

Christine Prosser, Submission to Stillbirth Inquiry, May 2018

1. Introduction

This is an individual submission providing a contribution to the Inquiry based on my own personal experience of stillbirth. I would like to thank the Committee for the opportunity to share my story and contribute my views on the future of stillbirth research and education in Australia.

The first part of this submission explains my own experience with stillbirth. It provides important context for my responses to the Committee's Terms of Reference and I hope it assists in providing the Committee with stronger insights on stillbirth and its associated impacts.

The second part of this submission provides my direct responses to items d) – g) of the Terms of Reference.

2. Background – my story

In 2014 I was pregnant with my first child. Everything had been progressing well and my husband and I attended our 20-week scan. At this scan the Doctor said she thought our son was a little on the small side but it was hard to tell because of the position he was in. No real concerns were raised with us, we were just advised to come back in a couple of weeks for another scan to get a better look. We advised the Doctor we were about to go overseas on holiday and wouldn't be back until just over three weeks, would it be ok to delay until then? That wasn't a problem, so we booked in our next scan for the day after we returned from holidays.

We enjoyed our holidays and we spent some time mentally preparing for the arrival of our baby. At this point I was still waiting to feel movement, but this hadn't been a particular concern to any of the Doctors at my last check-up and I had read plenty of literature that said that it often happens that a mother, particularly a first time mother, does not feel her baby until around 24 weeks.

We came back from holidays then early the next morning went along for another scan. The Doctor took one look at the screen then turned to us and told us that she was sorry, our baby had no heartbeat. It took a few moments for the news to sink in. Gradually, the tears started to fall and I realised that our baby had died. Our dreams and plans for life with our son were crushed in one foul swoop. The most awful of possibilities had happened to us. I couldn't believe it. I didn't want to believe it. This wasn't how our morning was supposed to go.

We saw our Obstetrician after this scan and she explained that she thought our boy had died up to two weeks ago but it was hard to say why. This was very hard to hear. It had happened while we were on holiday, enjoying ourselves, rubbing my tummy and planning our future. We had no idea. I thought about all the people who had seen my pregnant belly and wished us well over the last couple of weeks. Imagine if they knew the baby inside of me was no longer alive. My mind filled with questions, doubts and accusations. What if we hadn't gone on holiday? I should have noticed something. I should have followed up on the lack of movement. Why didn't they tell me to come back sooner? Was it something I did? Was it something I didn't do? Could we have stopped this from happening? Why did our son die? I felt desperately sad, guilty and angry all at once.

The next few days were a blur of appointments to sort out how and when I was going to deliver this baby and what would happen after he was born. I felt scared, unprepared and uninformed about giving birth – I hadn't yet gone to any childbirth classes and hadn't been ready to think about that part of my pregnancy yet. And not in our wildest dreams had we anticipated coming back from holidays to meet with Funeral Directors to discuss what would happen to our most precious and innocent child after he was born.

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It was 5 days between when we found out our son had died and when I was admitted to hospital for an induced labour. I was afraid to leave the house during that time in case someone saw my pregnant belly and gave some gushing congratulatory comment. We hid at home and carried on as best we could.

On the morning of 19 August a bright and bubbly young nurse admitted me to the labour ward as though I were just another expectant mother about to deliver her child. Thankfully the nurses that followed got the memo that this birth would not be normal.

My Obstetrician got the induction process underway quickly. I think contractions started in the early afternoon and late that evening, our son, Franklin Robert Yee, was born.

Straight after Franklin was born I had to be taken for surgery to remove my placenta. Although I had a brief cuddle with my son that night all I really wanted to do was sleep, I was exhausted from the effort and the drugs. I am forever grateful that my husband was able to spend time with our son and take some pictures of him immediately after his birth, whilst I was in surgery.

Franklin was brought back to us the next morning when I was awake – he was cold and his skin was dark and delicate. We spent time looking at him and cuddling him and had some more beautiful photos taken by a volunteer Heartfelt¹ photographer. My family travelled interstate to come and meet him and we wrapped him in a blanket my sister had made for him.

