

COVER STORY

‘HOW WE OVERCAME A SCARY SOUNDING CONDITION’

One woman shares her experience of coping with a child who was diagnosed as having “severe to profound deafness”.
By MILLICENT MWOLOLO



The paediatrician's words caused Esther Nduta's world to come grinding to a halt. She could not believe the sentence he had just handed her daughter, Natalie, who was then one year old. “Severe to profound deafness” was the diagnosis following what had started out as an innocent visit to the doctor five years ago.

“When Natalie was three years old, I began to notice that she would not respond when someone talked to her,” says Esther, a mother of two girls. “Even when I turned up the volume on the radio to full blast, she would pay no attention. I got concerned and decided to see an ear, nose and throat specialist.”

The paediatrician's pronouncement made Esther feel like her child no longer had a future, especially because her older daughter, 12-year-old Sylvia, had been born without any problems. “This was a bolt from the blue and the dreams I had for Natalie seemed suddenly unattainable... I had wanted her to have the best education her father and I could afford and grow up to be a successful professional.”

Sign language
Esther, 36, admits that she was filled with bitterness at the thought of her daughter having to use sign language for the rest of her life. “I felt low and confused. I even blamed God for the situation,” she recalls.

What followed were six months of agony. Her marriage came under pressure as she and her husband found themselves unable to talk about their daughter's condition. “The experience gradually drew me to God. As I slowly came to terms with the situation, I stopped questioning Him. I turned to prayer and eventually, my husband and I were able to deal with our fears and together start charting a way forward for our daughter.”

Through friends the couple was able to find a school for children with special needs for Natalie. By then she could not speak a single word. After about three months, however, Esther noticed her child was “behaving funny”. Although she still could not hear or talk, saliva would stream from her mouth down

to her chest. She was also making a croaking sound as if she was trying to communicate something.

“This got me concerned all over again. I suspected she had picked up certain behaviours from her classmates given that they all had different needs and were being taught together,” Esther says.

“I took her out of that school and looked for another one. I finally found her a school for children with speech and hearing problems.”

Natalie is now slowly learning how to talk and listen. “She uses analog hearing aids and through these we are able to communicate,” says Esther. “And she is doing homework just like other children her age. We hope that with time, she will learn how to communicate freely, join a mainstream school and be exposed to the many opportunities life has to offer.”

Esther says her family has come a long way since that dark day when the doctor gave his scary diagnosis. So far that she is able to talk about her daughter's condition freely, even to strangers.

“During one of my regular visits to the clinic, I met a parent who looked terribly depressed because she had just been told that her son's hearing could not be salvaged. As I listened to her predicament, my problems appeared minimal and I was actually able to give her advice, something I couldn't do before,” says Esther.

“I told to enroll the child in a special school where he would be taught how to listen and talk. I felt like I had triumphed over my challenges now that I could openly discuss my daughter's condition without shame. Natalie's condition has become a normal thing to me.”

Indeed, Natalie is doing so well now that the previously stay-at-home mother has even been able to go back to school to study business management while she looks for a job.

Still, the family continues to face challenges regarding proper care and facilities. “For instance, finding a good, affordable school was not easy,” says Esther. “And managing the condition is another thing – hearing equipment goes for between Sh50,000 and Sh260,000,” she adds.

Left: Pupils of JoyMereen Integrated School pay close attention to their teacher. Centre: Esther Nduta, Natalie's mother. Her family has managed to cope with their daughter's condition. Right: Edith Mbaya, the principal of JoyMereen School, says therapy goes a long way in helping hearing impaired children.
Photos/Jennifer Muiruri



A cochlea implant for those who cannot hear at all costs anything between Sh1.5million and Sh3million in India, America, Britain or Germany. She adds: “The school fees in special institutions for the hearing impaired is also very high compared to regular schools. And medical insurance organisations are usually not very eager to insure the equipment because it is expensive.”

Learning together
Many schools have come up with programmes that aim to rehabilitate hearing impaired children. At the JoyMereen Integrated School in Karen, both hearing impaired and normal children learn together. The pupils with hearing impairments are trained how to listen, lip-read and talk alongside their hearing classmates in the 8:4:4 curriculum. Edith Mbaya, the school's principal and also a hearing-cum-verbal therapist, says if hearing problems are noted in a child as early as between two and six years of age, the condition can be reversed through the use of auditory-verbal therapy.

