

▲ Telling a child about their diagnosis.

This section gives information about telling a child, siblings and extended family about the diagnosis of autism.

As a parent/carer of a child with a diagnosis of autism spectrum disorder, you will come to your own conclusion about whether and when to give the diagnosis to your child. However, it is suggested that the likelihood of problems occurring decrease if a child *is* told about their condition and given the support they need. When and how you do this though may depend on personal circumstances.

Some parents decide to inform their children when they are young, so they gradually become aware of their differences. Other parents feel they should wait until their child is a little older so they will understand the diagnosis better. It is very much a personal decision.

If you do decide to inform your child about their diagnosis they may experience a mixture of positive and negative emotions. To help you prepare for this the section below offers some suggestions that you may like to think about.

When to Tell?

A child's personality, abilities and social awareness are all factors to consider in determining when your child is ready for information about their diagnosis.

Some children will actually ask, "What is wrong with me?" "Why can't I be like everybody else?" These types of questions probably mean the child is ready. However, some children may have similar thoughts and may not be able to express them.

What/How to Tell?

Very importantly try and be as positive as possible. Try to tell your child in a quiet place, where you will not be interrupted. This will allow them to process what you are saying and give them time to ask questions.

The process of explaining an autism spectrum diagnosis will need to be ongoing, as many children only need minimal information to start. More information can be added over time. However, it may take weeks or months before your child initiates comments or asks any questions.

One way some parents start the conversation about ASD is to talk about personal differences. You could extend this by writing a list of family members' strengths and weaknesses. This could then lead into a discussion about what your child is good at and what they find difficult. You could then point out that there is a name to this particular pattern of strengths and weaknesses.

Some children may become concerned that there is something seriously wrong with them. You may need to emphasize that autism is not a disease and no one can die from it. Although it cannot be cured there are ways of helping to

overcome some of the difficulties. Use concrete examples, such as: 'Your support worker at school helps you with tasks you find difficult'. You could also try and get your child to think of some of the things that they are good at that other children need help with at school.

Some parents report that they felt it was more appropriate for a professional to tell their child or someone else within the family who the child is close with.

Alison Hale an able person with an ASD writes "I still believe one of my strongest defences against all my disabilities is the awareness of exactly where my problems lie".

What else could I do if my child feels anxious about the diagnosis?

Children are likely to have initially different reactions to the information; they may refuse to believe it, feel anger or become overly attached to the diagnosis. It is important to keep lines of communication open. You could ask your child if they would like to find more information by reading books, watching videos, and/or by talking with other people. (If so refer to list below).

Some children may have further questions but not want to ask them face to face. Having a question box, diary or email system can make it easier for them to ask personal questions. It also gives them more time to process the answer or think of more questions.

More information can be found on the National Autistic Society Website: <http://www.autism.org.uk/nas/jsp/polopoly.jsp?d=1032&a=10848>

Further sources of information for children with ASD

4-9 years

Larson, E. M. (2006). *I am utterly unique: celebrating the strengths of children with Asperger's syndrome and high functioning autism*. Autism Asperger's Publishing Company

Doherty, K., McNally, P., and Sherrard, E. (2000). *I have autism. What's that?* Down Lisburn Trust. This cheerful book helps children and young people with autism discover how they are different from neurotypical people.

Eye Television (2006). *A different life: Rosie's story* (DVD). Rosie is a girl with classic autism and here is her story, told through the eyes of her brother. Originally shown on Channel 5, this DVD is aimed at children aged five to 11.

8-12 years

Elder, J. (2006). *Different like me: My book of autism heroes*. London: Jessica Kingsley Publishers. This book is about famous people who may have had an ASD. It talks about the achievements of people such as Einstein, Kandinsky, etc.

Autism Helpline (1999). *What is Asperger's syndrome and how will it affect me?* A guide for young people. Written by members of the NAS Helpline, this

booklet explains Asperger's syndrome in simple jargon-free language. It also offers helpful contacts and strategies for making life more comfortable.

Vermeulen, P. (2000). ***I am special: introducing children and young people to their autistic spectrum***. London: Jessica Kingsley Publishers. Aimed at young people over the age of ten with autism spectrum disorder, this workbook is designed to be worked through with an adult - parent, teacher or other professional. The content and layout are devised especially for children who process information differently.

