

Living with RHD: Ruby's Story

Managing Pregnancy

Ruby is a wife and mother of three from the Western Cape Province in South Africa. She was diagnosed with acute rheumatic fever (ARF) at 16 years of age.



Ruby remembers her symptoms were like those one gets with the flu: coughing, fever, swollen ankles and feet, and an inability to move. When she went to the clinic and hospital, her blood was repeatedly taken and various tests were done, but no conclusive diagnosis was given. What further complicated the diagnosis was that the symptoms would come and go. When Ruby presented to a clinician, the symptoms were not always there but would reappear when she was back at home.

Finally, Ruby decided to seek help at a private hospital. She had an electrocardiogram (ECG) to check for rhythm abnormalities

and to measure the activity of her heart. Ruby's screening showed an abnormal heart rhythm and she was told that her heart valve was damaged by ARF – a condition called Acute Rheumatic Fever – which could lead to permanent heart damage called Rheumatic Heart Disease or RHD. She remembers the doctor saying that pregnancy may not be safe for her – that it may put too much pressure on her heart.

Life continued for Ruby after her diagnosis; she followed her prescription of monthly penicillin, completed high school and led a normal life. Her first pregnancy was in 2000. Ruby developed

pulmonary edema during this pregnancy – a condition where fluid accumulates in the tissues and air spaces in the lungs, usually because the heart is not functioning properly. To protect her and her baby, Ruby had a caesarean section and delivered a healthy baby daughter. Her second baby, a son, was born in 2005. Unlike her first born, she did not require a caesarean.

In 2007, Ruby fell sick again with all the symptoms she had when she was 16. The medication she was given did not improve her condition. Once again, doctors could not find out what was wrong with her. Eventually Ruby had another ECG done. The doctor told Ruby that the problem was with her heart and that she needed specialist care. The following day, Ruby made an appointment at a large public teaching hospital in Cape Town. There she met a cardiologist who explained to her what RHD was, the procedure for surgery and the six-week recovery time. Ruby was scheduled for a mitral valve replacement surgery.

Heart valve surgery is performed to repair or replace a valve or valves in the heart that are not working properly. Valve repair or replacement may be required if



a valve has been damaged by a heart disease such as RHD. Tissue valves are made from the tissues of animals (pigs or cows) whereas mechanical valves are made from durable metals, carbon, ceramics and plastics. Ruby and her medical team chose the mechanical valve because her valve was no longer able to be repaired. However, this option meant she would have to take blood thinners for the rest of her life to prevent blood clots.

On the evening of the same day, Ruby received a call from the hospital to say she was scheduled for surgery the following Monday. Her reply was “certainly most gladly I will be there”. When asked if she was afraid of having surgery, Ruby replied, “for some reason I was calm, and it was a good thing that everything happened at once... I did not have time to process everything and think about the ‘what ifs’. Everything was just action, action, action and for me that was good.”

Ruby recovered quickly after surgery. She says her faith, family and tenacious spirit successfully guided her through this journey.

After the valve surgery, Ruby wanted a third child. She consulted a fertility specialist and she eventually fell pregnant again. Ruby was referred to a gynecologist where an ultrasound found that her womb was empty. She was told that the blood thinner, Warfarin, had prevented the fetus from developing and as a result she had a miscarriage.

After some time, Ruby fell pregnant again. This time her pregnancy was managed by a combined cardio-obstetric team. She was very careful to keep all her appointments and adhere to the care instructions provided throughout her pregnancy. Ruby gave birth to her third child, a healthy son, by caesarean section.

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Ruby feels her experience with RHD has made her a more vigilant mother. When her children are sick, she always asks the doctor when she will see the results from the medication prescribed, asks for a follow-up appointment and gives medication to her children at the same time every day.

Ruby’s message for women who have cardiovascular disease is “Firstly, that you must take responsibility for your own health. I make sure to always check my INR. (International Normalized Ratio is a test used by people who take blood thinning medication on a regular basis.) There is stigma associated with heart patients. It is our responsibility to let people know that we do live normal lives. I think the biggest problem was



that when I had a throat infection (as a child) it was treated ‘normally’. I was given flu medication. There was never a follow up. I tell people that a sore throat can often be something bigger”.



In collecting these stories of women with RHD and their pregnancies we have sought to honestly represent the reality of our patients’ lived experiences. RHD Action encourages all RHD patients to stay in care and follow their medical professionals’ advice, to achieve the healthiest and safest outcomes for themselves and their babies.