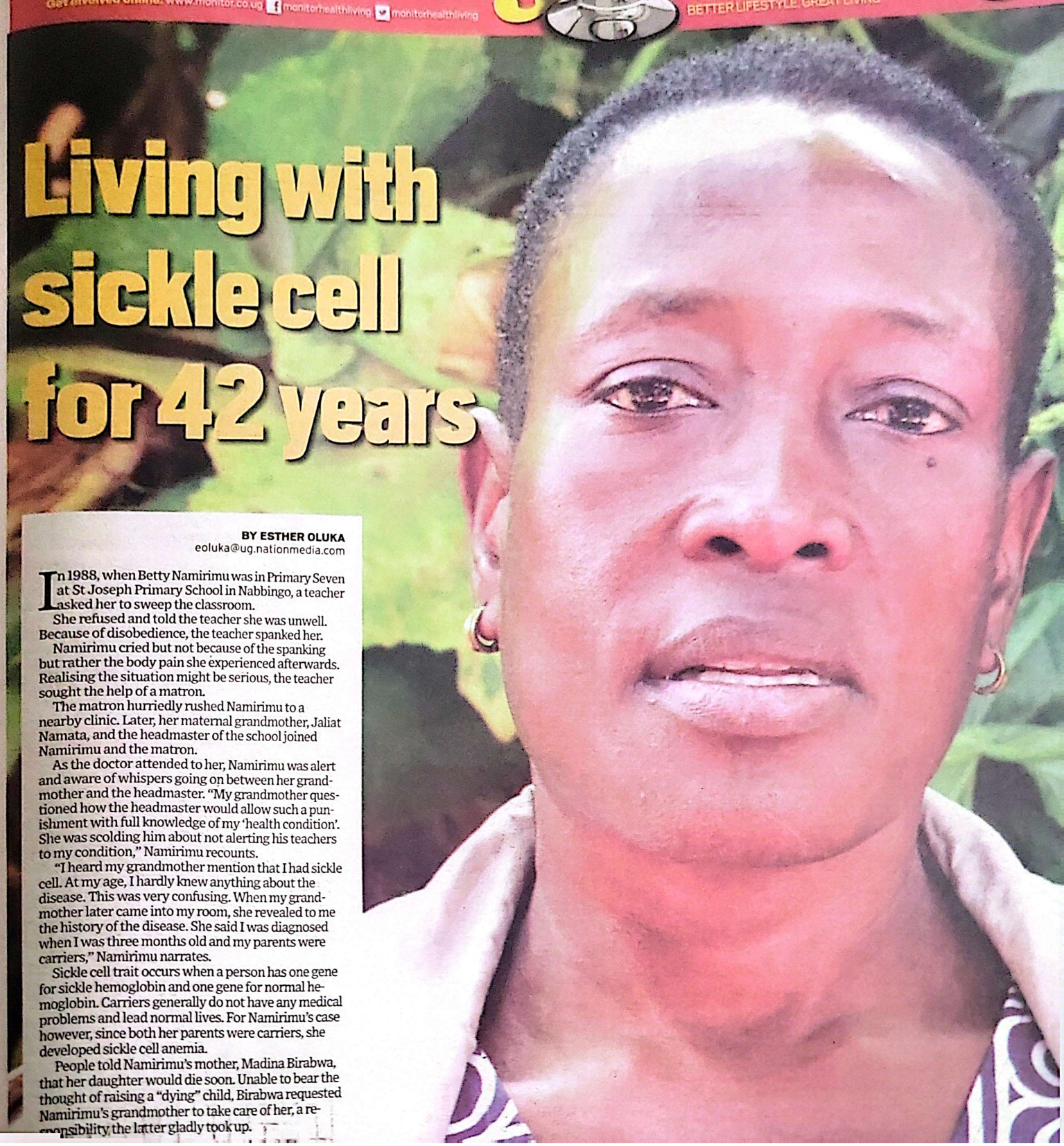
Living with sickle cell for 42 years



BY ESTHER OLUKA
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In 1988, when Betty Namirimu was in Primary Seven at St Joseph Primary School in Nabbingo, a teacher asked her to sweep the classroom.

She refused and told the teacher she was unwell. Because of disobedience, the teacher spanked her.

Namirimu cried but not because of the spanking but rather the body pain she experienced afterwards. Realising the situation might be serious, the teacher sought the help of a matron.

The matron hurriedly rushed Namirimu to a nearby clinic. Later, her maternal grandmother, Jaliat Namata, and the headmaster of the school joined Namirimu and the matron.

