

Sharing the Diagnosis of Autism Spectrum Disorder

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“Our child has been diagnosed with an Autism Spectrum Disorder – how can we tell our friends and the rest of the family?”
“How much should we tell our child’s school about their Autism Spectrum Disorder?”
“Do we have to tell anyone about the diagnosis?”

These are some of the questions that families frequently ask. This article gives you some answers, ideas and suitable resources to help you resolve these questions.

When a diagnosis of Autism Spectrum Disorder (ASD) is made, family, friends (and sometimes the individual themselves) want to learn more about what the diagnosis means. They look for more information for themselves, and then arrive at the dilemma of whom to share this information with, and when.

This article aims to help with the process. There is also information for individuals with ASD themselves about sharing their diagnosis with others. All books referred to in the article are available for loan from the Autism Victoria library (#accession number noted in brackets).

Informing Siblings

Explaining the diagnosis to brothers and sisters will differ depending on their age. It is important to remember that conversations about the sibling with ASD should be repeated as the brother or sister grows, so that a clearer picture of the diagnosis and its implications can be built by the sibling as their cognitive ability becomes more sophisticated. Open the lines of communication by telling the sibling they can ask questions about autism whenever they think of them.

Children aged 2-3 years will need a clear, short explanation about the sibling’s difficulties, most probably without divulging the ASD label. Sentences like ‘Talking is hard for Billy’, which state behaviours the sibling



can easily see are recommended. Pre-school aged siblings typically ask a lot of 'why?' questions, which provides an opening for parents to discuss the reasons behind the ASD child's behaviour. Parents can provide answers like 'Billy finds it hard to play. His brain works a little differently from yours and mine. He finds it hard to pretend with toys like we can'.

Early primary school aged siblings (6-9 years) will be able to take in the former explanation, plus similar explanations about other areas of difficulty for the sibling. They will also be able to understand more abstract explanations, such as 'Billy finds it hard to understand how other people feel'. In addition, siblings of this age can understand the explanation that the sum of these difficulties together is called 'autism'. Children of this age may grapple with unlikely scenarios like 'Can I catch autism?', 'Did I do something to cause my sibling's autism?' Children may not voice these concerns, so it is important to stop any misconceptions by explaining that autism is not contagious, it is caused by brain differences from when the sibling was very young, and that neither parents nor siblings cause the autism. The child should also be reassured that autism is not life threatening, and that both they and their sibling are loved and valued equally, despite their differences.

Siblings aged 9 years and into adolescence can understand more detailed written information about autism. The posters 'What is Autism?' and 'What is Asperger Syndrome?' that are available free of charge from Autism Victoria are a concise starting point for discussion about the characteristics of ASD. Parents can talk about the specific behaviours displayed by the sibling, and how this fits with the characteristics of autism. Questions arising from this discussion may

be 'When will he get better?' and 'Who will care for him when he gets older?' It is useful for parents to think about how they might respond to such questions. An excellent book for parents providing a more in depth explanation of siblings' ability to understand autism at different ages is 'Siblings of Children with Autism: A guide for families' by Sandra Harris (#2526).

There are also a variety of children's books to help parents explain to siblings the differences their brother or sister has as a result of their diagnosis. Parents may choose to read the books themselves and use the information as a basis to answer their child's questions in a developmentally appropriate way. Alternatively, parents may read the book with the sibling, and then have a discussion with the sibling.

For siblings 3-6 years

Various picture books, such as 'My brother Sammy' by B. Edwards & D. Armitage (#1900), and 'My Brother is Different' by L. Gorrod (#1692) show the characteristics of autism through stories with bright illustrations. The first book does not use the label 'autism', the second one does.



Siblings 7 years and over

For a sibling with a diagnosis of autism, the book 'Children with Autism, a booklet for brothers and sisters' by J. Davies (#1034) is helpful. For a sibling with a diagnosis of less

severe autism, Asperger's Syndrome, or PDD-NOS, the book 'Able Autistic Children: Children with Asperger's Syndrome' (#1138), also by Julie Davies is recommended.

