

Mr Stephen Sande narrates his experience as doctors explain experience during transplant, dos and don'ts after transplant, and who qualifies for transplant.

BY TONNY ABET

In 2025, Mr Stephen Sande lay bedridden at the Uganda Cancer Institute (UCI), his body ravaged by multiple myeloma, a painful and generally incurable form of blood cancer. The disease had weakened his bones, causing severe back pain that left him unable to stand or walk.

Today, Mr Sande, a Ugandan from Nayingiro District, is a symbol of hope. He became the first patient in Uganda to undergo a bone marrow transplant performed entirely on Ugandan soil by a local team of doctors and specialists at UCI.

After 22 days in intensive isolation at UCI, he was discharged last Friday, walking out stronger and full of life.

"I'm better, I'm going home now," he said with visible relief after being discharged on April 24. "You know, there is a way you feel when you have a bank loan, and then you clear it... that is how my mind feels," Mr Sande added, bursting into laughter as emotion overwhelmed him.

Lead doctors, including consultant haematologist and lead transplant specialist Dr Clement Okello, said the transplant has pushed the risk of cancer recurrence several decades into the future, possibly beyond Mr Sande's lifetime.

Dr Okello narrated what it takes to have a successful bone marrow transplant and what the patient should do after the transplant.

"For a bone marrow transplant, you are rebooting the person's system," Dr Okello reveals in an interview.

Dr Okello said before the transplant, a patient with the right kind of disease that can be treated or cured through a bone marrow transplant is subjected to a series of tests. He revealed that the procedure is done for stable patients.

A bone marrow transplant (or stem cell transplant) is an advanced medical procedure that replaces diseased or damaged blood-forming stem cells with healthy ones, treating conditions like leukaemia, lymphoma, and aplastic anaemia. Bone marrow is the soft, spongy tissue found inside bones. It is where most of the body's blood cells develop and are stored.

Taking a risk?

Mr Sande narrated the feeling before accepting to undergo the transplant, as the first patient being handled by Ugandan doctors in Uganda.

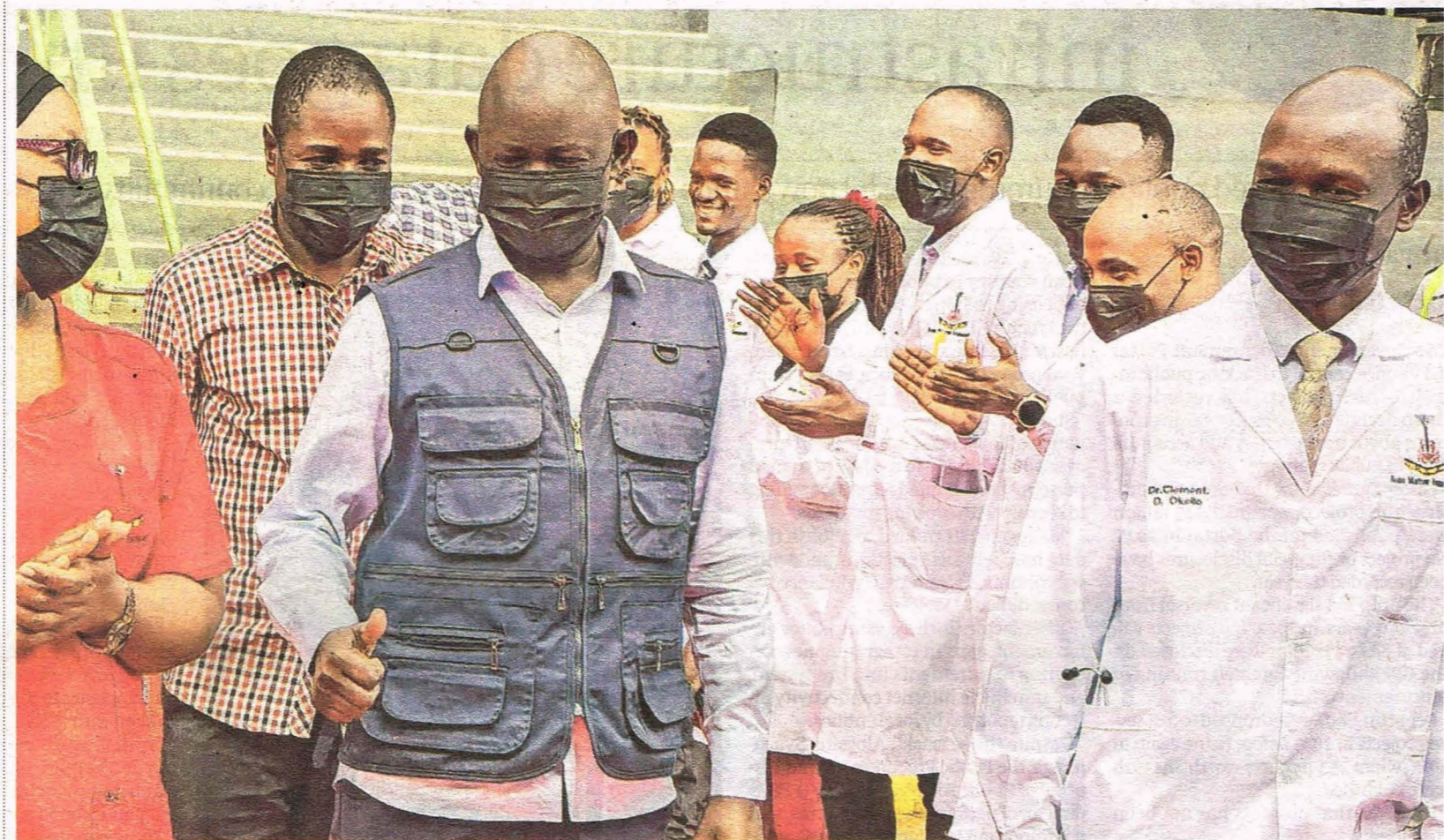
Mr Sande said he got the confidence to go through the transplant because of Dr Fred Okuku, another consultant who initially treated his cancer at UCI.

