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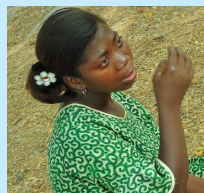
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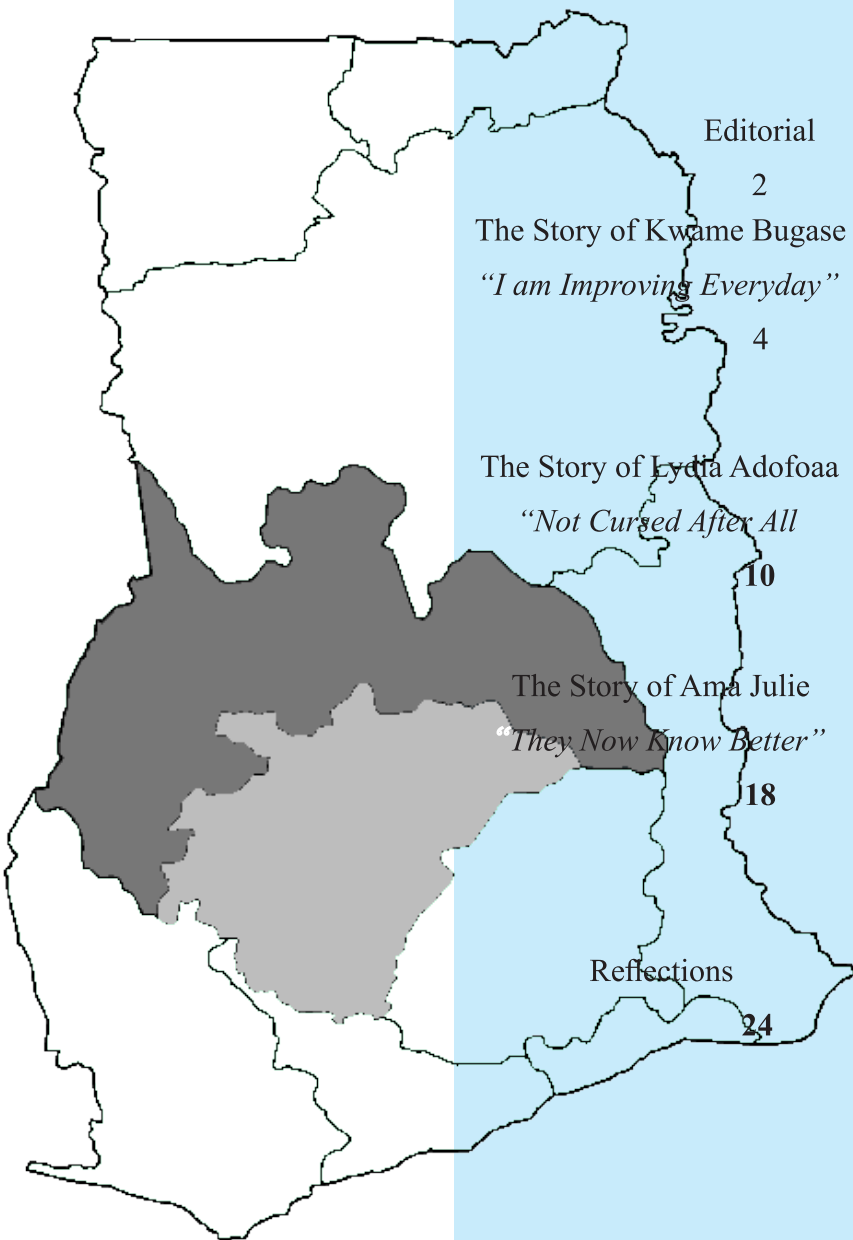
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Mental health is a right, not a privilege

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## Editorial

*These stories are about real people who have lived with mental illness or epilepsy and endured a lot of stigma, neglect and discrimination. They have, however, survived in spite of the odds and are building for themselves and their families a new and productive life.*

*The people who have so bravely and willingly shared their experiences of mental illness and epilepsy represent varying age groups, gender and married status, as well as educational achievements and locations. All their stories tell of suffering and endurance but with hopeful conviction which their involvement with BasicNeeds-Ghana has helped them turn their lives around positively.*

