INFORMATION FOR SIBLINGS

A guide for siblings who have a family member with an autism spectrum disorder (ASD)

Compiled by the Autism Information Line
Autism Spectrum Australia

Autism Spectrum Australia (Aspect)
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Who is Autism Spectrum Australia?
Autism Spectrum Australia (Aspect) is the largest service provider for individuals with autism spectrum disorder\(^1\) (ASD) and their families in Australia.

What is the Autism Information Line?
Autism Spectrum Australia (Aspect) recognises that there are many questions for individuals who have an autism spectrum disorder (ASD), as well as for their families, carers, support staff and professionals. It is with the support of fundraising that Aspect operates the Autism Information Line (AIL).

The role of the AIL is to:
- Assist in answering specific enquiries
- Provide a referral point for services within Aspect and the wider community
- Offer brief practical advice to assist families and carers with their day to day management of children with ASD

The information line is staffed by Aspect professionals from a range of disciplines, who access a wide range of information regarding services and resources. Interpreters can be arranged for callers (please advise language required on initial call).

Please call the Autism Information Line

02 8977 8377
1800 069 978

Email: infoline@autismspectrum.org.au

\(^1\) ASD includes autistic disorder, pervasive developmental disability – not otherwise specified (PDD-NOS) and Asperger’s disorder.
Introduction

This pack has been compiled by the Autism Information Line at Autism Spectrum Australia to assist siblings and other family members that have a family member/s with an Autism spectrum disorder (ASD).

Contents

- Issues related to siblings of children with exceptional needs
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Every care is taken to ensure that the information included in this Navigation Pack is correct but inaccuracies may nevertheless occur. If you discover any information which you believe to be inaccurate please contact Infoline@autismspectrum.org.au.

Services are included in the Navigation Pack to assist you. Their inclusion in the pack does not necessarily imply that ASPECT endorses or supports them, nor does the absence of a service imply that ASPECT does not support them. Aspect cannot be held responsible for any damage or loss caused by any inaccuracy in the Navigation Pack.
BUILDING BLOCKS® Early Intervention Service
Parent Information Sheet

**Issues related to siblings of children with exceptional needs**

In any family, it is difficult to accommodate everyone’s needs. When there is a child with a disability such as autism in a family, it can become even more challenging. It becomes difficult to manage the priorities of other children in the family when, by necessity, many decisions revolve around the child with a disability. However, as parents, it is essential to be aware of issues related to siblings of children with disabilities, as well as some practical suggestions for addressing these issues.

**Understanding possible feelings of your children**

It is important to remember that all sibling relationships are individual. A disability is only one of the factors that effect relationships between siblings. Brothers and sisters may experience a number of different reactions to their sibling’s exceptionality. Some children may not exhibit any reaction or outward feelings about their brother or sister’s differences, while others may go through phases of feeling guilty, anxious, confused, envious, angry, embarrassed, or isolated. These emotions are a normal part of childhood and a normal part of the adaptation process. Most emotions fluctuate, and children usually work things out for themselves. There are also many positive effects on siblings and families of children with disabilities. Siblings of children with exceptional needs tend to have increased empathy and compassion. Due to additional responsibilities, they can also be more adaptable, have good problem solving skills, and have a broader knowledge of some issues than their similar aged peers.

**What can parents do to assist?**

- Ensure some individual time with each child when possible.
- Talk openly with your child about what it feels like to have a brother or sister with a disability. Listen to what they say and understand that their feelings are normal.
- Try not to become too concerned or overreact to any feelings your child may have about their sibling with autism. Your own fears can exaggerate what may merely be a simple childhood emotion.
- Explain your child’s exceptional needs to your children as clearly as possible; this may require a number of discussions. Be guided by your children’s responses as to how much to explain, what is relevant and of interest to each child.
- Include siblings, when possible, when making family decisions by asking for and respecting their opinions.
• Remind yourself that your children are still children and should not take on responsibilities that they cannot handle.
• Remember that not every problem your children or family face is due to the demands of your child with autism.
• Let them be kids, which may include fighting at times, as well as enjoying growing up.
• Encourage your children to have their own friends, interests and ambitions.
• If you have particular persisting concerns or problems, you may want to talk to other parents in similar situations or seek professional advice.

