

CONFERENCE PAPER by JOSIE SANTOMAURO

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"I'VE GOT A BURGER SYNDROME"

"I've got a burger syndrome!" my nine-year-old son announced to his younger sister. *Well he may as well have – with the amount of cheeseburgers he can devour in one sitting!*

Jokes aside, how **do** you tell your child that they have Asperger's Syndrome? When is the best time to tell your child about their diagnosis? Hopefully, through my personal experience I can assist families with this awkward 'moment'. It can be a little like telling them that they have cancer, or that Grandpa has died, or that Mummy and Daddy aren't going to live together anymore. Your heart is breaking, you don't know how they'll react - and you keep putting off the inevitable.

Remember how you felt as a parent when you were told? You may have had mixed feelings. In one way you were relieved, because now you knew what 'IT' was, and in another, you felt a lump in your heart. Why us? Why our child?

If your child is mature enough to understand, they may also go through the same grieving and confusion as we, the parents did. Although the diagnosis can have a higher impact on the child because they are living it!

There may be differing reactions, eg:

"Why me? I don't want it – make it go away!"

The child can go into denial and suffer from depression. Then they'll need your support while trying to absorb all the facts.

"I'm great, I've got Asperger's Syndrome!"

The child hasn't quite understood what the syndrome is about, and thinks it's some kind of special game or title.

Your child may feel relieved

At last they know why they have always felt 'different'.

You may like to use these basic 'tools' when you've made the step to share the diagnosis with your child.

The Courage tool

How and when to share the diagnosis with your child.

When? A parent's decision should be made based on their individual child. Is your child ready? Only you can answer this question. You know your child better than anybody else. Don't be pressured to tell or not to tell. There is no 'set' age. Some parents tell their children immediately after diagnosis, others wait until they feel their child is able to cope with the information. If your child starts asking questions about their needs, or if their stress levels are unusually high for no

apparent reason, these may be the cues for you to sit them down. There's a lot to be said for good old 'mother's instinct' or 'gut feeling'.

Are you ready? Do you have the courage to share the diagnosis? Do you require support? A friend, your partner, paediatrician, or other parents in a support group may assist you. Are you still dealing with the diagnosis? You need to be calm and confident, if you're child picks up that you are nervous or tense, they may feel afraid or think they have a 'bad' thing. You may choose to wait until you are armed with enough information to deal with your child's questions.

How? These are a few ways in which you can share the information with your child, visually and verbally.

Videos obtained through your local support group or the Autistic Association of your state.

The social story book 'Pictures of Me' by Carol Gray introduces a child with Asperger's Syndrome to their individuality.

My booklet 'The Mystery of a Special Kid' introduces Asperger's Syndrome through clues, leading the child to solve the mystery about themselves. The booklet gives a basic explanation answering the how, what, when and why's of Asperger's Syndrome.

If you're child is a capable verbal learner, then you may decide just to sit them down and have a face to face discussion about the diagnosis. You may like to do this on your own, with your partner, as a family, or with outside support, e.g.: Paediatrician, support group, or an older child with Asperger's Syndrome.

The Support tool

Ways in which you can support your child after informing them.

Various reactions have been denial, indifference, and depression. Here are some easy strategies you can put into place to support your child.

Talk openly with them and other family members about Asperger's Syndrome, show them that it isn't a taboo subject;

Provide them with more information as a follow up to your first discussion;

Help build their confidence with self-esteem activities;

They may feel ready to share the diagnosis with their peers/classmates, discuss this with your child and if so, follow up with the class teacher on how and when to do this;

Ensure your child understands that they can come to you anytime with questions;

Have their pediatrician/psychologist/doctor confirm the diagnosis with the child;

Encourage your child to keep a diary/journal of their thoughts and feelings;

The Learning tool

How you can teach your child to look at themselves as individuals and in helping them to gain independence and self-esteem.

It is important for your child to continue their journey of learning about Asperger's Syndrome, that it's not going to 'go away', but that they can learn to live with it and be happy and successful.

Some ways to assist your child to do this are:

Join the local Asperger's Syndrome support group;

Explain that they are not 'alone', find a chatroom on the Internet where your child can talk with other kids with Asperger's Syndrome;

Attend social skills classes;

Encourage them to write to another child with Asperger's Syndrome. (The Morning News Pen Pal Registry);

Explain the importance of timetables, charts, and diaries. They will become essential tools for your child as they grow into adulthood. (Let's be honest, how many of us can get by without timetables, charts and diaries!)

DAMIAN'S INTERVIEW

How old are you?

I'm 9 years old – but my birthday is in two weeks and then I'll be 10.

How did you feel before you knew you had Asperger's Syndrome?

Not normal, I knew I wasn't like other boys.

Did you know there was something different about you?

Yes

How did you know you were different?

I didn't do what other boys did.

How did you feel when your parents told you about Asperger's Syndrome?

Happy – I liked it! Because then I knew what I've had all my life, why I've been getting uptight.

How do you feel now, about having Asperger's Syndrome?

$\frac{3}{4}$ good because I have it and I like being different

¼ bad because I get uptight a lot

What do your friends or classmates think about you now they know you have Asperger's Syndrome?

Nothing has changed.

Because you have Asperger's Syndrome, what are the things you can do to help yourself?

I don't like these types of questions!

What is Asperger's Syndrome?

A disability

A small part at the back of the brain that's not working the same as others.

Something that makes you uptight and makes you not look at the other person and stuff like that.

What are the things you find hard to do because of Asperger's Syndrome?

