

Fighting injustice through courage and resilience

JOY CHINYERE OSSAI

Profile: 50 years,
Female, widow
Place of origin:
Igbo-eze North,
Enugu State.
Diagnosed and
Treated for Leprosy
in 1988 at Oji River
Leprosy Hospital

*'Due to the circumstances, surrounding our sickness,
we are been neglected even by our family, friends
and relations'*

*'Discrimination sometimes sets in as usual in the
market. Sometimes when I go to sell vegetables, the
buyers will see that I have the best vegetables but
as soon as they see my fingers, they'll hastily divert
to another seller'*

It was leprosy!

My name is Mrs Joy Ossai, the only child of my late parents. My story started in 1986 when as a young girl, I was living with my cousin as their domestic servant. If my parents were alive, I would have gone to school but I never had the opportunity. As a result, I resorted to my fate as a domestic servant, taking care of the house and looking after my cousin's children. It was there that this sickness started. They showed some kindness by taking me to various places to seek help.

When hideous deformities began to appear on my hands and feet, it eventually realized that this was the dreaded disease, leprosy. So, the kindness turned sour. They considered helping me as waste of money and resources. Moreover, their children were kept away from me.

Incredible: A young girl courageously secures justice against discrimination from Police

Here was I, a young orphan girl, meandering through bush paths and track roads to push my way to succour. Having no one on my side, I took my destiny in my hands, courageously found my way to report my plight and injustice to the police. While I fled, I carefully and consistently viewed sideways (in fear) to observe if anyone was in sight to track me. When no one is in sight, I moved on faster. But once anyone was coming, I hurriedly hide inside the bush as if I went to poo until he passed by. I continued, not giving up until I got to the police station. I was tired and thirsty. Looking down, I observed that the cracks and blisters on my dusty bare feet were already bleeding.

Now, approaching the police station, my heart beat faster, here came another challenge. I was scared of getting close to the policemen because I know how people had repelled my strange looks (deformed hands and feet). So in desperation, right from a distance I screamed my complaints to those policemen I saw at the entrance of the station and voiced out my predicament. The Police Inspector then, was from Calabar. Alarmed, he instructed the police officers to interview me, so as to know what was actually wrong. To my surprise, they offered water with their own cup. I was reluctant to accept but they insisted. While I drank, they also bought *okpa* (locally prepared *Bambara* nut flour) for me and I ate and was well refreshed. I now relaxed to tell them all that happened, which they documented. In response, they decided to follow me to my place rather cautiously, putting on mufti (without their uniform) and walking some distance behind me, so as not to tip off my relatives.

They arrested my cousin brother and took him to the station. After series of interrogations, he pleaded guilty but lamented that it was his wife who misled him to disallow her from getting treatment. He was eventually charged to law court. It was even the judiciary workers that contributed money to enable me get to Oji River Leprosy Hospital for treatment. Unfortunately, my cousin brother was sentenced to life jail. The court ruled that he will not be free until I was completely cured and discharged at Oji River. Moreover, if I suffer any harm or die, that he will be executed. For me, hearing such terrible judgement, I began to cry and pleaded for that he was my only surviving

close family member. So, they agreed that the police will help me to get to the hospital to commence treatment. Even till today, the court still send people to inquire about my wellbeing. You can imagine how many years ago this happened, since 1988. Even that magistrate may have retired by now if at all he is still alive. Yet, they still bring along some papers from the court, interview me and receive feedback to ensure that I was still alive. That was the saving grace of that my brother. It was through this government intervention, that I was brought to the leprosy treatment centre at Oji River Hospital.

Leprosy patients are incorrectly seen as outcasts

I came to Oji River in 1988. I was still a young girl then. You know that leprosy as a dreaded disease was mostly managed by the missionaries, if not most leprosy patients would not have survived till now. One thing you must understand is that leprosy is usually seen as an abominable ailment by most families and it is associated with shame and disgrace. Therefore, once a member of the family gets leprosy, the whole family suffers humiliation. Sometimes, the leprosy patient is expelled from the family and made to live far away in separate buildings in bushes and lonely places to keep the disgrace far away from family members and relatives.

On the other hand, if anyone is affected by other ailments such as malaria, he rather attracts the sympathy and compassion of family members. Such receives great attention and care from everyone. You are even asked to choose what you wish to eat and often spoon-fed by loved ones as a plea

for his relief and recovery. But this is not so with leprosy. Leprosy is a peculiar disease where even a mother will reject her own child or a child rejects and deny his/her own parents. But there is something interesting about leprosy. Leprosy patients give birth to their children who are not found to have leprosy, even though they had breast-fed them and continually lived so closely with them. We realized that this observation now makes the society to wander and conclude that it may not be transmitted so closely as feared. So, they give glory to God.

Harrowing experience of discrimination in a local market

Discrimination sometimes sets in as usual in the market. Sometimes when I go to sell my vegetables at the market, buyers will see that I have the best vegetables but as soon as they see my fingers, they'll hastily divert to another seller. Some will even pretend to have received an urgent phone call and leave my stand. When things grew worse, I resorted to begging because I was incapacitated due to my physical deformities. Anyway, I thank God immensely, for the gift of foreign missionaries whose enlightenment made us to start feeling at home with others in the society.

Marriage and family life

I got married right here in the leprosy settlement. The marriage was properly contracted according to custom as we travelled home to ensure the right things were done. We had four children: two boys and two girls. I lived here with my husband till he died in 2008. I remain grateful and

happy to God Almighty for the gift of life. I am proud to be a mom. My children are very helpful to me, they help me do those things that I am not capable of doing due to disabilities. I sometimes send them to the market to sell the foodstuffs. Some of my age mates who stigmatized me are dead now, but God kept me alive and strong. I also beg God Almighty to enable my children (through the intervention of well-meaning individuals) get financial help to go to school and also learn a trade in order to sustain the family. Today, discrimination has been defeated. I am very active in my community in women activities. They regularly invite me to attend their meetings, even in my husband's place. I do go home for August women meetings with others. All those discrimination have now become past things.

Moreover, what will help anyone cured of leprosy to live longer and enjoy productive life in the community is to have a house of his own where he returns to. Then, if anyone cares to come to your house he or she will visit at will. With this, the person will be independent of relatives and manage his deformities of hands and feet which may sometimes start bleeding. So, you contain it in your house without drawing attention and questions. But for anyone to go back from here only to manage in the homes of other relatives, that can be very challenging. The discrimination will definitely continue. That is why many people still remain in leprosy settlements after treatment to avoid insults from relatives. So, we plead with German Leprosy and TB Relief Association to continue to help us as they were doing in the past. They built houses for some people in the past and out helped so many of us.

Present challenges: difficult times for leprosy patients at Oji River

Presently, we have no doctors or nurses to help out. As I speak now, a young man, a leprosy patient was abandoned, almost unconscious, smelling due to offensive ulcers with no doctor or nurse to help out. The suffering here is so much. We are soliciting help, because we are left with no doctors or nurses and most of us here lack proper healthcare and treatment as nobody is trained with the knowledge to use the medicines that has been sent to us. Please, we need doctors and nurses to enable us have adequate treatment here. Again, our children should be trained to become doctors and nurses so as to help eradicate the challenges that the leprosy patients have. As it were, I am not even sure the younger generation is still interested in studying about leprosy and working among the patients nowadays.

Some patients came here as elderly people while others came as youths. Due to the circumstances surrounding our sickness, we are being neglected even by our family, friends and relations. So that was why many of us as young patients believed that it was necessary to have a child of our own to assist us in things that we cannot do now. For instance, my child helps me in doing those things, that I am incapable of doing. Considering how we are rejected, we need children who will take care of us at old our age.

We also get help from various individuals and churches. Things worked well in the past. It was so until Enugu State was carved out from Anambra 1991. It was then that we started suffering as most of the doctors

left for their States. We were only left with a leprosy inspector called Donatus Chiekezie and now live at the mercy of the government who remembers us occasionally. We began to pay for our medications and services and it led to a lot of deaths because people are no longer care for. The death tolls kept rising day by day as people resorted to begging at the streets and market places as a means of survival.

It was not like this many years back as patients in Oji received proper care. It was ensured that they were fully cured, before they are allowed to visit their people again. But we have no choice when things turned worse, than to shun shame and beg people for assistance. People kept mocking and insulting us but we had no choice as most of us had children to take care of. And we strive to train them, so that they will take good care of us in future. Moreover, if our children are trained and they become doctors and nurses in future, they will not discriminate against persons with leprosy, but will take better care of such persons, knowing what their parents suffered unduly.

A devastating experience

GRACE OGADA

Profile: 52 years,
Female, Widow
Place of origin:
Aku-Uno, Nsukka,
Enugu State.
Diagnosed and
Treated for
Leprosy in 1988
at Oji-River
Leprosy
Settlement

"My lovely husband came twice to Mile 4 (hospital) while I was there. . . But, I left the hospital on 27th January and on getting home, my husband was already in the mortuary . . ."

Loved by husband, but rejected by neighbours

My name is Ogada Grace from Nsukka.

I got married in 1983 but I developed leprosy in 1988 and I have given birth within that period before it started. My husband did always care for me. At first, he was the one who suggested a native drug and considered the option of having my own personal utensils without sharing with others so that even when food is served, I would eat with my own separate plates. He tried this for two days but could not continue. My husband loves me even till now. He has never treated me with isolation. Even my entire family always accepted me except the neighbors in my husband's house.