“There is hope – children should not be taught sign language when they can still be salvaged from the looming cloud of deafness, unless the problem that caused the hearing loss also caused a disorder in the brain where speech and language is developed,” says the principal, who has taught in several special schools over the last 30 years.

The aim of the auditory-verbal therapy is to bring hearing-impaired children closer, or to the same level as other children. Once they have learnt how to listen and talk and they can communicate by themselves, Edith says, they are free to join a regular school if they wish.

“The children are fitted with suitable hearing aids and are trained how to listen in order for them to be able to hear and respond,” she explains. “It takes about one or two years for a hearing impaired child to learn how to listen and talk. The process, which uses the Montessori system of learning, is long because it aims at modifying the child to suit the environment.”

The Montessori system involves mostly



student-centred learning and engages the children in a wide variety of activities. In this way, concepts are simplified, thereby enhancing learning. Edith says these activities help young children – both normal and those with learning difficulties – in physical and intellectual development.

In order for a hearing impaired child to gain hearing and speech, parents must be fully involved in the process, constantly engaging their child in talking and doing so they can learn how to do things for themselves, such as dressing, serving meals and clearing the table.

“Do things together repetitively as you talk. Include the child in day to day activities as that is where natural language develops,” Edith advises, adding that mothers make the best therapists because they are usually the ones in close contact with the children for longer periods.

At the JoyMereen Integrated School, the pupils use only one language, English. Edith advises that children with impaired hearing need only one language of instruction so that they do not end up being confused thus complicating the learning process. The same language should be used at home.

“The aim is for them to acquire language as they learn speech and they can only do so easily if they are introduced to one language at a time,” she explains.

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Early intervention will correct hearing loss

Children with hearing disorders need early interventions because some of them can be corrected, says Dr Musa Kipingor, a hearing specialist at the Kenyatta National Hospital's ENT clinic. He explains that from zero to three years of age, before a child develops speech, most hearing disorders can be corrected. These include acquired hearing loss and hearing disorders of the middle and outer ear.

Acquired hearing loss is very common in children; so common that “about 90 per cent of children in Kenya are affected by it annually. It spreads through bacteria, and in the school environment it is very common. It causes fluid in the ears and most of the time will heal on its own,” explains Dr Musa. There are a few cases that progress, but these usually respond well to medication.

Acquired hearing disorder is common in communities that are highly congested, with poor healthcare facilities and a poor nutritional status. “Due to this, children in slum areas are predisposed to hearing disorders. North-eastern Province has a higher incidence of hearing loss disorders than any other part of the country due to inaccessibility to healthcare facilities and nutrition.”

Hearing disorders of the middle and inner ear are less common but more serious. These include conductive hearing loss, which affects the outer ear, and sensory-neural hearing loss, which affects the sound receptors in the inner ear.

“In most cases, there is a blockage or no canal, and the fluid is absent,” the doctor says. “But the most serious hearing disorder is when there is a combination of acquired hearing loss and disorders in the middle and inner ear. This is manifested in a number of children and in fact, most of them in special schools have this kind of hearing disorder.”

Locally, doctors are able to treat hearing disorders, but surgical correction, which Dr Musa says costs not less than Sh3million can only be done outside the country. In developed countries, hearing disorders can be detected in children as young as two days old, but locally, this is not done. “Although we have an auto-acoustic machine at KNH, it is rarely used,” he says.

Hearing disorders in children can also be congenital, resulting from genital viral and bacterial infections, including sexually transmitted infections and HIV. “These viruses can go through the placenta and affect the foetus,” Dr Musa explains, adding that delayed and prolonged birth can also lead to hearing loss. Bacterial infections of the middle ear can cause hearing loss and this is the most common cause of deafness.

Malignant tumours of the ear, endocrine disorders like diabetes and auto-immune based disorders like lupus can also lead to hearing loss in children. “In addition, toxicity of the ear by use of some medications such as quinine in children can impair hearing. That is one of the reasons why it was discontinued,” he adds.

