



LIVING WITH RHD

Zandile's Story

Zandile lives in the city of Cape Town, South Africa. She is one year away from completing high school, having been forced to drop out for a year due to rheumatic heart disease (RHD).



RHD is a preventable and treatable form of heart disease that affects 32 million people around the world, particularly children and young people living in conditions of poverty and overcrowding. It most often begins in childhood as strep throat, and if left untreated can progress to serious heart damage.

Zandile first became sick in 2007, while she was still in primary school. Her mother noticed that she was very thin and had no appetite. She would eat one meal a day – plain rice with oil and salt. She had a fever and was coughing all the time. Several different doctors were unable to find anything wrong with her.

Eventually a doctor diagnosed Zandile with rheumatic fever, which had now developed into rheumatic heart disease (RHD). She also had a large, swollen stomach – caused by an enlarged liver – so that some people were even asking if she was pregnant, despite her very young age.

Zandile was referred to Red Cross Children's Hospital in Cape Town, where she and her mother waited for several hours before she was given medication to drain the excess fluid from her body. When this proved ineffective, she was admitted for surgery.

The sudden prospect of an operation was terrifying: "I was so scared! I didn't know anything about rheumatic heart disease – nobody in my home had had an operation, I would be the first one."

There were many complications throughout Zandile's treatment. She was admitted to hospital in February and was not discharged until November, and then had to return the following month, causing her to miss a whole year of school.

Her treatment required two operations, both at Red Cross Children's Hospital. The problem was with her mitral valve, which continued to leak blood. Doctors removed her original valve and replaced it with a mechanical one. Thankfully, the replacement valve from her second operation succeeded.

Zandile can hear the clicking sounds the valve makes – "like a beating baby fist" – when she is running or doing another kind of physical activity. Having returned to high school, she says: "In my classroom, when it's really quiet, my friends will say "Listen, listen!" and they listen to my heart." Zandile has grown to like the familiar sound.

At first Zandile struggled to explain RHD to her peers, who did not always understand the disease or the function of a heart valve. Some people still make assumptions – including that she will struggle to find a husband or be unable to bear children – but her friends and family are largely very supportive. While Zandile used to avoid wearing sleeveless tops, so as not to show her scars from surgery, she is now much more confident in sharing her experience with people who mistakenly ask if she has been burned or stabbed.

Raising awareness about RHD to communities is a key step to reducing stigma around the disease. Greater knowledge of RHD symptoms could also have led to Zandile being diagnosed sooner, preventing her from needing multiple expensive operations and missing a year of school.

Now back at school, Zandile remains focused on her studies and maintains good grades. She hopes to go to study dancing at a prestigious arts university in the neighbouring province and has ambitions to be a professional choreographer: "I love dancing, and my body also loves me to dance!"

Zandile has shared her story in the hope that it will raise the profile of rheumatic heart disease. There is much to do to increase awareness of RHD at the local, regional and global levels. To find out more, please go to www.rhdaction.org





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Felicia's Story

Felicia is from the Western Cape, a South African province of around 5.8 million inhabitants. She lives there with her daughter and sisters, and enjoys playing netball and spending time outdoors.



The first indications that Felicia might have rheumatic heart disease (RHD) occurred after her first pregnancy, aged 27. After a difficult birth, Felicia was coughing and felt dizzy and tired. She did not have the energy to lift her baby, and was unable to breastfeed due to fatigue.

A doctor referred her to Groote Schuur Hospital in Cape Town, where she was diagnosed with RHD. The doctors tried to drain fluid from her body, which had caused swelling.

As she was a high-risk case, Felicia had an operation within two months, during which three of her heart valves were replaced. Due to complications following her operation, she had to return to the hospital for more fluid to be drained, but soon returned home to her family.

Before she was diagnosed with RHD, Felicia had worked as a cleaner. To support her during her treatment and time in hospital, Felicia received a disability allowance from the government. This was a difficult transition: as the first-born child of her parents she had been the major breadwinner, and worked hard to provide for her family.

Now, it is difficult for Felicia to gain steady employment, as she still sometimes experiences swelling and needs periods of rest before resuming work. Sometimes Felicia and her family do not have enough money for basic necessities, such as healthy food and public transport. Fortunately her doctors have managed to transfer her medical appointments to a local community clinic within walking distance of her home.

Felicia finds the strength to cope with RHD through her faith. She also stays healthy to help manage her disease by avoiding alcohol and smoking, and exercising outdoors. She loves to play netball with her sisters and friends in her community, and advises people living with RHD to find a similar outlet: "You leave the stresses inside and just concentrate on the game. And the fresh air is good for our bodies! [...] You go mad if you have a lot of stress."

Felicia also educates people in her community about RHD. In particular she tries to break down stigma by explaining that her current condition is not infectious, that it cannot be 'caught' by bodily contact.

Despite the challenges RHD has brought her, Felicia remains positive, affirming that "It is not the end of your life if you have this". She hopes to explore further education, having graduated from high school several years ago. She is also preparing for her daughter Mivuyo, now 4 years old, to start school.

Not every woman diagnosed with RHD can look forward to the future with her child. RHD is a significant cause of maternal death due to increased stress on the heart during pregnancy and labour. It also exposes newborns to an increased risk of disease and early death.

However there are simple ways to address these risks. Antenatal care visits offer an opportunity to identify cases of RHD among pregnant women. Doctors and nurses can then provide family support and counselling to women with known RHD to plan their pregnancies and make them as safe as possible.

There is much to be done in South Africa and other countries with a high burden of RHD. Find out what you can do at: www.rhdaction.org

There is a role for everyone to play in the effort to eliminate this preventable disease, whether you are a health worker, researcher, policy maker, or person living with RHD. To find out more, please go to www.rhdaction.org