*Issues of epilepsy and mental ill-health are still among the most neglected by society. Negative public perceptions and attitudes against people with mental illness and epilepsy (PWMIE) still prevail. Stigmatization and access to quality mental health care still remain at the top of the tall list of inadequacies facing mental health care in Ghana. Mental health is still one of the lowly prioritized and most under-funded development issue by government in the country.*

*These stories are just some of the many life-changing experiences that have come about through the interventions initiated by BasicNeeds-Ghana and partners. They also reflect the real urgency that is required to enable PWMIEs all over Ghana to live and work successfully in their communities.*

*For PWMIEs to reach their full potential as individuals and as Ghanaians, everyone must be involved in their care and support, helping them to realise their basic and fundamental rights protected by law - especially their right to good health.*

*In light of the passage of the Mental Health Law (Act 846), it is expected that Government would take the necessary actions to ensuring quality and comprehensive mental health care in Ghana. BasicNeeds-Ghana also calls on corporate Ghana, as part of their corporate social responsibility, to support restore the health and productivity of PWMIEs.*

*Through these testimonies, we hope that the full implementation of the Mental Health Law would be aggressively pursued without further delay since it is the key to improving the lives, and indeed the very existence, of all vulnerable persons with mental illness and epilepsy in Ghana.*

***“I am Improving Everyday”***

***The Story Of Kwame Bugase***

**Credits:**

***Centre for the Development of People (CEDEP)***

***BasicNeeds-Ghana Implementation Partner in Ashanti  
Region.***



## *Introducing Kwame*

Originally from the Upper East Region, Kwame Bugase's family migrated to the Ashanti Region to farm. Kwame Bugase, son of Abanabewa Bugase and Katiga Bugase, is a 21 year old young man with epilepsy. He lives in Adiembra in the Ejura-Sekyedumase Municipal Area in Ashanti Region. Kwame is the first son of his parents with whom he is very close. He has three brothers and a sister, who are presently in school. His father is a farmer and his mum is a trader. Kwame himself likes to help his father on the farm.



*Kwame Bugase*

## *Life Before Illness*

According to Kwame's father, Kwame was enrolled in school at the age of six. Kwame was said to be very active in his school. He narrated that "I loved athletics especially short distances such as 100 and 200 metre races". He was a normal schoolboy who enjoyed playing with his friends. He aspired to join the Ghana Armed Forces when he grew up. Unfortunately though, his life took an unexpected turn when he was in junior high school form 2.

Kwame remembers the first time he suffered a seizure in November 2009. He says, "I had returned from the farm with a friend one afternoon. We went to my brother-in-law's house to eat fufu. As we sat relaxing after eating, I lost consciousness and fell off my stool." His parents, upon hearing the news, concluded that it was high fever. However, there was a second seizure in a matter of weeks later. Kwame recollects that "my father had sent me to go and buy jute sacks for storing maize. I was riding a motor bike and on my way home, I had a seizure and fell off the bike. I was very badly wounded". At this point, Kwame's parents did not know what to make of the seizures. They no more believed them to be high fever.

## *In Pursuit of Treatment*

Abanabewa and Katiga (Kwame's parents) thought Kwame's first seizure was symptomatic of high fever. However, after the second episode, Kwame and his parents were convinced that his seizures had been caused spiritually through a head-butt he suffered from his cousin sometime earlier. Their conviction stemmed from the fact that his cousin was known to have seizures too.

In their quest for treatment, Kwame's father first took Kwame to consult with one herbalist in Mampong in the Ashanti Region. In recounting his experience, Kwame said "I stayed with the man for two months while he was treating me. My father was also there with me." Kwame's father added that "at the end of the two months, he gave us some herbal preparations and asked us to administer to Kwame daily. We came and applied the herbs as directed but saw very little improvement." Following this unsuccessful first attempt, Kwame and his family visited quite a number of herbalists both near and far. His father says "I have really visited a lot of herbalists and at a time, I thought that my son was healed, but it was not so because the sickness resurfaced after six months."

According to Kwame's father, when these herbalists failed to cure his son despite having spent so much money, he resorted to spiritual churches.

Kwame's father said "I believed there was a spiritual cause to my son's



*Kwame tells his story flanked by his father and mother*

condition. In view of this belief, we visited not less than five prayer camps seeking treatment.” Kwame, and sometimes his father or mother were subjected to intense prayer sessions and fasting. Kwame’s mother said that “all these visits were to no avail because Kwame started having seizures again when we returned from the prayer camps.”

