

Clinton Power: Hello, this is Clinton Power here and I'm speaking today with Sonia Neale who works at a peer support worker at the UnitingCare West in Perth and she's also currently studying at Edith Cowan University, and that's my old alma mater as well, towards a degree in psychology and counselling and today we're speaking about Borderline Personality Disorder. Hello Sonia, how are you?

Sonia Neale: I'm very good. Thank you Clinton.

Clinton Power: Wonderful. I want to talk to you because I know you can share some really personal experience about BPD but first of all tell us your story about how did you become an advocate for people with Borderline?

Sonia Neale: Back in 2005 I was in a psychiatric hospital and I already knew that I had some issues around emotions and I'd already done research on it and I'd already pretty much diagnosed myself. But when I was in hospital in 2005 nobody actually told me this. Nobody actually sat down and had that discussion about this is the diagnosis and this is the treatment. So it was a few years later that I saw a letter addressed to my GP in my file at my GP's office and she let me read it, and it said I was diagnosed with Borderline Personality Disorder.

I noted that the date was a few years ago, and I thought, "Why nobody even told me." Even though I was seeing a psychologist for a long time nobody had actually given me the diagnosis and my therapist and I had worked on healing and telling stories, but the psychiatrist was the one who had the power to do the official diagnosis and he didn't tell me. So that made me to feeling quite angry with the system and how people are treated. It's as though they cannot tell us because we may get upset.

But when you have a diagnosis you then have a bit of a blueprint to see what the issues are and how to deal with them, and it gives you a framework for healing and that was one of the most positive things I found when I got over my anger. Was using the DSM criteria as an actual framework to working and I found that was what lifted me out of BPD. Taking responsibility for what was happening within that framework.

Clinton Power: This is just extraordinary to here that Sonia. I'm going to imagine what it was like to suddenly realize that this was important knowledge that had been kept from you?

Sonia Neale: It's quite common for psychiatrists to keep that knowledge from people. It's a very stigmatizing diagnosis and I call it the Cane Toad of diagnosis

because it seems that we are almost reviled as Cane Toads are. Even the mental health industry do stigmatize people with BPD, who turn them away from treatment and don't want to have people with that diagnosis in their services because it's all too difficult for them. Really what they need is actual education and knowledge and information on the best way to engage a person with BPD.

It can be done and the mental health professional have to do it in a certain way. Recently I was in New York with a lady called Valerie Porr who runs the TARA Method and she run a workshop for families, partners and mothers and fathers of people with BPD, and she showed the best way to effectively engage with people with BPD and it's all based around validation. Validation and non-shaming and non-blaming. There was a certain way to do it and basically you go underneath the behaviour and you say, "Oh, it must be awful for you to feel that way. It must be awful for you to be in so much emotional pain."

That can sometimes dissolve the person's emotions to a point where, "My goodness, I'm suddenly being felt, I'm suddenly being heard. People are getting me, my mother finally gets me." That can have such a powerful impact on a person's emotions in the moment. With BPD the mood changes are so rapid. So up and down in the same alignment that that validation has the power to dissolve those emotions in the moment. It's quite incredible, once you get felt and understood you can then hear the other person and you can hear what they are saying to you and you're more receptive to anything anyone is saying to you after that.

Clinton Power: Sonia I think you are saying a couple of really important things here, but one that's capturing my attention is that diagnosis get a bad rep sometimes, but I think you're saying that diagnosis can also be beneficial because it gives you an understanding of what's going on in your emotional world.

Sonia Neale: It does. Not everybody wants a diagnosis, not everyone accepts it and people with BPD know themselves best. They know what fits and what doesn't fit. So receiving a diagnosis or not is purely individual and it's at a very personal level. If it doesn't fit for you then don't go with it.

Clinton Power: The other point, I think, was important and I think this is very true, what you're saying is that people that have this diagnosis sometimes are avoided even by mental health professionals. I've heard people in my own community talk very warily of, oh I don't want to work with that client because they have this diagnosis. So perhaps we can talk more about just further in the interview about what is helpful and what's not

helpful when working with people that are struggling with this. First of all I really like to ask you more about what is the lift experience of Borderline like?