Research suggests that providing children with access to age-appropriate information and open communication about their sibling’s disability can assist them to adjust, understand and relate to their brother or sister. Ask your children what they want to know; it may not be necessary to provide very much information. Communicating with your child about your child’s disability may be as simple as explaining that “James understands best if we show him what to do” or “Jane needs some extra help to tell us what she wants.” There are also a number of books designed specifically for children about autism and other disabilities that may be helpful.

Further reading

Positive Partnerships: supporting school aged students on the Autism Spectrum offers a number of online learning modules on subjects such as bullying, making friends and siblings. The siblings module will help you to identify the experiences and feelings of siblings of children with ASDs. It provides ways to support siblings including how to encourage them to communicate their feelings and cope with stress, and also ideas for enhancing their understanding of autism. For more information visit their website at www.autismtraining.com.au
Sibling Information

Aspect Siblings Camp

A three day camp for young carers aged 8-16 who have a sibling with Autism Spectrum Disorder. The aim of the camp is for young people to have some respite, enjoy lots of fun activities and meet new friends in similar home situations. There is a fee for the camp. For more information contact Anita Freeman (Camp Coordinator) on 8878 1807 or email anitafreeman@autismspectrum.org.au

Sydney and NSW Wide

Around NSW there are many Commonwealth Carer Respite Centres that each run a Young Carers Project. They provide support for Young Carers who are having trouble juggling schoolwork and family responsibilities and are falling behind. They can provide:
- School tutoring
- Opportunities to have a break (respite)
- Day events, camps and workshops.

To find out more call 1800 052 222 and ask for the Young Carer Co-ordinator.

Sydney and NSW Wide

The NSW Young Carer Program has lots of fun and supportive activities for young carers (25 and under). Some of these include:
- Camps
- Talk-link (group telephone counselling)
- Face-to-face counselling
- Information about Young Carer activities across NSW
- Interactive young carer website

For more information contact the Commonwealth Carer Resource Centre on 1800 242 636 or the Young Carer Program on 02 9280 4744 yc@carersnsw.asn.au

Statewide support for siblings through LIVEWIRE.
“A place where young people who have a brother or sister living with a serious illness or disability can support and connect with each other”. Website forum on wwwsiblings.livewire.org.au

New chat room and forum where siblings can chat. It is available both as a Yahoo group and as a Facebook group. Membership requires approval in order to protect members. This originated in the US. wwwsiblingsupport.org/connect/sibteen-facebook-group-and-yahoogroup

State Wide

CALD Siblings Support Network Multicultural Disability Advocacy Association of NSW offers siblings from a NESB support and workshops. For details call Sharon Smith, Project Co-ordinator 9891 6400 or 1800 629 072 sharon.smith@mdaa.org.au
www.mdaa.org.au
**NSW Sports and Recreation** Young people can apply to attend courses and camps throughout NSW in school holiday time. Ages 7-17
Some “Young Carer” programs may assist family with the cost of programs
Contact Client Services Centre on 131 302

**Sharecare** Support Groups throughout NSW. Contact Faye Kohlhagen on 0414 294 587 or email sharecare@ngo.org.au

**Western Sydney**

- **Autism and Asperger’s Support Group** Support group that provides workshops and events to parents and families of children with autism and asperger’s. Contact the coordinator on 0425 380 575 or email info@autismsupport.org.au

- **Family Development Services** “Kids Rock’ siblings program in Blacktown. They also run workshops, single events and support programs. Ages 8-13. Contact Kathy Sheridan on 9620 4194 or email info@fdsinc.org.au

- **SNAPP AMIGO** Sibling and Buddy programs. Run under the SNAPP program in LIVERPOOL

