

Information Sheet

Information for Parents: Siblings and Children on the Autism Spectrum

Updated April 2016.

Having a sibling on the autism spectrum brings with it challenges and rewards that others may not experience or understand. This resource explores those issues and suggests places in which more information and support for siblings can be found.

This information sheet is written with non-autistic (“neurotypical”) siblings in mind, but many families have multiple children on the autism spectrum. An autistic sibling may also benefit from the advice provided in this resource.

This resource is written about siblings and discusses some negative feelings they may experience. This is not meant to suggest the experience of having a family member on the autism spectrum is a bad thing. The value of every member of the family and the incredible love family members have for each other should be considered “a given” throughout this document.

A Special Relationship

Siblings have a special relationship which lasts longer than any other. Some siblings will play the part of teacher, protector, or role model. A younger child will share their first social interactions with their older siblings.

The sibling relationship is fundamental, providing the basis for children to develop their identity and social skills. The relationship between siblings in which one is on the autism spectrum can be

different than what many people experience, but no less important or formative.

The diagnosis

Although autism is thought to present at birth, it is usually not diagnosed until a child is at least 2 years old and sometimes not until they are in their teens. This means most families will experience a long process of worry, various assessments, until they finally reach a diagnosis. The process can take years and is hard on parents as they go to appointments and assessments, read reports, trying to piece everything together while simultaneously trying to get help for their child with autism.

Siblings have a unique perspective on this process. The stress as it unfolds impacts on them as well. The time following a diagnosis can be stressful for the whole family.

Siblings’ adjustment will be greatly influenced by



the reactions of other people in the family, particularly their parents. If their parents feel overwhelmed, siblings may feel they have to provide emotional support for their parents and put aside their own emotions. Seeing their parents struggle can shake the foundations of their world. This can lead to them feeling overwhelmed, anxious, or resentful, in both the short and long term.

Now and always, **good communication is vital.** Letting your child know you are there to answer questions is a good way to ensure they understand and feel valued.

(It is worth noting, a sibling's age will affect their ability to understand autism. Parents need to tailor the information they offer to a level appropriate with their age and development.)

If this sounds challenging, it might be helpful to engage a counsellor or psychologist to help the family deal with their emotions at this time.

Feelings

There are lots of feelings can be present in the siblings of children who are on the autism spectrum.

Isolation, Loneliness: Being the sibling of a child on the autism spectrum can be uniquely isolating. Siblings may feel isolated *from* their sibling as their autism makes communication and playing together difficult, while being isolated *by* their sibling as other people don't understand their unique family situation. On top of that, their parents need to give extra attention to the child with high needs, leaving the sibling on their own again.

Parents can put aside special time to share with a sibling, pursuing a hobby or going on special outings, to reinforce their bond and make them feel valued. Parents can also assist siblings by making sure they have many opportunities to socialise with other children and familiar adults. A

sibling might like to join a hobby club or sporting team so they can pursue an interest they enjoy while also socialising with other people.

Another way of making a sibling feel connected to others is to help them to engage with other siblings in similar situations. There are details on sibling-focussed services on the last page of this resource. Some support organisations run special camps and activities for siblings as well.

Guilt: Siblings might feel responsible for their sibling's autism or feel they need to fix it. Similarly, siblings who notice that their sibling has difficulty with things may feel guilt over the fact that they do not have difficulties. Guilt may arise along with other feelings, such as anger or frustration with their sibling.

Parents should be certain to remind siblings the brother or sister's autism is not their fault and they needn't feel ashamed of their abilities.

It is important to recognise that the child with autism is one part of the family and to try to balance the time spent with all of the children. Scheduling special dates or activities with siblings may aid in ensuring you are spending quality time with them. It is also vital that you celebrate sibling achievements, e.g. sporting events, school award ceremonies.

Embarrassment: All children are embarrassed by their families at some point, but siblings to children on the autism spectrum may find the behaviours such as melt-downs, stims, or noises to be acutely upsetting (especially once they are school age).

Parents can talk to siblings about why they feel embarrassed and help to frame experiences with people outside the family in a less negative way. You can explain "Some people don't understand about autism" if they are embarrassed when people stare, for example.