Both of these books explain what the diagnosis means, including the difficulties their sibling may have, comments about the positives and negatives of having a brother or sister with ASD, and how the child might explain to others about their siblings' diagnosis. The books also cover questions about ASD the sibling may not have asked, such as 'when will he get better?', so as to clear up any misconceptions the sibling may have. Another useful book is 'Everybody is Different' by F. Bleach (#2316) that explains



the difficulties of autism, as well as covering questions siblings frequently ask

A fiction book for children of this age group, where the main character has a brother with autism is 'Dolphins Dance' by Jutta Goetze (#2341). It is useful for siblings to know that they are not alone - that other children experience some of the same issues as they do.

Telling your child's teaching staff

Some advantages in sharing your child's diagnosis with their teaching staff are:

- Accommodations can be made for the child's behaviour, which may appear 'naughty', when it is really the result of lack of social understanding, sensory

overload, or problems with the organisation needed to complete a task.

- Accommodations can be made for the child's learning style, such as presenting more information visually.
- Accommodations can be made in the child's workload, if it can be acknowledged that it may take the student longer to complete tasks, even when trying as hard as other students.
- Social difficulties at break-times can be acknowledged, and the child supported or allowed to do alternative activities at recess and lunch.
- The child can be encouraged in their areas of strength or interest.

Sharing the diagnosis with the teaching staff is best done in a face-to-face meeting. The parent may wish to include other professionals who have assisted the child (eg speech pathologist, psychologist, occupational therapist), so these professionals can also help in explaining the child's needs, strengths and difficulties. Alternatively, copies of any assessment reports completed may be shared with the teaching staff, if recommendations are made in the reports specifically about education issues. The process of information sharing with teaching staff may need to be repeated each year, for each new teacher.



A note to parents: in fairness to teaching staff, it is best to ensure any written

information about Autism Spectrum Disorders given is very concise, so staff can very quickly gain an understanding, and gives some specific strategies to use for the student. Even the best intentioned teacher or aide may not have the time to read a whole text book in a timely enough matter to apply the information for the student. Using the posters from the Autism Victoria information packages*, discussing which points apply to the student, and which strategies have worked in the past for the specific child is an excellent start. Other issues can then be discussed during the year as they arise. The Asperger Syndrome information kit has a concise summary of difficulties for the student, and suggested modifications.

*These information packages can be obtained free of charge by contacting Autism Victoria.

A note to teachers: Every child with ASD is unique in their expression of the key characteristics of these disorders, so having one student with ASD in the past does not mean you can immediately apply the same strategies to the next student with ASD. Seek information specific to each child from parents or past teachers.

Talking about ASD with classmates and young friends

Often in lower primary school, the child's classmates begin to notice differences and ask questions about the student with ASD. The teacher may choose to respond to individual children as questions arise, or there may be several reasons to inform all the class together about the diagnosis. Reasons to inform classmates may include:

- Preventing bullying or teasing by pointing out why the child has difficulties in some areas. The teacher can

encourage students to be supportive and helpful to the student with ASD, by informing them about specific ways to help. (eg. 'Billy finds it difficult when people walk too close to him in line. If Billy looks upset, move one arm's length away so he can have some space').



- Stopping misinformation about the student being circulated in other student's gossip. (such as 'Billy is weird, don't play with him')
- Preventing 'perceived favouritism' – helping classmates become more accepting that some accommodations may be made for the student with ASD, that won't be available for them. A lovely picture book for lower primary aged students along these lines is 'Looking after Louis' by Ely and Dunbar (#2640).

Before disclosing the diagnosis to the student's classmates, it is imperative that teaching staff gain permission from the parents of the child with ASD. The diagnostic label should only be shared if parents wish for this to happen. Another consideration is whether the student with ASD should be present or not present when the class is learning about ASD. The child's ability to understand that the discussion is about them will influence this decision.