Changes being teased

Sports I get confused

Short memory

Worksheets you have to read and pick out stuff

What are the things you find easy because you have Asperger's Syndrome?

Maths Science

Long memory

Write a sad story about you and Asperger's Syndrome.

I lost control and got really angry at Dad and kicked him one day.

Write a happy or funny story about you and Asperger's Syndrome.

What do you mean?

Anything else you'd like to write about.

I'm wondering why my parents didn't tell me two years ago – at least last year.

Damian was presented with this questionnaire and willingly filled out all sections on his own.

He couldn't quite explain to me what he meant by 'normal boy', but knew that he was different. I

think this relates to when he wants to be part of a social situation, and doesn't have the instinctive skills to do so.

Damian has strong feelings of failure when he loses control with his anger, and this came through in a lot of his answers.

I'm pleased he doesn't feel ostracised by his peers, these children have known him since first grade and quite often just say 'but that's just Damian!' We also had 'show & tell' with Damian's class, explaining Asperger's Syndrome and why he has the aide etc, following the session with an activity sheet where the children had to fill in details of their own disability and personality details.

He doesn't like open-ended questions and hates comprehension (the worksheets that you read and pick out stuff).

He was obviously tired by the end of the questionnaire and couldn't be bothered with the 'happy/funny story' question.

Josie's Diary entry

March 1999

Damian had started to question why he 'wasn't like' other boys. He began to reject his Teacher-aide at school; it was a clear case of not wanting to appear 'different', wanting to fit in. He had many questions. Why did I have to go to that special school last year, other kids in my class didn't? Why do I need a Teacher-Aide? Why did I go to different types of doctors? He'd fallen into a depression. Wanted to stay home all the time, didn't want to go to school. He was constantly sad, going to bed crying. Not knowing why he was feeling this way. He seemed very confused.

It was time to tell him. The reasons we had waited 4 years were fading fast. Up until now we'd gotten away with self-esteem comments 'you need help with listening, and Johnny needs help with Maths, but you're really good at Maths and Johnny is good at listening'. The 'you're special' came up a lot! Damian was diagnosed at the age of 5 as 'mild' and we felt he was too young to understand this 'label' and that maybe he could get by in life with speech therapy and social skills classes and.....who were we kidding! I'd also heard of another child who used the label as an excuse without really understanding what the Syndrome was about, and so we decided to wait until he was mature enough to understand the enormity of it all. I started to feel a slight guilt, Should I have? Could we of? When he was first diagnosed, there was a minimal amount of information available, and what WAS available was quite depressing. The last four years have been a learning curve for us as well, and I now felt confident in answering his questions.

Early April 1999

He was going downhill fast, his dark moods and depression were heart wrenching. His reactions to his anxiety and stress levels brought him from 'border-line' to full-blown AS!

We decided to spend the Easter break at the beach, one of Damian's favourite places. One evening we were at a seaside restaurant and he looked out the window and the saddest look came over his face. I looked out to see a group of teenage boys playing on their skateboards, laughing, joking, and just 'hanging out'. Damian told me he wasn't like them, he knew he wasn't like other boys. I think that's when he felt the loneliness, the frustration of not knowing how to 'hang out', the sadness. I felt sad with him. I decided that evening that he should know and know now. My mind was swirling as we arrived back to our apartment and I sat down with him...I went blank. I couldn't get the

words out. 'You're special to us'; 'you're good at this' was all I could manage. I knew that he wouldn't just settle with a label. The questions would come thick and fast and I'd have to have the answers. Then the answers would have to be given in a way that he could go away and absorb them in his own time and way. I knew that Damian would want facts! I spent the rest of the week drafting up a booklet catering for his visual learning ability. I wanted the booklet to attract his attention, answer his questions and make him feel good about himself again.

Late April, 1999

After two days on the computer I produced a booklet titled 'The Mystery of a Special Kid'. It was ready, we weren't! We waited until his little sister was fast asleep and hit him with it that evening. Sat him down and read the booklet to him, his eyes lit up when he realised it was about him. A bag of mixed emotions. He was intrigued as well as sad, relieved and excited. How do you feel? I asked him. 'Glad that I know what's wrong with me' he answered. It was as if a cloud had lifted (from both of us!). Strangely though, he hit us with a question.

'What about Dad?' he said.

'What about Dad!?' I answered.

Dad was sitting in another chair very quiet and solemn.

'Is Dad sad that I have Asperger's Syndrome?' he continued.

'No, why do you say that?' I asked.

'Because you've been doing all the talking, and he hasn't said a word' he looked at his father with a look of 'has Dad accepted me?' or 'have I failed him?'

It was at that moment that I started to understand the importance of a special bond between a father and son.

We kept him home from school the next day. He spent most of the day re-reading the booklet over and over. He had his ups and downs that day, he even went through the 'why me?'. I call it his 'grieving' day.

He still has grieving days, I know because he has the booklet out on his bed.

He's still trying to absorb the information. Damian is a very visual learner and so I tried to cater for this. He had to solve the case of this 'special' kid and after clues, questions etc. he discovered that it was himself. I wanted him to know the hows, whens, whys and what's of Asperger's Syndrome, but in a lighthearted way. I wanted him to know that we all have a disability. There are also some self-esteem activities and hints on how he can continue to lead a happy life and carry on being a successful citizen.

Well I just got over that hurdle and now I have another dilemma. After reading the booklet to his sister, she asked 'Are you going to write a book about me Mummy?' – now that's another paper..And another booklet! **'You're Special Too!'** for siblings is in the making!

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