Sonia Neale:

It's not nice living with BPD because you're very reactive to anything anyone says or anything you read and you can feel this mushroom cloud and toxic neurotransmitters coming out from the bottom of your brain and spreading out to your entire body and that's not a really good feeling and I thought everybody felt like that, so I didn't really question it and it was only until I felt I was in full recovery that I realized that I can hear things about myself and I said, "Wow, that's interesting." And I've moved on within a couple of minutes.

It's quite incredibly liberating to know that there is peace at the end of the tunnel. Before that I was very sensitive to anything that looked or smelled like criticism and rejection and I would get so dis-regulated that I would end up in emotional turmoil for days, and through this I had many job losses where I just couldn't function at work because when you have BPD that can be a full time job, so there's no room in your life for anything else while you're in the really active phase of it.

You feel very empty and purposeless. I had no particular purpose in life. I was trying various different things, nothing fitted, nothing will fill me up except eating disorders, alcohol and drugs and it wasn't until I got older and I got into the beauty of nature and I got into walking and hiking and photography and bike riding and I learnt how to meditate and practice mindfulness and now I can look at a leaf and I can appreciate the beauty of what that leaf is telling me and that is what fills me up with all those positive neurotransmitters which we like to call happiness or contentment.

So my main purpose for saying that is that there is life at the end of the tunnel. You can feel good about your life and you can live a life worth living. Part of it is also feeling completely misunderstood. There are some people who are committed to misunderstanding your position in life and you really try your best to get your point of view across, no matter what way you put it, it can be misunderstood. You can also have a lot of self-hatred and shame at being the worst person in the world. You feel toxic and you feel evil and you feel bad and that can lead to a lot of suicide ideation and a lot of self-harming.

One thing that I did find with the BPD was that neutral comments ... I remember my father was saying to me once at the dinner table, "Would you like some rocket lettuce and my immediate thought was, "Why, do

you think I'm fat? Why are you telling me that I need rocket lettuce? I don't like the way you're speaking to me." And my hate space just went completely off the planet. However I was in a mindful state underneath and I managed to say thank you, but this is the thought processes that go on in my head and it's only when you're mindful enough, to pause and breathe before you respond, that you're able to do that.

Before, that would lead me in absolute turmoil for days afterwards, thinking that he must hate me because he asked if I wanted some rocket lettuce. So understanding the hate space of where somebody is at that level is crucial to people in the mental health industry because it's not the way most people react to someone when they say, "Would you like some rocket lettuce?" So what else does it feel like? Sometimes you can interpret neutral expressions on people's faces as hostile.

So someone might look sideways at you and so the next week or more you're whole being is taken up with the processes, trying to work out what they were actually thinking when you misinterpreted a neutral expression as hostile and that's most important because we have a heightened sensitivity and it's that heightened sensitivity that horns in on neutral expressions and neutral phases, and that's what gets us into a lot of trouble at times because we react without thinking towards it and we can lose a lot of friends, a lot of jobs, a lot of family members, we can lose a lot just by simply overreacting to neutral stimuli.

Clinton Power: That's wonderful to hear this Sonia, because this is such a unique opportunity and I've had lots of professionals talk about the experience but the fact that you've actually lived it makes it so much more special in a way with hearing that unique experience.

Sonia Neale: There's also this black head-space, your medulla or the emotional centre in your brain is over-reactive and the executive functioning centre, the prefrontal cortex is offline. So when something happens your medulla explodes and the prefrontal cortex this doesn't stand a chance. So that black head-space, the medulla hijack or emotional anaphylactic shock is something that we cannot help in the moment. We are born with a sensitive body, we're born over-sensitive and it's that biological sensitivity that allows us to explode in the way we do.

So when we're in that black head-space I use to smash things. Cookery, pots and pans, and video machines and hovers, I would just get in that black-space where it felt as though something was taking over my body. Afterwards I would feel so much remorse about what I've done that I would be suicidal. So the main thing that I found helped with that was

taking a step back, pausing and breathing, counting to 10 and doing a lot of self-reflection, self-talking to the point where I haven't done that for years.