A beautiful book to introduce lower primary aged students to the needs of a classmate with autism is 'My friend with Autism' by Beverly Bishop (# 2336). For a classmate

with Asperger Syndrome, 'This is Asperger Syndrome' by Elise Gagnon and Brenda Smith Myles (# 2034) is recommended. Parents may also want to visit the school during class-time to talk to the class about ASD, their own child's unique needs, and how classmates can be a 'good friend'. Carol Gray has developed a lesson plan 'The Sixth Sense-II' (#2314) through which teachers can introduce the social difficulties of a student with ASD to their classmates aged 7-12 years.

For upper primary and lower secondary students 'What does it mean to have Autism?' by L. Spilsbury (#2380), and 'Can I tell you about Asperger Syndrome?' by Jude Welton (# 2387) are useful for facilitating discussion about autism and Asperger's Syndrome respectively.

For upper secondary students, the Autism Victoria poster kit, with A3 size posters covering the characteristics of Autism and Asperger Syndrome is a recommended starting point for discussion. The resource package about the novel *The Curious Incident of the Dog in the Night-time* by Mark Haddon (#2305) is also useful. These are all available free of charge from the Autism Victoria office.

Curriculum ideas: To promote tolerance of difference, without using the ASD label in regards to a particular child, teachers may wish to try one of the following activities.

1. Discuss in the theme of 'difference', that everyone has strengths and weaknesses. Have every student identify one strength and something they would like to improve. Use the strengths to make a class 'Yellow Pages' directory, with a page from each student advertising their strength. When a student is having difficulty (eg with the computer), have them look in the class 'Yellow Pages' to

identify another student to help (maybe the person with ASD). abilities can then be shared, and the person with ASD is sought out for their strength, be it mathematics, puzzles, remembering facts, sharpening pencils, telling a joke, drawing, etc.

2. Setting a school project on 'differences', or covering the theme of difference in a series of classes. Various cultures and nationalities, disabilities and abilities could be covered, ASD included, with students reporting back to the rest of the class. If a project is set for the class, randomly assign topics so that each student has a different topic.
3. Reading books about accepting difference, such as 'Why can't Charlie Talk?' by Debbie Spencer (#2559), 'Trevor, Trevor' by D Twachtman-Cullen (#2318) (lower primary age students) or 'Amazingly Alphie: Understanding and accepting different ways of being' by Roz Espin (#2626) (upper primary age students).

Introducing the child to their diagnosis

As children grow older, parents often grapple with the question of if, and when to inform the child of their diagnosis. The benefits of explaining to the child about their diagnosis of ASD include:

- The child has an answer for their difficulties, which they may previously have attributed to inadequacies in themselves.
- The child can gain more insight into their own learning style, and know what kind of modifications (eg.visual supports) will help them learn and care for themselves best.

Luke Jackson, an adolescent with Asperger Syndrome and author of 'Freaks, Geeks and Asperger Syndrome' (#2252) advocates telling a child about their diagnosis as soon as possible. At 12 years of age, he noticed the behaviours of his younger brother (diagnosed with autism) were similar to his own, and began to ask questions. He had felt he was different for a long time and was relieved to have a name for why he was different. He wished he had been informed sooner.

So if parents have decided they want to inform the child about their diagnosis, and feel the child can understand the language involved, the next decision is exactly what to say. Parents may wish to talk to the child about their strengths and difficulties, and then inform the child that the name for these qualities is Autism/Asperger's/PDD-NOS. Carol Gray has developed the very useful format 'Pictures of Me' (#1615) to introduce children with High-Functioning Autism and Asperger Syndrome to their diagnosis.

The table opposite indicates some common areas of strength and difficulty for children with ASD, and ways parents might discuss these with their child.

A verbatim conversation between Jennifer Overton, and her 9-year-old son, in which she explains his diagnosis to him is printed in the book 'Coming out Asperger' edited by Dinah Murray (#2669). Parents may wish to use this actual conversation as a rough model about how their own conversation with their child may unfold.