### *The Hardship of Illness*

Due to his illness, Kwame had to drop out of school. He says that “it was difficult for me to understand most of the things that were being taught.” He also felt stigmatised and did not know how his friends would relate to him anymore. Kwame adds: “I enjoyed being with my father in the farms rather than being in the house or close to people, because I was afraid getting close to people. I was afraid of getting close to people because of my sickness.”

The time and effort spent seeking out treatment caused immense hardship to his family. Abanabewa laments that “I was farming by then, but that was the year maize could easily spoil, and so I could not harvest them. By the time I returned, it had already spoiled.”

There was also some level of financial difficulty involved. Kwame’s siblings had to bear their share of the impact of the illness. With tears in his eyes Kwame’s father bemoaned his situation; “I spend the little money I generate on Kwame’s sickness, and due to this I am not able to provide for his younger siblings. I am supposed to pay for the school fees of his younger brother who is just about to write his exams and am not able to.”

### *A Moment to Hope*

In September, 2012, Centre for the Development of People (CEDEP), BasicNeeds-Ghana project partner in Ashanti Region, organized a specialist outreach clinic at Ejura-Sekyedumase for people with mental illness and epilepsy. Through the Assemblyman of the area, Kwame’s mother learnt of the outreach clinic and decided to send her son.

At the clinic, Kwame’s condition was diagnosed as epilepsy. The family were given medicine free of charge and were told to see the resident community mental health officer (CMHO) for review after a month. They were also educated on how to manage Kwame’s condition. According to



Kwame's mother, "when he had access to the medicine the sickness wasn't showing at all; sometimes we even forget he has epilepsy when he gets access to the medicine." The CEDEP project officers also encouraged the family to join the self-help group which had been formed in the area as part of the DFID-CSCF funded project.

### ***Project Impact***

With routine treatment and availability of medicine, Kwame's condition has stabilized. He is a member of his community's self-help group of persons with mental illness and epilepsy (PWMIE) where he has made new friends with whom he can feel safe without fear of stigmatization or discrimination. Kwame also participated in the capacity building workshops in group dynamics, leadership, record keeping, book-keeping and advocacy organized by CEDEP in February, 2013. He was selected by his group to be part of a delegation to interact with Ejura-Sekyedumase District Assembly officials to advocate for the rights and needs of people with mental illness and/or epilepsy (PWMIE) at Ejura on 23rd March, 2014.

With financial support from CEDEP, Kwame is currently under apprenticeship with a master carpenter. Kwame is happy about this development in his life and says "I'm learning carpentry and improving every day". Kwame hopes to one day be able to provide for his family.



*Kwame is currently learning carpentry and improving each day*

## ***“Not Cursed After All”***

**The Story Of Lydia Adofoaa**

### **Credits:**

***Mission of Hope for Society (MIHOSO) International Foundation***

***BasicNeeds-Ghana Implementation Partner in Brong-Ahafo  
Region.***





## *Background*

Lydia Adofoaa's family hails from Yeji in the Pru District of the Brong Ahafo Region. With the exception of her eldest brother and sister, the rest of the family reside at Kwame Danso in the same region.



*Lydia Adofoaa*

Lydia was born in the Afram Plains in the Eastern Region. She is the third of eight children. Her father, Kuma Williams, is a retired game and wildlife officer while her mother, Rebecca Fobi, is a petty trader. Lydia is 28 years old and a graduate of the Kwame Danso Senior Secondary School.

In November 2012, during an outreach clinic organized by Mission of Hope International Foundation (MIHOSO) in Kwame Danso, project officers observed Lydia mobilizing service users into queues to facilitate the smooth running of the outreach. Upon enquiry, the project officers learnt that Lydia was a service user herself and also leader of her SHG. The team consequently has followed her progress with keen interest till now.

## *Life before illness*

Lydia attained her basic education at Kwame Danso. While in basic school, Lydia loved to play football and read story books. She participated in almost every activity in school and performed relatively well academically. She was very active in her Seventh Day Adventist (SDA) church and partook in almost every activity in the church. She made friends easily. Lydia affirms that life was a happy one. It was her regular practice to help her mother sell fish in the market after school. Lydia recounts that “though our family wasn’t rich, we did not lack anything. We loved ourselves”. She dreamt of one day being a nurse; She admired how they looked in their uniforms and the service they rendered to patients.

