

## **Is Uganda Losing Battle Against Nodding Disease?**

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As cases spread, parents are struggling to reach health centres to pick up medication.

As the nodding disease crisis in northern Uganda worsens, local health workers and parents have told IWPR that many of the children affected are still struggling to access treatment.

Meanwhile, parents are having difficulty providing children with the kind of nutritious diet needed to complement treatment.

Nodding disease remains a medical mystery – its cause is unknown and there is no cure, only medication to alleviate the progressive symptoms.

The disease was first officially recorded in northern Uganda in 2009, although some say cases date as far back as 2007. It is thought the disease originated in Sudan and Tanzania in the 1960s.

The illness usually affects children between the ages of five and 15, although some cases among adults have been reported.

Health centres prescribe anticonvulsant drugs to treat the symptoms, which include the brain seizures that cause the characteristic nodding.

In March 2012, a new outbreak was reported in the Kitgum, Lamwo and Pader districts.

Korina Awili, 41, lives in the village of Aromo-Wang-Lobo in Gulu district, also in the north. Her 13-year-old son Denis has nodding disease and is unable to go to school.

When an IWPR reporter arrived at Awili's house, Denis was walking around the compound, but did not notice him entering.

"[The disease] makes him fall unconscious," Awili said. "Sometimes he falls while eating."

The disease has taken its toll on the family's daily life. Awili cannot leave her son unattended, yet she must tend her crops and provide for the rest of the household.

"If I go to the garden, I must hurry back home to check on him because the young kids cannot take care of him," she said. "If I am not home, he disappears from home and I am worried that if he gets to nearby water he will drown."

Uganda's ministry of health estimates that up to 4,000 children in northern Uganda have contracted nodding disease, with at least 200 dying from it.

In March, the government set aside three billion Ugandan shillings, about 1.2 million US dollars, to deal with the crisis. It set up designated treatment centres in Kitgum, Lamwo and Pader. District hospitals in Kitgum, Gulu and Lira also act as referral units for those with the disease.

However, critics say the government's response has not been effective enough, particularly since March, when parliament rejected the health ministry's original request for seven billion shillings.

Three months on, the shortage of designated treatment centres at the local level, compounded by transport problems, leaves families children struggling to access the medication their children need.

"The biggest challenge is now transport to reach those patients, and for the patients themselves to come in to the health facility, because at the moment in the mental health department we don't have any sort of transport," Douglas Otim, a psychiatric nursing officer at a health centre in the town of Atiak in Amuru district, told IWPR.

The Atiak health centre provides patients with anticonvulsant drugs, but it is not a designated treatment centre.

"Some specific drugs that are needed we have not yet received, but I'm praying very soon we shall have them," Otim added.

Janet Cida lives in Okidi, a village about 12 kilometres from Atiak, and has a child with nodding disease. It

is hard for her to go and collect the necessary drugs from the town as she cannot leave her child unattended, and taking him with her is almost impossible.

“It’s difficult to transport him because he cannot even sit on a bicycle,” she told IWPR. “He falls off the bicycle because he is dizzy. So you find that my problem is walking on foot to collect drugs from Atiak.

“Sometimes I leave him alone at home [but] he [may] fall on the fire or anywhere.”

There are similar transport problems in parts of Gulu district.

“Apparently we have no transport [at all],” said John Bosco Adebbe, chairman of the local council of Odek sub-county. “Our ambulance for the sub-county is down and we are requesting... why can’t they [local government] give us a new vehicle?”

The outbreak of nodding disease has sparked interest and support from various quarters. In 2009, the Centre for Disease Control, CDC, in Atlanta in the United States was invited by the Ugandan government to investigate the disease and seek a cure.

The centre’s research into the cause of the disease is still ongoing. While a cause has not been identified, the centre recommends treatment with drugs normally used to treat epilepsy, in order to address some of the symptoms.