**Metro North**

- **ADHC Parramatta School Aged Team Sibling Group** This group organises “Siblings Days’ 8-12 years. Contact Kylie Huang (Case Manager) on 8855 3505 or email kylie.huang@dadhc.nsw.gov.au

**Northern Sydney**

- **Siblings under School Age (Early Ed)** Contact Leslie Burnett on 9923 2727 or email Louisa@chw.edu.au

- **Northern Beaches Interchange (NBI)** offers siblings support such as circus skills siblings days. For details call Sophie Kane on 9970 0500 or email sophie@nbi.org.au

- **“Volume – Siblings. Turning it Up!”** Program offer siblings school holiday programs. For details call Christi-Ann Tyler, Family Support Worker at Centacare on 8968 5100 or email christi-ann.tyler-st@dbb.org.au

**South West Sydney**

- **The Sibling Support Program** Aims to deliver activities that focus on supporting siblings through support, counselling, mentoring, siblings retreats, chat line and social activities, Liverpool/Fairfield/Bankstown/MacArthur area. Contact Marianna Zardo at The Junction Works on 4625 7333 or email siblingsupport@thejunctionworks.org.au
Metro Sydney

- **AGSA Projects** Working to launch a pilot program for siblings living in metropolitan Sydney. Contact Chui Lau on 9211 1462 or email projects@agsa-geneticsupport.org.au

- **St Anthony’s Family Care** offer a siblings program in Croydon, for children aged 9 and 10 years, called “Seasons for Growth”. For more information contact Vanessa Corbridge on 9747 5782 or 0418 476 339 or email vanesa.corbridge@safr.org.au

- **MDAA – Siblings Project**
  This project involves networking for young people ages 12 to 18 from Culturally and Linguistically Diverse (CALD) backgrounds that have a brother or sister with a disability, and live in Sydney Metro and Western Sydney. For 6 months the arts project will provide training and support to develop digital multimedia and website skills as support for young siblings with the opportunity to express their experiences by hosting workshops through animation, editing, photography, filmmaking and online video for young siblings with a disability in a CALD family and environment. There will be opportunities to develop the tools and resources to share and obtain further health and other information in the form of an online blog. For information, contact Feriha of Multicultural Disability Advocacy Association of NSW on 8203 1869 or email feriha.incesu@mdaa.org.au. | www.mdaa.org.au/service/advocdev/index.html

South Sydney

- **Sutherlandshire Learning Difficulties Support Group (SSLDSG)** Information sessions for carers and professionals. Contact for information 9545 1505 or emailautismgroup@optusnet.com.au

- **St George Life Care** run groups for siblings of children with autism. Information from their website on http://www.grlifecare.org.au/?page_id=35

Inner West

- **Siblings- Developmental Disability** Contact Louisa Corroll on 9701 6300

Eastern Suburbs

- **Siblings Support Group** for siblings of children with special needs and disabilities. The group has a drama and creative arts focus and offers sessions term time and holidays. Contact Lana Sussman Davis 0413 389 620 lana@creative-therapy.com.au
• **Aunties and Uncles Co-operative Family Project for children 0-12 years**
  Links children with trained volunteers “aunts and uncles” who provide mentoring and guidance. Contact Alison Lockyer on 9638 2480
  eastern@auntiesanduncles.org.au

Koorana

• **Siblings Club and Sibling days** Contact Tracey Hassesn on 9758 2666 or Website [www.koorana.org.au](http://www.koorana.org.au)

Albury

• **Cooinda Family Support** Siblings groups in school terms. Variety of ages.
  Contact Cooinda Family Support on 6065 4844

Hunter region

• **Educare** Support for 8-18 age group. Contact 4921 4895 or

Illawarra region

• **Family and Sibling Support Program** for siblings aged between 5-12.
  Social and Recreational support as well as education and annual camps.
  **Contact** Charity Duncan on charityd@catholiccare.woll.catholic.org.au or 4254 9334

Counselling Services

**ABI Siblings Counselling.** Contact 9969 2250 or email info@abinsw.org.au

Northcott

Useful reading for brothers and sisters

For younger brothers and sisters


Donlon, L *The Other Kid-A Draw it out guidebook for kids dealing with a special needs sibling* [www.theotherkid.com](http://www.theotherkid.com) This book invites kids to draw pictures and talk about their feelings, emotions and challenges of living in a household with a special needs or seriously ill sibling. Also available in Spanish.