"Dr Okuku got me from the bed to the wheelchair, from the wheelchair, I started struggling. Then, from that, he stabilised me. I even went back to my workplace. I can say he is my second god," Mr Sande shared.

"I think it was around November last year. He told me now, based on the tests I have done on you, that you are out of danger. But there is one thing. I'm going to refer you to my colleagues," he said.

He said Dr Okuku later referred him

The anatomy of a successful



Mr Stephen Sande (centre), the first patient to undergo a bone marrow transplant performed in the country, is congratulated by the medical team at Uganda Cancer Institute after he was discharged last Friday. PHOTO/TONNY ABET

to Dr Okello, who was leading the committee and was planning to perform the first bone marrow transplant in Uganda.

"I reached Dr Okello, we talked. He gave me an appointment, and I came another time. He had also now called his team," Mr Sande recalls.

Mr Sande says he was uncertain because he already felt fit and was back to work after being treated by Dr Okuku. At this point, he felt no need for another intervention, more so as the first patient.

"I was now able to work, walk, drive, go everywhere, even at midnight," Mr Sande remembered his status before undergoing the transplant.

As he struggles to make up his mind, Mr Sande reaches out to Dr Okuku to advise him.

"What we are going to do is not that we are going to cure cancer," Dr Okuku advised Mr Sande. "This (multiple myeloma) is not curable, but if we leave you now and we say you are out of it, it always comes back."

Mr Sande finally made up his mind. "So, I will follow his (Dr Okuku's) idea," he remembered telling himself after a phone call with Dr Okuku.

Dr Okello said Mr Sande was the only candidate recommended by Dr Okuku for the maiden transplant, and the assessment showed that he was the right one.

"He was in remission. Remission is the point at which the patient actually has no disease (after completing cancer treatment)," he revealed.

"So, Sande would come, and he's actually good. And we asked him, Sande, supposing you die?" he added. But Dr Okello said Mr Sande was determined because of the benefits of the procedure, which the medics had explained to him.

Mr Sande had to undergo a series of tests to make sure he's actually fit to undergo this. "We sent him to check for the heart, the dental checks, the lungs, and every organ we need to make sure that he's a perfect candidate," Dr Okello said.

Dr Henry Ddungu, a consultant in the treatment of blood cancers at UCI, said Mr Sande had been diagnosed with the cancer seven months before the operation.

"The disease had debilitated him. He had become bedridden, and then he moved on a wheelchair until he stabilised. It is after this that we now went into transplanting him using his own stem cells," Dr Ddungu said.

Admission and actual transplant

Dr Okello further revealed that after the test, Mr Sande was admitted to the special ward in UCI along with his brother (caretaker). At UCI, the patient was initially given a special treatment to trigger the growth of healthy cells in his body, and stem cells were harvested from him.

