

“Where do I begin?”

Introducing your child to his/her Diagnosis of Autism or Asperger Syndrome

It is an extremely personal decision as to when families decided to tell a child about their diagnosis, and it all depends on personal circumstances. “Why should I tell my child?” is probably the first question a parent will ask themselves. Well, just as parents, relatives and siblings require support and information to help them digest this diagnosis, so does the child.

Parents sometimes fear that by telling the child:

- They will not fully understand
- They will somehow lose some of his/her life options as a result
- That they will become angry and/or depressed by the information
- That the child (or others) will use the diagnosis as an excuse as why they cannot do things
- That the child (or others) will think of themselves as failures with no positive hopes for the future

When?

A parent’s decision should be made based on their individual child. The only person who can decide if your child is ready, is you. You know your child better than anyone else, and there is no “set age”. A child’s personality, abilities and social awareness are all factors which need to be taken into consideration.

Should your child start asking questions about their needs, this may be a cue for you to think about sharing the information with them. Your child may have already picked up that they are a little different to other children but like all children at certain developmental stages they have come to the wrong conclusion about their perceived differences. They see doctors and therapists, undergo assessments and treatments that their siblings and classmates don’t, and are not told why. Some children may actually ask “What’s wrong with me?” or “why can’t I do things like the other kids?” These types of questions are definite indicators that information is required about their diagnosis. It is vital that you do not put off answering these questions, or dismiss these questions immediately. You should be forthcoming and not suggest talking about it later. Not providing the answer could increase the child’s anxiety and make the topic and information more mysterious.

Try to imagine if you went to the doctor for a check up. You ask him/her “what’s wrong with me?” and his/her response is “I’ll tell you another time!”. Imagine the anxiety and worry you would feel leaving the doctor’s office, and how your imagination would run wild with possible explanations.

How?

Start by calming yourself. Any signs of stress in you can make the child uneasy and worried. You should also ensure that the child is calm and relaxed, as children with ASD can find it difficult to process new information, and their ability to process is even lower when they have high levels of stress. Choose a quiet comfortable place, and try to ensure you will not be disturbed. Allow plenty of time as your child may have a lot of questions, and they will require extra time to process the information. Siblings interrupting in the middle of this could lead to unnecessary frustration, so try to ensure that they are entertained or are in the care of someone else when you broach the discussion.

Most children may only require minimal information to start. Explaining an autism spectrum diagnosis to an individual cannot be done in one discussion. The child will need time to absorb and process the information at their own pace. It may take a while, weeks or months even, before they fully comprehend the information you have given them. It is an ongoing process. More information can be added with time.

If your child is a capable verbal learner, you may choose to simply sit them down and have a face to face discussion. It may be beneficial to use their questions as a starting point. You may like to do this alone, with your partner, as a family, or with outside support.

A good place to start the conversation would be to discuss the differences between people. Pick out obvious physical differences before moving to personality and individual differences. You could extend this by writing a list of family strengths and weaknesses. You can discuss what your child is good at and what they find difficult. This could lead you to pointing out that there is a name to this particular pattern of strengths and weaknesses. Endeavour to make the information meaningful to the individual, and try to keep a positive focus at all times. A positive focus will help to foster positive self esteem and an effective atmosphere for learning. You will need to stress that Autism is not a disease and it is not fatal, and although there is no cure, there are ways of helping someone overcome some of the difficulties that arise from it.

Should you not feel confident about this straight forward discussion, you may choose to utilise one of the many excellent books and workbooks available to guide your child through their diagnosis.

- Vermeulan, P. (2000). I am Special: introducing children and young people to their autistic spectrum. London: Jessica Kingsley Publishers.

I highly recommend this book, as it is a gradual introduction to autism. The focus is incredibly positive, and many of the activities actually build self confidence as well as understanding. The introduction and instruction portion of the book is extensive, so please allow plenty of time to study this before you begin the worksheet section with your child.

Other books that may be of assistance can be found below.

- Doherty, K., McNally,P., and Sherrard, E. (2000). I have Autism. What's that? Down Lisburn Trust
- Gerland,G. (2000). Finding out about Asperger syndrome, high-functioning autism and PDD . London: Jessica Kingsley Publishers
- Jackson, L. (2002).Freaks, geeks and Asperger Syndrome. London: Jessica Kingsley Publishers

Finally, ensure you tell your child not to be afraid to ask questions. Open communication between you and your child will be essential to their acceptance and comprehension of the diagnosis.