
How do I talk to my child about their autism spectrum disorder (ASD) diagnosis?

- Many families struggle with the decision about how and when to talk to their child about their autism diagnosis. As a parent you may need time yourself to process your child's diagnosis before speaking with your child. You also need to feel prepared for the questions that your child might ask you. However, it is important to know that you do not need the answers to every question right away! You can share information little by little as questions and concerns come up over time and as you and your child are ready for more in-depth discussion. Remember to use language that your child can understand and that is appropriate for their stage of development.
- Here are some things to consider before talking to your child about their ASD diagnosis.

The Benefits:

- Knowing about the diagnosis can help a child to explain the differences they have noticed between themselves and other children. Knowing why his or her experiences and behavior are different can often help to reduce confusion and frustration.
- If left unaddressed, these differences often affect how a child perceives themselves and can have a negative impact on a child's self-esteem.
- When your child more accurately understands their strengths and challenges, they may be more likely to ask for help, and/or advocate for themselves.

When:

- There is no specific time or age to tell your child about their diagnosis of ASD.
- As a parent you should consider your child's age, developmental level/understanding, personality, social awareness and abilities.
- If a child has started to ask about their differences, it may be an indication that they are ready to start this conversation. However, it is important to remember that some children may have similar thoughts or questions, and are either unable to ask or may be unable to express their thoughts. For those children who cannot yet express their thoughts, look for cues they may give that show you that they are aware that they are different than others (e.g., watching another child behave differently than they did in a similar situation).
- Start this discussion when everyone is calm (not when you and/or your child are upset).
- Make sure there is enough time for your child to think about this new information and ask questions.
- Be prepared to repeat information many times and as often as needed.

Who and Where:

- The person who speaks to your child about ASD should be someone with whom your child is comfortable. This person will vary from family to family (e.g., mom, dad, sibling, aunt).
- For some families, a professional may be able to help support you with this conversation.
- Choose a place that is comfortable for your child and that is free of distractions.

What and How:

- Setting a positive tone about each family member's uniqueness, strengths and difficulties may be a great place to start. Talk about different abilities in a positive way. That is, start with a strengths-based approach.
- Personalize the information to best suit your child. If they have asked a question, this might be a good place to start.
- Give your child the amount of information you think they can process. Start with clear and uncomplicated information. Add additional, and more complex, information over time as your child's understanding increases.

- Present the information in a meaningful and developmentally appropriate way. This might include books, videos, websites, meeting with others, or a sit down conversation. Get creative, and consider to your child's interests.
- Help your child cope with this new information. Some ways to do this are as follows:
 - Read books or stories about ASD.
 - Talk about other people who have ASD or famous people who have/may have ASD. For example, Temple Grandin or Mozart.
 - Take part in groups with others who have ASD.
- Assure your child that everyone is different and unique. Talking about other people that have ASD may help "normalize" the issue. It is important to emphasize that their ASD is merely a difference in how they experience the world. Let them know that if they need supports, that there are supports that can be received to help them overcome challenges.
- Make sure your child understands that they are first and foremost a person with many wonderful characteristics, and qualities. ASD is simply one part of who they are as a person.

RESOURCES

The Resource Centre (a Sinneave Family Foundation initiative) does not endorse or guarantee the exhaustive, complete, accurate or up-to-date nature of information provided and does not assume any risk for the outcome of information or referrals provided.

Books for Children and Teens

A Special Book About Me: A Book for Children Diagnosed with Asperger's Syndrome

Author: Josie Santomauro

Publisher: Jessica Kingsley Publishers

Can I Tell You about Asperger's Syndrome? A Guide for Friends and Family

Author: Jude Welton

Publisher: Jessica Kingsley Publishers

Different Like Me: My Book of Autism Heroes

Author: Jennifer Elder

Publisher: Jessica Kingsley, London, UK

Freaks, Geeks, & Asperger's Syndrome: A User's Guide to Adolescence

Author: Luke Jackson

Publisher: Jessica Kingsley Publishers, Philadelphia, PA

I am Special: Introducing Children and Young People to their Autistic Spectrum Disorder

Author: Peter Vermeulen

Publisher: Jessica Kingsley Publishers, Philadelphia, PA

What Does It Mean To Me? A workbook explaining self-awareness and life lessons to the child or youth with high functioning autism or Asperger's

Author: Catherine Faherty

Publisher: Future Horizons Inc., Arlington, TX

Books for Parents and Caregivers

Making Sense of Autistic Spectrum Disorders

Author: James Coplan

Publisher: Bantam

Siblings of Children with Autism: A Guide for Families

Author: Sandra Harris & Beth Glasberg

Publisher: Woodbine House

The Autism Sourcebook: Everything You Need To Know About Diagnosis, Treatment, Coping, and Healing

Author: Karen Siff Exkorn

Publisher: William Morrow

Websites

Autism Speaks

This website has family support tool kits, resource guides, and a library.

Website: autismspeaks.org

Interactive Autism Network (IAN)

An online article, "ASD Diagnosis: What Do We Tell the Kids?" is available at their website.

Website: iancommunity.org/cs/articles/telling_a_child_about_his_asd

Autism Victoria: Amaze

Autism Victoria has created a fact sheet, "Sharing the Diagnosis of Autism Spectrum Disorder" which is available in pdf form on the Amaze website:

Website: amaze.org.au/uploads/2011/08/Fact-Sheet-Sharing-the-Diagnosis-of-Autism-Spectrum-Disorder-Aug-20111.pdf

Asperger's Syndrome and High Functioning Autism Association (AHA)

AHA serves individuals on the autism spectrum, their families, and the professionals who work with them, providing crucial resources and support as they face challenges, build on their strengths and fulfill their potential. The following article written by Tony Attwood, is available here: "Should you explain the Diagnosis to the Child?"

Website: ahany.org/should-you-explain-the-diagnosis-to-the-child

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