The Patient Story

Professor Susan Walker
Head of Department

"Stillbirth touches the lives of one in 130 Australian families and nearly 3 million lives are lost to stillbirth around the world each year"

Transcribed directly from MOGCAST Episode 9. Listen here:
https://open.spotify.com/show/6dtXQ6jLjAIi7lHtP71cYe?si=7671224caacc4f4a

"Hi everyone. Welcome to this episode of the MOGCAST. I hope you're enjoying these. I'm Professor Sue Walker, Head of Department of O&G. And it's been a real delight working on these podcasts. But this one's a bit of a different episode. This one's a patient story about stillbirth, and I want to tell you that in advance because reproductive loss is very common in our community. So some of you might have been impacted by this, either you or your family, friends, someone you know or love. And so, this podcast might trigger a strong response for you. And as you know, all the staff in Women's Health are happy to talk this through with you any time. So, this is Shannon's story. Shannon's family is one of the many who lose a baby to stillbirth.

Stillbirth touches the lives of one in 130 Australian families and nearly 3 million lives are lost to stillbirth around the world each year. It's got many causes. Complications prior to pregnancy, so medical conditions like diabetes. Or complications of pregnancy, such as preeclampsia and fetal growth restriction, as you'll hear from Shannon.

And sometimes there are serious genetic or structural abnormalities of the baby that may be lethal before the baby ever takes a breath. You can find out more about the contributors to stillbirth in my lecture, where I go through this in much more detail. The aetiology, diagnosis, how to break bad news, and what happens next. But for now, I want you to hear the patient voice. And so, I'm going to hand over to Shannon.

Shannon: Hello everyone. My name is Shannon Boland. I'm 27 years old. I live with my husband, Aidan, and my son, Hudson, who is eight weeks old. I work as an advisor at WorkSafe and I've been working from home since the beginning of COVID.

In March 2020, Aidan and I were blessed to be expecting a miracle. Those two lines on the stick changed our world forever. We became a mother and a father from that moment. Everything was smooth sailing. We had our first scan and we saw our precious little baby on the screen. We continued along our journey and started planning for the future of what our life would look like with the baby in arms.

We had our NIPT test and this came back low risk and we found out that we were having a little baby girl. 17 weeks rolled around and I was continuously having a headache. My mother, who is a midwife at Werribee Mercy, decided that she would take my blood pressure to check in. This was sitting high, and we decided that a trip to the obstetrician would be best.

After my appointment with the obstetrician, there was a decision to begin blood pressure medication, Methyldopa. Due to this being so early in gestation, there was no diagnosis. After two weeks, we had another review, and my blood pressure was still high. I went into Werribee Maternity Assessment Unit, and they kept me in overnight, as my blood pressure was still high, and a change of medication to Labetalol was required.

20 weeks rolled round, and along came the scan. The scan went very well, and our little girl was so strong and moving lots. There was mention of low fluid and low-lying placenta, although we were advised that this would allow us to have more scans in our pregnancy, which of course every parent wants.

Along came the 22-week scan to follow up the 20-week scan. The sonographer at Werribee Mercy completed her scan and advised me that I needed to go straight down to Werribee Maternity Assessment Unit.

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Sitting in the assessment unit, waiting for one of the head obstetricians, my head was thinking, what could be happening?
Never did it come into my mind that a negative outcome to this pregnancy was going to be a result. After discussion, the message delivered was that my placenta was failing, and our daughter was measuring small and unwell. The scan showed that out of three blood vessels feeding the placenta, two were failing to feed our daughter.

This therefore advised by the obstetrician that our daughter potentially wouldn't survive and if she did, that she would be severely unwell and have a poor quality of life. Our whole world changed in seconds. The decision was left in our hands on what we would like to do for our daughter. We thought it would be best for her to make her own decision and destiny.

She was so strong and was a fighter. She was kicking lots and each movement I felt was a blessing and calmed me. I was admitted to Werribee Mercy Maternity Ward for the interim of finding a bed in a tertiary hospital to get more assistance. We faced scans, blood tests and discussions daily, which was exhausting not just mentally but emotionally and physically as I was still dealing with an ongoing headache and high blood pressure.

A week passed by so quickly yet so slowly. The pandemic was in full force and therefore had lots of time to think about so many outcomes and future for our little one. Finally, the news was in that Mercy Heidelberg had a bed for me and I would be under their care. A dose of steroids were given pre leaving the patient transport car as my last scan shown she was worse off.

Arriving at Mercy Heidelberg was weirdly a step forward. I knew the care I needed to receive was going to be the best of the best and that they would do all they can for my family. Moving forward, and once again, scans, bloods, and monitoring were completed every day. I had a second dose of steroids when arriving at Mercy Heidelberg.