"And then the lab people were there to tell us that he actually now had enough cells, enough seedlings (stem cells) that can be transplanted," he revealed.

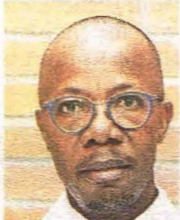
Dr Okello added: "Then we called our lovely nurses there to give us that machine called an apheresis machine to harvest the stem cells, to get the seedlings (stem cells). So, we got the seedlings (stem cells) out of him. So, we put this aside."

Available scientific information indicates that a medicine is administered about one week before apheresis that will stimulate the bone marrow to increase production of new stem cells. These new stem cells will be released from the marrow and into the circulating or peripheral blood system; from there, they can be collected during apheresis.

Stem cells are unspecialised "master cells" capable of self-renewal and differentiating into various specialised cell types in the body.

Scientists said at this point, the donor tests in this case of autologous stem cell transplant) is connected to a special cell separation machine via a needle inserted into the arm veins.

In an autologous stem cell transplant,



Dr Henry Ddungu, the lead doctor in the transplant

Costs involved. Many Ugandans have been going out... I hope we can reduce such travels... Travelling to various parts of the world, and depending on where you go, the transplant costs will be between \$30,000 and \$50,000 (Shs111.08m and Shs185.13m... When you make our simple calculation, we are doing an autologous bone marrow transplant at \$15,000 (Shs55.54m)." - Dr Henry Ddungu, the lead doctor in the transplant

the patient donates the stem cells, but in other transplants, like in sickle cell disease, the stem cells are obtained from a different person (donor).

Blood is taken from one vein and is circulated through the machine, which removes the stem cells and returns the remaining blood and plasma back to the donor through another needle inserted into the opposite arm.

After harvesting stem cells, the UCI doctors turned to the patient to prepare his body for the actual bone marrow transplant.

"He got very high-dose chemotherapy, one shot, to clear every remnant cell in him. Diseased cells, if they were there, and also healthy cells. He lost all his hair (showing that chemotherapy had worked)," Dr Okello revealed.

This means he had lost his body immunity, and he was highly vulnerable to infections. It was because the body's defence cells had been killed by the chemotherapy as they prepared his body for the transplant.

This was followed by the actual bone marrow transplant. "Then he got a re-infusion of the harvested seedlings (stem cells). That is the day zero when he got the harvested stem cells," Dr Okello added.

Anxiety and panic

According to information from UCI, the entire time from admission to discharge was over three weeks.

"Sande entered the clean room (admission at UCI) on actually day minus one. And day zero found him there. He received this infusion," Dr Okello explained.

He added: "And then we started counting days until his cells began to climb up. During that time, there were days when we were on zero-zero."

Dr Okello recalled the distress. "So, when the patient was on zero, completely zero count, somewhere along the way he got a fever, very high-grade fever," he narrated.

Dr Okello added: "We were worried

bone marrow transplant

that the infection set in. Oh, my goodness, you don't know what happened! We did all the blood cultures. We gave him all the types of antibiotics."

Every drug they gave him seemed not to be working. "And somewhere along the way, we gave him some magic drug. And along the way, that was engraftment syndrome," Dr Okello said.

"So, engraftment is the point at which these planted seeds now begin to germinate. And when it germinates, then all the cytokines, you would say, come up to play. All these things would cause the fever to come up.

"And so, after a few days, when the patient engrafted, his temperature just went down. And we clapped and said, 'Wow,'" Dr Okello recalled.

Dr Ddungu said he underwent a lot of stress, which affected his health during the time he handled the patient. Dr Ddungu is the specialist in cellular therapy and head of the unit for treating blood cancers at UCI.

"I got ulcers because of the stress related to the transplant processes," Dr Ddungu recalled. "You know, waking up at night, Mugerwa [George William Mugerwa is a nursing officer], is on duty, and say, Mugerwa, do we have fever? And he will be like Ah, we have."

"One day, one of the nurses on duty said, 'Ah, diarrhoea has come in. I think that's when I almost died,'" Dr Ddungu added.

He said the patient underwent an autologous stem cell transplant, meaning he was the donor of the stem cells. This is different from procedures for diseases

like sickle cell disease, where one requires another donor.

