



Our Experience in Getting the BPD Diagnosis for our Son

Words from a Dad

All of us in this room have been on a unique journey and while each one is different, there are some aspects that somehow, someway are similar with each other.

I want to begin with our pre-diagnosis journey of BPD to provide some understanding and background of our experience.

Our son was diagnosed with ADHD in elementary school and with that we thought the struggles he encountered in middle school related to ADHD symptoms.

As he entered his freshman year of high school, he began to experience bouts of depression and anxiety. He was already under the care of a

psychiatrist for the ADHD so we continued on that path for him. He then started to experience suicidal thoughts with actual plans on how to do it which alarmed us deeply. And we went back to the same professional who simply told him and us it was his ADHD medication and they would change the prescription each time. Then came the self-harm cutting incidents which led to him being lectured by this health care professional to focus on his academics, start exercising and stop seeking attention, with additional meds prescribed. Yes, they recommended and we sought out therapists to work with him as well, but they too lectured him on why was he was seeking attention in such a manner. So, hind sight being 20/20, there was no trusting mental healthcare relationship to enable him to truly open up and share what was going on in his dark, lonely, horrible world. And yes, we

followed the counsel of the mental health professionals as we thought they knew what they were doing because they were the experts.

After high school graduation, the summer before college was a challenge and there were some episodes of concern. We found a new therapist who our son appeared to connect with and open up to. However, with so much changing and the darkest thoughts so deep inside him, we now see while he tried to open up, it was too late to truly get him the therapy tools he needed to effectively manage his mental health issues.

He entered his freshman year of college with many roller coaster experiences which we attributed again to the depression, anxiety and ADHD. He kept the relationship with the therapist we had found before he left for Baylor by having conference calls. Unfortunately, our

son was not consistent in keeping the pre-arranged call times.

Let me stop and share that our son is extremely bright, loving and caring. He was a recognized leader on the soccer field, a member of the National Honor Society, and well-liked by faculty and staff. Yet he struggled socially with his peers. So I think you all may recognize the high performing, yet struggling with life young adult. With his past suicidal thoughts and actual plans on how to do it, we lived in fear when we knew he was going thru his bouts of depression.

We got the dreaded call on Wednesday night before last Good Friday that he had attempted to take his life by overdosing after cutting himself 19 times. On Good Friday, we met with the Houston therapist who convinced our son and us that he needed to be hospitalized. We are fortunate to have Menninger in Houston

and they had an opening on the Monday after Easter.

Our son walked into Menninger with a bounce in his step as he wanted to finally understand why he was hearing demons and experiencing the challenging emotional issues that he had been confronting.

I will not go thru the Menninger process except to say we learned about “over-functioning” parents. I heard from him and appropriately so that I did not “validate” him with additional frustrations from him of things I did or did not do when he was growing up. I realized that he was right on several points and while it hurt, he was appropriately venting with emotions as he was working thru his initial confrontation with his mental health assessments and struggling to open up. It actually took a tough discussion

between us that provoked him thoroughly before he really opened up to the Menninger team. And of course, at that time I still did not get what “validate” meant as I thought I always praised him for his successes. As you will hear later, I finally learned what “validation” means when we were in the Family Connections course.

We had our thoughts of what a diagnosis would be as bi-polar runs on both sides of our family.

Finally, we got to the much anticipated Diagnosis Session during week 6 of his stay at Menninger and that is when we heard the term for the first time in our lives “Borderline Personality Disorder”! And also accompanied it was the familiar ADHD, depression and anxiety. BPD? What is that? Well, when you are in a state of unknown and uncertainty and you hear the words “be prepared, there is even a stigma among mental health professionals who do not

want to treat BPD patients” your mind goes 90 miles per hour. What is BPD? What caused it? What did I do to cause it? Why was it missed in the past several years of care? Unfortunately not much other than the diagnosis was provided that day. We were told that we would find a lot of information on the Internet that is factually wrong, contain misperceptions and just incomplete. We were guided that Wikipedia has the best explanation of BPD on the Internet. And we were told that our son should follow up in a 6 -9 month step down transition program. WOW, so more extensive therapy for a condition that has a stigma even among mental health professionals? I must say that our emotions ranged from fear of the unknown, compassion for him for what he was and is living with, unfounded guilt that we caused it somehow, frustration with the prior mental health professionals he had been seeing

in high school, relieved that we at least know what he is facing and a drive to find out how we can best support him to handle it himself for the rest of his life while still being part of his life.