In Kenya, children with hearing impairment are subjected to hearing tests in which electrodes are inserted into the ears to check the transmission of brain stem impulses into the ear. If congenital abnormalities of the anatomical structure are suspected, a CT scan of the spine is done. “Then surgery is done to correct the disorder.”

Although cochlea implant technology is yet to kick off in Kenya, there have been developments and it is hoped that in about a year's time, the facility will be operational. However, Dr Musa says, the technology is very expensive.

- Millicent Mwololo

LIVING POSITIVELY

Love in the wrong places

The biggest problem with HIV is how desperate it can make you appear

When I was trying to have a baby more than two years ago, I received requests from many men, perfect strangers who wanted to donate their sperms. That's not weird. What's weird is that a good number of these prospective 'seed donors' were married men – both HIV-positive and negative – who wanted to help a sister out. I never imagined it would come to this.

What got me thinking deeply was the willingness of men to put their marriages on the line just to fertilise an egg.

“Will you tell your wife about this?” I asked one donor who was extremely persistent, bombarding me with e-mails.

“This is between the two of us,” was his curious response.

I didn't get it. This wasn't about a dress that a man was buying for 'the other woman'; it was about a life, something that's supposed to bring joy to both parents. The experience made me realise that sometimes, in the heat of the moment, it is possible to make decisions that could return to haunt us.

What I wanted for my baby was a father figure, not a Harry Houdini disappearing act type of man. I had raised my first son on my own and didn't want my second child to go through the same thing. It wasn't that I was weak, or that I had been a bad first-time mother, I just wanted to do things differently this time. Small wonder that in the “lonely hearts” column, HIV-positive sisters have one rider: “No jokers, please.”

Looking back, I guess I might have appeared desperate and, therefore, an easy target for a man with a twisted mind to take advantage of. After all, I was HIV-positive and my biological clock was ticking fast and furious. Some sisters living with HIV do themselves a great disservice by appearing desperate when they're looking for love. And it only takes a very married con artist to suggest that he can provide what is missing in our lives before we realise we've been tricked. We may not think about it at the time, but some of these players could come into our lives with a lot of baggage – like HIV re-infection, or even another strain of HIV.

The shock of such an encounter leaves us reeling in pain for years. What's worse, such characters might even manage to drain our life savings, leaving us penniless. I've been in love and I know it can do silly things to my judgment, fogging my mind and making me fail to question my so-called knight's real motives.

A mother who is HIV-negative wrote to me last year about a relationship she was stuck in, and how she only found out later that her new love was married, had children and was HIV-positive.

“He looked healthy when we met and I didn't suspect anything. He didn't tell me about his HIV status. His wife somehow got wind of our affair, got my phone number from her husband's phone, and sent me a text message informing me of their HIV-positive status.”

In this age of antiretroviral therapy (ART) and other highly effective treatment options, people living with HIV can pass any fitness test. In fact, a couple of years ago someone stirred up a storm in HIV circles when he commented on national TV that ART is “blindsiding us” because we don't know “them.” By “them” he meant beautiful sisters who are living positively with HIV.

Some of my HIV-positive girlfriends like to joke that anyone who dies in denial like people used to in the early '90s must have a death wish hanging over their heads. They don't see why anyone should go around looking they're waiting for death to knock on the door. I know of a woman who refused to date a man who had neglected himself to the point where he was emaciated and prone to every opportunistic infection.

“I'm looking for someone to share the rest of my life with, not someone to nurse for the remainder of his life,” was how she put it. I don't want to stick with him out of pity.”

When I was dating, I didn't wait for the other party to tell me their HIV status; I boldly took the initiative and asked, straight up, because I wanted to be clear from the outset. Knowing their HIV status would make it easier for our relationship because we would be able to plan for the bridges before we came to them. I also asked about that other ‘little’ status that some sisters don't see until it's too late: the marital status. I still bump into married men who want to date me. Some of them don't believe it, or aren't the least bit put off, when I tell them I'm HIV-positive. I guess I'll have to start wearing the T-shirt.

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This is the diary of Asunta Wagura, a mother of two who tested positive 20 years ago. She is the executive director of the Kenya Network of Women with Aids (KENWA).

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