But the process is taking responsibility of this black head-space and doing something about it and there are effective tools for it and mindfulness and meditation are the best ways to clean up that head-space. For some reason it seems to put the prefrontal cortex in power so that you have the ability to make decisions quickly instead of overreacting because it's gone offline, because your brain has been flooded with toxic neurochemicals. It's important to take responsibility of your BPD behaviour and find effective ways of solving your own problems.

Clinton Power: Sonia, what have you learned in your own journey about what are some of the contributing factors or causes of BPD?

Sonia Neale: One thing I found that's what causes BPD is that there are neurobiological underpinnings to it. I had no idea, until a few years ago, that there was a particular body sensitivity and emotional sensitivity, I just thought it was me. So it was really good to understand that some people are born sensitive and some people are born less sensitive. So what I found was in order to overcome that sensitivity I had to basically create a new brain for myself. I had to do a lot of work around mindfulness and meditation and that helps to create new pathways which bypasses all the emotionality.

It's a weird process because sometimes I can actually almost feel that cosmic shift in thinking that enables me to get on with my life and it's through a process of those 'aha' moments that you suddenly get what other people have got all their lives, and I think that's called neuroplasticity and that is a really, really important part of BPD. You have to change the structures in your brain through your thought processes.

Clinton Power: I was just thinking of that exact word Sonia, and it's like you're a living example of how powerful neuroplasticity can be.

Sonia Neale: It's very empowering to know that you have the ability to control your life and make your own decisions instead of feeling as though your life is out of control and decisions are made for you. It is a genetic condition but there's also the family generational to generational trauma. A lot of families with BPD have dysfunctional coping mechanisms and those coping mechanisms are passed out to generation to generation. So there's also the biological genetic part of it as well as the relational part of it as well. And the two together it's very hard to get out of that pattern

of coping in a certain way and not passing that down to the next generation.

I had to do a lot of work around how I talk to my children, talk to my husband, how I treated them. I really had to learn a lot of empathy. Because I was not sensitive to their emotional needs at all. There were times when I had a lot of empathy and I over empathized in a lot of situations and there was times when I was completely insensitive because I didn't have any idea of what was going on in their head. The theory of mind of what was going on in my family's head, I wasn't taking care of or looking at because my own head-space was so out of control that I couldn't possibly look after somebody else'.

So I've learnt to look after my headspace and that has to carry on, flow on effect of being able to look after my family's headspace as well and touch would we all function well, we're all doing good things in our lives.

Clinton Power: Sonia, are you saying as you developed, as you were able to manage your headspace and feel more peace and regulate yourself that that gave you the capacity to feel more empathy for others?

Sonia Neale: Yes, it does. I have more headspace, more listening capacity. I have acquired a headspace where I can sit back and observe, be the own observer of my own ego and other people's ego as well and put myself in a headspace where I can see their point of view and try to look after them and try and put their needs in front of my needs, which is very, very difficult, but it's something I practice deliberately all the time so that eventually it will become natural. Because none of these good behaviours are natural to me, because I have spent so much time getting my emotional needs met I haven't focused on other people and by focusing on other people you get your own needs met.

Clinton Power: Wonderful. Now Sonia I'd love to know what have you found most helpful in your journey with BPD when it comes to support from friends and family and professionals?

Sonia Neale: I think the best way to deal with it is to find a therapist, it takes time to learn how to trust. It took me a long, long time to trust my therapist, even though she was trustworthy from the beginning my perception of trust, I needed to test her over and over and over again to make sure she could withstand anything I might give her. So it needs to be someone who have preferably done a bit of work on themselves and knows who they are and what their buttons are and knows how to regulate themselves.

It's someone who can tolerate the behaviour, the erratic appointment attendants and also this is very important, be able to tolerate idealization and devaluation. Sometimes my therapist is wonderful and sometimes she's a bitch from hell and that-

Clinton Power: Tell us more about that. How does that come about in your experience?

Sonia Neale: She's a bitch from hell when she sets boundaries for me, because I didn't like boundaries, I didn't like the fact that I couldn't email her when she said to me, "Look, I can read your emails but I'm not going to reply to them." I found that very, very confronting. It's like, "You don't like me anymore so why am I seeing you." What she's actually doing is setting boundaries for both of us so that we can both be regulated within that same time frame, and that is very important, it's learning boundaries, your own and other peoples. Otherwise it can get out of control, chaos is going to ensue and you'll end up and a very disregulated head-space.