When their children and my children step out to play around and have fun, their mother will reprimand and beat them up because they played together with my own children. They warned their children against coming close so that they will get the disease too. But at a time, people told my husband what I was suffering and he suggested we go to Oji Leprosy centre but I refused. This was because he is the only child and his parents were dead when he married me. Perhaps, I was lucky that my husband's surrogate mother saw ahead of time that leprosy may strike someday and therefore took her children and they built a separate house somewhere else; leaving the usual family house to my husband and I as he was the first son of the family but the only child of his biological parents. And so, I refused to go to the leprosy centre since our

house will be abandoned to overgrow with bushes if I leave. I opted to get any possible treatment at home. Unfortunately, this led to the delay of about 3 years at home before I finally but reluctantly came to the leprosy centre.

Blame leprosy, not me for the public embarrassment

My husband was a driver at Okija and his boss asked him to bring me over and we went. After some time, the people with me in that hall started complaining because they were sick but theirs was not leprosy and they were scared of leprosy.

They suggested that I go to a religious healing home in Calabar, to the people of 'Olumba Olumba Obu'. You see, that was how I could have fallen into the hands of detractors. They asked us to go to Calabar to a place where you bath in the morning and night and you get healed from bathing.

My husband was so caring, never gave up in his search for care

My husband was in Onitsha while I was with the children in Okija. He came down to Okija one early morning when we have not even brushed our teeth and asked us to enter the vehicle because he came with one of his boss's vehicles. And so, I asked him where we were going to. But he just asked me to enter the vehicle then I asked him if he was finally taking us to Calabar as they suggested and he said yes. I was not conversant with roads but I saw the same signboards that I saw while we were going to Okija and I asked him again if it was Calabar we were going to and he replied

yes again that when we go down the road, we will join the road linking to Calabar. And so, we drove until we got to a market called Wonderful before I noticed that we were actually going to the Oji River Leprosy settlement I never wanted to go to.

When he noticed that I had realized the trick, he started pleading to convince me. He took the children to a restaurant where they ate and he bought mine and also for the child I was carrying as he continued to persuade and beg me to accept and urging that it was only in Oji that I can receive adequate treatment. He brought me here (Oji Leprosy centre) and Doctor Chiekezie and that other nurse started assuring me that within 2 years or even 6 months that all will be okay. They reassured me as I was crying and used that as consolation. I considered that within 6 months, grasses would not have overgrown in our house. They told him told to take back the children while I stayed alone. Within 6 months, I started getting better and that doctor was massaging my hands, giving me physiotherapy techniques to follow and that is why my hands are better now.

Perils of local traditional remedy as leprosy treatment

Before I came here, I have undergone native treatments from three different people, the last one made my leg this way because when it started newly, my skin was like one affected by harmattan while we were still in rainy season but got worse when we moved into dry season and harmattan came fully. The last man that administered native drugs

to me told me after boiling that I should place my leg on the pot and cover with wrapper.

After I did that, boils developed around that area making it worse than before. Since 1988 till today, that wound has not healed because I used native treatment. When I came here I felt painful strains in my leg veins. I've gone for surgery four times to make sure that this wound is perfectly treated. I've gone to Salvation Army thrice and also visited Mile 4 Hospital. It was my husband that took me to Mile 4 Hospital because after each surgery in Salvation Army and I attempt to walk, the wounds reopen and so, we went to Mile 4 around October, 2014.

Tragedy struck – the worst shock of my life!

My husband came to Mile 4 twice while I was there - in November before the surgery and December after the surgery too. He came on Christmas day and we ate together. He came back the next day and before he left, he assured me to visit again by the end of January to confirm when I shall be discharged. However, on the 26th of January, 2015 I received a call asking me to urge the doctor to discharge me so I can go home because my husband was ill. The people of my community as well as our church members have all gathered to support me. I was confused and asked if he was alive or dead, they told me he was still alive.

I left the hospital on 27th January and on getting home, my husband was already in the mortuary, I was thrown off balance.

I started asking myself what may have killed him, I knew he did not have a courageous heart and so, I was imagining if he thought too much about my health and died because of it.

Since then, I have been managing to care for our children and God has been preserving us through our church members.

So far, we keep thanking God for sustaining us through the church. If not for them, we don't know what our fate will be today. They are really trying for us.

Stories of conflict between community members and leprosy healthcare givers

So, I came to Oji River Leprosy Centre in 1991 during the period creation of new States in Nigeria. When I arrived, Doctor Chiegboka was already about to go but there was a foreigner that his father brought civilization to this community, he intervened in what went wrong at that time because the community people were no longer in good terms with the doctors and so, they disturbed them from duties. That foreigner treated us well. So did another Doctor Nkwo who was a leprosy expert. I arrived here towards the end of September.

Doctor Nkwo have been employed to work here but the community people did not allow him to carry out his job and so, he started working around 30th September, the same month I came. By then, I could not wash clothes with my hands, I could not pound ingredients needed for cooking.

I had three children then but they were very tender and did not know how to cook. My husband brought me here with the

children but they told him children were not needed and so, he took them back. From that 30th on which Dr Nkwo assumed duty, he worked with that foreigner bed by bed checking out our health status every Wednesdays. When they came to me, they instructed me on physiotherapies to heal my hand and also prescribed medicines. This he did to every other patient as they walked round prescribing different medicines according to each person's health need.

Hunger, anger and miscommunication among leprosy patients

There was conflict at that time which made the welfare department not to distribute our food supplies the normal way they're meant to. Doctor Nkwo called us together, introduced himself to us and asked us to do same in order for him to be familiar with people that surround him. He asked us to take away our attention from the food supplies that caused conflict and instead focus on the main reason why we came here which was our health. Some patients became angered and asked if sick people can take medications without feeding. They misinterpreted what he said by stating that he came to boycott food meant for us. The doctor asked for number of those who prefer their medications to feeding and when we indicated, the number of those who preferred feeding to medications was higher. Our fellow patients nicknamed us "ndi sabo" (meaning, saboteurs) because we stood with the doctor. But I told them I came here solely with the intention of curing my illness without even with the knowledge

that they were supplied food. Very few had same view but the majority went for food over medications.

Foreign doctors left, our fate worsened

And later, the doctor and this community people had serious issues which prompted him to leave. The father of that foreigner was killed in this community too which made him and his wife afraid that they will get killed by the same Igbos that killed his father and so, he left. So, we started treating ourselves. The doctor left also with fear the same period the foreigner left even though he was an indigene of this Awgu community. I can't remember the name of this foreign doctor. But, there was a school here that time named Savis Memorial School which his father established. I don't know his name but he is the son of Savis.

After the doctor left, we started suffering. We put ourselves in this state now because had it been the doctor stayed back, somebody like me could have gone home long ago but we were treating ourselves blindly; just like having headache and taking drugs for stomachache. Doctor Chiekezie who later died only gave us drugs, he never knew how to manage leprosy but Doctor Nkwo told us he studied about leprosy abroad. After Doctor Chiekezie died, the nurse that was employed to take over also died last year or this year I think. No nurse, no doctor. That period when Doctor Nkwo left, the foreigners that brought supplies refused to offload unless doctor Nkwo signed for it and because he was no longer with us, they left with it and this place became nothing to write home about.

Leprosy stigma defeated in community

When I travel now, members of my community, neighbours and all around me accept me and treat me well. This is quite unlike when I first developed the illness when some of them warned their children not to come in contact with anything that had to do with me. But now, we are all in good terms.

Cry for help: urgent request to deploy leprosy healthcare givers to the Centre.

I have nothing more to add only that I want you people to reach out to the government and tell them to at least send one doctor or nurse because they're urgently needed. People here die of their illness because they carry out self medication without knowledge of what they're doing but when a doctor or nurse is sent, it will help a lot so that anybody who is cured goes home. There are some that can not step outside any longer simply because they have taken wrong self medications that have allowed the leprosy to develop and become stronger in their system but in a situation whereby there is a nurse or doctor, you receive treatments and right drugs to take. Anybody that gets worse is taken to Mile 4 Hospital because they have more doctors.

We're up to 130 persons in this Oji River Leprosy settlement. Not all persons here are affected by leprosy as some are just here because of their family members who have leprosy. Children may be more than 100. Adult patients are up to 100 but when you include people free from leprosy that are only here because of maybe their husband or wife, you get up to 130 people total.

Learning from the mistakes of history

SAMUEL ANEKE

Profile: 102 years,
Male, Married

Place of origin:
Akpugo Nkanu,
Enugu State.

**Diagnosed and
Treated for Leprosy
in 1943 at Oji River
Leprosy Settlement**

*"We no longer
have a doctor. The
government does not
know if we exist, there
is nobody telling the
Governor about us.
Nobody should speak
of another civil war
because anyone who
saw the war, will not
allow another one to
happen"*

Leprosy was detested in those days

I'll start by introducing myself. I am Samuel Aneke, I'm a native of Akpugo in Nkanu Local Government. Now, I am 101 years old and after this Christmas (2018), I will be 102 years old. I was a young boy when leprosy struck me in 1943. Because of God's love for me, my uncle took me to Oji River despite my sufferings after the death of my father. I started receiving treatment at Oji River and had several surgeries because the doctor said they needed to take out some bones that were affected. But, after that my wounds remained the way they were.

In 1953, the doctors discharged me saying I was healed and so, I went back to Akpugo. But in those days, leprosy patients suffered much discrimination in my community. They stayed away from me and built a small tent for me near our town hall (in those days) and they were praying for me to get better.

As I said before, when my community knew I had leprosy, they discriminated against me. They withdrew themselves from me. Presently, I have no problem with anybody because I have received a discharge certificate stating that I am free from the disease. But there are some people who have no knowledge of what a discharge letter is all about. I join them in every activity in the community nowadays.

During those colonial times, a pastor in our community assisted me after I was discharged until the civil war began. I was one of those at Oji River during the war. The welfare department there helped me with some money as at that time because things were in disorder as a result of the war. Mr Mgbemena was the DO in our community at the time. He was the one that helped

me contact one Chief Larky. The DO was part of my source of relief at the time.