“Until we know the underlying cause, eradicating the disease seems like a long shot, but we do hope that these kids can be managed well,” said Dr Scott Dowell, who is running studies of the disease at CDC.

Anticonvulsants work better in some cases than in others. Many parents say their children have experienced little improvement, while others have been able to bring the symptoms under control.

“Sometimes anti-epileptic drugs make specific epilepsies worse,” Dowell said. “Anecdotally, what we hear from the families and the clinicians is some of these drugs seem to make some of these kids better – certainly for a while – although families come back and say they get worse again later.”

Trials of different treatments are still under way in the US, to determine which of the known drugs is most effective.

“Until those are put to the scientific test on what works, we won’t be able to tell the parents and the clinicians for sure what the best treatment is,” Dowell said.

Besides accessing the necessary drugs, a further challenge facing parents is providing children with a healthy, nutritious diet to support that treatment.

Dowell explained that many of the children involved are “very malnourished”, which affects the success of any treatment.

“Right now, there is no food in the house,” Margaret Achiro, who has two children with nodding disease in Amuru district, told IWPR. “In fact, they have not even taken their drugs because they have not eaten, because when I give them drugs without eating, [the consequences] can be very bad.”

Designated treatment centres are providing additional food for children with the disease. However, health centres providing the drugs on a more local level have not received foodstuffs to support the treatment process.

“All those cases that were confirmed, [the children] have at least some form of malnutrition and at the moment we are just planning to see how we can help them,” Otim, from the Atiak health centre, said.

Many communities affected by nodding disease are the same ones which were displaced by the 20-year rebel war in northern Uganda. Already struggling to rebuild their lives in the aftermath of the Lord’s Resistance Army insurgency, nodding disease has placed a further strain on these families.

“These families are traumatised,” Emmanuel Diini Kitembo, executive director of the advocacy group Health Watch Uganda, said. “The fathers of the children have abandoned the family and the mothers are trying to work hard so that they can take these children to treatment centres, but there are some parents who have given up; they just want these children to die.”

Some parents like Margaret Achiro have resorted to witchdoctors to try to cure their child, without success.

“There was no improvement and they told us to stay there for three months but I found that the drugs [from the witchdoctor] were not yielding results,” Achiro said.

In some areas, such as Lamwo district, the government says its treatment programme is having good results. Officials say that medication has allowed some children to start going back to school.

The Ugandan health ministry recognises that its handling of the crisis has so far fallen short of what is needed to reach everyone with treatment and food.

Ministry spokesperson Rukia Nakamatte estimated that approximately 60 per cent of children who have contracted the disease are being provided with care, while acknowledging that the treatment centres “are quite a distance from the affected children”.

The government has sent vehicles to help some district health teams respond to the disease, but Nakamatte says that programme is not yet fully in place.

“We did this, I think, two months ago, and we do not expect to have covered the entire districts – these are phases. Maybe, with time, the entire districts will be covered,” she said.

Although the funding allocation approved by parliament was less than half than what the health ministry wanted, Nakamatte said it was adequate.

“We have over three billion shillings for the nodding disease, and as per now that money is enough to conduct the various activities,” Nakamatte said.

Even so, obstacles remain.

“We don’t have some of the health workers that are required.... So we are working with the necessary and the available resources,” Nakamatte said.

Meanwhile, Dowell warns that it might take many years to find a cure for nodding disease. He said the Ugandan government and residents of the north needed to be prepared to provide long-term care for children affected by the disease.

“It is likely that these kids are going to need ongoing care and support for many years into the future, and that should be part of the planning,” Dowell said.

Arthur Okot, Gillian Lamunu and Bill Oketch are IWPR reporters based in Gulu. They report for IWPR’s Facing Justice radio programme, which is broadcast across the region in partnership with the Northern Uganda Media Club. Moses Odokonyero, head of the Northern Uganda Media Club and IWPR’s Africa Editor, Simon Jennings, also contributed to this report.

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