Raising a child with muscle disease

PARENTING

By Umar Nsubuga

In 2004, Rosy Anand gave birth to her second child, a boy she named Rushil Anand. Rosy says she was excited to have a bouncing baby boy after a girl. However, with time, she noticed that there was something wrong with her son.

"My son started having recurrent health problems," Rosy recalls.

Her son's constant sickness meant regular visits to the doctor – usually with different infections such as conjunctivitis (inflammation of the eyes).

Rushil's life was characterised by hospital admissions and constant medication. By the time Rushil was eight months old, he had suffered from many infections, some of which never seemed to heal.

"We would spend one week at home and two in hospital. Doctors could not explain why a child who was being given appropriate treatment was having relapses all the time," Rosy narrates.

When the family took Rushil to a hospital in India, he was diagnosed with a muscle condition known as duchenne muscular dystrophy characterised by the degeneration of muscles.

Since the diagnosis, Rushil's parents have taken several steps to take care of him.

"We had to hire private teachers – my son attained the greater part of primary school education at home. This was because every time he went to school, he would return with an infection. It became too costly and unhealthy for him to be in school," his father, Atul Anand, explains.

"Even at secondary level, he is home-schooled. In addition to this, every month, doctors have to pick him from home to take him to the hospital for review, treatment and monitor him for 12 hours at home."

According to Atul, every month, Rushil misses at least two days of school. He adds that it is a tough call for a teenager who would have enjoyed being in the company of his peers.

Rushil has since come to understand that he is different.

"He always wants to understand why he has to live on medication. It gets tough on you as a parent, but you have to be strong for his sake," Rosy explains.

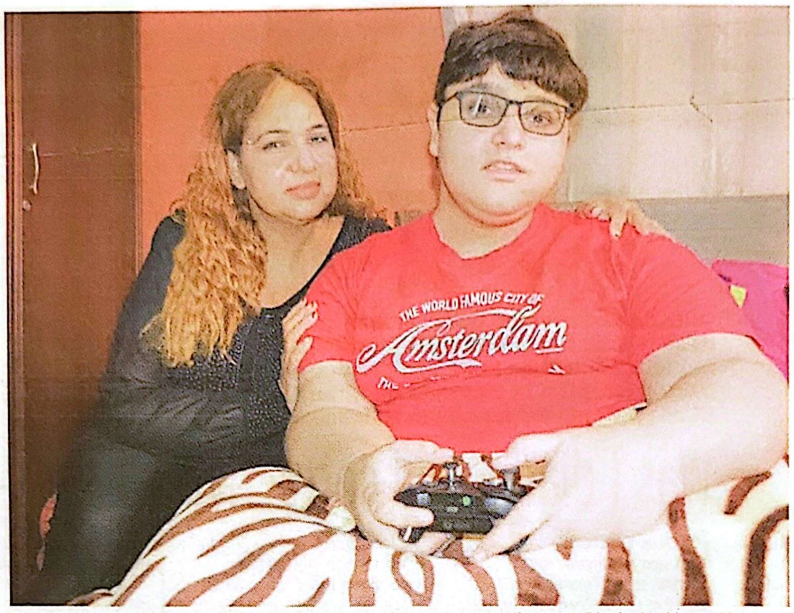
It has taken concerted effort of the family to take care of Rushil.

"As a family, his condition has brought us closer to each other. Everyone in the family brings in his or her contribution to support the only son in the home," Rosy says.

She appeals to experts to research on the condition, adding that the information they currently have shows that there is no cure. All that one can do is just give treatment to manage symptoms.

Rosy, who used to work at Crane Roofings Limited, says she quit her job to take care of her son because she could not leave him in the care of someone else.

She added that she keeps talking about her son's condition so as to raise awareness about it.



Rosy Anand and her son Rushil who lives with a muscle disease. Photo by Umar Nsubuga

DUCHENNE MUSCULAR DYSTROPHY

This is a genetic disorder characterised by progressive degeneration and weakening of muscles. It is caused by an absence of a type of protein that keeps muscle cells intact.

Dr Harriet Aciro, a physician at Adjumani General Hospital, says without that particular protein, muscle fibres break down and are replaced by fibrous and fatty tissue, causing the muscles to weaken.

Aciro notes that the condition is rare and mainly affects boys and girls can be carriers.

According to Save Our Sons Duchenne Foundation, the condition affects one in every 3,500 new-born baby boys.

Aciro explains that the first signs of the disease appear between the ages of one and three years. She explains that it usually affects the pelvis and legs first, making it difficult for the patient to walk. By the age of eight to 11 years, those affected are usually confined to a wheelchair.

Aciro adds that some children also develop learning and behavioural challenges. In addition to this, if the person survives into adulthood, the condition usually becomes life-threatening by the age of 30 years as it affects the heart and respiratory muscles.

How it is diagnosed

Dr Alex Kinene, a physician in Kampala, says the condition is diagnosed by finding out the patient's family and medical history, including any problems affecting the patient's muscles.

"A hospital may order tests for muscular dystrophy. The tests may also rule out other problems that could cause muscle weakness, such as surgery, toxic exposure, medications or other muscle diseases," he explains.

Dr Kinene notes that the condition makes it hard or impossible for one to move around or perform any physical tasks and, therefore, encourages caregivers to help such people. The limitations in physical activity can result in stress. Kinene advises that patients should regularly undergo counselling to strengthen them emotionally.