Strengths & Difficulties for children with ASDs:

Strength	Examples of possible explanations
Good memory for facts and/or for visually presented information	"You can always remember the directions to get to when we are travelling" "You remind me about important things like when birthdays are coming up" "You always remember who was at the family Christmas party" "You are good at finding things" "You are an expert on animals"
Good ability to solve non-verbal problems	"You can do jigsaws so quickly" "You can put equipment back together without instructions"
Attention to detail	"You make sure things are done in a thorough way" "You help others notice errors"
Honesty	"You tell people exactly what you think of them" "You are always truthful"
Difficulty	Explanations (add examples specific to your child)
Understanding social interaction	"Sometimes you don't notice how other people feel" "You find it hard to follow other children's games"
Difficulty with language	"Sometimes you don't understand what others are saying" "Sometimes you aren't able to follow instructions when others speak them"
Rigid thinking or repetitive behaviours	"You have to have things done in a particular way every time" "You like to be the boss in games" "You get upset if things change" "You find it hard to forget when something upsets you"

The following books have worksheets and activities to help children understand their autism (from ages 8 years onwards):

'I am Special: Introducing children and young people to their autistic spectrum disorder' by Peter Vermeulen (# 2003)

'What does it mean to be me? A workbook explaining self awareness and life lessons to the child or youth with High-Functioning Autism or Asperger's Syndrome' by Catherine Faherty (# 1892)

The following books introduce children to the characteristics of Asperger Syndrome:

'Asperger's, huh? - A child's perspective', by R.G.Schnurr (#2103)

'What is Asperger Syndrome, and how will it affect me?', by M. Ives (# 1947).

'The mystery of a special kid', by Josie Santomauro (# 1720)

For children with Asperger Syndrome, two common reactions to being told their diagnosis are relief, or vehement denial; insisting that nothing is wrong with them and that everyone else has the problem. For parents of children with Asperger Syndrome who suspect their child may reject the suggestions that they are different, a less direct approach may be useful. There are several children's books where the main characters/heroes of the story are children with Asperger Syndrome. Reading these together may lead the child to identify that they themselves have the same characteristics. This is a good way to start a discussion in a non-threatening way.

Kathy Hoopman has written several books, including 'Blue Bottle Mystery'(#2013), 'Of Mice and Aliens'(#2014) (for upper primary aged children) and 'Haze' (#2324) (for adolescents).

Nelle Francis has written a series of books 'Ben and his Helmet' in which the hero, Ben, has Asperger Syndrome. Ben is guided in his

behaviour by his magic helmet, which interprets difficult situations for him. This is a set of 3 books for ages 5-8 (#2489), and 'Ben, his helmet, and bees in your bonnet' (#2588) for ages 9-12 is now available.

'Different like Me' by Jennifer Elder (#2683) looks at famous figures who showed behaviours different from the norm, and may have been diagnosed with an ASD if assessed today. Many of the figures are famous in the USA, and not recognisable to Australian children, however reading about their achievements should still be an encouragement for children with an ASD aged 8-12 years.



Family and friends

After receiving a diagnosis for their child, and in the years that follow, parents benefit from the understanding and assistance of family and friends. Unfortunately some parents experience the loss of contact with those individuals who do not know how to assist, are confronted by the child's behaviour, or who are in denial that the child has a lifelong difficulty. Anna Tulleman has written booklet of tips 'Talking to friends and family about the diagnosis' (#2599) covering why and how to share the child's diagnosis with family and friends.

As per the suggestions above about talking to the child's teaching staff, parents may similarly invite friends and family to get together as a group, disclose the child's diagnosis, provide written information about

ASD's, discuss how this relates to their child, and share the strategies which are to be used with the child. Parents may also suggest that family and friends contact Autism Victoria for more information.

