

14 Year Old Girl in New Zealand

Diagnosis

My daughter was privately diagnosed with Pathological Demand Avoidance Syndrome in June 2015 at the age of twelve. After years of searching for answers to her unusual difficulties in day to day life, we finally had an explanation that felt correct. Many describe a light bulb experience when discovering PDA and I can confirm that receiving the diagnosis was a huge relief. We could finally understand why we struggled intensely with seemingly simple tasks and we had clarity that our parenting was not to blame for the mood swings and meltdowns that were occurring frequently at home.

Breakdown

Unfortunately, because we had never heard of PDA, we felt very shocked with her diagnosis and subsequently my daughter suffered a mental breakdown with additional severe OCD. This resulted in her being bed bound for seven months whilst we awaited hospital admission. During this time, we quickly realized that there were no professionals who could advise us or treat our daughter. Her greatest barrier for receiving help was her refusal to speak to anyone or engage in any intervention whatsoever. It was left to us to find ways to reach our daughter.

Reducing Demands and Making Changes

During the seven months of illness, we were unable to leave our daughter unattended. I was left with no choice but to learn about PDA fully and trial the strategies in the hope that we could make her well. It was a period of rebirth. We decided to scale back to zero demands or expectations. We adjusted how we communicated, and worked on building a trusting relationship and strong self-esteem, which was nonexistent at the time of her breakdown. We made plans to change my daughter's school so that when she recovered, she would be in the right environment for her. This offered hope for a new life with PDA awareness. Slowly, over a period of two years, we began to change.

We discovered that by treating our daughter as an equal (but with a quiet expectation of certain rules) we could communicate on a respectful platform and she was more willing to engage. We listened to what she wanted and allowed her to control her choices. We changed the way we asked for things and backed down if we felt her anxiety was rising. We learnt everything we could about anxiety and reduced it holistically, with all aspects of life rather than dealing with the direct problem. We discovered that removing all processed foods and focusing on a healthy real food diet has greatly eradicated intense mood swings.

We worked on understanding the triggers that caused unwanted behaviour and anxiety for our daughter. With an in-depth knowledge of PDA and autism, we started to see how certain social situations were being misinterpreted. Awareness allowed us to find the root causes of the difficulties and from there we could adjust how we responded. Simple things like joking could start World War 3 but with our new knowledge of how social difficulties in understanding could cause extreme upset and anxiety, we began to change.

We realized that patience and self-control on our behalf, gave the necessary processing time to get things achieved. We re-evaluated what was important in life and made way to allow our daughter total freedom to be herself.

Our Lives Now

Today our lives are happier, calmer and more loving. With knowledge and support from fellow PDA parents, we are able to live a good life with great expectations for a happy future. My daughter is an artist with many other talents in the arts, so we concentrate on following her gifts and passions rather than watering them down with expectations of a full and traditional education. Individuals with PDA need freedom to be themselves in order to thrive. They leave us no choice but to become better people, in the way that we support their difficulties specific to this form of autism.

Hopes For The Future

An ideal future for us is that PDA becomes as natural an explanation to a set of ways of thinking as Asperger's or ADHD. Doctors, teachers and the wider community should be educated on the differences of these conditions because it's really very simple to help the majority of the difficulties by simply changing the way we, as neurotypical individuals, communicate. Understanding PDA will save thousands of children who are suffering with school expulsions, violent behaviour, inappropriate parenting strategies, which will in turn can lead to depression, crime, addictions and even suicide later in life. I am so grateful to the doctor who recognised PDA in our daughter. Her diagnosis has changed our lives and my hope is that medical systems create faster pathways to awareness so that the amazing gifts these individuals have can be realized.