For older brothers and sisters


Davies, J (1994) *Able Autistic Children- Children with Asperger’s Syndrome: a booklet for brothers and sisters.* Nottingham: The Early Years Diagnosis Centre


Hall, K *Asperger Syndrome, the Universe and Everything* London: Jessica Kingsley Publishers, 2001 1853029300 Written by a ten year old with Asperger Syndrome, this gives a first hand account of what it is like to have Asperger Syndrome.


Hoopman, K(2000) *Blue Bottle Mystery.* London: Jessica Kingsley Publishers. Aimed at 8-13 year olds, this warm, fun filled fantasy story has a hero with Asperger Syndrome and is a valuable teaching tool that demystifies Asperger Syndrome.

Jackson, L *Freaks, Geeks and Asperger Syndrome* London: Jessica Kingsley Publishers. Luke, who has Asperger Syndrome was 13 when he wrote this book. He talks about a host of tricky teenage topics, including bullying and dating.
Soilsbury, L What does it mean to have autism? Oxford: Heinemann Library, 2001 0431139253. Explores autism in its various forms, this fully illustrated book is aimed at children 7-12 years old.

Harris, S Siblings of Children with Autism: A guide for families

National Autistic Society (UK) has a number of information sheets on the issues siblings’ experience. www.nas.org.uk

Sometimes it can be easier to initiate discussion with your child or gauge how they feel about a sensitive topic by talking indirectly about a character from a film or book that is going through a similar experience, so here are some links to book and film lists to get you started.


Arthur, the cartoon series has 2 episodes on making friends with a boy with aspergers. You can see these episodes by clicking onto the following you tube website or searching for “aspergers syndrome explanation for children” http://www.youtube.com/watch?v=HjJDdg6BDXk
If you have a brother or sister with a disability or chronic illness you may also be known as a Sib (or sibling). Most Sibs say that while they have some great experiences growing up in their family, they also face some extra challenges.

Sibs say...

"My sister has always been judged for what she can't do instead of what she can which makes me angry."
Jacqui, 24-year-old Sib

"I'm so proud of what my brother has achieved in spite of his illness, even though he can be really annoying some of the time."  
Ria, 12-year-old Sib

"It's so embarrassing when I go to the shops and people stare at me because he is different to other kids."
Cameron, 12-year-old Sib

Sibs, parents and service providers can access three Sib-related websites from the central homepage at www.sibs.org.au

www.sibs.org.au
Support for primary aged Sibs

www.yourshout.org.au
Support for adolescent Sibs

www.acd.org.au
Support for parents of Sibs aged 0-25

Turn over for info on Your Shout...
The Your Shout website

The Your Shout website was created BY Sibs FOR Sibs! Log on to Your Shout today to:

1. Get connected!
   Sometimes all you need is to know that there is someone out there who understands what you're going through.
   Sibs can connect up with other Sibs by:
   - joining a sibling group or going on camp with other Sibs. Check out the Services page on the Your Shout website for more info on Victorian groups and camps for Sibs.
   - reading some of the stories and pieces written by other Sibs on the Stories, Your Thoughts or End the Sentence pages of Your Shout.
   - signing up to Your Shout and posting comments to other Sibs through the Sib Chat page.

2. Share your thoughts
   Sibs also need the chance to share ideas with others about their experiences of being a Sib. Once you're connected, you might want to begin:
   - talking to people you trust about your experiences. You may decide to talk to a family member or friend, a counsellor, someone you met at a sibling group or camp, or another Your Shout Sib. A list of people Sibs can talk to is available on the Links page of Your Shout.
   - writing down your thoughts and contributing them to one of the pages in the Stories, Your Thoughts or End the Sentence sections of Your Shout.
   - posting comments on the online Your Shout Sib Chat.

