

Teaching your child about their diagnosis

When your child receives a diagnosis of ASD it is normal for you to experience strong emotions. Some people will feel anxious and upset, while for others there could be a sense of relief, that your parental concerns have been validated. Whatever you feel is OK, and will take time to process. However the thought of sharing the diagnosis with your child may be even more daunting. When is the right time? How do you even start the conversation? Hopefully this help sheet will be thought provoking, providing you with some ideas to ponder. Remember that everyone will have a different point of view which will be informed by many things, including your child's age and level of understanding.



Why is it a good idea to teach my child about their diagnosis?

Many parents have an understandable wish to shield their child from the news that they have been diagnosed with autism. They worry that their child will feel different to their peers, or will use the diagnosis as an excuse to avoid things they don't want to do: "I can't do that, I have autism".

However, in our experience of working with many children on the autistic spectrum these concerns are usually unfounded, or can be avoided by taking a sensitive approach to the subject.

- Many children with ASD are already very aware that they are different from their peers. They notice that they may struggle in areas their peers do not, but are less likely to spot their strengths.
- This awareness of their differences and struggles can severely affect the self-esteem and mental and emotional wellbeing of someone with autism, leading them to describe themselves as stupid, useless or rubbish, and to avoid situations in which they fear they would fail.
- This fear of failure can lead some children to exhibit distressed behaviour as they seek to avoid the situations they think they won't be able to manage. These behaviours can be very challenging for parents, teachers and peers to cope with, and can lead the child to gain a reputation among their peers. Sadly some children can become scared of others who behave in extremely challenging ways.



Teaching your child about their diagnosis can help them

- To understand *why* they feel different to their friends, that there is a reason for their struggles
- To understand that it is not their 'fault'

- To begin to see their strengths, and that their diagnosis comes with positives as well as challenges
- To begin to be able to challenge themselves in small achievable ways, making progress in areas which are tricky for them
- To learn coping strategies to use when they are struggling, reducing distressed behaviour.



Choice Wheel

Choice wheel provides the student with a list of strategies that can be used for a specific time (recess), area or activity. Each strategy should be taught, practiced and practiced.

When is the best time to teach my child about their diagnosis?

There are different opinions on the timing of such a conversation, and what is right for one family may not be the best decision for another. Here are some thoughts to consider:

- An early approach to the topic will prevent the need to have a BIG CONVERSATION when the child notices that they are different to their peers. This would prevent there being a big surprise and may help the child to I think of this as being similar to adoptive families who choose to be open with their children about their adoption from an early age.
- Waiting until your child is older means that they may be more able to understand the terminology and may be able to do some reading on the subject for themselves. Be cautious if your child is able to access the internet independently. Searching for 'autism' will bring up a wide range of sources. Since autism covers such a wide spectrum of conditions only a small proportion will be relevant to each person. Some websites are downright disreputable. We suggest that you support your child to filter through any search results. If your child is quite able, you may find that searching for 'Asperger syndrome' brings back more relevant results which are less likely to alarm your child, even though this terminology is not used in diagnosis any more.
- If your child starts talking about the fact that they are 'different' or describing themselves in negative ways it is almost certainly the time to begin talking about their diagnosis in order to safeguard their emotional wellbeing, as mentioned above.

But how do I even begin these conversations?

Many parents find the thought of broaching the subject of an ASD diagnosis with their children very scary. It is hard to know how to start, or what questions to be prepared for. This will depend on the age of your child and their level of understanding, and it is important to view this as a process, not a one-off conversation. You don't need to try to give them all the information in one go. This could take the pressure off a bit, and these ideas might give you a starting point:



- You could begin by talking with your child about the fact that everyone is different. You could look for people with different conditions in books and TV programmes, talking about the things that might be difficult for them. Talk about people they know who wear glasses, or use a wheelchair. Parts of their bodies work differently and they need aids to help them see clearly, or move about.
- Move on to talking about the fact that your child also has things that are a bit different to others. Their brain is 'wired' differently to others. This means that they think differently to many other people, find some things hard and are really good at others. Your child needs to know that there are ways that adults can help them with the things they find hard – structure, support with communication and social skills etc, in a similar way to those who wear glasses and use a wheelchair. Don't forget to point out that *everyone's* brains are slightly different to everyone else's – we all have strengths and weaknesses and different opinions, it's not just them. The difference for someone with autism is how their differences impact them, living in a world designed for neuro-typical people.



