HEALTH & BEAUTY

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HOW TO ERASE THE DARKNESS LIVING IN THE MARROW

Aplastic anaemia is a rare but life-threatening condition leaving thousands of Ugandans without access to life-saving bone marrow transplants locally. As one mother shares her family's costly journey to India, experts and institutions rally to change Uganda's medical landscape forever. Here is th story as told to **Agnes Kyotalengerire**



Luke, diagnosed with severe aplastic anaemia at age four, underwent a bone marrow transplant in India – a procedure Uganda cannot yet offer its own children

My name is Madrine Amuge, and I am a mother of two. My son David Luke was born very healthy. He was approximately 4kg at birth.

He brought joy to everyone who saw him. He was a lovely baby and very handsome. Throughout the first four years of his life, he was healthy and had no issues until 2024, when he was diagnosed with severe aplastic anaemia.

He was prone to infections such as bacterial infections and viral infections because he had no platelets and his white blood cells were low. As such, every week we were spending nights in the hospital, admitted for blood transfusions. All the same, we could not figure out what was wrong with him.

Luke could not go to school because he was bleeding. Later, we received the true diagnosis that Luke was suffering from severe aplastic anaemia; as a result, his body could not produce haemoglobin, enough white blood cells, or platelets.

Dr Henry Ddungu, a senior consultant in haematology/oncology at the Uganda Cancer Institute, said aplastic anaemia is a rare but serious condition where the bone marrow fails to produce enough blood cells – red blood cells, white blood cells, and platelets.

This leads to fatigue, paleness, dizziness, frequent infections, and easy bruising or bleeding, as was the case for Luke. A patient with aplastic anaemia will present with symptoms such as severe anaemia, bleeding, recurrent infections, and fatigue because all the cells are affected.

Dr Ddungu explains that a child can be born with aplastic anaemia (congenital), meaning they are not able to produce cells from birth. It can also be acquired. Risk factors include exposure to aggressive radiation, for example from drugs used for cancer treatment.

The other cause is an autoimmune disorder where the immune system attacks healthy cells, including stem cells, which then fail to produce blood cells. Viral infections such as hepatitis, Epstein–Barr virus, or HIV may also be associated with aplastic anaemia. Sometimes exposure to toxins and chemicals such as pesticides, benzene, or radiation is to blame. In some cases, inherited disorders can lead to bone marrow failure.

When we continued to engage the doctors on how best we could support Luke, they mentioned the possibility of a bone marrow transplant. We were excited to know that this boy has a future with a bone marrow transplant. But again, what was very stressful was the fact that we could not get a bone marrow transplant done in Uganda.

It was a very large sum of money required, and so we had to look for money through colleagues at work, friends, and relatives to take him to India for a bone marrow transplant. It was quite expensive because we had to incur costs on accommodation, flights, and feeding.

WHAT DOES A BONE MARROW TRANSPLANT ACTUALLY INVOLVE?

Dr Ddungu describes a bone marrow transplant as a procedure that is done when the bone marrow is failing to make cells in the body. Since blood cells cannot form, it means the primary cell – the stem cell – is not functioning.

When an individual has aplastic anaemia, the best treatment is to replace the stem cells through a bone marrow transplant. In this case, a donor who has the same genetic make-up is required to give stem cells to the recipient.

The preferred donor should be a matched sibling (sister or brother), although it could also be a mother or father to reduce the chances of rejection. Alternatively, doctors can use a matched unrelated or half-matched donor provided they have the same human leucocyte antigen (HLA) type.

Human leucocyte antigen (HLA) type is a set of protein markers on the surface of most cells that acts as an immune system identifier. In bone marrow or stem cell transplants, HLA typing is a blood or cheek swab test used to match donors and recipients so that the new cells are recognised as "self," reducing the chances of rejection and graft-versus-host disease.

Before the recipient receives the stem cells, they undergo screening to determine the cause of aplastic anaemia and then receive conditioning treatment to clear anything that could interfere with the uptake of the donated stem cells. In brief, a bone marrow transplant helps rebuild the bone marrow with stem cells from a donor after proper matching is done.

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MANAGEMENT

If you are diagnosed with aplastic anaemia, it is important to follow the doctor's treatment plan carefully. Patients are advised to avoid infections by limiting exposure to crowds and wearing face masks when necessary.

This is because aplastic anaemia patients often have neutropenia, a condition where the body has an abnormally low number of neutrophils – the white blood cells responsible for fighting infections. With a weakened immune system, patients become highly vulnerable to viruses, bacteria, and fungi that spread easily in crowded places.

Regular handwashing and wearing face masks are, therefore, recommended as protective measures.