Autism spectrum disorder - tips for parents

Summary

- Parenting is a difficult job, but a child on the autism spectrum may pose some extra challenges for parents, siblings and the extended family.
- See your local GP, paediatrician, therapists, local ASD associations or other parents at your support group for more information and advice.

Parenting is a difficult job, but parenting a child on the autism spectrum may pose some extra challenges.

See your GP, paediatrician, therapists and local ASD associations for information and advice.

Remember that other parents of children with ASD can be a goldmine of tips and suggestions, so a good idea is to join a local support group where you can share experiences in a supportive environment.

After a diagnosis of ASD

A diagnosis can bring about many different feelings for parents and carers. Some may feel an initial period of panic or distress, and this is completely normal. Others experience a feeling of relief as they are able to put a name to their child’s issues.

Many parents and carers experience feelings of grief and loss for the future that they had anticipated, which now may not eventuate. Some may feel a mixture of all these. All reactions are valid and normal.

During this time, you may like to consider:

- Counselling may help you to manage your own feelings about your child’s diagnosis.
- There are many different approaches to support the development of your child on the autism spectrum. You may like to research them yourself to find the best approach for your child and family. Good starting points include your doctor or paediatrician.
- Other parents who have children on the autism spectrum can be excellent sources of information. Contact an ASD support group for further information, support and guidance. Amaze (formerly Autism Victoria) has a list of support groups in Victoria on their website.
- When searching the internet for information on ASD therapies, be aware that not all information on the internet is reliable. Check with your doctor or ASD professionals, and be wary of any website that claims a ‘cure’ for ASD. It is a lifelong condition and while there are many therapies and strategies to help support your child’s development, there is no cure.
- The Raising Children Network’s Parent guide to therapies will help you find reliable information about a wide range of therapies and interventions for children on the autism spectrum. Each parent guide sets out what the research says about the therapy, and the approximate time and costs involved.
- TherapyConnect is a resource created by Amaze to help families of young children on the autism spectrum understand the therapy and what to expect.

ASD - choosing a therapy for your child

Suggestions include:

- Seek advice from your child’s paediatrician and other professionals involved in your child’s diagnosis. Your child’s diagnostic report will have recommendations. It may be worth collecting information on an intervention program you’re considering and discussing it with the medical or allied health team (or both) who know your
Only choose therapy programs that are evidence based. This means they have been evaluated by scientists to see if they work reliably.

Make sure the people offering the program are properly qualified. Ask questions about staff qualifications, their participation in ongoing professional development and their experience in working with children on the autism spectrum.

Find out about the time, effort and cost involved – for example, you may not have the time or resources to devote to an intensive program because of other children or work commitments.

Some programs are for children with particular abilities or who are a particular age, so check that it is appropriate for your child.

Be wary of programs that claim to work for all children on the autism spectrum – their approach may be too broad to be useful.

As a parent, you will know that there are things that your child has difficulty with. When researching therapists and programs, consider these needs. Therapy and programs should be family centred – which means listening to parents and what they would like to work on. Remember – you are the expert on your own child.

Coping with stress – tips for parents of children on the autism spectrum

Parenting a child on the autism spectrum can be stressful. Tips for coping with the stress include:

- Consider using respite care in order to spend time by yourself, with other children or your partner.
- Take your time making decisions about therapy for your child, and what is best for the family.
- Consider joining a parent support group (pdf) to meet people on similar journey. This can help with making friends with similar needs.
- Find time to look after yourself – whether this is a taking a walk or practising mindfulness.
- Tap into carer supports through Carers Victoria. There are a range of support groups and workshops that can help you.
- Ask friends and family for support.

Brothers and sisters of children on the autism spectrum can also benefit from support. Visit the Association for Children with a Disability for sibling support resources.

Behaviour and children on the autism spectrum

Some children on the autism spectrum may engage in behaviours of concern. Behaviours of concern are behaviours that put the child, other people or property at risk. They are due to difficulties with receptive and expressive communication. There are strategies available to help you to understand your child’s behaviour.

The best approach to behaviours of concern is to try to:

- understand why your child engages in the behaviour – talk with your child’s healthcare team about developing strategies for working out what triggers your child’s behaviour. This will be different for each child, and there may be more than one reason
- write down when the behaviour happens and what happened immediately before the behaviour. By writing down behaviours after they occur, patterns can be found, which can assist with finding our why behaviour occurs. This information is useful when speaking with allied health therapists as you will have a clear record of the behaviour
- create a positive behaviour support strategy – your child’s health care team (such as their psychologist or behaviour specialist) will help you to develop a support plan that you can use to teach and encourage appropriate behaviour. This will include teaching your child new skills and adjusting their environment to promote positive behaviour changes.

This is a complex task, so make sure you get help and support. Talk to your child’s healthcare professional, such as their psychologist, behaviour therapist, occupational therapist or speech pathologist, or contact Amaze on (03) 9657 1600 for advice.

Information about wandering can be found on the Amaze website.
Where to get help

- Your GP
- Your child’s paediatrician
- Your child’s psychologist
- Your child’s speech pathologist
- Amaze (previously Autism Victoria) Tel. (03) 9657 1600
- Aspergers Victoria
- Carers Victoria. Tel. 1800 242 636
- Commonwealth Respite and Carelink Centres. Tel.1800 052 222
- Early Days Workshops (pre-school) – attend a free workshop
- Positive Partnerships (school aged)

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