HOUSE OF ASSEMBLY

SELECT COMMITTEE INTO STILLBIRTH IN SOUTH AUSTRALIA

Constitution Room, Old Parliament House

Friday, 27 June 2025 at 9:40am

BY AUTHORITY OF THE HOUSE OF ASSEMBLY

WITNESSES

MEMBERS:

Ms O.M. Savvas MP (Chairperson)
Ms L.P. Hood MP
Ms D.J. Wortley MP

WITNESSES:

FOORD, CLAIRE, Founder, Still Aware

ANTUNES, GEMMA, Chair, Board of Directors, Still Aware

CLARK, TRACEY, Head of Community Engagement and Awareness, Still Aware

SHAHIN, AMIRA, Head of Strategy and Operations, Still Aware

381 The CHAIRPERSON: First of all, I want to thank you for coming in and acknowledge we are here on the lands of the Kaurna people. I pay my respects to elders past and present. I would also like to acknowledge all of the babies loved and lost; that is, of course, the meaning of our committee and the reason that we are here today. I acknowledge the work that you all do in their memory. It means a lot to each and every one of us, and we very much value their memories here in this room.

I know all four of you. My name is Olivia and I am the Chairperson of the committee. Here with us today we have Lucy Hood, the member for Adelaide, and Dana Wortley, the member for Torrens. We have two apologies from David Pisoni and David Basham, who are our other members. We have our parliamentary and research staff here, as well as Hansard recording.

This is a public hearing and will be broadcast to the public online via the parliament's website. A transcript of today's hearing will be published on the committee's website. All persons, including members of the media, are reminded that the same rules applying to the reporting of parliament apply to this hearing.

Information on committee processes and the protections afforded to witnesses has been provided to you. The protection only applies to evidence given at the hearing and published by the committee. You are not protected if you publish your evidence elsewhere or repeat your evidence outside of the hearing.

The committee does prefer to hear evidence in public, but if there is a specific section that you would like to be heard in private please indicate at the beginning of that section of evidence. Unless you have any questions, I ask you all to introduce yourselves. If you would like to make an opening statement, please do so before we move into questions from the committee members. Thank you, ladies.

Ms SHAHIN: Good morning. I am Amira Shahin. I am head of strategy and operations at Still Aware.

Ms FOORD: I am Claire Foord. I am the founder of Still Aware.

Ms CLARK: I am Tracey Clark, head of communications and community.

Ms ANTUNES: I am Gemma Antunes, the chair of the board.

382 The CHAIRPERSON: Thank you. Do we have an opening statement today, ladies?

Ms SHAHIN: Yes. Good morning, my name is Amira Shahin and I am the new head of strategy and operations at Still Aware. Before I start, I do just want to acknowledge the traditional owners of the land that we meet on and pay my respects to the elders past, present and emerging.

This always was, and always will be, Indigenous land. I also want to thank you all for coming—and the audience as well—and thank you, Olivia, especially for spearheading this parliamentary hearing.

I recently joined Still Aware, inspired by its community-led mission and also my experience in the non-profit and business space. I was also driven by personal experience. Before I was born, about 30 years ago, my parents lost a stillbirth baby boy, Ibrahim. They were given a pair of tiny blue socks and a hat, which they have kept decades later. The grief of losing a baby boy is still left in our house. My sisters and I grew up in its shadow, holding the pain of unanswered questions: the whys, the hows, the what-ifs and the silence of what could have been.

I am honoured to be here today with our founder Claire Foord; the board chairperson Gemma Antunes; Tracey Clark, our head of community and awareness; and supported both in the room and via live stream by our clinical and consumer advisory members. Today we are also supported by the broader Still Aware community who stand with us in our mission.

Still Aware is the first and only charity in Australia solely dedicated to stillbirth prevention. We are not here to reinvent the wheel. Some might say that we created the wheel. Still Aware already has the resources, the evidence and the community trust. What we need now is the support to take it one step further. With that, I hand over to Claire Foord who will share more about our legacy and the impact that we have made.

383 The CHAIRPERSON: Thanks, Amira, I will acknowledge Ibrahim for the record today.

Ms FOORD: Thanks, Amira, and thanks, Olivia, Lucy and Dana, for listening to us today and for getting this parliamentary inquiry and having the bravery to do that. It has never been done before in South Australia from a government level and so we are indebted to you for putting it on the record and recording it for *Hansard* and allowing our babies the voice that they deserve, because they never got a chance to speak for themselves.

