

Information Sheet

Introduction to Autism Spectrum Disorders: For Grandparents

Prepared by Amaze (Autism Victoria), January 2013

“I am blessed with two grandchildren who love me and whom I love dearly. One with a head full of curls and who likes to play with dolls and puppies. Another who’d rather climb trees and has autism. It does not make my job harder, just more important!” (Elizabeth, *Voices from the Spectrum*)

Grandparents worry both about their grandchild with Autism Spectrum Disorders (ASD) and about their own child’s struggles as a parent.

How can grandparents best support their child?

How can they bring out the best in their grandchild?

Grandparents

Grandparents play an important role in the family unit. A grandparent’s role may include:

- Supporting the parents (your children)
- Providing child care/babysitting
- Teaching
- Researching information
- Historian (recalling family stories)
- Some grandparents also fill the role of a parent for their grandchildren

Every family has its own dynamics; some are close, while other families may be separated by geography and/or family breakdown. Regardless of your situation there are a number of things you can do to help both your child and your grandchild.

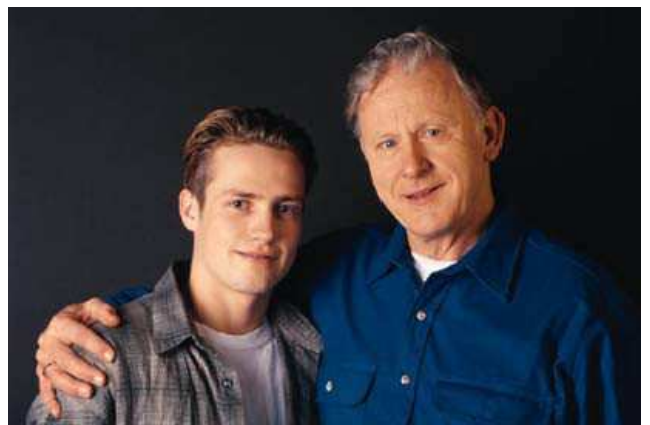
This sheet provides information and strategies to help you, your grandchild and your son or daughter in the role of parent.

Autism Spectrum Disorders

Grandparents have a unique and important role in the family unit. It is therefore essential that they have a good understanding of ASD. Some key points are summarised on the next page. For a deeper understanding, this information sheet can be read in conjunction with the Amaze Information Pack. The pack is an excellent source of information for families and is available at <http://www.amaze.org.au/resources> Alternatively you can request an *Information Pack* from the Info Line on 1300 308 699 (within Australia).

Key Points for Grandparents

ASD is a group of pervasive developmental disorders with core impairments in the following areas; social relationships, communication, imagination, restricted repertoire of activity/interests.



People with ASD are often unsure how to approach others or develop appropriate friendships, despite a strong desire to interact with people. They may find it very difficult to intuitively learn social skills and need explicit instruction

While we don't know exactly what causes ASD, we know that it is NOT caused by particular parenting styles (e.g. 'cold parenting'), by the actions of parents or something the mother did while pregnant

- ASDs affect 1 in 100-110 individuals in Australia. ASD is a lifelong condition, individuals do not "grow out of it" and there is no cure.
- Early intervention significantly benefits children on the spectrum
- Each individual is unique. People with ASD will have very different experiences. Some will live independent lives with while others require considerable care.

Your Grandchild...

- Is unique. Learn about him/her, not just about ASD
- Has his/her individual strengths and may do some things very well.
- Needs your love and respect
- May have a limited vocabulary, or perhaps has an impressive vocabulary but may not use the words appropriately.
- May use *your* hands to show you what they need.
- May engage in repetitive activities/behaviours.
- May prefer particular foods.
- May have rituals or repetitive behaviours.
- May not respond to your tried-and-true parenting techniques. What may appear like 'bad' behaviour may actually be a reaction to feeling overwhelmed and stressed, or perhaps extremely frustrated

"My grandson Daniel is a blessing. Daniel is bright, loveable, and irresistible. He charms everyone with his smile and big brown eyes. Daniel has autism.

"My wish is that grandparents of all children with autism will discover the joy and beauty in their own Daniels!" (Frances, Voices from the Spectrum)

Diagnosis

Authors talking about an ASD diagnosis frequently discuss the various ways different parents may react - shock, guilt, loss and grief, or perhaps the diagnosis may bring relief. Parents may need time to understand and accept the diagnosis emotionally, while others are keen to read every resource available.