Marriage and family life

I made some savings from the pocket money that I usually received and was able to get married in 1960. She bore a male child for me and was killed during the war. My son was born the day Aguiyi Ironsi was brought back - that's how we usually remember his age. Her father was a Christian and he did not mind that I had leprosy and was having pains in my leg. Meanwhile, the pains were not as severe as they are now. I used to ride a bicycle in those days and the Welfare department at Oji River was of help to me and I was successful in farming. So, this was part of why her father handed her over to me because I supported them with food when I was still strong. That was about 1960, the year Dr Nnamdi Azikiwe came on board in Nigeria.

I came to live here (Marist Brother's Leprosy Settlement, Emene in 1972. We were so many then, those from Uzuakoli and other places, up to 80 of us. I am 101 years and still alive because of God's love for me. All of them who came with me to this place are all dead by now. The Marist Brothers at that time came here and the white men taking care of us handed us over to them. It was Chief Larky that first brought us here. So, he gathered us to come and stay here - both people from Oji River and Uzuakoli. And by the grace of God, we were welcomed well when we came.

Experience during the civil war

My experience of the war is part of the reasons I thank God for keeping me alive despite my sickness. During that time,

I always looked around for places to hide because of the shelling and bombing from the air strikes. That is why I keep saying that nobody should speak of another war because anyone who saw the war, will not allow another one to happen.

During the war, when the *Hausas* conquered Akpugo, the Commander used to be compassionate on me because of my condition by allowing me to partake in relief activities. I used to ride a bicycle then and for those places restricted to only few people, he allowed me to enter and even partake in sharing food. The soldiers did not disturb me. He even ordered some soldiers to take some food home for me. I did not go hungry during the war but the bombing and terror was much. The war was a fierce one!

Injustice by the government and some health workers

We no longer have a doctor. The government does not know if we exist. There is nobody telling the governor about us. Only that the Marist Brothers help us by bringing us some things. That is all!

The doctors in charge at that time used us for business. They always come with the excuse of conducting a surgery for us by taking most of our bones off without any improvement. They kept coming but some of us were advised by some of the nurses who found out what was going on not to allow the doctors do something else with us. The doctors were paid for every surgery they conducted but at a time, we stopped undergoing the surgeries because it never showed any positive effect. I can no longer partake in little chores anymore. It is the little boy you saw here when you came, that helps me to do some chores. Maybe because I am now too old.

Moreover, the sickness made me to prioritize major treatment before any other thing. I wanted to study when I was at Oji River because I was still young enough to go to school. But my ailment allowed me to attend only up to Standard Two. My wounds did not permit me to sit for long in school.

A life of gratitude

Meanwhile, my son had four children: three girls and one boy before he died. As a result of God's love for me, a lady looked at my condition and helped my son in order that he will help me too. She asked him to first study in a university, IMT precisely. She was really helping me and that's why I said God loves me because he sends me helpers like you people and so, I thank God immensely and also those that help me especially German Leprosy and TB Relief Association. They always bring us many things like money, cloth, food and other things we need.

Other different individuals and groups also extend their helping hands towards us. Painfully, I just heard that the woman helping my son through school was kidnapped and that she paid about 15million naira as ransom. So, if in the end, she becomes financially unable to continue her support, please you people should come to my aid. I am thanking all of you who have come here to interview and hear my story. I ask for your help to relief me of my situation. I also thank you for the things you've done already.

Painful moments – marriage, family life and leprosy

Lest I forget, another painful issue is about one of my granddaughters who got impregnated and the boy eloped with her.

I don't know if it was juju – but I believe in God, not juju. He took her and kept her at home and she is having children for him. Yet, the customary rites of marriage have not been performed. If I receive anything, I still give to the children because they are not the cause. I guess the man is doing this because he knows I can't do anything. But, there is God.

I have four grandchildren: three girls and one boy. Two among them are in their husbands' house. Our people supported their union while nobody supported the union of the first daughter because she got pregnant out of wedlock. I was really angry then, I took her to the welfare department here and they asked her to do the needful as required by the tradition before she is considered but she did not. It was said she used enchantments and other things but I don't believe all of those things are bigger than God because I serve Him. If you can help me, please help me ask that man what I did to him to deserve such treatment. Or is it because I had leprosy?

After the man, whose name is Chinedu impregnated my first granddaughter, we have not been able to take appropriate actions towards that incident. There was a time she was about dying and the people she was living with brutally beat her to my house. I pleaded with the welfare department here assist me to go with my family to see my granddaughter at the hospital so that when the doctors or nurses see my condition, they'll make tremendous effort to save her life. They agreed and assisted me to the hospital and when we got there, the doctors and nurses did have compassion looking at my state and some other visitors there were able to contribute

part of the bills for her laboratory tests and some other expenses.

At a time when the doctor wanted to check on her, she ran off but I was billed more than 50,000 naira. In my name, the bill was settled by the current workers in the welfare department at Parklane Teaching Hospital, Enugu. After she was brought home in my house here, she now kicked me out of the house like a ball. Our leader at the time then told her it was me who owns the house but she came with Chinedu – the rogue guy – who came and destroyed my walls. He also threatened to kill me if anybody gets married to my granddaughter. I'm saying this so that you bear me witness, they live around this Emene, in case something unfortunate happens to me.

One of his kinsmen came with him to my house and asked him if that was how his mother was married but he could not render any answer. I don't know what to do. You people should please help me as you have seen my condition, please try your best that God will always be with you as you do so. Thank you, my children.

Final words

You people that remember me, please continue remembering me. It lends me dignity and self-worth and makes me feel like a rich man. Because asking someone “how are you” is the greatest cure of any disease on earth, do you hear, my children? Asking someone, “How do you do?” is part of the whole recovery process. The way you people come to hear our stories and help us, it is also part of what prompts longer life.





Assumpta Cathedral/Roundabout



Freedom Falls



Oguta-Lake



Hero Square



Owerri Town Metropolis



Nekede Zoo



GLRA Oral Leprosy History Project

***Practicing Lawyer,
destined Advocate
of Justice***

BARR. LILIBETH NWAKAEGO EVARISTUS

***Successfully called to Nigerian Bar
as Solicitor and Advocate of the
Supreme Court of Nigeria***

***Profile: 39 years, Female,
Legal Practitioner
Place of origin: Mbaise,
Imo State
Diagnosed and Treated
for Leprosy in 1996 at
Uzuakoli, Abia State***

***"Then, I lost most of my
friends, and most of them were
warned by their parents
not to come around me,
that it is a cursed disease."***

***"One day, I came to school and
found that my friends had
moved their lockers away from
mine. I was discouraged and
stopped going to school."***

***"My marriage broke down
because my husband and
father to my two boys
found out that I had
suffered leprosy".***

They knew it was leprosy but nobody told me.

It started when I was in my teenage stage, 23 years ago and it started with some scratches around my body especially on my face around my nose, my laps, my hands and this called for worry being a very innocent child then, and I didn't know what all these was all about. All I was thinking was "it's eczema" but when it kept on coming, my parents had to take me to several herbalists for me to take herbs. This didn't work, every day, the patches kept coming out. The patches always came out every time I was in school. I was in secondary school then, most of my friends thought it was eczema and people were looking at it as eczema. But in the community where I found myself then, **majority of them knew that it was leprosy but nobody told me.** Soon, I started developing ulcer, I had an ulcer on my foot and that gave me a very swollen leg.

Discrimination: Deserted at school by friends and neighbours

And when I got to school, I found out that most of my friends started deserting me for no just reason. And like in the secondary school setting where you have to place your school locker beside your friends' but before I came to school one day, I found out that most of my friends have moved their own lockers away from mine and that actually discouraged me, so I stopped going to school.

One day, I was pressed, I wanted to go do number two, we call it 'number two', so the woman, our neighbour, from the window saw me, then I was still having these

patches all over me, we were still going from one herbalist to the other. When she saw me coming out from the latrine and one of her sons was coming again to use the latrine as I was coming out, she quickly shouted from the window, "IK, IK, don't go there, don't even use it. Go into the bush, don't use it, before they give you whatever I don't know", you know, I was embarrassed. She didn't allow the son to use the latrine and while I stood there looking at them, she had to get a bucket of water and Dettol and began scrubbing the latrine I just left. I knew I didn't mess the place up, she was scrubbing it for her to see that every place I touched was washed out. And from that day, my parents asked me not to use the latrine again.

Again, one day too, another scenario too. We were sitting like girls, we came for a meeting and I saw one of us, she had a wound on her leg and I was saying, "what happened to your leg?" I was showing concern. The other one just came and said I shouldn't take paracetamol on another person's headache, "the one you are facing is more than this one". And you know, then I had no idea that what I had was leprosy until when it was diagnosed. It was after then that all those ones now came into my conscience that this is what was happening then in the village. Yes, it wasn't a good one in the village but because I have this strong will, I am a kind of person that don't subject myself to pity.

Kind treatment and compassionate care at Uzuakoli

I arrived Uzuakoli Leprosy Colony on the 30th of January, 1996. A Skin Smear Test was carried out and the result came out

positive and they told me that I had leprosy. **That got me devastated, I was really worried, and my mother couldn't believe it.** But they allayed our fears, that now that we are here and now that it has been diagnosed, "you will be placed on treatment immediately", and I was calm. Then, I had a very deep ulcer around my heel, it was so deep. But when I showed them there, the Medical Superintendent we met there, Mr. Emmanuel Ibowu, was very courageous and told me, "don't worry, all these things will be a story. I just give you one month" and that got me very calm and I was happy.

