

No fear, just lots of love

Parents of autistic children share with **Aneeta Sundararaj** their distress and heartwarming tales

NEXT time you are at a shopping mall and see a child running around and refusing to heed his parents call, don't be quick to judge. Instead of passing remarks like "not trained" or "lousy parents", Cason Ong Tzse Chun, 43, would be grateful for some compassion. This is because it hurts him when people criticise his parenting skills; his son, Cavin Ong Hsu Jian, 15, is autistic.

"Autism is a spectrum disorder," explains Dorothy George Dass, 57.

Her son, Abraham, 14, was diagnosed with "high functioning Autism" — Asperger's Syndrome, when he was six. She says that each autistic child is different even though they may have similar traits.

"Autism," she adds, "is a lifelong disability and caring for children with autism can be exasperating and painful."

The third person in this group is Norhasianita (Anita) Abu Hassan, 36, whose six-year-old daughter, Nabihah, has a condition called PDD-NOS, which stands for Pervasive Developmental Disorder-Not Otherwise Specified. This term is apparently applied to people who are on the autism spectrum but do not fully meet the criteria for this disorder.

Together, these three parents are determined to share their experiences and make people aware of what they go through.

SUNSHINE AND SUPPORT

To help them, Suria KLCC is joining forces with Alamanda shopping centre in Putrajaya and Mesra Mall in Kerteh. They'll run the Sunshine September Campaign to increase awareness about autism among Malaysians (www.suriaklcc.com.my).

The campaign will run from Sept 19 to 30. The aim is to raise RM400,000 through sales of exclusive Sunshine September merchandise and activities throughout the shopping centres. The funds will be channelled to the National Autism Society of Malaysia (Nasom).

To illustrate some of the problems parents of autistic children face, Cason says: "One day, we took Cavin to KLCC Park and he played on the monkey bars. When it was time to leave and I said, 'Come, Cavin,' there was no response. I called him over and over again. In the end, I had to go and collect him. He was screaming and everyone was looking at us. I had



From left, Norhasianita Abu Hassan, Dorothy George Dass and Cason Ong.

to tell people, 'No, I'm not kidnapping him; he's my son.'"

Anita tells of the time she sent Nabihah to the kindergarten. "My son is a year older than Nabihah and they used to go to the same kindergarten. One day, my son told me that the teachers were so angry with Nabihah that they wanted to tie her to the stairs and tape her mouth because she was crying." Anita was

furious and threatened to report the matter to the police.

The point they're making is clear — looking after an autistic child requires enormous patience. "They are so stubborn. This stubbornness is extreme," says Anita. "For example, when Nabihah wanted to drink her milk, she won't say the word 'susu'. It's so hard for them to speak."

"When they finally speak," says

Cason, "it's like they've opened the golden mouth."

Anita's advice, when the child is being stubborn, is to remain calm. "If you force them, they'll throw a tantrum. You know, sometimes they want to wear a dress. If you say no, they will rather wear nothing at all the whole day. Don't try to *pujuk* (persuade) them at this point. It'll become worse."

The kind of support these parents seek can be described as part help and part understanding. They find these in Nasom because it is an organisation run by the parents of autistic children. For Cason, such support is crucial because his other child, Carina Ong, 16, is also a special needs child.

"To put it simply," he says, "she was diagnosed with Global Development Delay. The easiest way to explain this to you is that my daughter may be 16 years old, but she looks and behaves like an 8-year-old."

"The moment we accepted them as they were, all the burden was lifted."

Cason Ong

I always felt that something went wrong during the delivery. She didn't cry when she first came out. So, when my son came out screaming, we were very happy."

The first years of his children's lives were very trying on Cason and his wife. He elaborates: "My daughter could not stand. Her feet would point straight down. At first we were told that she couldn't walk for life. Then, one day, my aunt and uncle who are living in Australia told us to seek help there. A spastic centre in Perth told us our daughter could walk. What we effectively had to do was to 'unbind her feet'. It was really painful to watch her go through treatment. But, after a month, she was willing to stand with the cast on. So, while we worked with our daughter, I feel that, sometimes, we may have neglected our son. He learnt all his 'A, B, Cs' and '1, 2, 3' from TV."

