Feelings after a diagnosis: parent perspective

After a diagnosis it's likely you'll have to navigate an array of different thoughts, emotions, and feelings. We want you to know that this is okay. Allow yourself time to process this within a timeframe that's right for you.

It is important to recognise and understand that everyone is on a different journey and will, therefore, process things differently.

We asked some of our families to tell us how they felt after a diagnosis was given to their loved ones. They shared candidly and honestly with us just a few examples of the vast array of reactions you may or may not experience.

To help you we've included their words as well as our own advice, tips, and suggestions.

Denial: "We never suspected there were any differences, or maybe you're someone who had assumed a different diagnosis would be given, so you may struggle like us to come to terms with the diagnosis you are given."

Suggestion – when processing an official diagnosis of a difference try to remember that different does not equal bad or abnormal. Viewing the diagnosis as a way to understand your loved one will help you accept the news and move forward on a positive footing.

Anger: "You may feel angry and think "why us?" You could even have feelings of anger towards the professional who gave the diagnosis, or even the family member who has been diagnosed."

Suggestion – Any news that isn't expected can come as a shock. Allow yourselves time to get your head around this development but bear in mind that anger is rarely a positive emotion to hold on to. Try and replace thoughts of 'why us' with 'okay, so now we know.' Viewing it as a new tool in your tool belt of support and understanding will help you take positive steps on your journey with the diagnosis.

Overwhelm: "If you are beginning this journey, you may not know anything about it. You could feel lost with no idea where to seek help from."

Suggestion – resist the urge to turn to Google. The internet is both helpful and a hindrance at times. Reading through our trusted guidance and advice in Family Resources is a great place to start.

Depression: "There may be days where everything seems like a struggle, and this is okay. Just start the next day with a clean slate. Believing this isn't the life you dreamed of for your loved to lead, can make you feel this way."

Suggestion – life rarely turns out how we imagined it would. And the same applies to our children. We understand hearing that they could face challenges and even difficulties will be painful for you. And difficult days will leave you drained and exhausted. However, your mental health is important. We know that holding on to 'what ifs' won't help in the long run but focusing on the small wins each day can boost your own serotonin levels.

Guilt: "A lot of parents say they feel guilty about having an autistic family member. Some people ask themselves if they did something to cause it, others over-analyse things that happened during pregnancy."

Suggestion – it's easier said than done but try and switch the focus to 'what can we do now' rather than going over things that can't be changed. Looking for a cause is natural – but as we are learning all the time so are the differences in how human brains work. You may never get an answer to why, but you can choose to use your time to improve the days to come.

Hope: "There will be days where you feel hopeful and positive. For me these are the days where things are working, and everyone seems to be coping well." Suggestion – celebrate these days. The stresses and strains of life, compounded by trying to get your loved one the correct support they need, can feel like an uphill struggle. But there is hope. Your child / loved one has a future full of possibility and progress – celebrate the good days! Isolation: "I sometimes feel isolated like we're the only people going through this situation."

Suggestion – join our North East Autism Society Family Networking group on Facebook. It's closed – so it's not open to everyone. And it's designed with you – and this exact feeling – in mind. You'll soon find that you're part of a large community.

Acceptance: "Once you feel you have a better understanding of autism, you can start to accept it."

Suggestion – there are some things we should never just accept; our children not being supported or being properly educated, for example. But many of our autistic adults tell us that acceptance of the diagnosis is so important because it equates to accepting them. You can't separate autism from the autistic person, so accepting the diagnosis not only helps you, it helps your loved one feel accepted as well.

Relief: "I was definitely relieved to finally have answers to questions that we had been asking about our child for years. It meant we could then begin to access the right support for them."

Suggestion – take a minute to let the sense of relief really settle. For so many of our families the story is the same: they've known their child, young person, adult or loved one is neurodiverse but without a diagnosis couldn't access the right support. Relief is a common feeling and you shouldn't feel guilty or wrong for being 'glad' a diagnosis is given.