



HeartKids

MYLES AND MANI'S STORY



My name is **Mandela Yu**, I am a Yawuru woman from Broome

Getting the diagnosis

Myles is my first child.

He was diagnosed with congenital heart disease (CHD) when I was still carrying him. It was picked up at 29 weeks after I had travelled to Perth for my first ever echocardiogram (ECG).

Thinking that it was just a regular check-up, I was on my own. It was a complete shock when I found out that he had CHD. The first question you ask is 'Did I do something wrong?' But it was just a case of bad luck.

I was lucky to have found out early because it gave me some time to prepare. The hospital gives you information. You do the research you need to do. Until it's happening though, it doesn't sink in.

I didn't know if I was having a boy or a girl. I wanted to keep it a surprise. I had Myles on my list of potential names. I read somewhere that it means warrior or soldier. When I saw him, I knew.

A heart warrior...That's Myles.



Myles at 12 months

Myles is born

Myles was born in Perth on 2 April 2020. He was born with pulmonary atresia and a hypoplastic right ventricle. In simple terms this meant no blood flow was going to his lungs. I still struggle to get the proper terminologies out.

Within 24 hours of Myles being born, he went to have his first surgery. He had a heart failure during that operation. But he pulled through. Two weeks later, Myles had his second surgery. After he got through that recovery, he started to do well.

We were hoping to be able to go home to Broome after his surgery. However, we ended up having to stay in Perth. I am grateful that I had my mum with me in Perth. She would cook me meals. That was a piece of home for me.

He went through what they call withdrawals. It was tough watching that because you can't do anything about it. The nursing staff and doctors at Perth Childrens Hospital (PCH) were fantastic in helping us all get through it. Once he recovered from that, he did well.

At the end of September, we finally got to come home. Right before my birthday.



Myles with some of his cousins (not all).

Travelling away from home for treatment

I had gone to Perth for one scan and ended up there eight months.

I come from a big family. We are all very close. Being away from home and them not being able to come see me because of the COVID-19 restrictions, that was tough. Being in hospital for a month without having any family being able to visit let alone meet Myles, was very tough!

There were a lot of hard days and nights in that first month with Myles. The hospital environment became our home. It was our normal back then.

Another surgery

Myles ended up having a third surgery in August 2020. Unfortunately, he caught a respiratory infection while he was on a ventilator in hospital. He was in the intensive care unit (ICU) for longer than we liked, under care 24/7.



TAKE SUPPORT

If you are travelling away from home, if you can have someone with you like family, it's a lot of help.



How we got through it

In any bad situation, I try and find one little positive thing to keep me going. What got me through it was knowing that we were in the best place for Myles at the time. He was getting the best care possible.

I'd like to mention also, as I haven't really heard or read much about it, that it is just as important that we as parents take time out to look after ourselves during such a stressful experience. For me, HeartKids and the staff at PCH helped me. Talking about Myles's CHD journey in a safe and positive way with other families also helped.

How HeartKids helped us

I first reached out to HeartKids about a week after Myles was born. I didn't really know what to say at first because back then I found talking about Myles very overwhelming and upsetting. However, after my first conversation I felt a weight lifted.

Knowing there was a bigger community out there, other parents like me experiencing the same thing.

Being able to talk to someone, without the focus on the medical stuff, was comforting on so many levels.



Up until then, I had felt very alone when it came to dealing with being a CHD parent and trying to get my head around it. A lot of the time I just wanted Myles to survive. The unknowns and 'what ifs' always got to me. After reaching out to HeartKids, my mindset shifted.

HeartKids are like family. That is very important. They aren't just there for the tough times, but for all the times. Thanks to HeartKids I have been able to connect with other heart families from across the state.



Get support from HeartKids

The HeartKids support team is made up of parents who have gone through it. It helps to connect with other people who can relate to you.

Taking your child in for surgery

Myles had his fourth surgery in July 2021.

The hard part for me is the surgeries. No surgery is the same, I will always remember this advice. From a newborn to four months and then 16 months of age, no surgery was ever the same with Myles. It doesn't get any easier. But we do it because there is no cure for CHD, surgery is what our children need to get better.

I thank the medical team at PCH who looked after Myles during all his surgeries, as well as with his ongoing care. I also thank the Heartkids WA team for supporting me through such a tough time.



Mandela's advice to other heart families



Stay in the moment.

Take it day by day. At first, I didn't understand what was happening with Myles and it was all too overwhelming. Try not to think too far ahead. Listen to the doctors and try not to think about the 'what ifs.'



Ask questions.

If you need to ask the doctor a question, don't be scared or shame. It's the not knowing that probably scares you the most. When you see your child going through this trauma, understanding it helps. As soon as you can get your questions answered, you can feel calmer.



Connect with other families.

I met up with other mums who had gone through similar experiences. When you can speak to someone who knows what you are going through, it makes the conversation easier because you can relate to each other. You can talk and not be scared about your emotions getting in the way.

Coming home to Broome

When Myles came home to Broome, everyone was cautious around him at first. One of the things the cardiologists said was to 'treat him like a normal child.' We've always tried to do that. It has shifted the focus away from his heart condition.

I am only aware of two other heart kids in Broome and I connect with the mums regularly. We have been lucky enough to host the HeartKids Two Feet and a Heartbeat Charity Walk in Broome for the past two years. It is a great way to bring our community together and help spread awareness of CHD and HeartKids.

One of the other mums and I have recently become Heartkids Regional Volunteers for the Broome / NorthWest WA region. Our aim is to let other families know we are here to help in anyway when dealing with CHD.



This information is general. It is based on the experiences of one family in our community. This information is not a substitute for medical advice from your doctor. Always talk to your doctor about matters that affect your health. This story was told to HeartKids in December 2021.

Our life now

Myles is doing well. The doctors are happy with him. He loves his food. Growth-wise, he is thriving. He is showing good physical signs.

We have had many visits to ED since being home and this will always be ongoing. We still go to regular check-ups and different therapy sessions (physical, speech, etc.). It's just all a part of the ongoing journey. I would like to thank my family for sticking by me and giving me all the support and help needed to get through this journey.

Everyone always comments to me on how strong I am, even though I have had many weak moments. It's just one of those things you must accept and all you can do is grow with it – the good and the bad.

Myles has just started daycare. He loves to go swimming, whether it be at the beach or pool. He loves being outdoors listening to the birds and watering the garden with his Mim (grandmother). Most of all he brings so much joy into my life.

Myles, he is a little heart warrior.

