

Mission... Possible

When Jo-Ann's son was diagnosed with severe autism, she did everything she could to help. Now she's turning her attention to all children with the condition, writes **Sue Thomas**

The first thing you notice about Jo-Ann D'Costa-Manuel is how tiny she is; she recently opened her door and was asked, 'Is your mummy in?'

Then how attractive and chatty she is (no surprise that she did a drama degree and worked in children's telly). But the lasting impression is of a woman (she's 39) who'll do anything to improve the lives of families whose lives are touched, as hers is, by the complicated, little-understood condition, autism.

In 2010, Jo-Ann and her husband, Wayne, quit their jobs (she was a recruiter, he designs telecoms networks), sold their house and moved to Australia with their daughter, Sienna, then four, and son Cruzy, one.

Less than a year later, Cruzy began to regress. 'He'd been so

sociable and easy-going,' says Jo-Ann. 'At story time in the library, he'd run to the front and dance. Now he'd cover his eyes. He'd been putting words together but now seemed to forget them - then stopped speaking altogether. He was like an empty shell. And where he once ate anything, he only wanted milk, or brown, dry food, like crackers.'

'Crowds or noise made him anxious, and he'd bite and headbutt us, or bash his head against the wall,' says Jo-Ann. 'When he stopped responding to us, I took him for a hearing test. I remember thinking, 'Please, God, let it be this, not autism.'

The GP told her boys can be late developers but Jo-Ann knew something fundamental had changed with her son, and did her own research. 'Every time

I put his symptoms into the computer, 'autism' came up. There was a six-month waiting list to see a specialist but having read about

Cruzy is now seven, and his sister, Sienna, is 10



the importance of early intervention, we paid to have him assessed privately. 'We're sorry,' we were told, 'but this is autism, it's severe, and may never improve.'

Jo-Ann and Wayne sold their house to fund a treatment they'd learnt about called ABA (applied behaviour analysis), which focuses on life skills, such as speech, social skills, play and personal care (many people with autism remain in nappies), which can cost around £45,000 a year. She removed gluten and dairy from Cruzy's diet and gave him organic food. 'When we took out gluten, he got his first word back, so I believe it was a combination of those two interventions,' she says.

Today, the family are back in West Sussex, with the council funding Cruzy's ABA programme, which is being scaled down year by year. He

still has challenges, but is at mainstream school, learning to read, has friends, communicates and eats a varied diet. Job done? Not quite. Now Jo-Ann and Wayne are helping parents who can't afford the treatment they believe in, by forming a not-for-profit organisation called Autism Parent Empower.

Its 12-week programme employs experts to arm parents with skills for communicating with their autistic child, cooking



Jo-Ann with her husband, Wayne...



...and alongside John Caudwell being interviewed at the Autism Parent Empower launch



What Is Autism?



'Around 1% of the population has autism spectrum disorder (ASD), ranging from severe communication and developmental problems, to Asperger's syndrome (social interaction difficulties, often with above-average intelligence),' says *WW's* Dr Melanie Wynne-Jones. The cause may be a mixture of genetic and environmental factors; ASD may be increasing or just being better recognised. Symptoms appear early in life, but children may be labelled 'naughty', and some people aren't diagnosed until late childhood or even adulthood. A specialist diagnosis opens the door to appropriate help and can transform education, work and social skills, although more resources and support are still needed for people with ASD and their families. Visit autism.org.uk for more info.

a card and teach him what it is. But he might not recognise it in other settings, so we go to Tesco, the farm - expose him to oranges in different ways and settings, until he truly 'gets' what it is.

The Richard Branson factor

Going on holiday can be so daunting for families affected by autism that many don't bother. Jo-Ann took Cruzy on a grounded plane that Virgin makes available for flying phobics, and families with autism. 'You can go several times, show children the food trays, how everything works. After I made a short video about it for parents, Branson's office asked me to be Virgin's Autism Ambassador along with another autism mum on a mission, and we're working on training their 4,000 staff in autism awareness. I'm also setting up a meeting with Richard Branson to discuss taking what I'm doing to a global level.'

Siblings are unsung heroes

'Sienna was four when Cruzy began showing signs of autism. Siblings are often forgotten as attention is focused on the child with autism and research shows some grow up with low self-esteem and depression. I have a 'date' with Sienna every week. Nothing interrupts our time.'