That same day we signed papers for his birth certificate and arranged for the Funeral Directors to come and collect him. They were to take him to another hospital for an autopsy before cremation and returning his ashes to us.

I had been relatively calm and unemotional for most of my time in hospital, focused on the practicalities of giving birth and recovering. But when the Funeral Directors knocked on our door I felt panicked and my heart leapt into my mouth. They came in carrying a baby-sized, box-shaped bag. They opened the bag up for us to put Franklin inside. Putting our son in that bag and saying goodbye to him for the last time was the hardest thing I have ever had to do. It felt so wrong.

We returned home and did our best to adjust to our change in circumstances, drawing on the support of our friends and family, professionals, and new support networks we established for ourselves.

When Franklin's ashes were returned to us I decided I could not let go of him again so he has remained where I think he should be, at home with us, ever since. I eventually returned to work and faced the inevitable hurdle of seeing people again for the first time. I am eternally thankful to those who stepped up or into my life at that time and allowed me to talk about what happened, who acknowledged my son, and who were just there. We were proud to receive Franklin's birth certificate in the mail some weeks later.

Although almost four years have passed since we lost Franklin, the sadness and pain of our experience remains, some days closer to the surface than others. We wonder what life would be like with him here and we love and miss him every day.

¹ <https://www.heartfelt.org.au/>

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3. Response to Terms of Reference

d) Sustainability and propriety of current research funding into stillbirth

With the stillbirth rate remaining constant over the past two decades it is clear that greater research investment is required. It is worth noting that many research projects that have delivered advances in stillbirth research have received significant funding from families and friends of stillborn children, through charitable donations to the Stillbirth Foundation Australia.

Friends and family of stillborn children should not bear the full burden of funding research and support services. I urge the Committee to recommend a greater level of government investment in Stillbirth research in an effort to reduce the stillbirth rate in Australia and minimise the social and economic impacts of this problem (see also g) below).

e) Research and education priorities and coordination

From my perspective there are two important areas of focus for research and education:

- 1) Research to better identify causes and factors contributing to stillbirth, with a view to developing interventions, technologies, and other methodologies to prevent stillbirth; and
- 2) Education to better inform mothers about current known risks, prevention strategies and warning signs.

Research to identify the cause of more stillbirths

I note that I am one of the many, many mothers who does not know the reason why her child has died. I have no idea about the contribution of genetics or environmental factors, if it was something I did or didn't do, or perhaps it was just chance. I know from my own personal experience that pregnancy is an incredibly complicated process and there is a lot we don't know about it. However I am astounded that our knowledge, particularly in relation to stillbirth, does not seem to have developed much over the last 25 years, with the rate of stillbirth remaining fairly consistent over this period².

I imagine I will never know why my son died but I hope that research in coming years will bring answers for a greater number of parents and more importantly, lead to the development of interventions that will save those babies and save those families from the pain of losing a child. Even for those not moved by emotional arguments there are plenty of economic arguments for working to minimise the incidence of stillbirth.

Technology to better identify warning signs

At my 20 week scan during my first pregnancy I advised the Doctor that I had not yet felt any movement. As it turned out, I would never feel my son move.

Through my own reading and research I have come to understand that a baby's movements are such an important indicator to a mother and to a Doctor of the baby's well-being. They are a baby's lifeline. Their only means of talking to their mother.

I have also come to understand that it is important for a mother to understand the patterns of her baby's movement and try to detect any changes in those patterns (e.g. <http://www.kickscout.org.uk/>).

² Perinatal Deaths in Australia 1993-2012, Australia Institute of Health and Welfare, Canberra.

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A year after losing Franklin I became pregnant again with my second child, Lincoln. Given my past experience I was quite anxious during this pregnancy and both my Obstetrician and I were keen for me to start feeling regular movements from Lincoln. Thankfully this time I did feel my son kick and roll and twist and turn. But many times throughout that pregnancy I questioned what I was feeling, whether he had been unusually quiet or inactive or whether his burst of activity was out of character. There were many times when I had been busy with other things and I couldn't remember exactly when his last movements were, or I remembered feeling movement but not really paying attention to what they were like or what time it was. My situation wasn't helped by the fact that I had an anterior placenta, which meant that Lincoln's movements were often subdued due to an extra layer of cushioning between the baby and the outside. I had many, many visits to the hospital for extra monitoring of my baby during my second pregnancy.

