

Built on family ties

A lot of love and patience, as well as intervention and discipline, are needed when raising a child with Down's Syndrome, a couple tells

Aneeta Sundararaj



The family bond is strong.

PICTURES BY AMIRUDIN SAHIB



"When we're gone, he has to be able to look after himself."

Sumathi Palani

Sumathi advocates plenty of patience when looking after a Down's Syndrome child.

"WE take our son everywhere," says Sumathi Palani, the mother of 14-year-old Dehveyann Soma Sundhareem Kumar. When Dehveyann comes forward with a polite greeting, it is obvious that he has Down's Syndrome. As the evening progresses, it's clear he's a delightful teen — with muscles.

Dehveyann (pronounced Dhivyan) has been chosen to compete in swimming at the first Asia Pacific Special Olympics Games in Newcastle, Australia later this year. To help raise funds for this, Procter & Gamble has started a two-month nationwide campaign with Mydin Mohamed Holdings Bhd.

The Special Olympics encourages parents to allow their special child outdoors and get involved in physical activities through a supervised sports programme. The facilitators will have the relevant training and expertise to design and monitor activities that are suitable for each child. Consumers can help with this campaign by spending a minimum of RM10 on P&G's range of products at participating Mydin stores until April 15.

THE EARLY JOURNEY

Dehveyann's journey to this point in his life has not been without challenges. "Seven days after he was born," says Sumathi, "I noticed he was bluish. I didn't know what Down's Syndrome was. No one in my family has it. But not knowing helped me. Nothing was fixed in my mind."

While waiting for her husband, Dr S. Kumar, a colorectal surgeon at a private hospital, to return to their Cheras home, Sumathi, 38, shares a little of what she's learnt so far. With absolute certainty, she says that the one quality you need when looking after a Down's Syndrome child is patience.

There is a limit to such patience though. "They can be very stubborn and lazy. They love to eat. And they're curious. For example, when we go to the market, he'll want to look at the chickens. I will wait for him, but he's only allowed 2 minutes.

Then, I become firm and say, 'We have to go. I have other things to do. We have rules and regulations'."

Having established a routine, Dehveyann is now Mummy's helper during marketing. "I give him the money, ask him to weigh the fruits and pay for it."

Sumathi is determined that Dehveyann must grow up to be independent. "I want him to come up in life. When I went to Kiwanis, I saw all the other children with problems. I don't want that for my son. When we're gone, he has to be able to look after himself."

INTERVENTION AND DISCIPLINE

Such an approach, Sumathi says, needs early intervention and lots of discipline. "I'm his teacher, not his mother. Most of the time, it's instructions. If he misbehaves, I make him sit in the corner. He can't get away. For example, he must go to school every day."

Dehveyann, fresh from his recent shower, says: "My mother's first word is always, 'No.'" He then gets up to open the door for his father. A while later, Dehveyann's younger brother, Yadhushan, 11, joins the discussion, but not for long. Something catches the brothers' interest and Yadhushan takes Dehveyann's right hand to lead him outside.

"See that?" Sumathi says, as she looks lovingly at her sons. "Yadhushan won't leave his brother alone. Even to cross the road, Yadhushan will hold his right hand."

When the boys are out of earshot, Kumar admits: "At first, it was very difficult to accept. This was our first child. And the first grandchild on my wife's side. The moment he was born, as a doctor, I knew. But I had to act as though everything was normal."

Nothing during his wife's pregnancy alerted him to the fact that his child might develop Down's Syndrome. "She had lesser fluid during the 34th and 35th week, but no complaints."

Sumathi's face clouds over. She first met her husband when she took a job at a clinic. They fell in love and married soon after. They looked forward to creating a family together. A

child with Down's Syndrome was the last thing they expected. "I was only 24 at the time," she says.

Once he accepted the reality, Kumar went all out to help his son. Doctors confirmed that Dehveyann had a mild form of Down's Syndrome.

As time passed, Kumar was determined to include his son in every aspect of his life. "I never leave him out. In fact, I always seek his opinion. When I wanted to buy a car, he chose it."

Kumar has support from both sides of the family. "My brother-in-law," says Kumar, "will go all the way from Selayang to Kepong to buy the food my son asks for."

Kumar's late father, who had an interest in numerology, gave Dehveyann his name. Kumar, smiling at his wife, adds that since he's the sole breadwinner of the family, the tasks of managing all Dehveyann's activities falls on his wife. Giving her due credit, he says: "She is the one who takes him to all the therapists."

As the boys return, Kumar reveals that there's one area where he alone can help the children: Swimming. Sumathi, who's afraid of water, will not go into the pool. Tongue-in-cheek, Kumar says: "At Kiwanis, we took Dehveyann to the koi pond they had for a pool. He was scared of water at first and used to resist swimming. But the therapists said that it would help his muscles improve. So, I started taking him to the pool in our condominium."

When Yadhushan began to swim as well, Dehveyann overcame his fear to show off to his brother. Having had swimming lessons in a proper pool, the brothers now compete with each other. There is an inherent discipline in Dehveyann. Kumar says it's in the genes. "My father was very disciplined. And I can see so

much of him in my son. Dehveyann will have that same look. They'll pretend as though they're not listening to you, but they'll give that sideways glance and you know they've heard everything."

When Dehveyann's sports teachers at his school, SMK Alam Damai, suggested he try out for the Special Olympics team for the Federal Territory, Kumar and Sumathi were all for it. "This requires vigorous training

and I take him for two hours every Saturday and Sunday for training," says Kumar. This will help Dehveyann acquire perfection and speed while building his stamina.

As our chat comes to an end, Kumar confides: "We do things as a family. So much so I can't go to India because my children won't come with me. I want my son to be included in everything. I want him to become a role model in life."

Special athletes

WHAT does it take to train special athletes? Mohd Shukry Hussain says working with athletes such as Zaim Abu Hirzan Zaidan — who excels in bowling — is extremely satisfying because it paves the way for the autistic teenager to go far in life. Read *Life & Times* this Tuesday for the full story.