Lydia successfully passed her Basic School Certificate Exams (BECE) and



was admitted to the Attebubu Senior Secondary School (SSS) during the 2003/2004 academic year.

Lydia looked forward to the day she would begin her secondary education with much anticipation. Her first day in school finally came. She was accompanied by her father to the campus of the Attebubu Secondary School. She was very excited to be there and had been given a clean bill of health when she underwent the mandatory medical examination which was a condition for her admission.

### *The early symptoms*

On the night Lydia reported to school, she collapsed. Lydia recalls the events on that fateful night; “I was unpacking my things and trying to lay my bed. I felt a sharp pain in my head. I became dizzy and felt myself losing consciousness.” She regained consciousness to find her dormitory mates looking down at her; some of them visibly shaken by what they had just witnessed. That night, she proceeded to sleep feeling very weak. The incident was reported to the house mistress who asked her to go home so that she could be taken to the hospital by her parents.

Upon arriving home, medicine bought from the local drug store was administered to her by her father. Lydia recounts that “I have forgotten the name of the medicine we bought but it was one of my father’s friends who advised us to buy it”. After taking the medicine, she thought she felt better and insisted on going back to school; “I didn’t feel weak anymore and I didn’t want to miss any lessons”. At the beginning of the next week she went back to school without visiting the hospital.

Upon returning to school, Lydia continued to experience regular light-headedness and occasional seizures. This prompted her parents to eventually request that she be transferred to the



*Mr Kuma Williams, Lydia's father*



*Lydia and her family*

Kwame Danso Senior Secondary at the end of her first term at the Attebubu Senior Secondary School. Lydia explains that “My father wanted me close to home in case anything happened.”

### *Interpretation of Symptoms*

Lydia’s seizures continued and she had by this time developed a lot of bruises as a result. She still complained of regular weakness and headaches and her family were very worried. Lydia’s condition also took a toll on her academically and she didn’t enjoy going to school anymore. Lydia recollects that “I was afraid I could have a seizure in class. This made it so difficult for me to concentrate in class.”

Her mother especially believed that her condition was a spiritual attack by some unknown enemy; “My mother was very disturbed and could not believe what was happening to me because she suspected that someone was working spiritually against me”. Sympathizers, in their attempts to explain what was happening to Lydia shared her family’s belief that her condition had spiritual causes or other such pseudo-scientific theories. Lydia’s mum explains that “One herbalist even explained that severe malaria was causing Lydia to convulse.”

### *In the Pursuit of Treatment*

Once Lydia’s seizures became regular, her parents began to take her condition seriously. She was taken by her father to see a herbalist in Drobo near Kwame Danso. The herbalist gave her some herbal preparation which she bathed with during the time she spent there. She was also instructed not to eat mutton or pawpaw. After three months of treatment no improvement in her condition was recorded.

Lydia was subsequently taken to see another healer in Kanto. According

to Lydia, “he gave me some foul smelling herbs to drink and bathe with. I had to endure this ordeal for the next six months.” She was also prohibited from eating groundnut or palm-nut soup. The seizures seemed to subside after this treatment regimen; “I had relief only for a short time after I stopped taking the herbal medicine” adds Lydia.

Lydia was also taken to some prayer camps in the hope of arriving at the roots of her illness. According to Lydia’s mother, “we did not understand what was happening to her and we were determined to find out.” During this time, Lydia confesses that she had lost hope of ever recovering. She adds that “I was confused and frustrated.”

Lydia had to frequently leave school in order to consult some herbalist or pastor on her condition. She was always accompanied by one or both of her parents. This affected her academic performance greatly and Lydia believes this contributed greatly to her inability to pass all her papers in the WASSCE examination. The inconvenience associated with her treatment regimes also took a toll on the physical health of both Lydia and her carers. According to Lydia “these were not easy times for me. I lost weight as a result of the fact that I could not eat well. I sometimes had to depend on tea which was difficult to afford”.

Lydia’s father and mother spent so much time and resources seeking treatment for their daughter. Lydia’s mother asserts that “it cost an average of GHS 120.00 each month to pay for travel expenses and other associated cost in our attempt to get treatment for her”. Lydia’s mother’s business collapsed since she used up her capital in her efforts to find treatment for Lydia. Money meant for housekeeping and fees for her younger siblings was sometimes spent in pursuit of Lydia’s treatment.

