

Learning to Live with a Disfiguring Disease

By Joanne Silberner

Aired on National Public Radio's "All Things Considered"

March 18, 2007

A health worker who is the son of missionaries has started a support group to help people suffering from a disfiguring and painful condition called lymphatic filariasis.

John Umaru speaks eight languages and dialects. He's the kind of person anyone feels comfortable talking to. Participants in his support group in Jos, located in Central Nigeria, arrive 45 minutes or an hour early just to make sure they will be there on time.

EMILY STAUB / THE CARTER CENTER



John Umaru (left), is a health worker in Jos, Nigeria with the Carter Center. He has started a support group for villagers who suffer from lymphatic filariasis, a disfiguring disease transmitted by mosquitoes.

At a recent meeting, six men and five women sat on white plastic chairs under mango trees in the courtyard of a public health mission sponsored by the Atlanta-based Carter Center, which also sponsors the Hope Club meeting.

Everyone here has lymphedema. Their legs are grossly swollen as the result of lymphatic filariasis, a disease transmitted by mosquitoes.

One of the members of the Hope Club has a question: "If one has this problem, does it mean that one is going to have it for the rest of your life? Or is there some hope?"

Umaru tells them there is "no cure, but yes, there is hope."

Umaru explains to the group members how they must take care of their legs.

"Keep it clean," he says. "Don't allow your leg to be infected. If you have a cut treat it early. If you do that you save yourself the repeated pains and infections that increases the swelling."

He tells them to keep the leg elevated when possible.

Umaru introduces Hamisu Isu, a group member who has followed all these steps carefully. Isu sits and smiles, natty in his spotless white robe and carefully wrapped brown and tan turban.

Hamisu Isu has lived with lymphatic filariasis for almost 25 years. Once completely debilitated by the disease, Isu's participation in the Jos support group has changed his life – he now has a job selling shirts and is engaged to be married.



JOANNE SILBERNER/NPR

"I see them when they come [into the support group], and then I see them improving and happy. And that gives me joy."

— John Umaru, Health Worker

Umaru passes around a picture of Isu from several years ago, when his leg was swollen and the skin was infected. He says those sorts of infections often have a bad odor, which may have been why Isu's family shunned him.

The "after" picture shows considerable improvement, though it is still very obvious that Isu has lymphatic filariasis. His leg is a little less swollen, and the skin looks healthier – with no running sores.

When Isu started coming to the Hope Club, he was initially in very bad shape.

"He was actually brought in because he couldn't walk," Umaru says. "Now that he can come and he's physically active and the legs are looking clean and good, this shows the others even if they were like this, there's hope that some day they're going to be better too."

LINDSAY MANGUM/NPR



Series Map: Health workers are trying to uncover the extent of parasitic infection in rural Nigeria, including the villages visited in this series: Fobur, Kerker, Nasarawa North and Seri.

Isu tells the group he's doing well now and selling T-shirts in the marketplace. He is getting his teaching certificate, and he is engaged to be married.

Some who are afflicted do not immediately take hope from the Hope Club. Two things were quickly noticeable about Helen Adamu, 20: her exquisitely beautiful face and her grossly disfigured leg.

EMILY STAUB/THE CARTER CENTER



Participants at the lymphatic filariasis support group in Jos, Nigeria look at photos of Hamisu Isu's leg – before and after proper treatment. The Carter Center

At the meeting she attended, she sat quietly, always looking down, never talking. Umaru says she didn't come back to the next meeting.

But he always has hope, and he hopes Adamu will come again. He's not giving up, not on Adamu, not on anyone. He has seen what can happen when people learn how to take care of themselves.

"I see them when they come in, and then I see them improving and happy, and that gives me joy," Umaru says.