WHYME?

To simplify his life, Cason, who works as a marketing manager in his family's business, has moved his family from a house to a condominium unit. Still, he admits to asking questions like, "Why me?" and "Why my child?"

Then came a point when everything changed. "In Perth, in that spastic centre, when I saw all the other children, we accepted that these were our children and this was going to be our reality. Yes, initially, my wife was depressed. We tried everything to help our children. The moment we accepted them as they were, all the burden was lifted."

Both Dorothy and Anita agree with him. "I was 42 when I was pregnant with Abraham," says Dorothy. "I already had one son who was 14 and a daughter who was 7. The doctor told me about the high chances of the child being a Downs baby. I refused to take the amniocentesis," says Dorothy, who works in a bank. "I decided not to know and was quite ready to accept whatever came. So, when Abraham was not a Downs baby, I was relieved. As he grew though, he became hyperactive. Then, one day, my girlfriend, who also has an autistic child pointed

Cason Ong and his family.



out some similarities between our children. Once Abraham was diagnosed and I accepted that my child was autistic, I was OK. If a parent is in denial, that's the end of it."

Anita's story is a little different. "When I was still pregnant with Nabihah, one day I went to an Open House. There, I met a friend who's a doctor. While we were chit chatting, her child was running around. Without hesitating, my friend said, 'My son has PDD-NOS'. She didn't hide the fact from anyone. She was not ashamed of her child. I always remembered that."

This Assistant General Manager at Telekom Malaysia noticed that even at the age of 2½ years, Nabihah still didn't address Anita as 'mama'. "Then, her squint got worse and she couldn't focus. I realised something was wrong."

Anita doesn't have pleasant memories of the visits made to the doctors. "We were referred from one specialist to another. From paediatrician to another doctor to even a psychiatrist. They hardly spent five minutes with us. One said something was wrong with Nabihah's skin tone and one even told me, 'Look it up in Google.' Finally, it was a doctor in HUKM that came up with the correct diagnosis."

THERAPY AND EDUCATION

The moment she knew that Nabihah had PDD-NOS, Anita updated her Facebook status and within moments received enormous support from her friends. They're the ones who suggested she contact Nasom for help and treatment for Nabihah.

Dorothy says behavioural therapy may sometimes be necessary. "Say there's a wedding and there are women in saris. He would go to them and poke at their midriff. While it might be funny when he's a child, this kind of behaviour will not be accepted when he's older."

Such therapy is essential if an autistic child is to have an education. As Cason says: "If a child can read and write, he has a right to an education."

Indeed, with the support and guidance he received from Nasom, Cason's son was enrolled in an integration class at a mainstream school in Kuala Lumpur. It is the same with Abraham who is now in Form 1 in a school in Sentul. In fact, Abraham is also a member of the Nasom Maestros, the first autistic choir in Malaysia.

Even with all the challenges they've had to face, there is no doubt that these special parents have found happiness. Cason says: "I don't have any tears left to cry. Everything is happy now."

While he may have no tears, both women struggle to hold back theirs. "When my mother passed away

last year, I was very quiet after the funeral," says Dorothy. "Abraham came up to me and said, 'Mum don't worry. Popo is OK. She's taken care of.'" Smiling, she says: "Abraham is now a boy who gives lots of hugs and kisses." Anita adds: "When Nabihah first called me 'Mama' I cried. I really cried."

The message that these parents would like to share is that one needn't be afraid if one's child is autistic.

"You're not alone. There are people there who can help you," says Cason.

"Yes," adds Anita. "I'm now in a WhatsApp group for parents with autistic children. We share our stories and experiences."

Dorothy says it best: "There is a reason why a special child is given to us. I believe God knows that we have the strength and the capability to carry it through."



Nabihah and her mother, Norhasianita Abu Hassan.



Abraham is a member of the Nasom Maestros, the first choir of autistic children in Malaysia.



Dorothy Dass and her son, Abraham.