Lydia’s life was also affected by her illness in other subtle ways. She could no longer go to the market to help her mother sell; “I was afraid I would have a seizure while

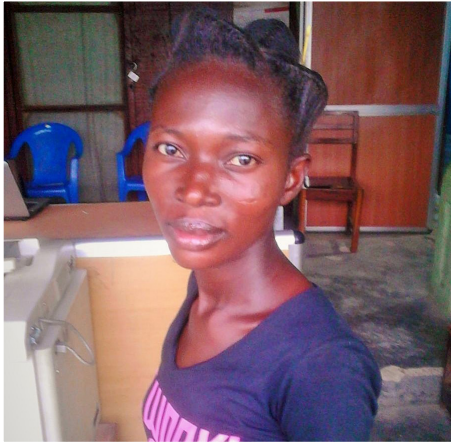


*Madam Rebecca Fobi, Lydia's mother*

at the market and cause her to lose customers”.

Lydia's Church members and schoolmates exhibited an indifference towards her. Her family, however, remained very supportive.

### *Season of Stability*



*Lydia is now stable enough to be productive to herself and her family.*

In November, 2012 Lydia was officially diagnosed as suffering from epilepsy during a specialist outreach clinic at Kwame Danso. She had earlier on been encouraged to become a member of the “Enso Nyame ye” (*It is not beyond God's ability*) self-help group in Kwame Danso on the advice of Mr S.K. Antwi, an elder from her church. The self-help group had been formed as part of community entry activities of the DFID funded project.

Christopher Akanchi, the resident community mental health officer, was supported by Mission of Hope for Society (MIHOSO) International (BasicNeeds-Ghana partner in Brong Ahafo Region) to periodically run follow-up outreach and home visits as well as educate members of the self-help group on how to manage their respective conditions. Lydia recollects that “Mr Akanchi came with some officers from MIHOSO on that day. He explained to me that I was suffering from epilepsy and gave me phenobarb. It made me sleep a lot and I complained about it at the next outreach and it was changed to cabamazipine”.

Since joining the programme, Lydia's health has significantly improved. She says “apart from the 2 seizures I had when I defaulted in my treatment, I have not had any seizures in the last two years”.

Lydia has participated in a number of capacity building training workshops organized by MIHOSO. These include training in leadership and group dynamics. She has ridden on the back of these training programmes to take up leadership responsibilities at different levels. She is currently



the secretary of the “Enso Nyame ye” SHG in Kwame Danso. She was also voted to the office of national treasurer at the 4th Annual General Meeting of the Mental Health Society of Ghana (MEHSOG) held in 2013, a position she still holds. In her capacity as a national MEHSOG executive member, Lydia has been part the advocacy efforts of the national user association.

Lydia has also become active again in her local church. She is currently a member of the women fellowship of the SDA church in Kwame Danso and also preaches in her church sometimes. She says that “I can now talk in public without panic.”

Lydia intends to register to re-take her WASSCE examination. She is hopeful that she will be successful the second-time. In the meantime, she has applied to the Ghana Education Service (GES) to be a teacher and she hopes to receive a positive response.

## *Conclusion*

Lydia Adofoaa is one of many people whose lives have been positively impacted by the DFID-CSCF funded project. The story of her stabilization asserts the fact that given the right treatment, epilepsy can be managed and enabling people living with epilepsy to have productive lives. Having benefitted from the project, Lydia currently devotes a lot of her time to helping others with her condition to access treatment and live more productive lives. Her very presence and activities in her community is helping to change the public's negative attitudes towards people with epilepsy.



*Lydia (3rd from left) in a pose with the national executive after the end of the 3rd MEHSOG AGM*

***“They now Know Better”***

**The Story Of Ama Julie**

**Credits:**

***Centre for the Development of People (CEDEP)***

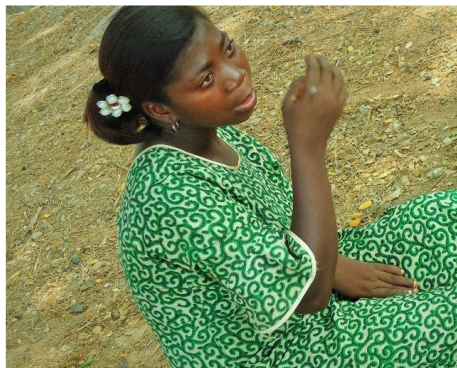
***BasicNeeds-Ghana Implementation Partner in Ashanti  
Region.***





## ***Background***

Ama Julie is a 28 year old woman who is single and has no children. She resides at Sanfo Aduam community in the Bekwai municipality of the Ashanti region and lives in Nana Amakye's house near the roadside. Ama is the 6th and last child of her parents.