Let me be clear, we are BIG fans of the teams at Menninger and are thankful to them for getting our son and us on the right path to his overall wellness.

My wife and I then went into “Internet investigation mode” that consumed us. Thankfully, we were fortunate to get a referral to Ellen Safier who spent time with us explaining BPD and all the aspects of it that applied to our son and gave us the lead to Carl’s outstanding support group that meets weekly here in Houston for loved ones of BPD patients. And through our Internet searches we found a site that also provided us excellent material to better understand BPD and gave us

the much needed information that there is indeed HOPE – the NEA BPD website!! Through the NEA site, we learned about Family Connections. I now understand what “validate” means!! And it works! Through Family Connections we learned we did not cause his BPD, but we were doing actions that did not help his condition. We learned valuable tools to help us better support him and found great tools to use to support ourselves.

So for the loved ones in the audience, we understand the confusion, alarm, and fear of loving someone suffering from the pains of BPD, the unfounded “stigma” of having someone who is struggling with a mental health issue, AND we know how unfortunate it is to have family and close friends who do not understand and may say things that are not really supportive. Their intent is pure, but they just don’t get it. We highly recommend loved

ones supporting a BPD patient to complete the Family Connections course. The Family Connections course truly delivers on its stated goals of helping loved ones to understand the problems, suffering and behaviors associated with BPD and its related features, to understand more how to manage our own emotional responses to situations to reduce our suffering and to provide a support network of family members with others in similar situations. I can confirm that our 12 weeks with our fellow class members in Family Connections provided us the environment of a caring support group we needed for our journey and our peers have felt the same. The course taught us multiple aspects of BPD, meaningful tools on how to best respond and not react, how to validate their legitimate feelings, to learn how to radically accept a given moment, how to set limits and love and

care for our loved one suffering from BPD and how to love and care for ourselves.

Family Connections provides a valuable and much needed resource. We need more leadership training courses to enable more folks to facilitate more classes as the waiting list in Houston alone is several hundred. I am confident the need is strong and the rewards of the program are great!

We acknowledge that we are blessed in that our son has embraced his diagnosis and his different therapy tools to help him manage his BPD in order to live his life as best he can and perform at a high functioning level. We also know that he still experiences pain, depression and fears. He knows and we know that this is going to be a life-long journey that will have its joys and scares. He is at a wonderful program in Oregon – Dragonfly Transitions. They are skilled at working with teenagers and young

adults with various mental health issues to become self-sufficient, independent and productive young adults able to maintain and manage their lives, including their mental health.

We are confident that there are compassionate, dedicated and determined professionals, some in this room, that are on a quest to continue to find solutions and tools to enable therapists, persons in recovery and loved ones to enjoy a much better life with BPD. Our son has taught us so many things along his journey – how to meditate, how to be non-judgmental, to be open to change and to have courage to be transparent and candid about mental health conditions as much as society does about cancer, allergies or a broken-leg.

For the therapists in the room, I ask three things – first, BPD is not just a female diagnosis, males have it too! One of his therapist that asked me for an update was shocked by the diagnosis as he said BPD only affects females, not males. Secondly, if you have a teenager patient who is suffering from self-harm and has suicidal thoughts with plans, I hope you will consider the possibility of BPD as a diagnosis. Even if a teen does not meet all the criteria, they can still have some of the characteristics which can also be debilitating. When you can approach a younger person in a trusting non-lecturing manner, I believe you can learn more about their other symptoms which may not seem so obvious.

If your practice is based on using a standard intake script, I'd like to strongly encourage you to rethink how you interact with your patients. People with BPD often fall through the cracks

or get misdiagnosed. I want to commend any professional who came today to learn more. Attending today's conference and learning from Charlie Swenson is a good first step, however it's not enough. I hope you will continue learning about Borderline so that you can become more skilled at recognizing it and be in the position to support those in need. Third, have some printed materials on BPD in your office. Even if it's just a printout from Wikipedia and also a sheet of referrals on DBT, CBT, books and Internet sites such as NEA BPD to give to families and patients. Find out more about your local Family Connections programs and perhaps even consider becoming a co-leader. Having access to these resources and materials will help families leaving a diagnosis meeting adjust as quickly as possible and be in the best frame of mind to successfully move forward.

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