HEALTH WATCH

Will to live: Cheerful youth battles sickle cell for a long life as he encourages others with same condition

My 'expiry' date was six years ago but my life's dream is bigger

By JOY WANJA MURAYA

He claims he will live long. His will to live must override the treatment he has been on since he was barely a teenager.

Meet Joe Mudukiza, 21, who has sickle cell disease. Rather than grieve over this incurable ailment, he is confronting the condition which is largely misunderstood and receives little attention.

"My red blood cells assume an odd shape, thus limit the oxygen that goes around my body; but I have found ways to cope with this limitation. I encourage others unaware that we can lead normal productive lives," says Mudukiza.

Red blood cells are normally round-shaped, and their function is to carry oxygen to all parts of the body. However, in persons like Mudukiza, they assume a C-shape, similar to a farm tool called a "sickle".

"Normal red blood cells have a life span of 120 days, but for those born with sickle cell disease, these crucial blood cells do not live longer than 20 days," says Dr Jamilla Rajab, who monitors diseases of the blood and blood-forming organs at the Kenyatta National Hospital (KNH).

And because charity begins at home, Mudukiza has begun awareness campaigns with his 16-year-old cousin who also has the condition.

"When I was joining Form One, my mother explained the reason behind the frequent hospital visits and a blood transfusion I had at 13 years old. I want to show those with similar condition that you can live beyond the condition," says Mudukiza, the second born in a family of six.

He adds: "Over the years, I have learned to control my diet and activities to prevent straining my body because it can lead to pain attacks known as Crisis."

Dr Rajab says as these oddly-shaped blood cells travel through small blood vessels, they get stuck and jam blood flow, causing pain and infection, acute chest syndrome and in some cases, stroke. For Mudukiza, the pain episodes are not only disabling but also humiliating because they take control of the entire body.

"Two years ago, the pains paralysed my body for about seven minutes and those around me could just sit and watch as I wailed," Mudukiza recalls.

But what worries him most is a common myth that persons with Sickle Cell Disease have shorter lives due to the blood disorder.

"As I grew up, my greatest fear was that I would not live to see my 15th birthday. But look, six years after my supposed 'expiry' date, I want to give hope to Sicklers," says Mudukiza, who hosted the World Sickle Cell Day on June 19 in Vihiga.

"I know I will live well into my 80's and even my 90's," Mudukiza says.

The young man has taken advocacy to another level as he is currently collecting signatures to petition Parliament through legislator Isaac Mwaura to give more attention to this blood disorder by recognising it as a national health priority.

"The challenges facing persons with sickle cell disease are enormous and need to be put under a national health priority. We need to look at the high cases of suicides and premature deaths among the affected," said legislator Mwaura who is working for a law that provides access to counseling and medication for Sickle Cell Disease.

Mudukiza says this is in line with the World Health Organisation (WHO) which in May 2010 at the 63rd World Health Assembly adopted a resolution on the prevention and management of birth defects, including Sickle Cell Disease.

According to WHO, the condition is more common in Africa, and especially in tropical areas, and urges member countries to increase awareness on these disorders, support their prevention and treatment through equitable access to health services.

Approximately five per cent of the world's population are healthy carriers of a gene for sickle-cell.

The percentage of people who are carriers of the gene is as high as 25 per cent in some regions, WHO notes in an advisory on blood disorders.

Dr Rajab says the disease runs in families and its prevalence can range from about five per cent to about 36 per cent in certain regions in Kenya.

"The first signs are evident when a child is six months old. Concerns that parents can look out for include unexplained swelling of hands and feet, pain and yellowing of the eyes and skin," says Dr Rajab.

Other symptoms include excessive fatigue or irritability, frequent infections and chest pains.

A child of two carriers has only a quarter chance of receiving two trait genes and developing the disease, and a 50 per cent chance of being a carrier. However, according to WHO, most carriers lead normal and healthy lives.

Dr Rajab points out that red blood cells in persons with Sickle Cell Disease have a shorter lifespan, and this subsequently leads to anaemia.