*Ama Julie*

## ***Life before illness***

Ama Julie was born with a deformed left hand and left leg. As such, even before the onset of her illness, she was stigmatised against, explains Abena Fobi, Ama's elder sister. Ama could not walk until she was five and was unable to do much for herself.

With this form of disability she was not active enough to be taken to school. However, she was loved and cared for by every member of her family except her father who had turned a blind eye to looking after Ama and the rest of the family.

## ***Signs of More Problems***

Ama's first seizure occurred when she was seven years old. It was first thought of as a convulsion and so she was rushed to hospital for treatment. She was placed on admission for a week and discharged. Three months later, Ama experienced another seizure. After this second seizure, it was no longer thought of as mere convulsions.

## ***Keeping Hope Alive***

Initially, Ama's mother sent her to the hospital for treatment quite frequently. However, after one year, Ama and her mother's visits to the hospital were less frequent since the hospital bills had become too expensive for her family. Around this time, she had frequent seizures. Her family decided to seek treatment from various pastors and spiritualists to ascertain the cause of her illness as it was perceived to be a spiritual disease. However, these visits to the prayer camps did not yield any results.



Upon the recommendation from a relative, Ama was sent to a herbalist in a nearby village where she was given some herbal mixture to drink for some time. However, her seizures became more frequent but because her family could not afford any other treatment option, they stuck with the herbalist with the hope that things would get better.

### *Impact on the Family*

During this time, stigmatization was not only limited to Ama; It was extended to her family as well. Abena, Ama's sister, intimated that her sister's illness affected the family's income and their relationship with others in the community. Ama's mother, for instance, had to stop her trading so as to take Ama to pursue treatment. In shedding light on the matter, Ama asked rhetorically; "how can one trade when people isolate themselves from you? I was seen as an omen and a curse to my family".

### *On the Path to Stability*

Ama first came into contact with the Centre for the Development of People (CEDEP) in October 2011 at a nearby community called Bogyawe. CEDEP was there to sensitize the public on better ways of relating with and treating people with mental illness and epilepsy as part of a DFID-CSCF<sup>1</sup> funded project<sup>2</sup>. Earlier on, the community health volunteer for the project had succeeded in convincing Ama's family to allow him to take her to consult with the community psychiatric nurse at Bekwai. She was diagnosed as having epilepsy. She also received medicine free of charge.

When Ama begun treatment, she was advised to join the self-help group (SHG) which had been formed by people with mental illness and epilepsy and their carers through officers. Being a member of the SHG has made it possible for Ama to be trained in advocacy, leadership, record keeping, how to manage one's own business and on the Mental Health Act



*Abena (in black), Ama's sister making a point*

of Ghana. Describing some of the benefits that have accrued to her upon joining the SHG, Ama says, “as a member of this SHG, I have benefited from training which has been passed down by some members who had been trained by CEDEP. I have also been enrolled onto the National free and so I am able to go the h any fear of spending money.”



*Ama receives livelihood support from a CEDEP project officer*

### ***Relief***

Ama recounts that working with the project has had a great impact on her condition. The frequency of Ama’s seizures have greatly reduced. She attributes this to the medicine she is taking saying “I can say that the medicine from the hospital has almost ceased the attacks and so people no longer stigmatize against me.” According to her, even when the attacks do happen at seldom times, it is mostly at night when she is sleeping which saves her from public ridicule.

Ama is now integrated into her community and even attends church service every Sunday without any fear of stigmatization from church members. She says “through the consultation meeting by CEDEP, most community members who even thought this illness is communicable now know better and do not isolate themselves from me”.

With support from CEDEP, Ama now sells soap and detergents. Ama also makes extra income by helping her sister produce palm oil. She says “I charge GHS3.00 (about \$1.00) per day when I help my sister.” According to Ama, her business is doing well because she is applying knowledge from business management training CEDEP gave to her SHG.

Again, the advocacy and leadership training have also given her confidence. She says because she is better informed now of her rights she feels in charge of her own affairs. She says “I can now arrange for my own medicine in times of shortage.”

