

PFA Tips

“You Have Autism”

I’ve often been asked if I’ve told my son about his Asperger’s diagnosis. My response has always been the same. “If Hunter had a medical condition I would give him all of the necessary information to help him manage his physical health. Why would I treat a neurological condition any differently?”

Why tell my child?

Knowledge and education are powerful tools. If Hunter had diabetes, I certainly wouldn’t keep that fact from him. I would explain it to him and go over what that medically means, and teach him how to treat the condition. If he didn’t have that information, he could potentially die from a diabetic reaction. Now, I don’t believe he’s at risk for death if I didn’t explain his Asperger’s to him, but he certainly can’t learn to cope with the symptoms he experiences if he’s never taught the tools. Our kids on the Autism spectrum are extremely perceptive, even if they are not able to articulate their thoughts. They know that something is just different, and not understanding what that is can really spike their anxiety. If no one ever talks about the “difference”, then it’s perceived to be bad. Plus, if you are always taking your child to doctors and therapists and not telling them why, they are left to develop their own conclusions which might include fears and thoughts of terminal illness.

This discussion is not meant only for our children that can converse and ask questions. We sometimes forget that our children who are nonverbal may have just as many questions about their differences, but simply are not be able to express their concerns. Just imagine how many questions may be locked inside our kids. Noted author William Stillman emphasizes that we must always presume intellect and remember that intelligence is not connected to verbal expression.

How do I tell my child?

It’s all in how you frame it. Telling Hunter about his diagnosis doesn’t imply that I’ve ever told him that what he has is bad, or debilitating, or something to keep hidden from others in shame. As a matter of fact, Hunter recently had to fill out a survey and it asked him to list if he had a disability. He checked the “no” box. At that moment I realized I’ve never used the term “disability” when talking about Autism with him. It’s simply a **difference**. Point out the gifts that your child has, such as his intense passion or expertise for a certain topic, or his tremendous capacity for empathy due to his heightened senses. If you act nervous and upset then he’ll think this is something awful.

What does my child need to know?

I first told Hunter about his Autism about five years ago (he’s 11 now). But for this article I asked him to think about what he might want to know if I was just telling him for the first time now. He said there are three things he would want me to answer: **What is Autism? Is it bad? How did you know I had Autism?** I was surprised that he did not include “How did I get Autism?” Keep in mind the child’s age when you are formulating what you want to say, and how you answer their questions. Younger children are better suited for the basic, minimal content as this is already a complex topic. Older children may want to supplement your discussions with their own online research. If that’s the case, you may want to monitor what they pull off the internet because as you know there is a lot of false information about Autism posted on the web.



When is the right time?

There’s no perfect time. Don’t wait for that “perfect” moment, or day or month. There will never be one. You will always be too busy, too overloaded, too tired, too nervous. Waiting doesn’t lessen the impact and not telling your child won’t make Autism go away. You have a diagnosis. This isn’t a phase. You can’t hope that if you wait a month or a year that he will outgrow his Autism and then you won’t have to deal with this. If your child begins asking questions, that may be an ideal time to begin the conversation as it shows he is interested and open to knowing. And while there are no “perfect” times, there are however “bad” times. Refrain from blurting out the diagnosis during a challenging moment or right after a negative experience. Instead, tell your child about his diagnosis after a positive behavior or event and when things are calm (or relatively calm...). That helps you set the stage that Autism isn’t “bad”.

How do I present the information so my child will understand?

Provide the information in a manner that matches his learning style. When learning

continued on page 2

“You Have Autism” – cont.



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about something new, does your child prefer to read books? Talk with someone? Watch a video? Look at pictures? Converse in emails or text messages? Also keep in mind how much information your child is able to digest at one time. You may want to break the information up into small parts over several discussions, and tell your child that this is an open, and ongoing dialogue. Think about the discussions you have with your child's teachers about how your child learns best, and apply those same tactics. Be mindful of your language. Remember, people with Autism tend to have difficulty with euphemisms, metaphors, sarcasm, white lies or flowery language. You are not going to “soften the blow” by dancing around terms. Use straightforward literal matter-of-fact language to dissolve confusion.

Who should talk to my child about the diagnosis?

You might immediately say it should be the parents. Well, in many cases, the parents are

the right people. However if you are afraid that you might become too emotional and that your reaction may make your child upset, then you might want to ask a professional to help you or even explain the diagnosis to your child. A professional would be able to talk to your child in a matter-of-fact and objective way. You may also want to include additional people in your child's life to talk about your child's Autism from their perspective relationship. For instance, your child's teacher can explain why your child is receiving certain accommodations. “I know your Autism may make the lights feel too bright or the classroom noises sound too loud. When that happens you can show me this card and we will give you a break to a less bright, more quiet room.”

Your child may benefit from talking with someone else who has Autism to learn about their perspective and experiences. Also keep in mind that your child may know other kids at school who have Autism

but are quite dissimilar from themselves. Explain that no two people with Autism are alike even if they share a common diagnosis.

Should I include my other children in the discussion?

Don't leave the siblings out. There are days you will refuse to believe this statement, but your child's siblings are part of his natural support network. (Yes, even when they are fist fighting over the remote control.) You can encourage compassion, tolerance, patience and acceptance. Tell your child with Autism first before you tell his siblings because you don't want to create an environment where you child is “the last to know.” For more resources for siblings, take a look at our PFA Tips: Siblings at <http://pathfindersforautism.org/articles/home/pfa-tips-siblings/>

Additional Resources

Video: Explaining Autism to Children: ASD and Me
<https://www.youtube.com/watch?v=SU-7946HIMw>

Video: Stephen Shore talks about telling your child he has autism
<https://www.youtube.com/watch?v=MmrR4UgKFyA>

The following books are available on Amazon:

Different Like Me. My Book of Autism Heroes Ages 8-12

What It Is to Be Me!: An Asperger Kid Book Age 4+

What is Asperger Syndrome and How Will It Affect Me? Age 12+

Freaks, Geeks and Asperger Syndrome Age 12+

I Am Utterly Unique: Celebrating the Strengths of Children with Asperger Syndrome and High Functioning Autism Ages 4-9

I Am Special: A Workbook to Help Children, Teens and Adults With Autism Spectrum Disorders to Understand Their Diagnosis, Gain Confidence and Thrive Age 10+

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