorian-bpd-network.php
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