You see the problem with the concept of a baby's movements being a lifeline, a baby's only means of communicating to the outside world, is that it puts a huge responsibility on a mother who may or may not, through no fault of her own, have the knowledge, skills, time, ability, experience, or confidence to successfully hear and interpret those messages.

Most of the time it probably works out alright because either a mother reads her baby's messages correctly or because it is a normal, uneventful pregnancy. But what about when it doesn't work out? What about circumstances where a mother needs a little extra help to interpret her baby's messages? What if her child is trying to tell her something but she can't hear it? I still blame myself for not picking up on the messages from Franklin's lack of movement. If only I had queried it further, if only we had checked it out earlier...

Substantial benefits could be realised from the development of technologies that help a mother and doctor listen to and interpret messages from a baby's movements, including reduced incidence of stillbirth and reduced anxiety for parents. Such technologies could be used to provide further information where questions arise regarding a baby's development e.g. if a baby appears smaller than expected or if movement is not yet felt, or where a mother feels she needs additional assistance or assurance as to her baby's health.

In the age of personal 24/7 fitness trackers, heartrate monitors, and sleep sensors it seems an obvious development and I have read about a number of researchers looking to develop such devices. I strongly support these developments and think they would provide a vast improvement on the home Doppler devices many anxious mothers buy online (home dopplers are generally not recommended by Doctors because they can give a false sense of security and are better off interpreted by experienced professionals).

I imagine there are plenty of other technological solutions that could be developed to assist in detecting early warning signs and monitoring, particularly high risk pregnancies, should additional research investment become available.

Education

To my immense relief my second pregnancy progressed to the stage where my husband and I could attend pre-natal classes at the hospital – this felt like a significant milestone for us to reach. Although these classes took us back to the ward where I had given birth to Franklin a year before we were excited to be there and hopeful of a different result this time around.

We were however dismayed by the information provided to this room full of prospective parents. There was no mention of stillbirth or the importance of monitoring movement of the baby and in

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fact the nurse even noted that it is normal for a baby's movement to slow down towards the end of a pregnancy – advice that I knew was outdated and incorrect.

I understand it is challenging to talk to pregnant women about a subject such as this but by withholding information from parents and ignoring what is known we perpetuate the statistics and we do not arm mothers with the knowledge or tools to help keep their baby safe.

f) Communication of stillbirth research

I know from my own experience and from those around me that very little information on stillbirth is provided during pregnancy, including in relation to risk factors and preventative measures. Where information is provided it may be entirely untrue, for example the advice about a baby's movements slowing down provided to mothers during my pre-natal class. Such information presents a direct risk to babies.

As the research progresses it is important that mothers are presented with up-to-date, clear, and consistent messages from all those involved in their care during pregnancy. We know the potential impact a well-coordinated public health campaign can have – look at the 'Back to Sleep' campaign that reduced the incidence of Sudden Infant Death Syndrome by over 80% (<https://www.betterhealth.vic.gov.au/health/healthyliving/sudden-unexpected-death-in-infants-sudi-and-sids>). Healthcare providers, researchers, government and the media each have a role to play in identifying and actively communicating key messages to mothers in a way that is meaningful and accessible to that mother.

g) Quantifying the impact of stillbirths on the Australian economy

On this point I wish to record my support for the study commissioned by the Stillbirth Foundation *The Economic Impact of Stillbirth in Australia*. The findings of this study accord with my own personal experiences.

I further note an obvious point not included in this report – the potential benefit to our population and our society that could be achieved through a reduction in the stillbirth rate. My son, like all babies and children, was full of potential. His whole life lay ahead. But for whatever reason it was cut incredibly short and he never had a chance. I am not sure how this benefit, this potential, can be quantified. But if children are our future, let's invest in them and give them every possible chance of success.