So being able to tolerate boundaries is crucial for someone with BPD and this takes a very long time to learn, I'm talking years for me, but other people that may be a bit quicker. The other thing I find very important is that in a therapeutic relationship there would be rapture, there would be arguments, there would be power struggles, there would be times when you are so upset with your therapist you'll walk out, but it's in the repair of the relationship, sitting down and saying, what happened, what can we do so this doesn't happen again, what was your experience of it, what was my experience of it.

So it's repairing that rapture. By repairing that rapture you're creating a new learning experience for the person with BPD. They suddenly get that you can have a blow-up but you can still be friends afterwards and you separate the person from the behaviour, so that the person with BPD isn't their diagnosis, they're a person and they display this behaviour in a moment. It doesn't define who they are.

Clinton Power: Sonia, I'm imagining that's so important because many people with BPD probably have experienced ruptured relationships that haven't repaired.

Sonia Neale: Yes, that just exacerbate the BPD condition and behaviours and feelings. One thing I found very, very important was learning to let go. I had to let go of something yesterday and I was able to do it so quickly. I was very proud of myself, I gave myself a pat on the back. What I found not useful is medication.

Medication doesn't give you social skills, it doesn't give you coping strategies and there's no medication that is dedicated to BPD. Sometimes there's medication that you take if you have a coexisting depression or anxiety but medication in itself is not the first treatment of choice. Psychotherapy is in the form of a dialectical behaviour therapy and there are DBT programs all throughout the First Metropolitan area, except there's not enough clinicians and there's way too many people with BPD on waiting list.

So the government really need to step in and give more money to the DBT program to enable more people to come on the program because that has been proven to work for most people with BPD.

Clinton Power: That's very concerning to hear, I wasn't aware that there were even a waiting list of people wanting treatment.

Sonia Neale: It's a 12 month waiting list.

Clinton Power: Do you imagine that ... You said that's happening in Perth but I guess that's happening in other states as well?

Sonia Neale: It is. There's a place called Spectrum, over in Melbourne and that has a lot of DBT style programs there and that has proved very successful and they're hoping to replicate that model throughout all of the state and I would love to see Spectrum over in Perth, I think that would be the way forward. I'm hoping with the Perth mental health commission they have a 10 year plan for the Perth area and I'm hoping that when they sell grey lands and there's money available for community services that we do end up with something like spectrum over here, that would be fabulous to see.

I think that would finally give BPD treatment some sort of credibility that not only are people suffering greatly with it but they don't have to suffer and that the mental health professionals who dismiss the whole BPD population might finally around to thinking that, hey, there is a way to deal with this, an effective way, let's get on-board. That's what I would love to see happen.

Clinton Power: I think there's another great message here for therapist that we need more therapist trained in dialectical behaviour therapy.

Sonia Neale: We do. But there's a lot of therapist who find that they can't take on more than one or two clients with BPD because it is very exhausting to deal with someone not only in the session but outside, phone calls, text

messages and emails. It can be very confronting and exhausting for them. So not all BPD patients are the same by the way, I'm talking about myself and maybe a few others. The therapist have to look after themselves as well.

So I think even if there's just more awareness of the fact that BPD is a treatable and recoverable illness and that mental health professionals try and engage in the process of helping people with BPD, 2% to 6% of the population have BPD and I continually hear stories about people who are just turned away from a hospital because there's a red flag on their medical files and as soon as the clinician sees it it's like, "Okay, you can get out of here, we don't deal with people with BPD."

It's as stigmatizing as that and that links the person to thinking they're worthwhile, they go away, they're self-harm, they become suicidal and it's so unnecessary. There are ways to talk to people with BPD which validates how they feel. Even in emergency departments, especially in emergency departments people need validation because the pain you feel when your body is dis-regulated is like a physical pain. The chemicals that your body produces when you're emotionally out of control affects your body, it can cause autoimmune diseases.

