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Understanding Autism Spectrum

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Sharing a Diagnosis of Autism Spectrum with Family and Friends

Podcast 2

Welcome to my podcast. I'm Anna Tullemans bringing you information, support and tips on all aspects of Autism Spectrum.

Today's podcast is part of a series of podcasts on how to share a diagnosis of Autism Spectrum. Today we will be discussing sharing the diagnosis with family and friends and further individual podcasts deal with sharing with the child, grandparents and siblings.

You will find more information in my book "Disclosing the Diagnosis" which is available on my website: www.annatullemans.com.au . Each chapter gives specific ideas and encouragement on how to approach the topic of diagnosis and how to explain it in language that people will understand. It includes chapters for grandparents, siblings, extended family members and the wider community such as schools.

Remember that the following is just a starting point to give you ideas. It is not definitive by any means. You need to look at what approach will work best for you and your family. You know your child best so follow your instincts and it will be the right way for you.

People often ask whether they should share a diagnosis with family and friends, and my answer is always yes. As I said in my previous podcast it is not the label that we are discussing today, it's about how to find the right language to use that is appropriate and that people will understand.

When extended family and friends understand the diagnosis and how it affects your child, it can help them become mentors for your child and an ally for you. By understanding and learning how to interact with your child, family and friends can help teach communication and social skills. Part of this knowledge helps them to understand that normal expectations can't necessarily apply to our children and that family and friends will need to make adjustments and modifications so that they (the family and friends) can enjoy their interactions with our children.



Some things to think about before sharing information:

- Choose words that you understand or terms that you can fully explain when questions are asked
- Use some written information that people can take home and re-read
- Choose carefully who you are going to tell
- Be prepared for negative reactions. Not everyone will agree with the diagnosis
 - Be prepared to find that some friends will never really understand and that that friendship may be lost to you

Always provide family and friends with:

- Clear, honest information
- Include a brief description of the challenges that your child faces eg
 - “John doesn’t look you in the eye when you talk to him. If he does, it takes him so much concentration that he can’t hear your words.”
 - “Peter is not good at sharing his toys with Sammy yet, but we are teaching him about taking turns. It’s just that his ASD means that it takes him a little bit longer to learn how to do this.”
 - “Sometimes at family gatherings Daniel has trouble playing with other children because there is so much noise, colour and smells and he gets too excited. When this happens he needs to go to a quiet place and be by himself for a while.”
- Balance this with positive skills eg
 - “But he reads really well”
 - “He’s great at building things with Lego.”
- Explain some simple strategies that you already use and that are successful eg
 - I use a picture of a book (visual) when I need him to sit down and relax
- Give them other strategies to use when the previous ones don’t work eg
 - using a timer to show that an activity has finished
- Show them what to do when your child is having a meltdown eg
 - Move everyone away, or move the child outside
- Give them information on the tell-tale signs of when a meltdown is about to happen or is in its rumbling stages eg
 - A young man I was working with would often hum at a higher pitch before a meltdown



Here are 8 tips to use once you have given family and friends the information on the diagnosis:

1. Encourage F and F to discuss their fears, disappointments, confusion and concerns
2. Offer friends a short list of internet resources, books and websites that you have found useful
3. Don't insist on hugs and kisses if they are not part of a daily routine. We want to be able to de- sensitise and teach this culture that is accepted by our children. (See my book *The Fun Side of Asperger's* for ideas on how to teach giving hugs and cuddles to our Autism Spectrum children. This book is available on my website). There are also downloadable tip sheets that you can use too.
4. Help F and F to choose appropriate gifts to avoid sensory issues eg No loud whistles
5. Teach F and F the skills they need to know for family functions and get-togethers (More downloadable tip sheets available from my website)
6. Remember that sometimes F and F need reminding that some strategies will not work every day
7. Encourage them to modify strategies to suit the situation
8. Always give F and F encouragement for every effort they make whether it worked or not

When you are sharing the diagnosis, be guided by your instinct. You know your child best and you know your family and friends. Be gentle with them too as they don't live with Autism Spectrum in the house 24 hours a day like you do. In time many will understand that you are doing your best for your child.

Well I hope you have enjoyed this podcast on sharing the diagnosis with family and friends. This is number 2 in a series of sharing the diagnosis with the child, grandparents, siblings, extended family, and friends.

If you would like more detailed information on this topic or to purchase a copy of my book "Disclosing the Diagnosis", you can go to my website: annatullemans.com.au

Thank you for listening and we'll see you next time.