Doherty, K., McNally, P., and Sherrard, E. (2000). ***I have autism. What's that?*** Down Lisburn Trust. This cheerful book helps children and young people with autism discover how they are different from neurotypical people.

Gerland, G. (2000). ***Finding out about Asperger's syndrome, high-functioning autism and PDD***. London: Jessica Kingsley Publishers. Gunilla's book can be helpful to all young people who receive a diagnosis of Asperger's syndrome, PDD or high-functioning autism. It will also be of interest to their peers in school, siblings, and other children.

Jackson, L. (2002). ***Freaks, geeks and Asperger's syndrome***. London: Jessica Kingsley Publishers. Luke has Asperger's syndrome. He was aware how little information there was for teenagers like himself so, with the help of his teenage brothers and sisters, he wrote this honest and witty book when he was 13. It covers a host of tricky teenage topics, including bullying and dating.

12years +

The National Autistic Society (2008). ***Being Me***. London: The National Autistic Society. Being Me is a CD-ROM and DVD set. The DVD focuses on people with an ASD talking about their experiences in a series of short film clips. It's a useful way of introducing the idea of the autism spectrum to newly diagnosed young people and adults and encouraging discussion about what it means to be on it. Many people with an ASD find that they benefit from visual learning and have enjoyed using the DVD. The scripts for each film clip were written by people on the autism spectrum.

Alongside the DVD, there is a CD-ROM with ten session plans on it. Topics include:

- feelings around diagnosis
- the positive aspects of being on the autism spectrum
- disclosure
- socialising
- employment.

The Autism Helpline (0845 070 4004) has also written an information sheet entitled ***What is Asperger's syndrome and how will it affect me?*** This is aimed at older children.

Talking to siblings:

The impact of having a brother and sister with ASD should not be underestimated. Their siblings behaviour may display challenging behaviour and affect their general home life, they may feel reluctant to bring friends home also completing homework might be difficult. There are many useful publications and web sites for siblings. It is perhaps wise to check them out yourself first and start with recognised sites e.g. National Autistic Society or SIBs, a national charity for people growing up with a disabled sibling.

<http://www.autism.org.uk/siblingsinfo>

<http://www.autism.org.uk/nas/jsp/polopoly.jsp?d=2173&a=13726>

www.sibs.org.uk

East Sussex has a county-wide group for siblings of children with disabilities. Although this is not ASD specific, there will be many children who attend the activities who will have a sibling with ASD. The contact details are:

37 Sorrell Drive
Langney
Eastbourne
BN23 8BH
01323-762024

Points to think about before talking to your other child/children about ASD:

- **Do you feel ready to talk to your child/children about ASD?**
You need to feel confident to answer some searching questions in a calm and reassuring manner.
- **Your other child/children will probably already be aware that their sibling is different.**
Are they afraid that they may 'catch' autism?
Are they anxious or angry about their sibling's behaviour?
What level of development (age) are they at? You will need to give your explanation at the right level (e.g. a 5 year old will not want the complete guide to autism!!)
- **Will you be available to talk to them at any time about their worries/feelings?**
They will need different levels of explanation as they grow up. Don't give too much information at one time (remember how you felt at diagnosis, could you take in all the information given to you?)
- **Older children (adolescents) may worry that they will have to be responsible for their sibling in future years but may feel ashamed/worried by these thoughts.**
Can you reassure them? Can you talk openly and calmly about their worries and reassure them that such feelings are natural? Can you include them in drawing up a plan for the future? Can you include them in educational planning meetings?
- **Is there a right time to talk about this?**
No, it must always be an individual family decision. You know what is best for your family. You may find it best to take the lead from your other child/children.

My Family is Different, written by Carolyn Brock, is a useful work book for children with a brother or sister who has Autism or Asperger's syndrome. It is available from the National Autistic Society and currently costs £8.99 (2009). ISBN: 978-1-905722-30-3

The NAS has a range of books for brothers and sisters of people with autism. Here are some recommendations.

