



Parents with some of the survivors of heart complications, supported by the Healthy Heart Foundation. PHOTO/ SHABIBAH NAKIRIGYA

Caring for a child after heart surgery

For parents of children born with congenital heart defects, surgery is only the beginning. Sleepless nights, repeated hospital visits, financial strain, and emotional stress often define the real journey once a child returns home.

BY SHABIBAH NAKIRIGYA

For many parents, the moment their child is wheeled into the operating room feels like the end of a long and frightening chapter. Prayers have been said, funds painstakingly raised, and surgeons finally reached. The operation, often costly, appears to be the finish line.

However, for families of children living with congenital heart disease, surgery is only the beginning of a much longer journey. Many people assume that once the operation is over, everything returns to normal. In reality, recovery and care at home present their own difficult and often unexpected challenges.

When Rehemah Nansubuga gave birth to her daughter, Rely Namigge, at Nsambya Hospital in Kampala, the delivery went smoothly, and both mother and baby were discharged shortly after.

Unfortunately, the calm was short-lived. Soon after returning home, Re-



Recovery. The period after surgery was the hardest. I had to protect her from coughs or flu, from any contaminated environment, because even a small infection could be dangerous. Every health scare meant another hospital visit, each straining the family's finances. It was very expensive, but we had no choice. Even after surgery, Rely still requires regular medical reviews, often costing thousands of shillings per visit," **Rehemah Nansubuga, mother.**

ly began struggling to breathe. Alarmed, her grandmother rushed her back to the hospital. At first, doctors treated her for pneumonia. However, further examination by a heart specialist revealed a more serious condition. Rely was diagnosed with Down syndrome, a genetic condition often associated with heart defects. Scans also showed she had three holes in her heart, a severe form of congenital heart disease.

Racing against time

Rely was referred to the Uganda Heart Institute (UHI). Doctors initially placed her on medication, hoping the holes might close naturally, but after three months, surgery became urgent. At that time, the procedure could not be done locally, and she had to travel abroad.

"I was stressed and terrified," Nansubuga recalls. "I did not know how to raise the money, and I also did not understand what Down syndrome or heart disease really meant." With support from multiple sources, the surgery was eventually carried out successfully before Rely turned six months old.

The struggle begins at home

Survival brought new challenges. "The period after surgery was the hardest," Nansubuga says. "I had to protect her from coughs or flu, from any contaminated environment, be-

SIGNS TO WATCH OUT FOR AFTER SURGERY

Children recovering from heart surgery require close monitoring at home. Doctors advise parents to seek medical attention immediately if they notice any of the following symptoms:

Breathing difficulties. Fast breathing, shortness of breath, or chest pulling inward while breathing may signal infection, fluid buildup, or heart strain.

Bluish lips or fingernails. A blue or purple tint can indicate low oxygen levels in the blood and requires urgent medical evaluation.

Poor feeding or appetite loss. Babies who refuse feeds, tire easily while feeding, or fail to gain weight may not be recovering properly.

Unusual tiredness or weakness. Excessive sleeping, low energy, or reduced activity compared to normal behaviour can signal complications.

Swelling of legs, feet, abdomen, or face. Fluid retention may indicate the heart is struggling to pump effectively.

Persistent fever. A fever can be a sign of infection, especially dangerous after heart surgery.

Excessive sweating. Heavy sweating, especially during feeding, may indicate the heart is under stress.

Delayed wound healing. Redness, swelling, discharge, or opening of the surgical wound may indicate infection.

out we had no choice after surgery. But thousands of shillings of medical costs, hospitalisations and occasional monitoring. Parents often bear the responsibility, but medical needs will hold duties.

A widespread challenge
In Uganda, congenital heart disease remains underdiagnosed and poorly understood. About one in 1,000 are born each year with a heart defect, but many are not diagnosed before six months of age.

Dr Andrew Ssekubwa, a heart specialist at the Uganda Heart Institute, says symptoms are often noticed after birth. "You may notice a blue, breathing difficulty, or swollen hands or legs, or a child who grows at the same rate as other children," he explains.

Some risk factors are linked to maternal health, including infections during pregnancy. In many cases, however, there is no clear cause.

"The biggest challenge is access to treatment," Dr Ssekubwa says. "Heart surgery in Uganda costs Shs30m per procedure, which is beyond most families' means. Also only one centre is performing these surgeries, which is frequently overwhelmed. Parents with hospitals and insurance can help bridge the gap, but the system is limited."

Support beyond surgery

While surgery is life-saving, post-operative care is equally crucial. Families often face financial and logistical challenges. Many parents stop working to care for their children, deepening poverty. Some experience social stigma surrounding heart conditions.

Community initiatives have emerged to help families cope with the financial demands of post-operative care. One such effort is the "Worship, a gospel music ministry" that raises funds to support recovering from heart surgery. Support helps families with such as transport for follow-up visits, medication, and emergency care, which are essential for a child's recovery but often difficult to afford.

"Many children die not because surgery fails, but because post-operative challenges are too great," Nansubuga notes. "Transport costs, medication, and regular follow-ups are overlooked, but they are vital."

Hope and awareness

Awareness and timely diagnosis are as important as funding. Many children die simply because the condition is never detected in time, Nansubuga says. With proper care, children can recover fully, attend school, and live healthy lives.

For parents such as Nansubuga, the journey is far from over. Beyond medical care, increased awareness, children such as Rely have a chance to thrive, one step at a time.