

Information Sheet: Sharing an Autism Diagnosis

When a diagnosis of autism is made, family, friends, and the individual themselves may wonder with whom to share the news with, and when.

This information sheet describes ways you can share a diagnosis of autism with people. It is for families of someone who has been diagnosed with autism and for autistic people.

Introducing a child to their diagnosis

Autistic people are often diagnosed as children and their parents may grapple with the question of when to inform the child of their diagnosis. Benefits of explaining to the child about their diagnosis of autism include:

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

When parents have decided it's time to inform the child about their diagnosis and feel the child can understand, the next decision is exactly what to say.

The first thing to consider is the age of the child.

Younger children will have less ability to understand so the information will need to be tailored in an age appropriate way. Explain what autism means as best you can, using simple words which are within your child's vocabulary.

Be Positive! Being diagnosed with autism is a big deal, so it's important to be clear autism comes with a number of unique strengths as well as difficulties.

This table indicates some common areas of strength for autistic children and ways parents might discuss these with their child.

For autistic children, the two common reactions to being told their diagnosis are relief and vehement denial. (A child in denial may insist that nothing is wrong with them and everyone else has the problem.)

Strength Examples

Amazing memory (for facts, music, imagery)

"You always remember directions to where we're going."

"You remind me of important dates when I've forgotten."

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“You’re great at finding things.”

“You are an expert on animals.”

Good spatial problem solving

“You are the fastest at jigsaws.”

Attention to detail

“You are thorough and make sure things are done properly.”

“You help me to know when I’ve made a mistake.”

Excellent understanding of systems

“You know how things work without reading the instructions.”

If your child reacts negatively to the news they are autistic, it may be helpful to teach them more about autism. There are several children’s books written about autism, such as those by Kathy Hoopman and many others or ask the librarian at your local library for more. Reading these together may lead the child to relate to the autistic characters or qualities.

Helping your child to connect with other autistic children may help them to see they are not alone. Another idea might be to talk about famous autistic people, like Temple Grandin, and all the amazing things they have achieved with their different brains. As Dr Grandin herself says “The world needs different kinds of minds to work together.”

Explain the autism your child has. Autism varies so much from person to person; it is important to talk to your child about their experiences specifically. For example, you might say “you know how you say the lights at the supermarket are bright and flickering and hurt your eyes— being sensitive to that kind of light is part of your autism”.

Or maybe “you know how you’ve told me you don’t know how to join in and play with the other children at school? Having autism can make those sorts of things difficult.”

Explain the ways autism affects them directly and include ways of working around these issues so they don’t seem hopeless or overwhelming. We’re in this together. Remind your child you love them exactly the way they are and you will be there to help them.

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.

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“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.

If there are people with whom the child interacts regularly or who babysit, it will be helpful for them to know about the diagnosis. Parents may want to tell key people one at a time or invite the family to get together, discuss the diagnosis and share the strategies which are to be used with the child. Parents may also suggest people contact Amaze for more information if they need it.

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 indicate how 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 (e.g. ‘Billy has difficulty learning to speak, please use very short sentences for him’). As awareness about autism is increasing, more people will understand what it means to have a diagnosis and simply saying “Billy is autistic” will suffice.

Informing Siblings

Explaining the diagnosis to brothers and sisters will differ depending on their age.

Children aged 2-3 years will need a clear, short explanation about the sibling’s difficulties, without divulging autism specifically. You might say ‘Talking is hard for Billy’, which describes a behaviour the sibling can easily see.

Pre-school aged siblings typically ask a lot of ‘why?’ questions, which provides an opening for parents to discuss the reasons behind the child’s behaviour. Parents can provide answers like ‘Billy finds it hard to play. His brain works differently from yours and mine. He doesn’t like to pretend with toys like we do’.

Early primary school aged siblings 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 ask ‘Can I catch autism?’, ‘Did I cause my sibling’s autism?’ It is important to stop any misconceptions if you become aware of them.

Siblings aged 9 years and older can understand more. Parents can talk about the specific behaviours displayed by the autistic sibling and how this fits with the overall characteristics of autism.

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“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. There are books and resources which target various ages that families can read either alone or together.

Telling the School

Amaze has an information sheet about informing the school on our website.

Disclosing your own diagnosis

Autistic individuals 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 autism.
- Sometimes disclosing the diagnosis may make others react negatively towards you. People who react negatively are not helpful people to stay involved with.

Guidance for parents found earlier in this information sheet may be helpful to autistic people as well when disclosing. For example, it can help to explain what autism means to you in particular, but in terms of both your difficulties and your strengths.

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