Informing the broader community

Which people in the community should know about the child's diagnosis is a matter of personal preference. Individuals who may benefit from knowing could include neighbours, service people whom the family sees regularly, local shopkeepers, etc. A common reason for sharing this information is to provide an explanation for the child's unusual behaviour, or to indicate how such people may better interact with, and respond to the child. In order to prevent lengthy explanations, some parents choose to disclose the child's area of difficulty relevant to the situation (eg 'Billy has difficulty learning to speak, please use very short sentences for him'), other parents give a fuller explanation including the ASD label.

A recent media story depicted parents dressing their child in a t-shirt proclaiming his ASD diagnosis, in order to stop the staring and comments of others in response to the child's behaviour. A more diplomatic alternative for explaining the child's diagnosis to others in the community is an Autism Victoria 'alert card'. This is a business-sized card giving a succinct sentence explaining ASD's, and Autism Victoria's telephone number for people to find out more information. Parents can hand this to people in the community who are curious, and it is especially helpful if a parent needs to leave an event or shop mid-transaction (without time for verbal explanation) to attend to the person with ASD. The alert cards are available to purchase from Autism Victoria, and are an ideal template from which to make up an

alert card personalised to the individual child with ASD.

Disclosing your own diagnosis

Teenagers: Luke Jackson, a teenager with Asperger Syndrome, gives the following advice about disclosure in his book 'Freaks, Geeks and Asperger Syndrome' (#2252). He suggests that the diagnosis be shared with teachers, so they can make accommodations and be supportive of the student. He also suggests that the diagnosis be shared with supportive friends. As a person with Asperger Syndrome, he concedes it is difficult for him to know who will be supportive, and urges parents to help their children with identifying appropriate people. Luke usually waits until someone comments on his unusual behaviours, then he discloses his diagnosis by explaining that his difficulties are caused by 'differences in his brain', which collectively are called Asperger's Syndrome.

Other advice for teenagers wanting to disclose their diagnosis to their age peers can be found in the chapters written by Heta Puki & Penny Barrat in 'Coming out Asperger' edited by Dinah Murray (#2669).

Adults: Several adults with autism spectrum disorders have written about their experiences with disclosing their diagnosis, and give suggestions to others planning to do the same. Lianne Holliday Willey is an adult diagnosed with Asperger Syndrome. She likes to share her diagnosis often, in order to spread knowledge about Asperger Syndrome. She writes in her book 'Pretending to be Normal' (#2565) about using a business size card to inform people she meets about her diagnosis.

It reads:

“I have Asperger’s Syndrome, a neurobiological disorder that sometimes makes it difficult for me to speak and act calmly and rationally. If I have given you this card, it probably means I think I am acting in a way that may be disturbing to you. In short, Asperger’s Syndrome can make it difficult for me to: speak slowly, refrain from interrupting, control my hand movements and my blinking. It also makes it hard for me to follow your thoughts so that I might misunderstand what you are trying to say or do. It would help me if you would speak calmly and answer any questions I might have, clearly and completely. I apologise if my behaviours seem inappropriate. For more information contact ... (insert your Autism association’s details) ...”

Lianne offers some interesting anecdotes about her experiences of disclosing her diagnosis, both positive and negative, and her system for deciding who, and how to tell.

Stephen Shore, an adult with ASD, suggests individuals think about what they hope to gain by disclosure. He discloses his diagnosis on a ‘need to know’ basis, and often just discloses specific deficits (eg. difficulty with sensory information) to others when a difficult situation arises, rather than stating that he has an ASD. He has developed a good guideline letter to help individuals disclose their diagnosis to their employer, which helps individuals outline the specific aspects of their diagnosis that may impact on their work performance. This can be found in his chapter in ‘Asperger Syndrome and Adolescence’, edited by Lianne Holliday Willey (# 2280).

In summary, individuals with an ASD who have experience sharing their diagnosis suggest:

- Choosing carefully who to tell. Involve a trusted person to help in making the choice of who to inform.
- Thinking carefully beforehand about the exact words to use.
- Using either written or verbal explanations for the other person to help in their understanding of ASD.
- Being prepared that disclosing the diagnosis may make others react negatively towards you. People who react in this fashion are not helpful people to stay involved with.

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