Up to this point you could use these discussion prompts and ideas for any child who is struggling, whether or not they have a diagnosis.

- As your conversations develop your child may start to ask more questions. Or they may not, and you might find that you have to drive the process, giving them a little more information at a time as you deem they are ready. At some point, the next step will be to mention the A word.
- If your child can read, they and you might be more comfortable using a book to guide your conversations about autism. We have a list of books specifically designed to help children and young people with autism learn about the condition. There are books suitable for different ages and levels of understanding, and you will also find lots of other resources which may be helpful on our website (see link at the end of this help sheet)
- From this point it is important to continue to talk with your child about their diagnosis. They may know the word *autism* but do they know how the condition



impacts them? It is helpful to talk about this little and often, making it a natural and positive part of your interactions. Choose times when your child is in a good mood, as they will be more receptive.

Talking to siblings

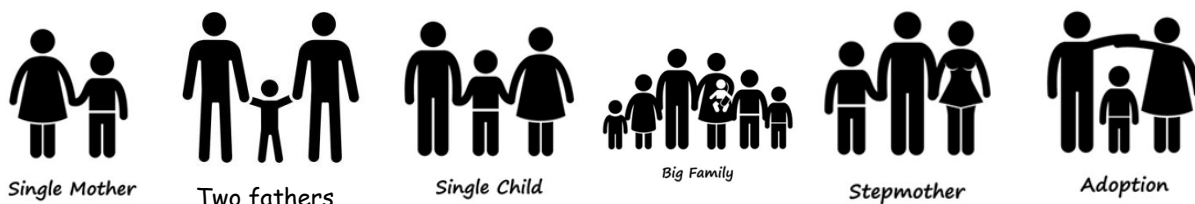
Siblings of children with autism often have to cope with quite a lot.

- Mum and dad may have to expend a lot of time and energy on their autistic sibling
- They may experience distressed behaviour as a result of the anxieties their brother or sister experiences, sometimes including physical aggression
- The way the family operates may be dictated by the needs or rigidity of their sibling.

Your other children also need to understand what autism is, why their sibling behaves the way they do and how their own actions might have an impact, but explaining to them might be risky if you haven't yet shared the diagnosis with your autistic child. I'm sure you can imagine scenarios where information slips out, intentionally or unintentionally.

There are books aimed at supporting the siblings of autistic young people, which can be found at the same link, found below.

Summary



Every family is different and you will need to make your own decisions regarding when and how to speak to your children. However, there are many reasons why it can be beneficial to teach your child about their diagnosis from a fairly early stage, and as long as the topic is presented positively there are very few negatives to doing so.



Resources

Resources on a variety of topics can be found on our website -

<https://www.freeoutreach.org.uk/Resources/>

The book lists mentioned in this help sheet are in this section -

<https://freemantlesoutreach.org.uk/Resources/Autism-Awareness/>

Girls with autism often (although not always) present differently to boys. We have a book list specifically about ASD in girls, as well as other information. These can also be found here:

<https://freemantlesoutreach.org.uk/Resources/Autism-Awareness/>

You may find the links in this section useful - <https://freemantlesoutreach.org.uk/Useful-Links/>

Here are some links to other useful websites and videos which might be useful for you, your autistic child or their siblings to read or watch:

The Autism Education Trust website has a section for parents -

<https://www.autismeducationtrust.org.uk/for-parents/>

And a Kids Zone, including videos aimed at those with autism and their siblings -

<https://www.autismeducationtrust.org.uk/kids-zone/>

The National Autistic Society has produced a range of resources which are available on their website - <https://www.autism.org.uk/>

Their videos can be found on their YouTube channel -

<https://www.youtube.com/user/NationalAutisticSoc>

My Autism and Me (BBC) is a lovely video presented by autistic young people and looking at a variety of ways autism can affect different people -

<https://www.youtube.com/watch?v=ejpWWP1HNGQ>