In attesting to the impact of the project in her life, Ama Julie says “I now

have faith and can firmly attest to the effectiveness of treatment which I am undertaking through the help of the CEDEP. I no longer think of my illness as something spiritual.”

### *Conclusion*

Ama's health is stabilized. She agrees strongly that taking her medicine has brought about great improvement to her health. Ama was aware of the effectiveness of orthodox medication from her first treatment though she could not obtain them due to the cost associated. Through the support of CEDEP in running regular and free outreach clinics proximate to her area, Ama is now able to obtain drugs at little or no cost from the nearby district hospital.

Ama is no longer dependent on her family. She is economically independent as she is able to sustain her livelihood through her small business venture which was supported by the project. The family no longer has to spend time and money on her treatment as Ama is in charge of her own life and is able to seek the treatment on her own.



*CEDEP project officer interacts with Ama (seated) and her siblings*

## *Epilepsy*

Epilepsy (from the Greek “epilambanein” meaning “to seize, possess, or take hold of”), a disorder overwhelmingly common among children and young adults of the developing world, is a group of neurological disorders marked by involuntary seizures of varying severity; the episodes can occur as brief, harmless shaking of the body or long episodes of violent convulsing. Although the causes of epilepsy are not entirely known, it can develop as a result of an injury or abuse to the brain where the disorder originates.

Epilepsy, like the psychotic disorders, is often observed as a “supernatural” occurrence that carries a heavy amount of stigma, social isolation, and poor school attendance among epileptic children and young adults in developing countries. Individuals suffering from epilepsy are also discouraged from occupations requiring them to operate vehicles or machinery – occupations that often offer higher wages and professional growth.

However, the abnormal brain functioning that produces the disorder can be effectively treated and controlled with proper medication that dramatically reduces the number and severity of seizures one has in a lifetime. The negative social impact of the disorder can therefore be greatly reduced with effective treatment and, as such, should be sought out by these individuals and their carers to improve their quality of life and the possibility of a better future.

## *Reflections*

Epilepsy is an incommunicable yet chronic neurological disorder that, according to the World Health Organisation (WHO), affects an estimated 50 million people worldwide. Nearly 80% of people with epilepsy are found in developing regions of the world. According to WHO, no identifiable cause can be cited for the condition among half of the people who have epilepsy.

Epilepsy is usually characterized by episodes of involuntary seizures that affect a part of, or the whole body. Seizures are sometimes accompanied by loss of consciousness and control of bladder and bowel function. These seizures can vary from the briefest lapses of attention or muscle jerks, to severe and prolonged convulsions. Seizures can also vary in frequency, from less than one per year to several per day.

People with epilepsy respond to treatment about 70% of the time. However, approximately 75% of affected people in developing countries do not get the treatment they need. People with epilepsy and their families usually become victims of stigmatization and discrimination in many parts of the world.

In Ghana, the situation is not very different. While a lot of efforts have been directed at increasing access to treatment services and public sensitization aimed at changing public attitudes, behaviour and perceptions towards people with epilepsy, there are still issues of stigma and discrimination to contend with in some communities who still see epilepsy as a spiritual curse.

Irregular supply of medicine is also a major issue here in Ghana. Coupled with low levels of care infrastructure, stabilized people with epilepsy face the real threat of relapse. This is contributing significantly to eroding gains made in getting people with epilepsy to seek treatment.

To address these challenges, BasicNeeds-Ghana, with funding from the UK Government's Civil Society Challenge Fund, implemented the project titled 'Enabling People with Mental Illness or Epilepsy to Access their Rights in Mid-Ghana' across 16 districts in the Brong-Ahafo and Ashanti Regions of Ghana.

The aim of the project was to enable people with mental illness or epilepsy and their carers in Ashanti and Brong-Ahafo Regions of Ghana to satisfy their basic needs and their basic rights. The project also ensured that people with mental illness were able to access the best possible health care leading to the stability of their condition and their ability to live and work within their community.

These life stories are testimonials that with the right amount of investments in mental health and epilepsy care, people with mental illness and epilepsy can become stable and function productively in their communities.

Using the mental health and development (MHD) model, BasicNeeds-Ghana is leading the public advocacy drive to mainstream mental health care and ensure that mental health care is consciously planned and budgeted for in Ghana.

We are hopeful that these stories will serve to influence you to join in the fight in promoting mental health development in Ghana.





