

Knowledge about the diagnosis

Now that your child has received a diagnosis, you'll probably have many questions about what it means and what to do.

Research suggests that seeking information can be a positive strategy and coping mechanism for parents^{1,2}. Gathering information can help you:

- Understand your child's diagnosis and how to manage it
- Find out more about your child's behaviours so you understand what they're thinking and feeling
- Explain your child's diagnosis, needs and behaviours to others

One parent describes researching their child's diagnosis:

"I automatically went to a reputable website and they've got videos, so I found that really useful. I didn't get too carried away with my research, but we did some research."¹

Things you may want to learn more about:

- What does the diagnosis mean for my child?
- What are the early intervention options?
- What supports and resources are available?

You can gather information on your child's specific disability or diagnosis by:

- Reading books and articles
- Gathering information from reputable websites
- Attending workshops or conferences in your area
- Speaking with health professionals and researchers

You can find some helpful resources to start your research at the end of this factsheet.

Important things to remember

Information isn't always reliable

While there is a lot of information available, not all of it is reliable and evidence-based. There are many controversial therapies that may claim to cure your child. Ensure you are looking at parent resources from organisations with a good reputation and that the interventions you are considering are supported by evidence³. You should discuss the information you find with the health professionals involved in your child's care.

Find a balance

Although doing research about your child's diagnosis can serve as a positive coping strategy, it's important to find a balance between gathering information and taking time for yourself^{3,4}. If you don't step back from your research from time to time, you may find yourself becoming overwhelmed with the amount of information out there.

Self-Evaluation

What would you like to know more about regarding your child's diagnosis and relevant therapies?

Resources

This website provides some general information about what early intervention is, what interventions are available for children with disability, and some ideas on what to look for and think about:

<https://raisingchildren.net.au/disability/services-support/services/early-intervention#therapies-and-services-nav-title>

These resources will help you get started on learning more about your child's diagnosis and the various therapies available:

Autism Spectrum Disorder (ASD)

Raising Children's Network: <https://raisingchildren.net.au/guides/a-z-health-reference/asd-overview>

AMAZE (Victoria): <http://www.amaze.org.au/>

Autism Spectrum Australia (NSW): <https://www.autismspectrum.org.au/>

Autism Queensland: <https://autismqld.com.au/>

Autism SA: <https://www.autismsa.org.au/>

Autism Tasmania: <https://www.autismtas.org.au/>

Autism Association of Western Australia: <https://www.autism.org.au/>

Autism NT: <http://autismnt.org.au/>

Autism Awareness Australia: <https://www.autismawareness.com.au/>

Therapy Connect: <http://www.therapyconnect.amaze.org.au/>

NED video (explaining autism for Indigenous families): <https://www.youtube.com/watch?v=bQcWvYi5EqY>

Early Days Workshops: <http://www.amaze.org.au/events-home/early-days/>

PlayConnect: <https://playgroupaustralia.org.au/national-programs/playconnect/>

Books

More Than Words – Fern Sussman

Talk Ability – Fern Sussman

An Early Start for Your Child with Autism: Sally Rogers, Geraldine Dawson, Laurie Vismara

Talking With Your Child About Their Autism Diagnosis: Raelene Dundon

Intellectual Disability

Raising Children's Network: <https://raisingchildren.net.au/guides/a-z-health-reference/intellectual-disability>

Inclusion Australia: <https://www.inclusionaustralia.org.au/>

Victorian Advocacy League for Individuals with Disability: <https://www.valid.org.au/>

Attention Deficit Hyperactivity Disorder (ADHD)

Raising Children's Network: <https://raisingchildren.net.au/teens/behaviour/adhd/adhd>

ADHD Australia: <https://www.adhdaustralia.org.au/>

ADHD Support Australia: <https://www.adhdsupportaustralia.com.au/>

Specific Learning Disabilities (Dyslexia, Dyspraxia, Dyscalculia, Dysgraphia)

Raising Children's Network: <https://raisingchildren.net.au/guides/a-z-health-reference/learning-disabilities-signs-and-support>

Learning Difficulties Australia: <https://www.ldaustralia.org/>

Australian Dyslexia Association: <https://dyslexiaassociation.org.au/>

AUSPELD: <http://auspeld.org.au/>

Understood: <https://www.understood.org/en>

References

1. Rabba AS. Parents' experiences of an early autism diagnosis: Insights into their needs. Res Autism Spectr Disord. 2019; forthcoming
2. Mackintosh VH, Myers BJ, Goin-Kochel, RP. Sources of Information and Support Used by Parents of Children with Autism Spectrum Disorders. Journal on developmental disabilities, 2005; 12, 41–51.
3. 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>
4. Rabba AS. 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