Breakthrough and cost-cutting

"We've gone through several years of preparation for this procedure, but now we're happy to say it is official. We have our patient going to be discharged today," Dr Ddungu said last Friday.

He added: "We are going to continue with this breakthrough. We need to know why this matters for all Ugandans. As you know, previously, many Ugandans have been going out. They will continue to go. I hope we can reduce such travels."

"Travelling to various parts of the world, and depending on where you go, the costs will be between \$30,000 and \$50,000 (Shs111.08m and Shs185.13m) without these other additional things. When you make our simple calculation, we are doing an autologous bone marrow transplant at \$15,000 (Shs55.54m)," he said.

Dos and Don'ts after transplant

After discharge, Dr Okello explained that there are things that the patient should do and should not do at home.

"But what we encourage the patients not to get involved in public affairs in terms of going into the crowd. He will go home on a face mask that will protect him until he gets vaccinated," Dr Okello said.

He added: "So, vaccination will now come after six months. Remember, this is a brand-new patient, almost like a newborn baby who is still fresh out

there, so his immune system is completely down to zero."

Dr Okello appealed to the public to protect the patient. "So, he has to protect himself and the people out there. If you recognise this patient, please give him some space.

ABOUT BONE MARROW TRANSPLANT

Bone marrow transplant (BMT) is a special therapy for patients with certain cancers or other diseases. The goal of BMT is to transfuse healthy bone marrow cells into a person after his or her own unhealthy bone marrow has been treated to kill the abnormal cells.

Bone marrow transplant has been used successfully to treat diseases such as leukemias and lymphomas since 1968. Patients who have the following diseases might benefit from a bone marrow transplant:

- Leukemias
- Severe aplastic anaemia
- Lymphomas
- Multiple myeloma
- Immune deficiency disorders
- Some solid-tumour cancers (in rare circumstances)
- Sickle cell disease

Source: The Johns Hopkins University

"Don't greet him with your hand because you're going to infect him. He is so fragile that he has to wear a face mask, all through until he starts vaccination and has completed it," he added.

The other requirement is to keep clean and to eat a healthy diet. "The rest of the things are really the same as any other person," Dr Okello said.

On vaccination, Dr Okello said the patient has to start from the very first day-old baby vaccine. "But of course, we shall give him specific vaccines, not the live vaccines, so we will select which vaccines to give him. He has to get all the series of vaccines that our children get," he stated.

Who can get a transplant?

Dr Ddungu and Dr Okello revealed that they want to expand the bone marrow transplant programme to handle a range of conditions and patients, including sickle cell disease.

Dr Ddungu said multiple myeloma patients are quite numerous, but not all of them qualify for a bone marrow transplant.

"The person qualifies when the disease has been cleared, but we also look at the functionality of the patient. We look at how strong you are, even if you're 70, you can still qualify," he said.

Dr Ddungu said they intend to do another five transplants this year, adding that each patient spends around 30 days in the hospital before discharge.

"There are many patients that qualify, but it is quite costly, and we want to get more resources, in terms of staffing, in-

rastructure, and other necessities to do this," he said.

Dr Jane Ruth Aceng, the Minister of Health, said a transplant is very expensive. She explained that although the first five patients may get free transplants, eventually, patients will be required to pay for them.

"The UCI receives Shs150 billion (budget per year), and that is aside from the projects. But with this money (Shs150 billion), they can treat Ugandans (who come with a range of cancer care needs)," Dr Aceng said.

She added: "There are many Ugandans who need a bone marrow transplant, and ultimately, patients will be paying. Paying \$15,000 (Shs55.54m) is very cheap because you are not paying for a flight to India, you are not paying for an attendant to travel to India, you are not paying for accommodation in India, you are only paying for the transplant, but abroad, the \$30,000 (Shs111.08m) is only for the transplant but not the related cost."

Dr Aceng also said the government would support the Uganda Cancer Institute to have more specialists recruited. "There are many specialists who have been trained, so we need to absorb them into the system," she added.

Dr Okello said: "Multiple myeloma is a very common disease here; it is even more common in blacks than in whites. It's even more common in males than in females. At UCI, out of every five or 10 blood cancer patients, you might get about two or three patients with multiple myeloma."

UCI gets around 7,000 new cancer cases every year, with cancers of the blood and other complex blood disorders as one of the common conditions seen at the institute.

7,000
The number of new cancer cases recorded every year at the Uganda Cancer Institute.