



HeartKids

MAHLI-MAY MOONEY'S STORY

We are **Monique and Clinton Mooney**. Clinton is a Birri Gubba man from Townsville. One of our daughters, Mahli-May, is a heart kid.

We hope that sharing our story helps other families.



Finding out about Mahli's condition

We didn't find out about Mahli's condition when she was still in the womb. It started when she was a day old. We were preparing to go home from the hospital. The paediatric team were doing their last check when they said that Mahli had a light pulse.

They did an ultrasound and told us there was a hole in her heart. We were distraught. We were heartbroken to hear that. They immediately arranged for her to be transported to Brisbane.

Mahli's surgery

We had nothing arranged in Brisbane. We were there with Mahli and nothing but the clothes on our back. Some kind nurses arranged temporary accommodation for us.

Mahli was scheduled to have open heart surgery at four days old.

Mahli was looking quite sick before surgery. Her skin was a grey colour. The nurses were getting ready to take her into surgery when Mahli went into cardiac arrest. It felt almost like watching a movie. The hospital staff sprung into action. They were so well organised.

At some points we were told Mahli might not make it through the night. You feel really vulnerable. We're resilient people. But we still felt this intense fear. Nothing really went to plan.

It's hard to keep an open mind, but you just need to take everything day by day. We learnt to focus on today and accept



the things we couldn't change. She did eventually overcome it.



When the hospital becomes your home

From that point, we spent about nine months in hospital. We weren't moving until we knew Mahli was going to make it. The hospital became our home. We were staying at Ronald McDonald House.

Being away from home adds a big element of stress and anxiety. The doctors can't always tell you what's going to happen because they don't always know. It's difficult because you can't plan your life.



The impact on our sons

At the time our eldest son was six and our youngest was three. It had a big impact on the boys. They had to be uprooted from their routine, their home, their life as they knew it.

They had to move to a different school structure, a different daycare centre. It was confronting for them as young kids to be in that hospital environment, to be around kids in intensive care.



They experienced grief. They were really worried about Mahli. It was a lot for them, but they just found a way. It's made them sensitive and understanding. They can be really caring towards other people. It's made them even more resilient.



The social workers were a huge help

We're very grateful to the social workers from the hospital. They help with a lot of things on the journey.

The social workers helped us by:

- Getting our son enrolled in the hospital school
- Showing us all the services that could help us
- Helping us to access Centrelink (like childcare payments)
- Helping to advocate for us as parents

There are times when you feel vulnerable and don't have anything else to give. In those times, they have your back.



Social workers

Our advice: Ask to see the social worker. Have a conversation about what they can do for you.



Mahli's recovery

Mahli was about 10 months old when she had her second surgery. When we went in to see her after that, she looked so well. She had colour in her skin again. As daunting as it is to see your baby with all the tubes in, she looked better. After the surgery, she just started to thrive and grow.

She's mostly healthy now. The prolonged ventilation has affected her

neurodevelopmentally. She can be quite impulsive. She has certain unusual traits. But they work for her. Mahli's so different, she doesn't fit into any box. She's so funny, and she's smart in a lot of ways.

Mahli really likes to sing. She's trying to teach herself how to play guitar. She is very culturally aware. She's always been really drawn to everything culturally, even when she was little. Artwork, music, stuff like that, she just loves it. She plays rugby league too. She's the only girl on her footy team.



When she grows up, she wants to live in a bus, drive to the beach and watch the sunset every night. And sell Lamborghinis.

She says she wants to be a doctor and help heart kids because they'll trust her as she shares the same scar. She has been bullied for her scar at school before.

**We remind her how strong she is.
You've got that scar because you're really strong.**



Our advice to other heart families



Ask questions.

Try to feel empowered to ask questions if you're not sure about something. It really adds to your stress and anxiety when you don't know what's going on. A lot of people don't know medical lingo and sometimes doctors forget that. You can ask them to slow it down. Ask them to draw a picture.



Ask for help.

If you need help, don't be shy to ask for it. No one is there judging you. If you don't feel comfortable asking the doctors or hospital staff, ask someone that you feel safe speaking with. That could be a social worker, a HeartKids support worker or an Indigenous liaison officer.



Look after yourself.

When you come out of hospital, set yourself up with some support services. There are women's groups and men's groups. It can be reassuring to share experiences and hear from people who understand what you've been through. As parents, we need to remember to look after ourselves too.

Our life now

Mostly Mahli is healthy and happy and enjoying her sports. She has her yearly check-up. She used to get anxious about it, but now she understands why it needs to happen. If you give her a copy of her ECG (picture of her heart scan) to take home, she's happy because then she can show people what her heart is doing.

The boys are doing well. They still get anxious sometimes if they don't know what's going on with Mahli. They are protective older brothers. They love teaching their sisters' new things. All four of our kids play rugby league. Their favourite team is the Rabbitohs.

Mahli's so full of life, it's too much sometimes! We wouldn't have it any other way though. We put it down to what she's been through in her life.

**She fought so hard to be here,
so she's making the most of it.**



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 July 2021.



**The Mooney Family: Daysharn, Clinton,
Monique, Izayah, Jayahra and Mahli-May.**