



Caring for a child after heart surgery

Demanding. 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. **P.20**



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

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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.

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Every health scare meant another hospital visit, each straining the family's finances. "It was very expensive, but we had no choice," she adds. Even after surgery, Rely still requires regular medical reviews, often costing thousands of shillings per visit.

Many children face repeated hospitalisations and require ongoing care, including monitoring, medications, and occasional emergency attention. Parents often bear the brunt of this responsibility, balancing the child's medical needs with work and household duties.

A widespread challenge

In Uganda, congenital heart disease remains underdiagnosed and poorly understood. About 16,000 children are born each year with heart defects, nearly half requiring corrective surgery before six months to survive.

Dr Andrew Ssekitooleko, a paediatric heart specialist at Nsambya Hospital, says symptoms are often visible soon after birth. "You may see a child who is blue, breathing very fast, with swollen hands or legs, or one who fails to grow at the same rate as other children," he explains.

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

"The biggest challenge is access to treatment," Dr Ssekitooleko adds. "Heart surgery in Uganda costs about Shs30m per procedure, a figure far beyond most families' reach. There is also only one centre capable of performing these surgeries, which is frequently overwhelmed. Partnerships with hospitals and charities abroad help bridge the gap, but access remains limited."

Support beyond surgery

While surgery is life-saving, post-operative care is equally critical. Families often face financial, emotional, and logistical challenges. Some mothers stop working to care for their children, deepening poverty, while others experience social isolation due to stigma surrounding heart disease or genetic conditions.

Community initiatives have also emerged to help families cope with the financial demands of post-surgery care. One such effort is Etendo Worship, a gospel music initiative that raises funds to support children recovering from heart surgery. The support helps families meet costs 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-surgery challenges are too great," Dr Ssekitooleko notes. "Transport costs, medication, and regular follow-ups are often overlooked, but they are vital to survival."

Hope and awareness

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

For parents such as Nansubuga, the journey is far from over. But with proper support systems, access to medical care, and increased awareness, children such as Rely have a chance to thrive, one step at a time.