

Early Childhood - Caring for Carers

NAVIGATING THE DIAGNOSIS - IT'S OKAY TO FEEL

Research shows that there is a significant emotional impact on parents and carers following their child's diagnosis. You are likely to experience a range of feelings while you process and adjust to the news – this is completely normal.

Parents have reported both positive and negative emotions following their child's diagnosis^{2,3}. It is important to know that everyone's experience will be different - there is no 'right' or 'wrong' way to feel.

Common feelings and responses following a diagnosis¹⁻⁷

Anger: You may feel angry about how the diagnosis is affecting you and your family. You may even feel resentful towards your child, other parents, or other children.

Acceptance: Over time you may come to feel more accepting of your child's diagnosis and their unique strengths and challenges.

Belonging: Meeting others who are going through similar experiences may help you feel less isolated. Some parents and people with disabilities describe this sense of belonging as 'finding their tribe'.

Denial: This is one of the strongest feelings that immediately follows a diagnosis. You might have thoughts such as "the diagnosis is wrong" or "the professionals are wrong about my child".

Fear: Your child's diagnosis may feel daunting and you might feel scared for your child's future.

Frustrated: Parents at times struggle to find and access the right supports for their child. It can be hard and confusing to navigate an unknown system. This can lead to feelings of frustration.

Guilt: Some parents may feel responsible or blame themselves for their child's diagnosis, or for not seeing the signs earlier. It is important to know that there is nothing you could have done differently that would have prevented your child from receiving a disability diagnosis.

Hopeful: You might feel hopeful and optimistic about the supports, services and interventions you are now putting in place for your child following their diagnosis.

Isolated: You may feel lonely during this time, especially if your friends and family do not understand what you are going through or how to support you and your child. You may also have less time to spend with your friends and family if your time is taken up with appointments for your child.

Loss: You may experience feelings of loss; the loss of what you thought your child's future may look like, the loss of control over what is happening in your life and the loss of your previous 'everyday' life.

Love: Feelings of love and pride for your child are common as you support them and watch as they overcome difficulties and challenges and develop new skills and abilities.

Overwhelmed: Parents will often find themselves in unfamiliar territory and may feel overwhelmed as they are learning about the diagnosis, the supports that their child will need, and wonder what the future will hold.

One parent described the overwhelming feeling after their child was diagnosed:

"A hundred rooms with a hundred doors with no key and no signs on any of the doors. You've got to work out how to get out."²

Purposeful: You may feel a sense of purpose once you begin to organise supports for your child.

Relief: You may feel relieved to finally have an explanation as to why your child has been experiencing difficulties.

One parent described the relief they felt after their child was diagnosed:

"When he actually relayed the diagnosis to us it was quite a relief and he did give us a good understanding of how they see my child, which matched what we saw, so it was good in that sense."⁷

Sad: Low mood and feelings of sadness are common. You may still feel sad even if you were expecting the diagnosis.

Shock: You may not have been expecting to receive a diagnosis, and you may experience a sense of shock or disbelief.

Validated: You may have been expressing concerns about your child's development to multiple health professionals and your concerns were not acknowledged. Knowing that your concerns about your child were real and that you were right to voice them may feel validating.

Healthy strategies to cope

- Be kind to yourself and give yourself permission to experience these feelings – try not to dismiss or repress them.
- Talk to a friend or family member about your feelings or, if needed, access professional support. Looking after yourself will put you in the best position to help your child.
- Take care of yourself. While you may want to focus all your energy on your child at this time, it is important that you also engage in self-care. Take time out to see friends and family, have some 'me time' and try to get a good night's sleep.

Self-Evaluation

What feelings are you experiencing at the moment?

Who can you talk with to help process these feelings?

(e.g., a friend, family member, another parent of a child with a disability, a professional?)

What advice would you give a friend who was experiencing similar feelings?

References

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