

## Early Childhood - Caring for Carers

# NAVIGATING THE DIAGNOSIS - SHARING THE DIAGNOSIS

### Telling others about your child's diagnosis

When your child has been newly diagnosed with a condition, it can be challenging to tell your family and friends about it. You may experience reluctance or difficulty openly talking about the diagnosis with others<sup>1</sup>. You may want to tell people as soon as you find out, or you might want to wait until you've had time to come to terms with the news. You may choose to only tell your closest family and friends rather than everyone you know.

Remember it's your choice who you share the diagnosis with and when. You may want to consider what role that person plays in your child's life and if knowing about any diagnosis will be helpful for you and your child<sup>2</sup>.

### Managing others' misunderstanding

You may be faced with negative reactions or misunderstanding about your child's diagnosis<sup>3</sup>. It can be hard to experience your own emotions while also managing the reactions of others. It's important to remember that your friends and family are likely experiencing feelings of grief, anger and sadness as well.

### One parent described their difficulties sharing the diagnosis:

*"I need you to support me in supporting him to get through this. So, knowing how to speak to the people who care about you and who care about your child...to know what to say to people so you can deal with their denial. Because you've worked through yours, you've got the diagnosis, and then you've got to go around and CONVINCED people who don't want to know because they want everything to be okay." <sup>1</sup>*

### One parent described her mother's denial following the diagnosis:

*"My mum didn't believe it. Everyone would say he's alright, he's just a bit funny or he's just a bit slow." <sup>1</sup>*

### Tips for sharing your child's diagnosis

#### Focus on your child's behaviours

When talking about the diagnosis with others, focus on your child's behaviours and how they relate to their diagnosis. Doing this can shift the attention from the 'label' of the diagnosis back to your child and what they are finding difficult. For example, *"Have you noticed how it's hard for her to tell us what she wants using words?"*

Remember your child's diagnosis is not an excuse for bad behaviour, but an explanation – it can help people to understand your child's current challenges and any supports they may need to help them learn or communicate with others<sup>2</sup>.

## Talk about your child's strengths

Don't just talk about your child's challenges – remember to talk about their strengths and what they like and enjoy! Your child is more than their diagnosis and talking about their strengths and interests will also help others understand them, and think about them in a positive way.

## Openly discuss and invite questions

Disclosing and discussing your child's diagnosis with others will help start a conversation about what you and your family are going through and the support you need. Be open with others about how you are feeling – let them talk about their feelings and ask questions if they need to. You might not have all the answers, but it is a good place to start to help them understand what is happening with your child and your family.

## Self-Evaluation

### Consider what you might say to others about your child's diagnosis.

*It might help to write it down and take it with you when you tell people. Think about what might be helpful for others to know about your child.*

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### Consider how your friends and family might react and how you could deal with these reactions.

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### List some of your child's differences related to their diagnosis.

*You might choose to focus on these when talking to others about your child's diagnosis.*

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## References

1. Rabba AS, Dissanayake, CA, Barbaro, J. Parents' experiences of an early autism diagnosis: Insights into their needs. Res Autism Spectr Disord. 2019; 66: 101415.
2. Rabba AS, Dissanayake, CA, Barbaro, J. The development of a family support package for parents following a child's diagnosis of ASD: What do parents want? PhD [dissertation]. Melbourne: La Trobe University; 2019
3. Dyson L. Unanticipated Effects of Children with Learning Disabilities on their Families. Learn Disabil Q. 2010; 33: 43-55.