Other complications include poor blood oxygen levels and blood vessel blockages, leading to pain syndromes, bacterial infections and sometimes the death of some tissues.

Some effective management tips for Sicklers, their colleagues, friends and family include increasing their daily fluid intake, observing a healthy diet, taking folic acid and pain medication. "I take four tablets a day to keep pain away and this has worked for the last two years because I have not had a pain attack since I turned 19," says Mudukiza.

Dr Rajab suggests genetic counseling for carriers of risks because the condition could be passed on to their children. It is thus important to be prepared on treatment and management. Whereas the only cure for this condition is an expensive bone marrow transplant, the procedure is not available in Kenya yet.

Again, not all persons with the condition are eligible for it. For now, young Mudukiza is upbeat about life: "I will focus on eating healthy and being active in my lifestyle as I prevent pains," he says.

> "Allergic diseases and symptoms occur because of an over active or hypersensitive immune system that reacts or fights things that the body should ignore
>
> — Dr Mbira Gikonyo

Diagnosed with Sickle Cell Disease while barely a teenager, 21-year-old Joe Mukidiza is petitioning Parliament to treat the condition as a national health priority.
[PHOTO: EVIS OGINA/STANDARD]

About Sickle Cell Disease

Symptoms:

Unexplained swelling and pain of hands and feet and yellowing of the eyes and skin. Excessive fatigue and irritability, frequent infections and chest pain

Dangers:

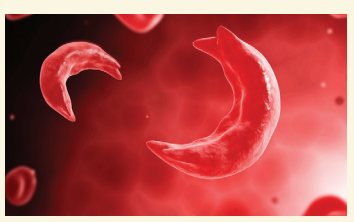
Delayed growth and the children are generally shorter but regain their height by adulthood.

Blood oxygen supply to the heart can cause an enlarged heart and later subsequent heart disease.

How to deal with the disease:

Increase daily fluid intake, and eat a healthy diet. Take folic acid and medication for pain

Seek genetic counselling for carriers of risks because the condition could be passed on in families



The Clinic

Men's lifestyle lowers their lifespan

Dr Robert Shmerling has kicked off a debate in the Harvard Health Publication on whether men live longer than their female counterparts or vice-versa? Dr Shmerling said although the average lifespan is about five years longer for women than men in the US, and about seven years longer worldwide giving reasons, he believes women outlive men. He refers to the difference in 'biological destiny' between men and women, where the frontal lobe of the brain – the part that controls judgment and consideration of an action's consequences – develops more slowly in boys than in girls, making men take bigger risks. "This tendency towards lack of judgment and consideration of consequences may also contribute to detrimental lifestyle decisions among men, such as smoking or excess drinking," Dr Shmerling says. He also observes that men take up more dangerous assignments, like working in military combat and working at construction sites. Men are also more predisposed to heart disease advanced by poorly treated high blood pressure, lower estrogen levels and/or unfavourable cholesterol levels. That men are less likely to see a doctor for an ailment is another contributing factor. He also notes that men with fewer and weaker social connections tend to have higher death rates.

Why Vitamin D oral spray is good for you

Sun exposure, perhaps as little as 10 to 15 minutes a day has been found to increase Vitamin D in your body. The essential vitamin makes your bones stronger and more flexible, thus better able to resist disease. However, in countries where adequate sunshine is a luxury throughout the year, it is interesting to note some of the innovations made to achieve the recommended daily dosage of Vitamin D. In the last fortnight, researchers at Cardiff University tested a Vitamin D oral spray to supplement levels of the 'sunshine vitamin' in individuals. They found out that absorption within the mouth was far superior to the more traditional Vitamin D tablets and capsules. "By taking just one spray daily of our oral sprays, vitamin D levels can be effectively managed and many health conditions and diseases associated with deficiency avoided. Over the years, Vitamin D has been hailed as a wonder vitamin due to accrued health benefits ranging from offering protection against some cancers, bone-weakening osteoporosis, heart attack and Alzheimer's disease. But too much of it can trigger skin cancer.

– By Joy Wanja Muraya
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