

## **DUMISANI MATARE: AN UNLIKELY HERO IN HIV/AIDS FIGHT**

*A gripping story of a teenage boy from Kasupe who has lived with HIV/AIDS since birth*

At 14, he looks shorter than other boys his age. You can easily mistake him for a nine-year-old boy. But when you speak to him, you discover a boy whose intellect is superior. He is in the seventh grade, and speaks English better than most Malawian children in high school. When I recently visited his house, I was amazed at how he easily conversed with our missionary from Maryland. Many kids at Kasupe are afraid to speak with this lady because their English is barely comprehensible. But this is Dumisani, one of the outstanding students at Chikowa Primary School. He is HIV/AIDS positive. Dumisani is a boy who has never experienced life without HIV. His life is dependent on five different drugs. These drugs are taken every day. *“He doesn’t forget to take the drugs, he is always on time, when he goes to school he takes some tablets with him and chews them on time. In the past, he had a wristwatch with an alarm to remind him, but now the time is in his head,”* said his grandmother, Rebecca Chakukuma. As I heard the story, my mind went back to 1995, the first time I gathered enough courage to go for an HIV test. I was sweating profusely, and I nearly left a will at home. As Dumisani’s story went on, I started thinking of the many things I complain about in life. I am not a fan of medicines, but there I was, looking at Dumisani, a boy who thanks God that there is enough medicine for him to take every day, for the rest of his life.

Born on November 12, 1994 to Chiotha and Edna Matare at Queen Elizabeth Central Hospital in Blantyre, Dumisani had a relatively quiet and good life in his early years. In 1996, his father died and no one knew why. The mother, with her son, continued to enjoy a good life for more than a decade. Edna would later remarry and have another child, Felix. Despite enjoying a good life for some years, both mother and son got a surprise in 2005. The second husband died, and Dumisani and his mother also fell seriously ill. No one could figure out what was wrong with them. They were advised to go for an HIV test, and both were found to be HIV positive. Only the mother was told this news. Dumisani suspected nothing. His mother died towards the end of 2005.

The death of Edna marked the beginning of a whole new life for the eleven year old boy. He was put into the care of his aunt (a sister of his late father). His aunt was a well-to-do person and she put Dumisani in a private school. His dwindling school performance improved tremendously. But tragedy struck again in 2006 when the only real hope for him vanished. The aunt responsible for his daily needs died. Dumisani was taken back to the village where his grandparents agreed to take care of him and his younger brother, Felix.

Dumisani was kept unaware of his HIV status until August 24, 2009. I knew about Dumisani’s status before he knew. *“But how could that be?”* I asked the grandmother. Rebecca replied, *“We had been told by medical people that this was in his best interest. It was mainly done to protect the boy.”* I thought to myself that Dumisani had the right to know this important news for his life. In Malawi, it is unclear when a child needs to be told if he or she has the virus. It seems that this is a debate no one is interested to spark. For five years, Dumisani was told to take medicine every day because of many illnesses facing his life; HIV/AIDS was not part of the discussion. When Dumisani was finally told that he was HIV positive, many questions he had were answered. The

boy had always wondered why his grandfather had insisted that he should use his own bathing towel, bathroom, and even eating utensils. He also realized why there were always arguments between grandma and grandpa. The arguments were always about him, and grandma always backed him, no matter what. But Dumisani is forgiving and in my conversation with him, he never mentioned his grandfather. I only heard about this from Rebecca, a grandmother who cherishes every minute of Dumisani's life.

When Rebecca narrates the story, you get a feeling of a 60-year-old lady who has had a fair share of life's hardships. She gave birth to eleven children; four are dead due to HIV/AIDS, two are living with HIV, and one grandchild is sick with the virus. Several children and grandchildren are suspected of carrying the virus but she can't do anything now for them as she has a lot to worry about. She takes comfort in the fact that Felix, Dumisani's younger brother, was born HIV negative. The six-year-old boy has been tested for HIV six times, six months in between, but no HIV has been detected in his blood. There are times she thinks the doctors are not telling the truth. She thinks the negative results are phony. She wonders how Felix, born to HIV/AIDS parents, managed to be born without the virus. I comfort her with whatever little knowledge I have gathered about HIV/AIDS over the years. I tell her that Dumisani was born at a time when AZT (azidothymidine), a drug that is used with other antiretroviral medications in expectant women who are positive, was not widely used. Many children were born with HIV before the introduction of AZT. Although some children are still born with the virus, since early 2000, use of AZT among pregnant women has significantly reduced MTCT (mother-to-child transmission).

In early 2006, Dumisani's CD4+ T-cell count was detected to be dangerously low. CD4+ T-cells are generally treated as having a pre-defined role as helper T cells within the immune system. It was during this time that he spent about six months in a hospital. Rebecca recalls a prayer she overheard Dumisani uttering on many nights from his hospital bed: *"Lord, take me to go where my father is."* Five different drugs were immediately introduced on him. These included Abacavia, Aluvia, Didanosine, Adosine, and Bacterium. He has been taking these drugs ever since. However, he was in and out of the hospital despite regular use of the drugs. It was at this time his grandmother brought him to Kasupe Ministries.

Kasupe has an HIV/AIDS support group that meets on a regular basis; but Dumisani's problem was not just access to anti-retroviral drugs or a failure to handle persistent illnesses. He needed nutritious food on a regular basis, as well as monthly transportation to a hospital three hours away -- a monthly trip he will have to endure for the rest of his life. We immediately decided to put Dumisani on a special support program which provides him with \$30 each month for transportation to the hospital. Dumisani also receives the following items every month: 4 kgs of sugar, 8 kgs of VitaMeal (a fortified mixture of roasted maize and soybean porridge), 2 kgs of powdered milk, 3 tablets of soap, 2 bottles of lotion, and \$7 for vegetables and meat. We encourage him through counseling sessions, and above all, we pray with him. As a result of this holistic approach, Dumisani's life has completely turned around.

Our hope and prayer is that Dumisani will live long just like everyone else. This optimism is shared by Dr. Kevin Clark, Dumisani's physician. Dr. Clark, an expert in children living with HIV/AIDS, thinks that a combination of medicine, home-based care support, and nutritious food will help Dumisani live longer. We also hope that Dumisani will inspire other children in the same

predicament not to despair but to always know that we care about them. With hundreds of children beginning to show signs of full-blown AIDS, the story of Dumisani is an inspiration for many children in the Kasupe area.

May this story help us remember to pray for all children who live with HIV/AIDS in our communities and beyond our borders.



***Fletcher (right) & Dumisani (left) at the boy's home in Chikowa Village, September 12, 2009***

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*Story from interviews with Dumisani and his grandmother, Rebecca Chakukuma, at their home (September 13, 2009) and at Kasupe Ministries (September 15, 2009), published with permission from the family*