It was confirmed that I had early severe preeclampsia, and due to this, our daughter had severe fetal growth restriction. Her heart was enlarged from pumping over time to supply the body to continue on. I was taking 150 bd of labetalol, and myself and our daughter were stable but still unwell. Two weeks later, the choice was made to go home on the Friday as I could be in a more comfortable environment, taking medication and blood pressure at home with my husband and my family and going in for scans as needed.

Monday came and the next scan was due. My husband and my mother had to wait downstairs and up I went alone. The Doppler was put on and there was a struggle to find the heartbeat. I said to the midwife I felt my daughter was no longer with me. Moving to a private room and an obstetrician coming to complete a scan, there was no movement and no heartbeat detected.

The words, "I'm so sorry, your daughter has passed away and we are sorry for your loss, we will call your husband and mother up now", will forever be embedded in my brain. My husband and my mother had to come up to find that our daughter was no longer with us. My husband and I stayed overnight and prepared to be induced the next morning to deliver our daughter at 24 plus 4.

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“A simple tablet like Metformin could potentially extend a pregnancy up to 8 days ”

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Never in a million years did we think this would happen to us or that we would become a statistic. I was and am a fit, healthy, active person along with my husband and family. The shock had well set in and I had no tears to cry. It was time to deliver our little girl knowing the outcome. After being induced and delivering our daughter at 10.41pm, she arrived into the world asleep at 420 grams. We received the best care for the worst outcome possible from Werribee Mercy and Heidelberg Mercy. Sue, David and the team at Heidelberg were our rock during this all. Even though there was no treatment to cure preeclampsia or extend our daughter's life, they did everything they could to make the journey bearable.

If it wasn't for the team and the incredible midwives, we wouldn't be here today. The passion, hope and drive they have to help all families that have unwell babies is life changing. They educated us in what we're dealing with and what our future could look like. They kept us hopeful, which is what we needed.

The outcome of losing our daughter meant that it was up to us to share her name, Mia Boland. We told Sue and David that we wanted to help in any way possible to help future families dealing with the same or similar situation and that we would strive to raise awareness about preeclampsia and severe growth restriction.

Moving on to three months down the track and where we were fortunate enough to be blessed with a second pregnancy. NIPT tests completed and finding out we were going to have a little boy was incredible. The emotional rollercoaster that comes with dealing with a loss is indescribable. Although, there was a light in our future and our little girl was now going to become an older sister and watch over our family.

Having my pregnancy journey start with Mercy Heidelberg perinatal unit was the best decision as I was seen to every fortnight to make sure that our son was growing, the placenta was well, along with myself. Jumped to 37 plus 3, I delivered our son Hudson via vaginal birth rapidly. This was empowering, beautiful and emotional.

Sharing the news with our family, friends and the team at Mercy Heidelberg was such a proud and blissful moment. Finally, we could bring our little one home safely, which we are cherishing every moment. I was asked to share our journey, which we were more than willing to do. Knowing that so many people have learnt so much about preeclampsia and fetal growth restriction and raising awareness to help research like Kathy's, Sue's and Stephen's to assist women like me and babies like our daughter Mia.

A simple tablet like Metformin could potentially extend a pregnancy up to 8 days which could save so many children's lives and severe families of loss and bereavement. This is an exciting discovery that if we had the opportunity, I would have taken this tablet once, twice, or 50 times a day to change the outcome for us.

I'll finish with thanking the team at Mercy Werribee, Mercy Heidelberg, in particular the perinatal unit, Sue and David. There are no words to express the gratitude we have. It could bring me to tears, although I don't want to start sobbing. We are grateful for everyone watching tonight to learn more about how to deal with someone like me in this position and to raise awareness about this horrible condition that affects one in three women. I know this might have been a lot for some of you to hear but fortunately and unfortunately this is a raw story that you're hearing firsthand. I'm still standing, healthy, positive although still coming to terms with our loss. Alongside with my husband, thriving son, and my family. We are eternally grateful for you all.

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Please continue the amazing job you are doing, especially during the crazy world we are living in. I wish you all well and stay safe. Thank you.

Sue: Isn't she incredible? Shannon is such a strong and inspiring woman and as you can hear is a powerful advocate for families in a similar situation. It was such an honour to look after her and also to hear the story of Mia and Hudson's pregnancy from her perspective.

This is just a little reminder to you that the patient voice is an incredible resource across all of your career. Firstly, peer networks are incredibly important for families, but also the patient voice should inform all that we do, how we provide clinical care, how we teach and how we research. So can I encourage you to partner with patients and their families whenever you can.

Nothing can replace deep, unhurried listening to patients to display compassion and empathy. I hear you, I'm here for you. As we are for you, as I said at the beginning, if you have any questions or big feelings as the paediatricians call it, that have arisen from this podcast, please let us know. So happy to work it through with you over a coffee, a corridor chat or a Zoom call.

So, that's it from the MOGCAST for this episode. I'll look forward to seeing you next time. Take care for now. Bye.