

Early Childhood - Caring for Carers

MANAGING THE STAGES OF GRIEF

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Receiving the news that your child has been diagnosed with a condition can be a very challenging and emotional time. Research shows that following diagnosis, there is a significant emotional impact on parents and carers^{1,2} as well as the child.

You are likely going to experience a range of feelings and emotions while you process and adjust to the news – this is completely normal and to be expected. Research suggests that parents' emotional experiences following diagnosis can include feelings of shock, denial, fear, guilt, anger and sadness^{2,3}.

What is grieving and how does it relate to my child's diagnosis?³⁻⁶

Stages of Grief	"How do you feel?"
Denial	Shock and denial are the strongest feelings that immediately follow a diagnosis. You may think "this can't be happening" or "they're wrong about my child".
Anger	Once the news sets in, you might be thinking "why me?" You may feel resentful towards the professional, your child, other parents, and typically-developing children.
Bargaining	You may find yourself focusing on what you could have done differently to prevent the diagnosis.
Depression	Feelings of sadness and low mood are also common. You may feel hopeless or that things will not get better.
Acceptance	Over time you will come to feel more accepting of your child's diagnosis. You might never feel completely 'comfortable' with the diagnosis, but you learn to get used to this 'different way of life' and keep moving forward. This will help you to have a healthy relationship with your child and your family.

Important things to know

- Everyone experiences the grieving process differently. The order you go through these stages and the time spent at each stage will vary from person to person
- You may not go through each stage, you may even skip stages or go back to stages
- The acceptance process requires time⁵
- Everyone's experience is unique, and there is no right or wrong way to feel following your child's diagnosis
- Your child is the same person, now living with a diagnosis that explains some of their differences.

One parent described their challenge accepting the diagnosis:

*"I just found it very difficult to accept the diagnosis, I didn't want to accept it initially. I couldn't cope well with the decision, I was very emotional about it."*²

Healthy strategies to cope

- Acknowledge your feelings when they appear and allow them to come and go – try not to dismiss or repress them
- Take care of yourself. You might want to focus all your energy on your child at this time. However, it's important that you also engage in self-care. Take time out when needed, see friends and family, or have some "me" time, and try to get a good night's sleep
- Access professional support for yourself if needed. When you look after yourself you will be in the best position to help your child
- Stay connected with friends and family
- Ask for help! It's not shameful to ask for help when you need it.

One parent describes their emotional experience:

*"It completely transforms you, it's like all the supports beneath your feet have collapsed and you have to construct them again. With all this comes grief...it's that breakdown, you know? You go through a terrible emotional stage..."*⁵

Self-Evaluation

What feelings are you experiencing at the moment?

What are some things that might help you feel better while you process these feelings?

Who can you talk with to help you process these feelings?

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

For immediate support

Beyond Blue 1300 22 46 36

Lifeline 13 11 14

Longer term supports for carers can be accessed via the [Carer Gateway](#).

References

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4. O'Reilly B, Wicks K. *Australian autism handbook: The essential resource guide to autism spectrum disorder*. 2nd edition. New South Wales: Jane Curry Publishing; 2013. Retrieved from <http://ebookcentral.proquest.com>
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6. Watchel K, Carter AS. Reaction to diagnosis and parenting styles among mothers of young children with ASDs. *Autism*. 2008; 12(5): 575-594.