People with fibromyalgia are often diagnosed with BPD. But the condition is a physical one, you are still in pain whether the doctor believes you have a condition or not. A lot of doctors don't believe that fibromyalgia actually exist. But you are still in physical and emotional pain and this is what isn't taken into account. This particular pain that we feel is real and a lot of doctors tend to think it's just in our heads. So trying to get that message across is very, very difficult.

Clinton Power: Sonia, do you have any advice for family and friends of people who may be struggling with borderline?

Sonia Neale: Learn validation skills. Validate, validate, validate. Learn active listening skills and clump your tongue between the teeth no matter what you hear. That would be one of the best things you can do, because once you feel validated then your emotions come down and you can start to have a proper conversation. I guess speak with the person. There is a person underneath the diagnosis and that person is a loving person, very intelligent person. This is a biological illness that causes emotional dis-regulation and once you can accept that there is treatment and recovery from it you can really live a life worth living.

I think a lot of people without BPD don't know what shame feels like. Most people are more familiar with guilt and guilt is more about your behaviour done who you are inside. But when you have BPD there's this shame that you feel simply for being alive or for taking out oxygen to taking up space on the planet and that shame is so pervasive and you hate yourself so much it leads to self-harming and cutting and burden and all sorts of awful feelings because that is what relieves the shame. That is what takes away the physical pain of shame and what it does to you.

It's also important to learn too that sometimes information processing ... The way we take in information is different to how other people take in information. It's difficult to tolerate ambiguity. We need to be told exactly what is going on, especially for mental health professionals, knowing exactly what is happening without any ambiguity at all. Because ambiguity leads us into black and white thinking, everything is all good or all bad, we don't take in those nuances of grace and we need to know exactly what is happening so that there's no misinformation given.

I think for family members and professionals the best thing to do is not get involved in a power struggle when the person is hyperactive or hyper aroused. I think it's a good idea to just concede that maybe you're right, I'm really, really sorry, and then there's time to debrief and resolve it later because in the moment the person who is out of control isn't hearing anything, isn't seeing anything because the blood is pumping in the head and it's pumping at such a vast rate that you cannot hear what is being said. There's no memory laid down in your head of what the other person is saying.

I think that's important for other people to remember that when it's all over and the person prefrontal cortex is back online as best as possible that's the time to sit down and very quietly say, this is what happened and the other person, the family member or professional, try and keep their voice low and calm and try and be in control of your own emotions because that's the best way to get through to somebody who's dis-regulated, is to speak in a quite low voice.

So I think learning how to deescalate a situation, even if you feel that it's not right, that the other person with BPD is in the wrong and they should know better, it doesn't work like that. You can't take in anything if all your processes have been shut down.

Clinton Power:

Some great points there Sonia. What mistakes are you seeing professionals making? You've eluded to a couple there already.

Sonia Neale:

Some of the mistakes professionals make when working with people with BPD is not giving a diagnosis because of the stigma and shame. When you don't have a diagnosis you don't know what is going on, you just know that there are a lot of different things happening but you don't have framework, you don't have a context to be able to find out what you need to do. Even though the DSM isn't perfect by any stretch it gives you a descriptive idea of what it looks like and I fulfilled all 9 criteria of the DSM and I found that extremely helpful.

Another mistake that professionals make is thinking that we're drug seekers or time wasters. I was kicked out of a doctor's surgery when I was given a drug called Zyprexa which is like restless legs times a thousand, and I didn't realize that the drug was causing my anxiety and agitation and I went to a GP's clinic saying, "This isn't me, I'm not like this but I don't know what's happening?" I was eventually kicked out of there as a drug seeker. He literally said, "You have to go now, I can't help you."

I went straight to Joondalup Emergency Hospital and the psychiatric register there gave me a drug to counteract the side effects and I found that that was tolerable after that. So don't make assumptions that we are drug seekers or time wasters and please be aware of the side effects of the drugs that you give us that sometimes you get all the side effects and no benefits of the actual drug.

I think too professionals don't understand that some of us are vastly relieved at the diagnosis and I think sometimes because people with BPD usually have abandonment and rejection issues we can attach to our therapist very, very quickly and sometimes when clients reveal feelings for their therapist, that's it, you're referred on to somebody else immediately, there's no explanation given. Transfer of feelings within the clientele of BPD is usually very high and very intense, very difficult to deal with.