As the doctor attended to her, Namirimu was alert and aware of whispers going on between her grandmother and the headmaster. "My grandmother questioned how the headmaster would allow such a punishment with full knowledge of my 'health condition'. She was scolding him about not alerting his teachers to my condition," Namirimu recounts.

"I heard my grandmother mention that I had sickle cell. At my age, I hardly knew anything about the disease. This was very confusing. When my grandmother later came into my room, she revealed to me the history of the disease. She said I was diagnosed when I was three months old and my parents were carriers," Namirimu narrates.

Sickle cell trait occurs when a person has one gene for sickle hemoglobin and one gene for normal hemoglobin. Carriers generally do not have any medical problems and lead normal lives. For Namirimu's case however, since both her parents were carriers, she developed sickle cell anemia.

People told Namirimu's mother, Madina Birabwa, that her daughter would die soon. Unable to bear the thought of raising a "dying" child, Birabwa requested Namirimu's grandmother to take care of her, a responsibility the latter gladly took up.

HOW DO YOU CARE FOR A SICKLER AT HOME?

"Encourage the patient to exercise. This will help reduce pain and ensure better functionality of the body."
ALEX KAKOOKO, DOCTOR AT MUKONO BAY HOSPITAL, LUZIRA

Caretakers need to closely monitor and encourage patients to adhere to treatment.
TABITHA SKELLO, EMPLOYEE OF WHITE RIBBON ALLIANCE - UGANDA

"Continuously show the patient love and affection to help them accept their condition."
ETHEL KWANKWA, PHARMACIST

Compiled by Esther Oluka

42 years with sickle cell disease

Betty Namirimu has lived with sickle cell anemia for the past 41 years. She shares the highs and lows of her journey with

Esther Oluka

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School woes

At Katikamu SDA Secondary School in Wobulenzi where Namirimu enrolled for O' Level in the boarding section, she faced a number of challenges, especially discrimination from other students.

"Some students did not want to sit near me or share plates or cups, for fear of catching my disease," she says.

Her explanation that the disease was genetic fell on deaf ears. One student even went to the extreme of threatening to beat Namirimu to death as a way of putting an end to her numerous complaints.

"I would report some of the cases and the students would be warned. While some stopped, other continued," she says.

The bullying was combined with name calling. Some students gave her the nickname, "*ka*-sweater" because of the tendency to wear a sweater at all times. "They did not understand that my body was sensitive to cold weather. I had to wear a sweater at all times to keep my body warm. If I failed to wear a sweater, I would be in pain," she says.

Cold water

Another challenge Namirimu faced at school was having to bath with cold water.

"After scrubbing myself, I would quickly rinse my body and wrap myself up in a towel until I felt warm. Fortunately, after some time, the senior lady and some of the cooks who knew about my condition started warming my water," she says.

Whenever her health deteriorated, she was allowed to leave school. "I was out of school almost every two weeks. I would read from home or hospital and try to keep up with my classmates. I also endevoured to consult my teachers on what I had missed during my absence," she says. Although she passed her O' Level exams, she was unable to further her studies. "I told my grandmother that there was no point of studying if I was going to die anyway. Although she insisted that I had to study, I stood my ground until she gave in to my request," Namirimu says.

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AGE (IN MONTHS) AT WHICH NAMIRIMU WAS DIAGNOSED WITH SICKLE CELL ANAEMIA

Life after school

With nothing to keep her busy, Namirimu decided to get married at 19. Her husband was 25 years.

"I did not tell him about having sickle cell anemia out of fear he would leave me," she says.

A few months later, Namirimu discovered she was pregnant. "It was a difficult pregnancy. I was always ill and had a lot of body pain," she says.

At one time during that pregnacy, Namirimu was admitted after complaining of severe body pain. It was while at the hospital that she requested the doctor to tell her husband about the condition.

"I was surprised when he said that rather than leave me, he would stay and take care of me. I was humbled by his response," she says.

The couple had a son and a few years later, a daughter, who are both carriers.

Coping all these years

On how she finds life today, Namirimu admits that life is still tough. "I have to take medication every day and keep warm at all times. "I also visit a hospital for review every three months."

Unlike in the past where she lived in denial, the 42-year-old who makes crafts for a living says she has embraced the reality that she has sickle cell anemia. She helps others in the same condition through counselling and guidance sessions.

Coping

The Pain

Namirimu takes her medication as prescribed. In case the pain persists she rushes to hospital.