So, immediately, they started the treatment. I was placed on MDT, they call it Multi Drug Therapy then and the Medical Superintendents took it upon themselves to see that every day, I took my routine drug. I was admitted again to take care of my ulcer and every day, their Medical Superintendent and the nurses, they come, they clean the room and before you knew it, within 3 weeks the wound healed. I was admitted there for about three months in total. In fact, it was like magic because immediately I started to use the drugs, the patches got darkened and got better. I was happy with the treatment.

During the time I was admitted, around 1996, I had a friend Calista by name. She never wanted to disclose to anybody about her status and she didn't want to talk about it. When visitors come to see the people in the ward, then people come to see and donate whatever they have but she would never want to stay there. And at a time, I had to call her and said, "why are you doing this?" and she said, "it's a taboo from where

I come from, they wouldn't want to know that I have leprosy. In fact, they had to hide to bring me here. Lilli, nobody must know, that is what I am saying. They said if get healed, I am not going to get married as long as my town is concerned." She ended up learning how to sew, she said she doesn't want to go to school and she doesn't want to be identified with German leprosy and tuberculosis whatever, that she doesn't want to go to school, that she wants to learn how to sew and get back to the village.

Discrimination continued in my community

At the village, people were still looking at me, people deserted me, I lost some of my friends... most of my friends not some of them because most of them that kept coming around were warned by their parents not to come around me, that it's a cursed disease that in fact, it's a contagious disease, that they shouldn't come close to me. But let me remind you once again that my family never believed that it's leprosy and my family never segregated, my family was showing me love and that love really kept me going. My family especially my mother she kept advising me, she kept encouraging me all the time that see I can always be what I want to be irrespective of this disease and not to come to the fact that it has been cured and the sky is just my starting point and that helped me.

There was a day while coming up as a teenager, we went in group to fetch firewood and while we were coming, one of my friends said, "Lilli, you are a greedy person, see how huge your firewood is", you know, we got talking. At a time,

it resulted in a fight and we fought. So, people now ran to her home to call her mom that "Lilli is fighting your daughter". And the mother came and starting shouting, "you are a leper, you are a leper, leave us alone. Lilibeth Nwakaego leave us alone in this community, you are a leper, you don't belong here" and I felt really bad. When I got home, I asked my parents "am I a leper?" and my parents incurred me and said "no, you are not a leper" and that kept me going. And I found out that from that day the woman called me a leper, so many people didn't want to be identified with me any longer until I left for treatment.

Then I can remember then, I wanted to buy Maggi, my mum asked me to go and buy Maggi. I got to the kiosk then and when I requested for Maggi, she then brought out the Maggi and dropped it on the table. And when I tried giving her money, she didn't want any part of her body to have contact with the money - then was the time we used coins - and she found it difficult to pick the money, she called someone else to pick the money, I realized it was because of me.

Journey to the Bar

After just two weeks in the village, my elder sister from Lagos came in to take me to Lagos. After working for few months as a Sales Girl at one shop, my immediate elder sister got me a form for me to take JAMB. When I sat for the exams, as the Lord may have it, I passed and was admitted to go and study Law at University of Lagos. For me, it was the beginning of new hope. I informed the German Leprosy and Tuberculosis Relief Association and they were happy for me and went a step further to enrol me into their scholarship scheme then.

It was a tough one for me because I wasn't living very close to the University and I wasn't given any accommodation and I was taught at the Leprosy organization that I should avoid long trekking. I was trekking from the place I was living then with my elder sister to the campus and eventually that resulted to having osteomyelitis of the foot, it was so deep and that made me not to be regular in my studies. But gain, through the help of Mr Gilgen from GLRA, I was able to receive treatment and resume class.

A bump on the road

By the time I finished my University education, I saw this man and I fell in love with him and I got married to him. I had 2 children with him, Michael and Emmanuel. At a time when Emmanuel the second son was a year and three months, he started behaving funny. The man said he was no longer interested in the marriage because he just found out that I was a leper, that had it been he knew he wouldn't have the issue and as long as he's concerned, he is no longer interested in the marriage. That put me on balance because I have not gone to Nigeria Law School and I have to take care of my kids and eventually, we were separated. He kept saying that if he finds me around his house that he was going to kill me and I took the report back to my parents, they told me to leave the house. I was separated with my kids it was as if the whole world has crushed.

My husband did not know that I had leprosy. Okay, when I had my first child and the second one, I believe when Emmanuel was now a year and three months, he knew because of my involvement with people.



I told him about the German Leprosy and he asked me what was the connectivity, how I got to know them. And as a woman that is in love with her husband, I told him the way I am, I told him where I am coming from and where I have gotten to now. I thought he would be happy and all that. At a time, at any little provocation he would call me a leper, “after all, I don't know what am doing with you”, disregarding the fact that I had had two boys for him. But the one that really got me was the time that he said if I don't leave the house, he's going to kill me and I asked him “why? I have not been a wayward wife”. He said he doesn't want to know all that that I should leave. But initially, he said I should leave alone and leave the kids. But from my little experience, then I have not gone to Law school, but my little experience then as a Law student, I found out that as long as the children are still minors, I still have the right to be in custody of those kids. So, I insisted and I said “I am going to leave with my kids. If you want me to leave, I will leave with my

kids”. So, at a time, he was really using ugly words, calling me a leper, calling me all manner of names. That if he didn't pick me up, oh, that is why family has not been visiting me, they just dumped me around him to infect him with leprosy and all that, it was getting too much. When my sister that stays abroad came, she saw me as I was looking tattered, he stopped providing for me and my children all in a means for me to leave the house. When my family eventually came to see how am faring with my kids, I had to open up because then when I was experiencing all that, I never opened up because my father had warned me against marrying him but I insisted.

'I married out of low Self-esteem'

Then let me tell you what actually lead to that marriage was low self-esteem, I was thinking that nobody else is going to come for fact that this one has come my way let me quickly go into it after all it's marriage. So, I got in and I never complained of anything I was going through but when it

was really getting overhand, I couldn't bear it, I had to call my people and told them. My people said "okay fine, we are coming". And then, if you looked at me, I wasn't looking like a woman that has been in a good marriage, I was looking so haggard, so depressed and there was no food, he didn't provide anything for me and my children.

So, when my family came in one day like that, 20th of May, 2010 and said "we are here for a peaceful resolution of whatever quarrel you people have. Tell us, what is your problem? Tell us what the problem is all about, let us know". In fact, categorically, he told them that he is not interested in the marriage, that I should just go out of his life and his universe, that I have been the cause of his misfortune, no money, nothing, his business was booming before I came in and now that I have come with my witchery and all that, nothing is moving. I should just leave his house. And having told that to my family, they didn't have any objection than to move me out of his house. And even when one of the concerned neighbours ran in and said "see, if you are throwing this woman away with the kids, it's not going to be easy getting them to come back", that he will still go to the village. He said he doesn't care, that he doesn't want to know and that was how we left his home.

The family came and asked me what happened and I told them why I did not disclose my status to the family. I was thinking it shouldn't come from me, for as long as I'm concerned, I have been cured, nothing is wrong with me. I can produce, I have children, I'm a wife, educated as well. I don't know what will make me classify myself as a Leper. My mother, in particular, told them that if they are ready, they should

come for settlement, they never came, they never asked of the kids, their school, nothing.

Timely intervention by German Leprosy and Tuberculosis Relief Association

I ran back to the German Leprosy and Tuberculosis Relief Association to tell them my ordeal and they were not happy about it. They said, "Lilli it is not over until it's over. Please go back to Law school and get the professional training you deserve to be a proper lawyer". And they took me back to Law school, gave me all it takes financially for me to get enrolled and I got in. I was really determined but then I didn't have accommodation as well, there was no accommodation because accommodation was given to the first people that came on time, then I decided to be sleeping at the portal's lodge. There is a portal there I knew, I went to talk to him. I said, "Sir, please if you can give me a little space around your office let me be sleeping, very early in the morning I will find where to clean myself up for the lecture and he agreed". Believe me, the program is for a year and I spent four months sleeping at the portal's lodge, I was really determined, I wanted to be a lawyer.

At a time, most of my new friends now said, "Okay Lilli, come squat in our room", which I did. At the end of the program, I was among the successful candidates that were called to the Nigeria Bar as an Advocate and Solicitor of the Supreme Court of Nigeria. So, I was so happy to be called. So, that was how it all ended and now I am a practicing lawyer and I am a mother even though I have been separated with their father. Life has not really been

too rosy but I thank God and the German leprosy and tuberculosis relief association who were there for me.

A New Dawn of Justice:

Since I became a Barrister, I have garnered respect and fairness from my co-workers and some of my superiors will say, "Lilli, can I have your card?"

There was a time I travelled to the village, people were surprised about the transformation, they were like "wow, is this the Lilibeth we used to know? What happened? Where are the patches?" In fact, let me tell you, they just gave my family one name, they called my family a "magic family" that they don't know how they did the magic about everything, because what they expected to see was not what they saw.

My husband's people heard that I have been called as a practicing lawyer because one day, while I was going to the court, I saw one of his best friends and he told me that he will call him now and tell him I'm a practicing lawyer. And the next day, he called, "how are the kids? How are you? I want to see you" and all that. And since then, the family, one or two of them, have been calling me. And even at times, they will have a problem that they needed legal services, they will call me to clear off that. But they've never come to say, "we are sorry, come back home". Even the father of the children, he has never called to say, "come back home".

Advocacy Against Discrimination

Having experienced it, an adage says, 'he who wears the shoes, knows where it pinches', so as a lawyer too, I have made up my mind to advocate for the rights of the

persons that are affected by leprosy of which I am into. In my little way, I have been visiting colonies to tell them how to take care of themselves and sharing my experience, Most of the time, let me tell you when I get to those referral homes, because I don't want to be calling it 'colony' and 'settlement' because to me and as a lawyer, it's degrading, I want to call it a referral home. When I got there, all of them were really surprised how could I be like this, "how did you manage the wound, how come?" **I go about telling them that if I can be this, you too can.** I try as much as possible to encourage them. And I have one little project that I want to embark on, I have been waiting for the Ministry of Education to answer me, I am looking at getting most of the children from the centres to school.

