

Godfrey Zaake is Youth Coordinator with Purple Bench Initiative, an NGO seeking to raise awareness about epilepsy and create support for people living with the condition.

## **Godfrey Zaake**

Uganda



As part of our awareness-raising campaign about epilepsy stigma around the world, Godfrey shares the following story.



I was taking my routine evening walk in a small town of Moyo district in Northen Uganda.

As I enjoyed the breeze from the trees that are planted along the road that leads to the biggest church in the town. I heard noises and screams from a group of people that were running from the nearby bushes.

As I got closer, I asked an old woman that seemed to have been running for her life what was happening with the group of people making noises.



"It is that boy again. He falls whenever we are coming from church," she answered as she quickly walked away.

I approached the boy and he was lying on his face on the rough ground with strong movements from his arm, legs and abdominal section. He was having a seizure.





People were running away and pointing fingers at him and others laughing.

I knelt down to turn him off his face and everyone shouted, don't touch him or else his demons will get you as well.





I tried to clean his face and mouth and others shouted, you shouldn't touch his saliva! You will get his disease.

Everyone was shocked that I touched a person with such a "demonic possession".





I gave him the required first aid and once he felt better and strong enough to walk, I stopped a bodaboda(motorbike) and asked the driver to drive us to the nearest hospital to help with the injuries on the boy's face.





## Bystanders shouted out to the bodaboda driver not to take us.

I had to explain several times that what he has is not a demon and not contagious but also pay an extra fee before he agreed to take us to the hospital.





When we reached the hospital he unfolded his left hand that held a sweaty paper with the phone number of his uncle whom he asked me to call and ask to come to pick him up.

On receiving the call the uncle said, I should leave the boy alone and that he would be fine when he finds something to eat on his own.





This incident showed me that many people are misinformed about epilepsy. Myths like epilepsy is a demonic possession, a contagious disease and many other false things make it so hard for people to cope and they live in fear.





Young people are struggling silently because they can't trust anyone to understand what they are going through.

It's up to us to equip ourselves with the facts and create a strong support system for young people living with epilepsy.





Young people like him have dreams like anyone of us but these dreams die every day when they are told that they can't make it in life.

This kills their self-esteem and if they are not given the right support their dreams are not realised and their life is at risk too.







Accurate information sharing and education is a pillar that needs to be strengthened in the fight against stigma and discrimination towards people living with epilepsy.



It is our collective role to be there at the right time whenever young people need someone to talk to, to listen, hold their hand and walk them out of the tough experiences they face daily.



## - Godfrey Zaake



International Epilepsy Day



### Discover more stories like Godfrey's and learn about epilepsy stigma at https://internationalepilepsyday.org