Some level of embarrassment is unavoidable,

especially with teen siblings as they are very sensitive to social pressure, but allowances need to be made for the sibling as well. If a child is so embarrassed they feel they cannot have friends visit their home, steps need to be taken support them, lest they become isolated and miss out on important childhood experiences like these.

Anxiety: Anxiety is common in siblings of children



with special needs, autism included. Unfortunately, the more responsibility the sibling is expected to assume, the higher their risk of anxiety. Siblings may worry that they will be responsible for their brother or sister when they grow up or worry about specific things which are happening now, like if they tend to run away in public or engage in self-injurious behaviours. Anxiety can become generalised if a member of the family feels their home environment is chaotic or unsafe.

Another facet of anxiety in siblings can be directed inwards, as some siblings struggle to be “perfect”. This may be a way they feel they can win their parents’ attention and approval or it could be their way of making life easier for their parents. This perfectionism can have adverse consequences as a child grows up.

Parents can support siblings by offering unconditional affection, not only as a reward when they have done something “good”. It is also important for parents to be encouraging while

having realistic goals for the sibling.

Responsibilities

At home, siblings might be expected to take on extra responsibilities and chores than their peers.

It is important that the sibling is not overburdened with responsibility and is allowed to have time to enjoy themselves, cultivate friendships, and develop a sense of identity. Some siblings are eager to help out and take on extra tasks, but it is important that they have regular periods of time to wind down and relax. Making sure each family member has time and space to themselves benefits everyone in the family.

“It’s not fair!”

In a household with a child on the autism spectrum events such as tantrums and broken items are a common occurrence. It must be recognised a sibling may start to feel resentment if the child on the autism spectrum ‘gets away with’ things for which they themselves would be punished. To avoid these feelings of unfairness, communication can promote understanding.

It is important that expectations at home be set and clear for all children. Having a clear set of house rules visible may also help. Having clear expectations and consequences may assist in developing a more predictable environment.

After an unusual or upsetting event (such as an explosive meltdown which might involve violence or breaking things), siblings may put on a brave face, putting their feelings of fear, anger, sadness or pain to one side. Parents can help by explaining to the sibling it is normal to have emotional reactions to things. Remind them that understanding of their brother or sister’s needs are important, but it does not mean you can’t have your own feelings as well.

A lot of children on the autism spectrum will go to a mainstream school. Whether your children

attend the same school or not, it can be helpful to talk to the sibling's teacher about pressures they may be faced with at home. The sibling might be expressing their frustration or anxiety at school. It is helpful for the teacher to understand their home life so they can act appropriately if concerned about the sibling's behaviour. For example, a stressed and overwhelmed sibling may be attentive and compliant at home, but disruptive, disinterested, or withdrawn at school. Recognition of this makes it easier for teachers and parents to work together to ensure the sibling is supported in every environment.

The Good News

With parental support, there are many positive things which come from having a sibling on the autism spectrum.

Compassion: Having a sibling with special needs can teach children to feel for other people years before their same-aged peers. Many siblings find their compassion draws them to a career in the "caring professions" such as medicine or allied health or areas associated with social justice like the law.

Independence, Resilience: Taking on extra responsibility when young and learning to cope with challenges can help young people develop a sense of competence and independence.

Love: The fierce, protective love one sibling feels for another is a powerful and wonderful thing.

Resources for Siblings

The following is a list of other organisations which provide resources and support to the siblings of people on the autism spectrum:

Association for Children with a Disability –
acd.org.au/sibling-program-directory

ACD has a directory that provides opportunities for young people to connect through activities like camps. (They have also written the excellent

sibling support booklet "Growing Together"
acd.org.au/growing-together-resource.)

Interchange – www.interchange.org.au

Interchange represents agencies who offer support, respite and recreational opportunities to children with disabilities and their family members.

Livewire – www.livewire.org.au

The livewire community is a safe online environment for young people (between 10 and 20 years), living with chronic health condition or disability - and their siblings.

Siblings Australia – siblingsaustralia.org.au

Siblings Australia aims to create connections between siblings, between parents and siblings, and between families and professionals.

Young Carers – www.youngcarers.net.au

Young Carers run programs across Victoria.

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