3. Find some headspace
   It's important that all Sibs have time away from their family to develop their own interests. Sibs can try:
   - checking out the Sib Chat page of the Your Shout website for ideas on how to get some headspace.

Where else can Sibs go for support?

If the challenges start to be overwhelming, Sibs can talk to trained counsellors by ringing the Kids Help Line on (freecall) 1800 551 800, Lifeline on (freecall) 13 11 14 or registering as a Young Carer with the Commonwealth Carer Resource Centre by phoning (freecall) 1800 242 636.
Sibs say...

“Most of the time I feel happy to be able to help my sister out when I am asked but every now and then it can be a bit of a pain, especially if I’m busy with my own things.”
Dan, 15-year-old Sib

“My favourite moment last year was watching my sister play the drums solo at the school concert – I was so proud of her!”
Emily, 12-year-old Sib

“It upsets me that my brother is stubborn and plays up for my mum and dad. He stresses them out and can be very determined.”
Aker, 17-year-old Sib

A Sib (or sibling) is someone who has a brother or sister with a disability or chronic illness.

Sibs often develop a range of admirable personal qualities and feel enriched by the experience of growing up in their family. Some Sibs are more tolerant and understanding of individual differences, take great pride in their brother or sister’s achievements, and go on to work in helping professions. On the other hand, Sibs also face a range of extra challenges, and many report feeling guilty about being able to do things their brother or sister can’t, being embarrassed at other’s reactions to their brother or sister, or being angry about receiving less attention than their brother or sister.

The extent to which these challenges affect Sibs depends on many other factors such as their age, where they fit in the family, where they live, and the severity of their brother or sister’s condition. Although each Sib’s experience is unique, all Sibs can benefit from a bit of extra support during their childhood years.
How can parents support Sibs?

There are lots of things parents can do to support Sibs.

1. Communicate openly with Sibs

Sibs need regular explanations about their brother or sister’s disability or illness when growing up. Build open channels of communication with Sibs so that they feel comfortable talking about the good and not so good aspects of their experiences. Encourage them to ask questions about things they don’t understand. For tips on communicating with Sibs, check out:

- the ‘Supporting Siblings Booklet’ available from www.acd.org.au
- the links to book and film suggestions listed in the Sibs section of the website www.acd.org.au for ideas on books and films to use to initiate discussion with Sibs.

2. Help Sibs to feel connected

Sibs also need the chance to feel that there are others out there in a similar situation. It can be invaluable for Sibs to meet other Sibs face to face at sibling groups or camps, or link up with other Sibs through one of the many sibling websites. Parents can:

- look at the directory of sibling groups on www.acd.org.au to see if there are any suitable sibling groups in their local area
- sit down with primary aged Sibs at the Siblink Sibs website, or direct adolescent Sibs to the Your Shout website through www.sibs.org.au.

3. Give Sibs opportunities for ‘headspace’

Sibs also need opportunities for time away from their brother or sister to develop their own individual leisure activities and skills, and to have a rest from their family. Parents can:

- read a range of Sibs headspace ideas by visiting the list of ‘Headspace Ideas’ in the Sibs section of the website www.acd.org.au.

Where else can I look for more information?

• Carers Australia

Most Sibs do their bit to help out at home and can access support offered to Young Carers through the Commonwealth Carer Resource Centre. Phone 1800 242 636 or visit www.carersaustralia.com.au for more information.

• Siblings Australia

Siblings Australia provides a variety of resources and services for Sibs as well as aiming to create awareness about the needs of Sibs among parents, professionals and the general community. Contact Siblings Australia on (08) 8361 8361 or visit www.siblingsaustralia.org.au for more information.

To get a hard copy of any of these Sibs resources contact the Association for Children with a Disability on the number below.