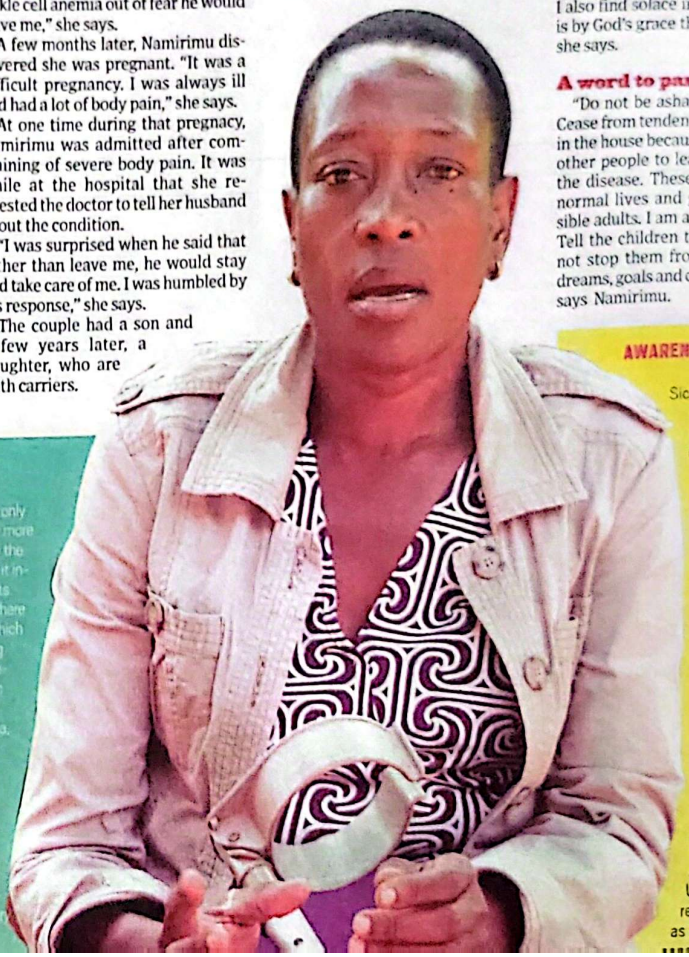
The stigma

She gets support and guidance from Ruth Nankanja Mukiibi, the executive director of the Sickle Cell Association of Uganda.

"Nankanja has been a pillar of hope and strength. There were times in the past I wanted to end my life but she always encouraged me to hang in there. I also find solace in prayer because it is by God's grace that I am still alive," she says.

A word to parents

"Do not be ashamed of your child. Cease from tendencies of hiding them in the house because you do not want other people to learn that they have the disease. These children can live normal lives and grow into responsible adults. I am a testimony to that. Tell the children the ailment should not stop them from achieving their dreams, goals and career aspirations," says Namirimu.



ABOUT SICKLE CELL:

What is sickle cell anemia

It is a hereditary disease characterised by the presence of abnormal hemoglobin (a protein inside red blood cells that carries oxygen). The normal red cells in the body are doughnut shaped, flexible and able to pass through small vessels. For sickle cell patients, the red cells are sickle shaped, rigid and have a lower oxygen carrying capacity. The lifespan of a normal red blood cell is approximately 120 days but that of a sickle cell is 20 days. This means your bone marrow has to work overtime to replenish the frequently damaged red cells.

The diagnosis

A test is often conducted to identify the different types of hemoglobin and the quantities of the abnormal hemoglobin (hemoglobin electrophoresis).

How does someone get the disease?

The disease is developed when one inherits the abnormal gene from both parents. If it is from one parent, they develop a sickle cell trait, hence becoming carriers.

Treatment

Bone marrow transplant is currently the only curative treatment available. It is usually more successful when done in patients below the age of 16. Its high cost, however, makes it inaccessible to most lower earning patients. Along with lifestyle recommendations, there is medication to manage the disease, which includes pain management drugs during crises, blood transfusion because of anemia, hydration, blood tonics such as folic acid, antibiotics to prevent and menage infections, vaccinations and Hydroxyurea, a drug which is both accessible and available to even low income patients.

Prevention

It is always advisable for couples intending to either get married or have children to go for genetic screening.

– Courtesy of Dr Ken Bagenzo, general practitioner, Aga Khan University Hospital, Kampala.

AWARENESS DAY

Sickle Cell Awareness Day is celebrated on June 19 every year with a variety of awareness campaigns to help increase public knowledge and raise awareness of Sickle Cell Disease (SCD) and the struggles sufferers and their families go through.

Observed since 2008, the date was chosen to commemorate the day on which a resolution was officially adopted by the General Assembly of the United Nations, recognising SCD as a public health