Because most of the referral centres I have been to, old people there said, "please use your position to make sure that our children go to school the way you've gone, that will be our joy" and that is what I have been on now with my committee. We have Nigeria Bar Association, we have the Woman Rights Committee, which I'm a member of, we have a plan to go to Lagos state Government (we want to start from Lagos state to be precise) for them to give us the number of children we will bring to school for scholarship, to grant them scholarship even to the university level. That is what I feel like I can give them in my position as a lawyer, because having seen myself now that am educated, people want to identify with me, I have been empowered, I believe if they are educated, their children will in turn take care of them and would cater for their needs and that will as well reduce discrimination.

Leprosy took both legs from me

CLIFFORD UBECHU

Profile: 73 years, Male, Married,
double amputee
Place of origin: Ikeduru,
Imo State.
Diagnosed and Treated
for Leprosy in 1970
at Uzuakoli Leprosy
Settlement

*"Before this leprosy, I was married;
she left me immediately I contracted leprosy."*

"My both legs were amputated in one month.

*The story behind this sickness cannot be completely told
in one or two days. In fact, I suffered a lot. Oh, I suffered."*

My name is Clifford Ubechu.

I developed the illness around 1961 as I observed a skin patch here. I wondered at this over sometime, even when I eventually joined the Biafran Army. From there, I came to Uzuakoli for further treatments but it was not confirmed at first. My in-law insisted that I should go back to be examined and so, I went back to the warfront. It (the leprosy) had a small patch on my hand. It was after the war that I started receiving treatments in 1970.

It was my in-law that insisted we went back to Uzuakoli for thorough check which we did and it was confirmed. I stayed there and at that time, it was Onyejekwe who was in charge. There were no doctors then; we only prayed. I had a motorcycle accident that led to a wound on my leg and we searched for a doctor who would carry out a surgery on my leg for so long, until Dr. Chukwu finally showed up as the doctor who would be in charge of us and we were all happy about it. After some time, Dr. John came too. Dr. Chukwu's wife would cook and bring to us at that time. After the accident, the sickness affected there also. It was disturbing me and the only alternative was to amputate the leg. The news of amputation greatly distressed me.

The story behind this sickness cannot be completely told in one or two days. In fact, I suffered a lot. Yes, I suffered. When any patient among us remember Dr Chukwu, a fresh breath of life and hope is usually reassured. He is the reason why most of us are living today. When I was about to be amputated, Dr. Chukwu assured me that all will be fine after the operation. My both legs were amputated in one month. Even the wheelchair I used was given to me by

Dr. Chukwu. We thought we would all die when Dr Chukwu left us. But we are happy to see him whenever we go to Enugu.

Before this leprosy, I was married; she left me immediately I contracted leprosy. So, I met my current wife at the market. On approaching her, she asked me to go and bring my people. I went with my late brother, Sylvester Ubechu and he approved the marriage. I went and performed the necessary rites in Bendel State. I got married while I was there and had four children; two boys, two girls.

I was a tailor; but this illness gave me a huge set back that I could not come out of. Nevertheless, I thank God for everything. I thank God for my family and the gift of life.

None of my people discriminated against me, even now. I was very happy that my relatives accepted me. But when it comes to somebody without two legs, it can't be compared; when I ask them for something, it's either they insult me or they promise today, promise tomorrow, without doing it. When I remember my condition, I become bitter.

I am hopeless at the moment; I have no legs, I have no hands. I seek financial assistance in order to earn a living. I am just thanking God for everything despite the fact that I have no hands nor feet. I want to also thank the Methodists, German Leprosy and TB Relief Association. I appeal to German Leprosy, Dr. Chukwu and the entire public to please help us out so that we can survive.

They (the Community) involves me in all they do. I attend the meetings of the Christian fathers in the Parish. Coming to the aspect of my kinsmen, I also attend their meetings and we relate very well.

A life of gratitude amidst difficulties

AGNES UBECHU

Profile: 55 years,
Female, Married
Place of origin:
Amaimo - Ikeduru,
Imo State.
Diagnosed
and Treated
for Leprosy
in 1971 at
Leprosy Centre,
Uzuakoli

*"I thank God for
sustaining us this
far, and I seriously
hope that things
will still turn out
to be better."*

My name is Agnes Ubechu. I was born in Bende Local Government Area of Abia State but now married and presently live with my husband, Clifford here in Imo State.

I was very lucky that when the illness started, my parents were there for me. They took me to various places for seek care without success.

Eventually, it was our village head who gave me a letter referring me to Uzuakoli Leprosy Centre. It was one of the best leprosy treatment centres at that time. So, it was there that they confirmed I had leprosy and my father was notified of what was happening. Despite the sickness, I was able to complete primary six at that time.

I can remember the doctor that was in charge then. He was always there to assist each and every one of us. In the leprosy settlement, I was trained on some skills to help me earn a living. So, I was among those privileged to be trained there. Later on, it didn't pay off as expected due to lack of finance to continue.

Loving care received from my parents

My parents always brought food for me, perhaps, because I am the first child of my parents. It was my father and mother that took care of all my needs, even when I was in the hospital. They took up all the responsibilities.

But now things have changed for me; I have no parents again and my husband is still struggling to make end meets.

Marriage life – changing times

My marriage life began during one of my gospel evangelism visits in the leprosy hospital wards. I never imagined that my future husband was there present.

After my preaching, he met me and declared his intentions to marry me. Initially, I despised and mocked him and told him that I was no longer interested in getting married. I insisted that my parents will always take good care of me. Later on when he came again to me, I had a change of mind and told him that if his parents accept me, then, I will have no other choice. So, the parents accepted me and that was how we got married.

Happy moments

What makes me happy is the fact that I got married and the marriage was blessed with children. I managed to work hard to sustain them and the family but as it stands now,

Eventually, it was our village head who gave me a letter referring me to Uzuakoli Leprosy Centre. It was one of the best leprosy treatment centres at that time. So, it was there that they confirmed I had leprosy and my father was notified of what was happening. Despite the sickness, I was able to complete primary six at that time. none of them earns a living yet. What pains me most is that I have no work to do in order to sustain the family. It is just by the grace of God that we were able to survive.

I am also very happy that I enjoyed a cordial relationship with different people in the community. I freely participate in religious and other activities in the community.

What I want in the future is the gift of life. Everyone in the house loves me; including my husband's relatives. I wish that my children will be assisted to start a life of their own. Me and my husband have been living happily and joyfully and it is a thing of joy to me.

A Question of Justice

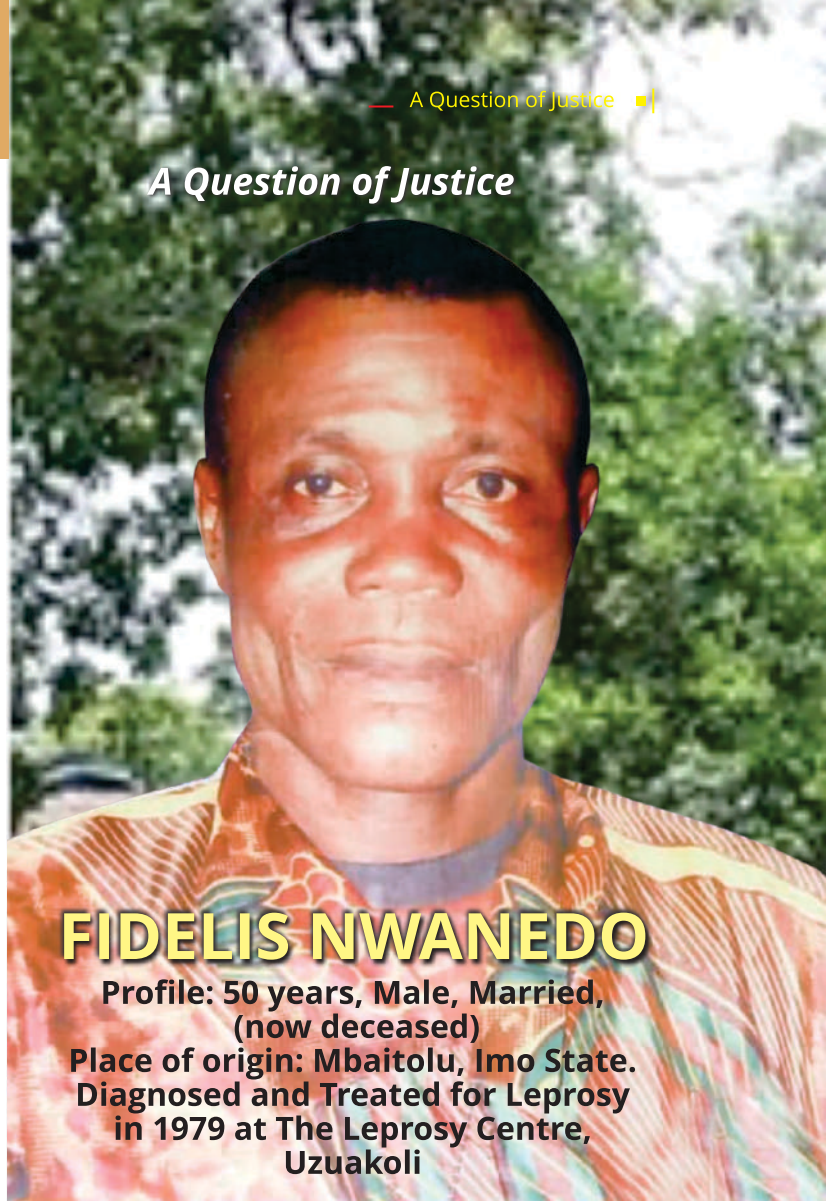
By the grace of God, I have no regrets and I always give thanks to God for everything.