For younger brothers and sisters

Everybody is different: a book for young people who have brothers or sisters with autism, by Fiona Bleach. Published by The National Autistic Society. This book is different! The author, Fiona, has worked in a National Autistic Society School and she explores the characteristics of autism, and what it feels like to be a brother or sister of someone with an ASD.

Able autistic children with Asperger's syndrome: a booklet for brothers and sisters, by Julie Davies. Published by The Early Years Diagnostic Centre. This booklet focuses on people with Asperger's syndrome and their brothers and sisters.

My special brother Rory, by Ellie Fairfoot and Jenny Mayne. Published by The National Autistic Society. Ellie is six-and-a-half and has a brother with autism. This is her cheerful and positive book about life with her brother.

My brother is different, by Louise Gorrod. Published by The National Autistic Society. A beautifully illustrated colour book which helpfully explains the behaviour of a child with autism for brothers and sisters.

My sister is different, by Sarah Tamsin Hunter. Published by The National Autistic Society. The ups and downs of life with a sister who has autism, written and illustrated by ten-year-old Tamsin, whose sister has an ASD.

What about me? The autism survival guide for kids, by A. Koutsis. Published by The Wantirna Heights School. It can be really tough living with a brother or sister who has autism. Join Spike the dog as he looks at autism and check out his survival tips to help make life a little easier.

Can I tell you about Asperger's syndrome?: A guide for family and friends, by Jude Welton. Published by Jessica Kingsley Publishers. Adam is a nine-year-old boy with Asperger's syndrome. Here, he explains his talents and the difficulties he has. Jane Telford's cheerful pictures bring Adam's words to life. For adolescent brother and sisters.

Blue bottle mystery, by Kathy Hoopman. Published by Jessica Kingsley Publishers. This warm, fun-filled fantasy story has a hero with Asperger's syndrome. Tied up with the exciting mystery is the story of how Ben is diagnosed with Asperger's syndrome and how he and his family deal with the problems and the joys that come with this.

The curious incident of the dog in the night-time, by Mark Haddon. Published by David Fickling Books. A really good read for readers old and young. The hero, Christopher Boone, is a teenager with Asperger's syndrome. Contains some strong language. Winner of the 2003 Guardian Children's Fiction Award and the Whitbread Book of the Year award.

Freaks, geeks and Asperger's syndrome, by Luke Jackson. Published by Jessica Kingsley Publishers. Luke has Asperger's syndrome and wrote this book when he was 13. It is honest and witty and covers a host of tricky teenage topics, including bullying and dating.

For the adult sibling

Asperger's syndrome: a guide for parents and professionals, by Tony Attwood. Published by Jessica Kingsley Publishers. This accessible and readable book aims to assist carers, parents and professionals in the identification and treatment of children and adults with Asperger's syndrome. It is based on extensive review of the literature and his experience as a specialist in this area over the past 25 years.

Why does Chris do that? by Tony Attwood. Published by The National Autistic Society. Tony Attwood offers a better understanding of the unique difficulties associated with autism and Asperger's syndrome. This is a really practical book, full of useful advice.

I'm a TeenagerGet Me Out of Here! By Carolyn Brock published by The National Autistic Society.

This book is written especially for teenage siblings of people with an autism spectrum disorder (ASD). The author hopes it will help them to realise that they are not alone and to be honest about their feelings, to understand their siblings better and to know where to look for further help.

Information for extended family members

Members of your family may have noticed that your child sometimes behaves differently from other children. It is important that family members understand what an autistic disorder is so that they can support your child and you appropriately. The National Autistic Society has a leaflet to help explain the condition.

<http://www.autism.org.uk/nas/jsp/polopoly.jsp?d=1939&a=16975>

Out and about:

The National Autistic Society has created an Autism Alert card. It was developed in consultation with adults with autism and parents, the Autism Alert card can be carried by a person with autism and used in difficult situations, where they may find communication difficult.

The Autism Alert card is designed to tell people about the condition, and asks them to show respect and tolerance. The card comprises a wallet which contains a leaflet of key facts about autism, and a credit-card style insert where people can write emergency contact details.

<http://www.autism.org.uk/nas/jsp/polopoly.jsp?d=350&a=6233>