The cost on relationships

'When Cruzy was diagnosed, I cried; Wayne immersed himself in work... But we managed to hold on to each other until we met in the middle again.'

free-from foods, teaching them life skills. Currently only in Crawley (she asked the council for premises), Jo-Ann's mission is to expand it across the country, even globally. Here's how she's done it and what she's learnt.

Dear Mr Billionaire

With the money from the house sale almost gone on ABA and nutrition intervention, Jo-Ann approached the charity Caudwell Children, which gave them funds to continue. For Autism Parent Empower, she went on to social

media and contacted its founder, telecoms billionaire John Caudwell. 'I said, 'Thank you. Because of your charity, you've helped my son,' and added how I had ideas which I hoped would transform the lives of people in the UK, asking if we could meet. Seconds later, he replied, 'Hi Jo-Ann, how can I help?' He's now funding a year's treatment for several children in West Sussex.

An orange isn't just an orange

Often you can show an autistic child a picture of an orange on

What You Can Do

- ❖ **If a child's having a meltdown in the supermarket, don't stare.** As a parent you can feel very judged. Walk by or offer help.
- ❖ **When meeting a child with autism, ask how they're doing, what school they go to.** Take away labels. Don't see them as 'Jack with Autism'. Just Jack.
- ❖ **Keep it simple.** Children with autism may have difficulty processing lots of words, particularly when upset. 'Shoes on' is more effective than, 'OK, finish what you're doing, find your shoes, then get your coat...'
- ❖ **Don't ask, 'What's his special gift?'** You may have watched *Rain Man* or read about someone who's an amazing painter, but less than 1% of people with autism have that kind of gift.
- ❖ **If your child or grandchild is in a class with someone with autism, include them on play dates.** Embracing differences is a life skill.
- ❖ **Don't believe stereotypes - not every child with autism needs a strict routine and dislikes crowds.** There's a saying, 'If you've met one child with autism, you've met one child with autism.'
- ❖ **Visit autismparentempower.org for more details**



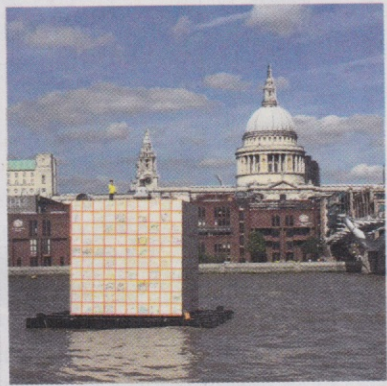
Hello!



A Peek At My Week

Art On The Water

This unusual art installation - Floating Dreams - appeared on the River Thames just opposite WW HQ as part of the Take Me To The River festival. By South Korean artist, Ik-Joong Kang, the three-storey-high box constructed from 500 drawings is a memorial to the millions affected by the Korean War. Designed as an illumination, the poster (right) shows what it looks like after dark.



Taste Test

Oreo has introduced two new filling flavours - mint and strawberry cheesecake. So members of the WW team felt it was only right to try them out. The verdict? Thumbs up all round! Oreo, £1.08 per packet.



Blooming Wonderful

Look how glorious the flowers were at the beautiful wedding I was lucky enough to be invited to at the weekend.



Embrace The Difference

Reading about Jo-Ann D'Costa-Manuel's experience of fighting to get the treatment her autistic son needed (page 10) struck something of a chord with me. I have a family member who is on the autistic spectrum, but unlike Jo-Ann, his parents didn't have to struggle to access all the support and input he, and they, needed from a very young age. As a child, he was prone to obsessions and terrors and required a lot of loving structure in his days to help him cope. His parents have been unstinting in their dedication to him over the years. It has been a joy to watch how he has developed and blossomed into a remarkable, confident, witty, articulate young man now, making his university choices and looking forward to what the next stage of his life has in store. Yes, he still has his quirks, but they're what make him the delightful character he is. Autism is such a little-understood condition and watching him grow up has been as much a lesson in what it means to be on the spectrum for us, as it has for his parents and brother. Being a part of his life has taught me about embracing idiosyncrasy, enjoying difference and, crucially, about challenging expectation and judgement. Jo-Ann and her husband have sacrificed so much for their much-loved son, and I hope he brings them as much joy in the future as my family have all experienced with our very special boy.

*Diane Kenwood,
Editor*



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