Difficult times

At the time we got married, my husband was able to walk with crutches as only one of his legs was amputated. The other leg was amputated later. I suffered a lot here in Ikeduru because of the fact that there was no sufficient food for me and my family. But, I thank God for sustaining us this far, and I seriously hope that things will still turn out to be better.

There has been a cordial relationship between me and the community members. The only problem I have is that I am doing nothing to sustain myself and the family. The people who were meant to assist me were all deceased. The ones remaining are all incapacitated.

At the moment, what gives me sleepless nights is the future of my children. My husband and I are gradually getting old and none of my children is working. This poses a serious worry to me. I pray that God should send a helper to ensure that my children become successful in life. My major concern is that I have no money to start a business. I would have loved to start a business of my own or get employment and avoid hawking around the streets.



FIDELIS NWANEDO

Profile: 50 years, Male, Married, (now deceased)

**Place of origin: Mbaitolu, Imo State.
Diagnosed and Treated for Leprosy
in 1979 at The Leprosy Centre,
Uzuakoli**

"When I went back home to my father's house, my village came in groups and asked my father to send me back. They even threatened to send my father away from my village instead of me coming back to the village."

My name is Fidelis Nwanedo, and I am happy with you people coming and I am willing to tell you people my story. Thank you.

How it all started

This leprosy started when I was in primary three in the year 1979, that time I was staying with my parents and I started noticing one map (patch) on my buttocks. We were staying along water side, so if I went to swim with my friends, they will be showing me the map on my buttocks while taking my bath. If I pinch the map, I would not feel anything but I used to feel other parts of my body. Sometimes, when my mother will tell me to fry Garri; after frying the Garri, everywhere will swell, I will start noticing blisters all over my body and I didn't know when these things happened. When my uncle took me to his house, the blisters started re-appearing on my face. They started looking for what was happening to me and they concluded it was a traditional curse. They even called many native doctors.

My initial treatments

Later, my family called one man that used to work in general hospital, the man will heat the needle and inject me but all to no avail. These things kept happening till my primary five, then, I went to take my common entrance and after that, I entered college in 1982. In that college, my sickness did not allow me so we started looking for solutions. There was one woman who told my parent that she knew where they could treat me that they should take me to Uzuakoli that they have treated this case before. Due to the fact that my father didn't have chance, he sent our first son to take me there.

When we reached, they refused to allow my elder brother enter because they said that he may run away. So, after everything, they told me that I had leprosy. They told my brother to take me home that he couldn't look after me here. So, he took me home

and they sent me to our local government and took me to our village. When I was taking medicine in the village, my village people called my parents and told them to come and carry me because I may infect other people with my sickness. My father came back immediately after the call and took me to Uzuakoli. When I reached Uzuakoli, they admitted me, and in the first two to three days, I was left alone crying like a dejected child but within one week, I found some children who were going through the same thing as I was and I consoled myself on seeing them. The medicines they were giving to us then were Dapsone (DDS) and Lamprene. That time, there was something that used to itch my hand, making my hand to bend so, they started giving me another medicine. While they were giving me those medicines, my body started changing back to normal. Due to the fact that I took my common entrance in primary five, I now went to primary six in Uzuakoli.

The ulcers

When I finished my primary six, I was still there taking my medicine till December during harmattan. My leg started blistering and I taught it was a minor issue till it entered under my foot. From that time, I turned into an ulcer patient. I started treating it. If it stopped, after a little while, it started again. If I went back home to my father's house, my village will come in groups and start telling my father to send me back. They even threatened to send my father away from my village instead of me coming back to the village. Anytime I came back to my village, they started disturbing my father till 1985 when I got discharged. When I got discharged, I came to back to the village and started learning petty

trading. I was staying at the village till my village people came again and started telling my father to send me away. During that time, the welfare department gave petty traders a little help.

So, when my village started disturbing my father again, my father started planning to take me back to Uzuakoli considering my wound. The welfare department said that we were going to return all the money they have given us, my father returned the money and sent me back to Uzuakoli. While I was staying in the ward, I wrote a petition that I wanted to learn work. I learnt shoe making but they did not pay me off. While staying there, I also met a woman going through what I was going through also that I said was going to marry. They refused to allow me marry that woman and I told them that if I reach my village, they will not allow me to marry anybody and so, it was better I married the woman that had seen what I had seen. They still refused to allow me marry her but I went to the girl's village and did all the marriage rites and asked them to write a letter to the welfare telling them that I and their daughter have gotten married. They did as I said. So, after all said and done, I and the girl stayed together in Uzuakoli where she gave birth to three children for me and one later died. I also started small petty business in Uzuakoli through my hustle and from there, I sent some things back to my parents to show that that I was not doing bad.

An accident

My village people started noticing that my body had change except that I was still suffering from ulcer. Later, Rev. Okeke said that I had to go due to trouble. So, I told them that I didn't have any house in village where I was going to stay so, they later

agreed to help me build a small place for me and my family. They later helped me and built a house with two rooms for me in my village; although they didn't finish the house, I used my sweat to make sure that I finished the house. I and my family now moved to the village and continued my petty trading. The trade was moving well until armed robbers attacked me so, I went to the village and started riding "Okada" (commercial motorcycle). The "Okada" business was not that okay because my hands and legs were not good. I was riding "Okada" till I later had accident and so, I went back to Uzuakoli to operate on my hand in the year 2016.

There was one English doctor that operated on my hands that said my legs were dead because my legs were also affected in that accident and so, in other to stop suffering from that pain, I wanted the doctors to cut my leg but my family members did not allow me to cut my legs. Then, I met brother Micah; he asked me whether I was sure that I wanted to go ahead with this decision and I told him yes. He said okay, that if I was really sure I wanted to go ahead with it that he was going to write a note to the German people. It was brother Micah that ran all these for me until I met Njideka and we spoke and she asked me whether I really wanted to have my legs amputated. I said yes. She now said that if I really wanted to cut (amputate) my legs that she would see to it. So, I was in Uzuakoli and they now told me to start looking for a place that they were going to cut my leg from but before then, Dr. Chukwu had operated on my leg. Dr. Chukwu was the man that helped us very well; he would do anything in his power to treat us till they brought Dr. John from India.

He and Dr. Chukwu worked together to save lives; even if you call them in the midnight, they will still come to your aid. So, I'm begging God to bless him and his family. As I was in Uzuakoli, brother Micah told me to prepare and I suffered a lot with the money I got from the petty trading and with the transport fare Uzuakoli gave me, I went to Abakaliki. That was where I cut my leg. Thanks to God everything went well but when things started getting hard again, I called brother Micah and Dr. Chukwu and they really tried for me, I was happy going to Uzuakoli because if not for them, I could have been a dead man by now and I also thank God for keeping me alive because some of the people I started this journey with have died while God still kept me alive. As I was at home doing nothing, I couldn't ride "Okada" because I didn't have legs again so, I met my boss and told him that I wanted to ride "Keke" (tricycle) and we discussed about it and he told me that I would be giving him 6,000 per day and that was how I and my family were surviving.

Family

I am with 8 children but what is remaining now is only 5 and all of them are in school. One of my daughters that finished secondary school has not entered university because there is no money to continue; that is why I am begging people, I really need help. Even the house that they helped me to build that time, now has a lusted zinc; when it is raining, water enters my house. My "Keke" is the only means of sustaining myself and my family, that's why I am asking for help whichever way it comes. Even when we went for meeting in Niger state; I am the head of leprosy patients Imo state based on IDEA. I went there and asked them for help; they told me to come, which I later went there. The little help they gave

me is what I am still managing now. That is why I am asking people to help me in whichever way they can because my wife is an ex leper and I am also an ex leper so, I am asking people to help me so that I can leave a longer life. Now in my village, I am the home vice-chairman so, if they have any problem that needs suggestion, I give them, that's what they are going to take. They no longer discriminate me, we relate well. My other leg now has ulcer.

So, thinking of all those things makes my heart bitter. But seeing my children and relating with my people make my life a little longer; that's why I am asking for help. In my family, we are 8 in number but none of them are capable of helping me because they don't have that much. I was even planning to join the force before this sickness started but anyhow it is, I thank God for giving me life. Thanks. All my wife is doing is job; like, if you have a farm to weed, you can negotiate with her and that's what she does. Or she may buy palm kernel, I will be sorting it at home, that is how we use to survive the time I don't have anything doing. But if I can go back to my petty trading, I will like it because my kinsmen use to buy something from me, they don't discriminate me.

Friends

I have many friends at Uzuakoli. Before coming to Uzuakoli, I thought I would never have a family but I got my family in Uzuakoli. If I see my children, it gives me joy because I didn't expect to have a family. Even if I see those people that treated me like Dr. Chukwu; the day he was transferred, I cried but God provided us with brother Micah who carried on the good work Dr. Chukwu was doing, although, he is not really a doctor but he is

trying his best in treating us. So, I have a great joy seeing my friends in Uzuakoli. Some of the people that rejected me then, now come to visit me and it gives me joy. In my family, I am not the first son but anything I say is what they do and it also gives me joy. Uzuakoli taught me many things; even in our kinsmen gathering, there is somethings that I will say, they will start asking me where I learnt all those things but it was at Uzuakoli and so, I am very grateful for Uzuakoli. When I came to Uzuakoli, I met the headmaster, Ihegbu, I met Mr. Aniche, I also met Morris and many other teachers in the school and they welcomed me well. I used to play football for the school when my leg was still good. I took my first school leaving examination there and they asked me to go to their secondary school but the way the town use to discriminate people with leprosy made me to say no.