You find yourself attached to people that you normally wouldn't look twice at on the street and it's just to do with the feelings of loss and emptiness and grief and purposelessness inside of you. You're looking for someone to fill it up, this person comes along, they fulfil all your dreams, they listen attentively to you and you fall in love with them, who wouldn't.

But there are some clinicians who refer one immediately and that means that you pay yet another attachment loss in your life, you are bereft and you have to then attach to someone else while dealing with the feelings that you have with this other person who's totally rejected you. So there

needs to be a lot of training around client's feelings for them. I think that is possibly the most crucial thing that a professional would do. Is learning to live with those feelings that the person with BPD has.

I have feelings for my therapist and she knows about it, and we deal with it, we deal with it in the present context and in the historical context as well. That is probably the most important thing I can say. Work out your own feelings, work out your own personal triggers and feelings and why is this person triggering you, why do these feelings that this person has for you why are you reacting to them? I think a lot of, especially, medical doctors have not had therapy themselves and they're unaware of feelings that people with BPD can have. So I think it scares them and I understand how frightening that can be for both parties.

Clinton Power: Fantastic advice and comments there Sonia. I think there needs to be so much more education around this condition and I think you're doing such incredible work. I know that just this year you were awarded the SANE Australia's inaugural Barbara Hocking Fellowship and I believe you've been doing some travel to the USA and UK and Canada to study and research organizations for the betterment of services and programs for consumers related to BPD.

We're almost at the time but just tell us briefly what is that involve in and what's that being like for you?

Sonia Neale: That was a wonderful experience because before I went all I had was my own experience. There were not services or programs in Perth, there were not support groups for consumers or carers, so I really have had my own experience mainly to learn from, so it was fantastic going to places like New York and Victoria Island and sitting in with support groups, people with BPD, about 20 or 30 sitting in a group and everyone is talking about their experiences and how they feel and I'm thinking, "Wow, these people feel exactly the same way I do. They have exactly the same issues."

Although I've read it in books and I've seen it on YouTube and DVD it's not the same as being in a room with people who actually gets you. So that was most important, that was being able to resonate with people and connect with them and having your own experience completely validated and looking at people and thinking, "Yeah, I know exactly what it feels like for you." It's the most incredible, liberating experience to be with other people who are like-minded.

So with that support group in mind there were also groups for families as well, for families to know what's like to cope with someone with BPD and find if there's strategies to work with them. I also went to a place in England called The Haven, which is actually a brick house and it has crises bed the people BPD as an alternative to going to emergency and they also have, as well as crises and respite bed, a 24/7 hotline so that people who are registered service users can phone up and can actually turn up and be looked after in that moment and they also have the taxi service, so they have taxi vouchers so that if you are really upset you can get into a taxi, you can go to The Haven and they would pay at that end.

So you've got all those things in place, which means that instead of going to emergency department and getting the invalidation experience you can go to The Haven and you can have people who know exactly how you feel because it is run part by peer workers, but you get validated immediately and that decreases and deescalate your feelings so that the crises is a lot shorter in duration and you have more insight and awareness as to what's happening around you.

So all those services that I visited or that support group, that's what I want to try and bring back to Western Australia. I would like to see more services, more support groups, more consumer and care groups. I would like to see more awareness and more focus on BPD as a legitimate mental illness rather than something that just gets pushed to the back burner because it's all too difficult.

Clinton Power: If you like to find out more about Sonia or contact her you can go to her website which is sonianeale.com and you can also contact her via email through that website. Sonia, it sounds like you're doing such incredible work in this area and I think ... First of all I just want to wish you all the best for the rest of your psychology and counselling degree. I think our profession is definitely going to be enhanced by having you join us and if this is what you're doing right now I can't ever imagine where you're going to be when you graduate. So thank you for all that you do. I feel like I've learned so much about BPD just from speaking to you today. So wishing you all the best and thank you again for giving up your time to speak on the Australian Counselling Podcast today.

Sonia Neale: Thank you Clinton. It's been a pleasure.

Clinton Power: Bye for now.

Sonia Neale: Bye, bye.