Grandparents too respond to a diagnosis in their own ways. In fact there may be a sense of 'double grief'. Not only are they coming to terms with what the diagnosis means for their grandchild, but also what it means for their own son or daughter.

Your grandchild's parents may have reactions that differ from your own – or you may respond in similar ways, depending on your personalities. It is important to respect both your reaction and theirs. Give yourself and others time to work through this.

"As a grandparent I felt pain for my child as well as for my grandchild".

I watch with admiration the life my son and daughter-in-law build around Daniel for Daniel". (Frances, Voices from the Spectrum)

Denial can be a natural part of the grief process. If you have a difficult time dealing with the diagnosis, you may like to:

- Speak with your GP or doctor
- Speak with trusted friends/family

Supporting Your Grandchild's Parent(s)

The nature and amount of help that parents need - and accept - from grandparents varies considerably depending on the grandchild's age and individual needs, family dynamics and other commitments.

Some grandparents want to help more but are afraid their grandchild's parent(s) may see this as 'interfering', or perhaps the grandparent is limited by geography or their own health considerations.

The best rule of thumb is to ask the parent(s) what would be helpful. Openly discuss their ideas and expectations, and talk about any limitations you have on the support you can provide.

There are things you can do to support your child in their role as a parent. Firstly, try to gain more knowledge about ASD and strategies, such as those in this information sheet or visit www.amaze.org.au

Be understanding if your grandchild has a meltdown or shows 'bad' behaviour – understand that it is a sign of your grandchild feeling overwhelmed at that moment and this is their way of communicating their stress/difficulty. Let the parents handle the situation. They may not use the discipline strategies you might expect and this is okay. The parents will appreciate your support. Try to avoid criticism.

Get your son or daughters advice about handling 'meltdowns' and handling behaviour. Consistency is important for the child

Offer to care for your grandchild in their home or yours. This may be for a couple of nights every few months, or regular nights each week, depending on what you can realistically manage given your circumstances. This gives your grandchild's parent (s) time to spend with other children, sleep or have some much needed 'down time'

Siblings who do not have ASD often feel neglected or that their sibling with ASD gets more attention. Spending time with the grandchild's brothers and sisters will help them feel important too.

Take your grandchild to school or pick them up

Practical assistance such as mowing lawns, gardening or grocery shopping (within your limits and abilities) might help.



Bring out the Best in your Grandchild

Below are some practical ideas to support your grandchild and help bring out their best. Everyone with ASD is different. Some strategies will work for your grandchild, some will not. One strategy may work some days, but not others.

It is helpful to have several strategies to adapt to the situation and the day.

Your grandchild's parents will also use a wealth of strategies.

General Suggestions

- Learn about ASD.
- Include your grandchild – your grandchild may have difficulty communicating effectively but still needs to be included.
- Encourage independence – avoid learned helplessness. The more independent your grandchild can be (within reasonable expectations of age and ability), the more your grandchild will thrive as they become older.
- Be positive – children tend to do best in a positive environment with support.
- Do not focus on ASD, focus on him/her as a child.
- Let your grandchild teach you
- Let your grandchild know when they do something well. Share successes.
- Prepare your grandchild for any change in advance.
- Keep your sense of humour

Communication Strategies

People with ASD often need longer to process information. After you speak, allow 10 full seconds for your grandchild to process the information and respond

Visual Cues: it is important to support communication with visual cues – e.g. when asking the child to put on shoes, hold up the shoes as a visual cue. Again, give the child extra time to process what you are communicating.

Make instructions brief and concrete: "I'd like you to put your book down now so I can tell you about what's happening after lunch" is a complex sentence and hard to understand. "Book down, listen" is more effective. If your grandchild uses

pictures or symbols to communicate, keep a set in your home/car.

Sign language: If your grandchild uses sign language learn their most frequently used signs (or all of the signs, if the child spends a lot of time with you)

Offering Choices: When offering choices, limit the number of options to two. This will help avoid confusion and feeling overwhelmed by the decision. For example, if you are in an ice-cream shop with 48 flavours “which flavour ice cream do you want?” will be too much for your grandchild.

Instead try “banana or chocolate ice cream?” You could further support this by pointing at the flavours as you name them

Be specific with your praise. For example, “Well done. You packed up your game straight away.” Is better than “You were good.”