Yes, I have many friends at Uzuakoli. Before coming to Uzuakoli, I thought I would never have a family but I got my family in Uzuakoli. If I see my children, it gives me joy because I didn't expect to have a family. Even if I see those people that treated me like Dr. Chukwu; the day he was transferred, I cried but God provided us with brother Micah who carried on the good work Dr. Chukwu was doing, although, he is not really a doctor but he is trying his best in treating us. So, I have a great joy seeing my friends in Uzuakoli. Some of the people that rejected me then, now come to visit me and it gives me joy. In my family, I am not the first son but anything I say is what they do and it also gives me joy. Uzuakoli taught me many things; even in our kinsmen gathering, there is somethings that I will say, they will start asking me where I learnt

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Even when I was at Uzuakoli, I used to go fishing and also set trap for animals to avoid being idle. Like I said, I learnt work like, printing press, computer, art, and the last one was shoe making which I learnt for 4years but they didn't settle me. As for my children, they know about my condition. They have seen my condition and they understood but the problem I used to have is at certain age when they see other children getting everything they want from their parents, they start to feel that their own parents brought them to life to suffer them.

So, the other thing I remember is that whenever we have meeting of the disabled, people used to have problem of transportation while some will come and after the meeting, if they went back home, they will not have any other money to even buy food to eat. So, I am pleading if there is anyhow the government can help us so that we will be able to come out in mass and share our various ideas. Their difficulties are mobility. They don't have the money to come and go back after the meeting.

Thank you.

Leprosy sufferers are often neglected

MAURICE EZE

Profile: 60 years,
Male, Married
Place of origin:
Isiala Mbano LGA,
Imo State.
Diagnosed
and Treated
for Leprosy
in 1976 at
Uzuakoli

“What makes me feel bitter is the hardship I encountered; there are so many people that are not privileged to be taken care of. I was not privileged and it made me feel bad.”

“After my training and education, I became very happy and fulfilled. I got married and had my own children. At some point, I was appointed as the head of a school. These series of activities gave me much joy till my retirement.”

My name is Maurice Eze.

Leprosy as I have experienced it is a sickness that is curable. I came here in November 1976. I started my primary education in Uzuakoli, NCE and B.S.E. The thing about leprosy is that if adequate attention is given to it, then, the patient will not really suffer so much but if the

reverse is the case, then, the patient will find it very hard to sustain him/herself.

German Leprosy and Tuberculosis Relief Association then, really tried a lot in assisting us. On the other hand, they organised a rehabilitation programme where many of us were being trained in various skills or fields. By God's grace,

I learnt that a leprosy patient has a key role to play too because leprosy is a very dangerous illness. The only reason why people are being avoided is the fact that the symptoms are so bad.

The only pitfall I observed is the fact that they only take care of leprosy patients only when they are still in the centres. Once you are discharged, they tend to forget about you. I suggest that leprosy patients should be taken proper care of even when they are fully discharged. Sometimes, people when discharged, resort to begging in order to sustain themselves. Rehabilitation should be handled effectively so as to ensure continuity of development among the leprosy patients. The patients at the centres might not even have anyone looking after them.

I suggest that doctors and nurses should be deployed to the centres and then, ensure that they receive proper medications. This is some of my observations about the place because I was there from 1976 till 2016. Hunger is one of the major challenges that leprosy patients face in their quest for survival. I also solicit for assistance in order to meet up with the demands of the society. In other words, proper assistance is needed urgently in the welfare of the leprosy patients.

I was once a beneficiary, they assisted me in building my house. After the completion, the person that brought the money came with a host of others and everyone were very happy seeing a white man in the village. It was the first time that foreigners were visiting the village and everyone was happy seeing them. So, visiting the leprosy patients even after their discharge makes them to feel at home but reverse becomes the case when they are being neglected.

Dr. Chukwu, as he will always say, that everyone has a member that is willing to take good care of him/her.

When I was still under medication, I was given DPT, (and) a famous medication at that time, Lamprene; but I took mainly DPT for 8 years. It has no side effects but the patient must be fed effectively in order to match with the effectiveness of the drugs. The inability of a patient to take proper care of him/herself, will lead to people avoiding the individual. Therefore, there is really need for them to live a comfortable life and be able to associate with others in the society.

What makes me feel bitter is the hardship I encountered; there are so many people that are not privileged to be taken care of. I was not privileged and it made me feel bad.

After my training and education, I became very happy and fulfilled. I got married and had my own children. At some point, I was appointed as the head of a school. These series of activities gave me much joy till my retirement. I was asked to stay around but I persisted and went home. So, these are the memorable things that give me joy. But I must regret that the Government failed us in terms of gratuity but we thank God for everything. I wish that the general public should assist me in other to finance their education. All of my children reside in Umuahia; including those that are in school and those learning different forms of trade.

The only thing that I will like to drop now is to call upon the German Leprosy and Tuberculosis Relief Association to assist every leprosy patient in order to ensure that they earn a living for themselves.





Stories from RIVERS STATE



Port harcourt Tourist Beach



Bonny Island Terminal



Pleasure Park, Port harcourt



Dinosaur remains, Bonny Island Nature Park



GLRA Oral Leprosy History Project

A Question of Justice

BASSEY MEETING

Profile: 55 years, Male, Married
Place of origin: Ekim, Khana LGA,
Rivers State.

Diagnosed and Treated
for Leprosy in 1995
at QIC Leprosy Hospital,
Ekpene Obom,
Akwa Ibom State

*"My mother was chased out
of the compound because of
my illness; nobody could
come to drink water in our
house; nobody came closer
to me or my mother"*

*"My wife and I are 'lepers';
we are at home suffering,
we both have amputated
legs. We are just at home
suffering, nobody to
help us"*

I am Bassey Meeting from Ekim in Khana Local Government Area of Rivers State of Nigeria.

I started schooling in 1969 and I finished my primary school in 1976. Then, I went to technical school to do Electrical and Electronics. On my coming back from the technical school in 1995, I fell ill with leprosy. I suffered leprosy in the community when my mother was alive, and my mother was chased out of the compound. Because of my illness, nobody could come to drink water in our house, nobody came closer to me or my mother till 1997 when Donald, the man helping us in the clinic showed up and told us where we could be treated at Akwa-Ibom State. He took me from there to Akwa-Ibom State with Sister Duru of Daughters of Charity.

That Sister took me to that area, and I was there, (*until*) my coming back in 2000. After then, the illness had gotten to the point of cutting my leg. So, as my leg was amputated, I stayed there, suffered because I had no relative there; I was alone, if not for the Sister that comes to give us something, I would have died there. It was the Sister that helped me. After my amputation, I came back home.

That amputation disturbed me because they cut my knee like elephant leg. I suffered and I went back again to Akwa-Ibom State in 2002. As I went back, I was there, they did the below-the-knee amputation. I was in Akwa-Ibom when my mother died at home; I couldn't see my mother before she died. I can't recognize where she was buried. I suffered there;

then came back home to my native homeland (*and until*) today there is nothing I am doing.

There is nobody to support my electrical and electronics work, I am just at home and it is by the grace of God that whenever people pass, they give me something to eat. I thank God that I Bassey, I'm alive to speak in the presence of GLRA today. Who am I? And I am happy that today, the people who rejected me are passing and saying "Bassey, Good morning."

The first day we got there (*Ekpeneobom*), they rejected us. They said that Rivers State is an oil state, they pursued us but by the grace of God, the doctor said "No; that we should stay at the place they treat people with leprosy". I was there in Akwa-Ibom State in Ekpeneobom in an Akwa-Ibom Church that controls the area. I went to church with them, they gave me clothes to wear; they gave me food to eat. If I wanted to use the toilet, they would help me. What I passed through there, even water to drink was hard because of its nature. I suffered in that area but by the grace of God today I am back at home today.

I don't have anything to do. My wife and I are 'lepers' (*use of the terminology "leper" is highly discouraged as it connotes stigmatization*); we are at home suffering, we both have amputated legs. We are just at home suffering, nobody to help us. I need help, just take a look at the house I am living in.

That is how I suffered leprosy and I am not shy, it is only me and my wife together. I don't know how tomorrow will be but I need help so that I and my wife will be able to feed and manage our lives.

This my wife, she is from Akwa-Ibom too, she is from that area. Because there, as a leper if you say you want to marry a wife they would say “No; I won't marry you, don't (come) near me; you are nothing to me how will you come with leprosy and say you want to marry me”. Even in my community if I say I want to marry a wife they will say “Bassey No; I can't give you a wife, do you want to kill my family? How will you feed my daughter? Will you be able to 'put mouth' in my house? No; you can't.” I said Ok no problem and I left.

When I got to Akwa-Ibom, I *met* this my sister; and I told her “will you be my wife?” And she said “she will be my wife”. I have seen a cripple person that married an able person but due to the fact that I am a leper, they said we should to marry each other. She was just in her place suffering and there was nobody to marry her, that was why I took her to my home as my wife and married her but we don't have a child yet. That was how I married her as she is also a leper like me (*use of the terminology “leper” is highly discouraged as it connotes stigmatization*).

Before I got the sickness, I was a good footballer. I was always on the soccer field. I am also a man of everything, there was nothing in this community that I didn't participate in. But when I had this sickness, I was left alone; nobody came close to me, I couldn't join the groups again because if I went to meet them, I can't clearly speak for

myself. I don't have legs to run. So, that was how it was and most of them today, they don't greet me as they used to do before.