Children with ASD take things very literally and misunderstandings often result. Many grandparents (and parents) become frustrated over misunderstandings such as:

Grandparent: Can you put the dishes away?

Grandchild interprets as: “Are you capable of putting the dishes away?” and answer “Yes”. Grandparents think the child will put the dishes away and the child thinks they have answered the question.

To avoid confusion, family members may find it easier to rephrase questions as direct instructions like “Put the dishes away please”.

Judith, Melbourne Victoria

Connecting with your Grandchild

- Show love and affection as you do with any/all other grandchildren
- Focus on your grandchild, not the autism
- Just like any child, your grandchild needs to have fun! Find out what your grandchild likes – e.g. puzzles, cars, Barbie movies – and use these activities to spend quality leisure time together.
- If your grandchild wants to play alongside you (rather than engaging directly with you), that’s okay
- Your grandchild may struggle with body language, facial expressions, tones of voice, jokes, satire and emotional situations – you may need to explain these in detail
- Don’t insist on eye contact. Direct eye contact

may be uncomfortable.

- Your grandchild may need your assistance socialising with cousins, neighbours and other children.

Behaviour

Maintain a normal speaking voice when your grandchild is yelling – your shouting will escalate the situation (even though they are shouting!) especially if the child is sensitive to loud noises

Most children (and adults) with ASD develop their own coping strategies such as hand flapping, finger licking or rocking. Watch for your grandchild’s coping strategies and do not try to stifle these - they help your grandchild cope with stressful situations.

In Your Home

Create a quiet, safe retreat where your grandchild can go when overwhelmed. If your grandchild is with you after school, ensure they have a retreat to unwind in. Let them watch TV, spend time in their room or quiet place, or do anything they find calming/relaxing.

You could create a visual calendar of planned events you will do with them and put it on the fridge. Mark off events as you do them. This helps create a sense of security around what is going to happen. Ensure they have a favourite toy or “security item” if they have one (especially younger children). This might be a cuddly toy or blanket.

Fluorescent lighting can be problematical for some children with autism. If you have fluorescent lights and aren’t sure whether it is affecting your grandchild, simply turn of the lights and see whether your grandchild’s behaviour changes - or ask your grandchild about the lights (if they are verbal). If fluorescent light bothers your grandchild, replace with incandescent lights or experiment with other lighting.



Sleep can be an issue for many people with ASD. Avoid giving your grandchild anything sugary or caffeinated before bed.

Before you have a sleepover with your grandchild, speak with your grandchild's parents about how they manage sleep and sleep routines.

Maintaining routines will help the child relax to sleep.

Family Events

- Plan a break in the event for your grandchild.
- Explain any change of routine/event.
- Give your grandchild a special job to do.
- Label your grandchild's pencils, toy box or other items that stay at your house
- Ensure there is food present that your grandchild will eat.

Grandparents Resources & Support Groups

- **Autism Tasmania (03) 6231 2745**
- **Autism Tasmania**
 - Fact Sheets
 - Website (www.autismtas.org.au)
 - Directory of Services, over 3000 services (Phone 1300 308 699)
- **www.familyrelationships.gov.au**
- **Carers Tas** 1800 242 636
- **Council on AgeingTas** 1300 135 513
- **Gateway** supporting Grandparents carer program 1800 171 233,

www.dhhs.tas.gov.au/disability/gateway_services

- **Uniting Care Tas.** Family Support and Parenting Programs (03) 6333 8000
- www.facebook.com/pages/Autism-Grandparents-Support-Group/103835282991525

References

- Behaviour Management Strategies for Individuals with Autism Spectrum Disorders* Information Sheet, Autism Victoria Trading as Amaze,
- Modify Your Message: Communicating Effectively with Individuals with Autism Spectrum Disorders* Amaze Information Sheet
- The Autism Checklist: A practical reference for parents and teachers* (2009) Paula Kluth PhD
- Voices From the Spectrum: Parents, Grandparents, Siblings, People with Autism and Professionals Share Their Wisdom* (2006), Edited by Cindy N Ariel & Roberts A Naseef.



©2014 Amaze (formerly Autism Victoria). This document has been published with the permission of Amaze. Permission is granted for the content of this information sheet to be reproduced in its entirety, provided Amaze (Autism Victoria) is acknowledged as the source and the website address is given:

www.amaze.org.au