Bassey is now a pure person and that was why they said we should not stay in the clinic but we should go home so that we would associate with people and with groups; so that they'll know that leprosy is curable. That is how I've been, I am happy today when some of them come and greet me say, “Bassey, Good morning”.

When I get to Church, nobody separates me from the seats, they always seat beside me. I am a member of Anglican Church. When I get to Church, they appreciate me and I moved with them, some people also gift me money so I will be able to make donations in Church, that's how it is in Church.

The only thing I am pleading with God is that God should help me with my accommodation. I am living in this house with my wife but take a look at how the house is, assuming I had something doing, I would have had money to fix the sticks in this house but there is no money to fix it. Assuming I and my wife had something doing that brought in income, we would have fixed these things since. That is why I am letting GLRA know the way I am living with my wife. That is, the way my accommodation is and I am not pleased with the accommodation.

Leprosy denied me basic education

MRS. HARRIET BASSEY

Profile: 35 years,
Female, Married

Place of origin: Ekim,
Khana LGA, Rivers State.
Diagnosed and Treated
for Leprosy in 1994
at Ekpene Obom,
Akwa Ibom State

*"While I suffered leprosy,
I was rejected by my
people; they threw me
outside and they didn't
take care of me. People
from outside also
rejected me and didn't
treat me like human, I
couldn't walk freely
outside".*

I am Harriet. I was born in Akwa-Ibom State. While I suffered leprosy, I was rejected by my people, they threw me outside and they didn't take care of me. People from outside also rejected me and didn't treat me like human. I couldn't walk freely outside. So, I was suffering at home with my mother. Nobody came close to my compound because of the sickness. They also moved away from my mother, brother, and sister because of me.

I was left alone with my mother (going) from one place to another so that I could survive. Then one day a man came to tell my mother there was a place where I could be treated. My mother agreed to take me there. He told my mother to pay ₦25,000 before he took us there. So, my mother paid and I was taken there in Ekpene Obom, Akwa-Ibom State.

It is a leprosy hospital in Ekpene Obom. They took me there and there were white doctors there who tested me and started giving me drugs, I was kept and treated for so long. Then I had ulcer on my leg that I couldn't walk and I was treated for long on the bed. I was also given free things. I forgot my employment and also my home because they treated me. I stayed there and forgot everything. My ulcer then started healing. I was there and they told me not to go home. Nobody came to check on me, I was the only one staying there. They took me like family; they gave me cloths and all other things, I forgot my people because they rejected me and thought I was dead, they didn't know I was alive. So, I was there for so long till my ulcer healed and I was okay, then I went home.

As I got home, my leg injury returned and it was so serious that I couldn't walk outside, I was only at a place and water started

coming out of my leg. My mother was like, "how will we treat it because it doesn't leave the body easily", wondering what kind of thing it was. Then she took me to the hospital and the hospital applied plaster and did all other things and I stayed for a long time but the ulcer couldn't heal, I was operated upon but the ulcer didn't heal so the doctor asked me to stay longer.

I stopped going to school because of the sickness. I ended in Secondary School, JSS 3. I was in JSS 3 before the sickness started so, I stopped to go to school because I couldn't walk.

I am happy because I am alive. People come close to me -those that are not a sick, a lot are dead but I am alive. Even the people that rejected me, some are dead but I am alive, that is what makes me happy about my life. And I also have a husband, if I had been at home, I wouldn't have had someone to marry me but now, I am living in someone's compound as a wife. Our doctor over there used to tell us that anybody that wants to get married should marry someone like him or herself because nobody will look at our face outside and they won't marry us, that was why I married my husband.

I want you to help me because I can't walk with this leg again and I don't have money to do anything in my life, or to eat. I don't have money and everything now is all about money. I don't have money and I want to trade but I don't have money to buy things. I need money to start selling little things to take care of both myself and my husband. That is what I beg of (people) and I pray God to bless them in Jesus' name.

Bitter life experience

**PROSPER
NWADINE**

Profile: 62 years,
Male, Single

Place of origin:
Abua Odual,
Rivers State.
Diagnosed
and Treated
for Leprosy
in 1973

*"There was a girl I said I wanted to marry
and the girl accepted but after a short
while with the sickness, the girl ran away"*

*"I don't have a wife. It was this disease
that made me not to marry."*

I was born into Nwadine family in 1957. I didn't know my mother and my father died and left me. People took me (*in*) to babysit their children then. When I became of age, I came back and I went to school and because I had nobody, I couldn't finish my school. So, I went to tap (*palm wine*) in Primary 3 at Abua Odual in Rivers State.

I was there in 1973 (*when*) something like this came upon me, on all over my legs, and even my leg was itching. I thought it was a minor thing. I went to General Hospital but they could not treat me then. The thing (*lesion*) became a wound and by the Grace of God, I asked myself how will I fare? I don't have a father or mother or anybody. I started learning umbrella jobs and it was this job that I used to feed. I am not doing anything presently; and there was a girl I said I wanted to marry and the girl accepted but after a short while with the sickness, the girl ran away.

By the grace of God, the Daughters of Charity Home met me one day and they looked at me and told me that I was infected with leprosy. So, that was how they just picked me and I followed them to where I would be treated. That was how I met them. They kept me there and they amputated my leg. From 1973 to 1982 I did not have any treatment until the Sisters met me. I went to the General Hospital several times but they didn't know what it was.

Anytime I was about meeting people, they (*would*) run away from me because of the

sickness but I thank God that people are somehow being close to me now. But then that I was infected by the disease, people always stayed away from me, nobody came close to me.

I don't have a wife. It was this disease that made me not to marry.

You know people nowadays when they see that you are sick, they will think you will die. So, that was why they took some of my property. They took some of my property because of the sickness. My father's property like farm, since I can't farm again, I do give it out to people to farm and I will beg them to harvest little for me to eat.

(*Now*) If they have any meeting in this our community, I usually go and listen to what they say but if they talk about money, I don't contribute because I don't have money and they understand the condition I am in. I am happy with my Church. My church members come to visit me.

The thing I will like to say, (because it was God that brought you people today) is that: I am begging you to help me with my house. If not by the grace of God, the house may fall on me at any time but God won't allow that. And for somebody to help me so (*that*) I can find something to help myself with, not something seasonal. Those are what I need sir, those are my problems.

I can't get angry with myself. If I had done that, I could have died.

A Question of Justice

NDOALE KPONANADUM

Profile: 68 years, Male, Married

Place of origin: Rivers State

**Diagnosed and Treated for Leprosy
in 2000 at Wiiyaakara Health Centre**

Immediately, they knew I had the sickness, my wife ran away from me; till now, my wife is not with me... My relatives pursued me from the building and also from some lands. If not for someone that helped me with this place to stay, I have nothing because this sickness doesn't allow me to do anything. Because of this sickness, I could not complete my TTC that is why I am here and I was even chased away from the school.

In the year 2000, I was at home one day when I noticed the manifestation of leprosy disease on me. There were nodules all over my body, then, I thought since I was growing up, I never experienced this type of illness. So, they took me to the hospital and one day, I went to Eleme, then, they referred me to our center at Wiiyaakara and they registered me there.

Immediately, they knew I had the sickness, my wife ran away from me; till now, my wife is not with me. I had 5 children; my children are outside leaving the building which we built. My relatives pursued me from the building and also from some lands. If not

for someone that helped me with this place to stay, I have nothing because this sickness doesn't allow me to do anything. So up till now, I am here, people dash me things, I don't have any personal thing, that was why I am here now I have nothing to do

I was working at NDE Port-Harcourt, I was there when the sickness struck me and I was sacked because of the sickness. Before I had this sickness, I was in my father's house, my brothers were helping me and I was also working then. I was free and able to feed myself, my wife was with me then. You know, *(then)* I was in good relation with

people, moving with people freely because I wasn't sick. But because of this sickness, I (*now have*) no friend, all my friends ran away from me and even my relatives ran away from me.

That time I was with the club. Even in the church that I was attending during that time, I was pursued from the Church, they moved away from me. I was a member of Methodist church during that time and I was the President of Men's Fellowship in the Church but because of the sickness, I was pursued.

When I was young, when I was never sick, I and my friends did eat together, we played together, we did everything together but immediately I was sick, they ran away from me. They shared the sickness information - they heard or saw people tell them I was infected by leprosy and that was why they ran away from me and chased me away. They told me not to come closer to them again, that I should go to where the lepers stayed (*use of the terminology "leper" is highly discouraged as it connotes stigmatization*). So I went to a leprosy centre at Wiyaakara. I stayed there for over 2 years.

Because of this sickness, I could not complete my TTC that is why I am here and I was even chased away from the school. My parents' properties are with my uncles, they didn't give me because I did not see my father before he died so, there is no property with me. Even when I met my mother, she did not give me anything and it wasn't long before she died too. My father's brother took all my properties from me.

My parents had 3 children but I'm now the only surviving child.

I have 5 children. 2 females and 3 males. When their mother left me, she took all the children with her. I am the only one remaining, my children are not with me. I don't know where they are. Because of my sickness, they did not come with me and they don't even want to see me because their mother told them I suffered leprosy.

Now, I am trying to force myself to be with them (*the community*) but they are not even happy because of the condition of this place -immediately they hear you have leprosy they will stay away from you. But I am forcing myself to be with them; attending church. When I go to church, some of the members try to be close to me, some even want to shake hands with me and do things with me now because some of them know I am now fine and alright.

The thing that makes me happy now is *that* I am now with the people and I am now received by the people; that is what makes me happy now. And that even makes me happy the more because now, I can mingle with people and I have the opportunity to do some of the things I couldn't do before. I am able to do a little work to feed myself and also able to do all other petty things unlike before that I wasn't able to do anything because I was infected by the disease. But now, I am happy I mingle with people and I am also able to get a little thing to eat.





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