A bit of background as to why I am sitting here today is probably to understand where Still Aware—

384 The CHAIRPERSON: Take your time, Claire. Can we get you a cup of tea or anything?

Ms FOORD: No, it's fine. It is very surprising actually because—I will just breathe. This is normally not a hard subject for me to talk about, because I have spoken so broadly about it internationally and have forged a new understanding for the way in which we speak about stillbirths. However, I think what I realised today—which is totally uncalled for, I should say—in terms of my own journey, is that for 11 years, since Still Aware's inception, I have done this, spoken up for babies and families and for other expectant parents in the hope that they do not have to experience the grief and loss that myself, my husband and our family did. I did so, I think, almost without allowing myself to feel it. It's unfortunate that that realisation hit today. So on that note, this is difficult.

I do want to say that I sit here not just in honour of my daughter Alfie, but for all of the children who never got a chance to scream, to shout, to grow up as they deserved to. Prior to the birth of my beautiful, perfect little girl Alfie, we didn't talk about stillbirth in pregnancy. We still have a really long way to go.

I think what actually happens nowadays is there are a lot of assumptions, particularly in the clinical setting. People assume that, because I know it, they know it. The time for assumptions is over, and we really need to speak up and allow an opportunity for people to hear the word 'stillbirth' without fear but with empowerment so that we can reduce anxiety, because with more information comes power, and hopefully we can reduce the rates of stillbirth in Australia, particularly in South Australia as it sits today.

You may know my story: I had a blissful pregnancy. My daughter was utterly perfect. There was nothing wrong with her. She had no illness, no abnormality and she should be here walking this earth with her siblings, but instead, when I delivered her and held her lifeless in my arms, I had to give her straight back. I felt like she didn't belong to me. I had to ask to hold her. I had to ask to see her. She wasn't even left in my room.

All the things I had wished and hoped for during pregnancy, up to that 40-week period, that I had dreamed of—three years of trying, IVF, having midwives, having a private obstetrician, going to breastfeeding classes, doing hypnobirthing. I covered every possible base. I read every book, I downloaded apps, I inquired whether there was anything I needed to know.

There was a question I was asked in pregnancy, which was closed, and it was, 'Is your baby moving?' The answer was yes, because she was a mover and a shaker. I got to know her incredibly well. I knew what music she liked and what she didn't like. I was encouraged to not exercise too heavily. I was encouraged to not eat certain foods. I knew about the risks of listeria. I knew how to wrap her safely once she was born. I knew about not having a cot a certain way. I had been given all of these tools about how to breastfeed, how to sleep her once she was here, but nothing was there for her in pregnancy. It was very much around what can you do and your ability to cope.

As a strong woman it was assumed that I knew all of the risks, but I wasn't told about stillbirth. I was asked, 'Is your baby moving?' Yes, yes, yes, was the answer, until the answer was no, and then suddenly they were interested. Suddenly, the fact that her movements had drastically changed over the course of my pregnancy didn't interest them until she was no longer moving, until in the hospital they searched for a heartbeat, until they sent me into a waiting room full of pregnant women to go and have another ultrasound, just to confirm that, no, she didn't have a heartbeat, until they made me lie in a birthing suite next to other woman delivering their babies, until they said, 'I'm sorry, this is so rare.'

Unfortunately, it is not rare. I started counting and figuring out that actually the data is there, the research is there. Why in the world did no-one tell me that the chance of me losing my baby, the chance of me experiencing the loss of my daughter to stillbirth, was one in 135? I went to school with more women than that, so chances are I wasn't the only one in my school who experienced stillbirth. I certainly wasn't the only one at the concert I went to with Alfie in my belly who would have experienced stillbirth, yet nobody told me the word. Even in the hospital they still didn't use the word 'stillbirth'. They just told me I was unlucky. 'Don't worry it won't happen again.' What won't happen again? This was even before I had delivered her.

When I delivered her lifeless body, I felt, I am ashamed to say, repulsed, because I thought that I had killed her because I ate a burger—it sounds silly, right?—that had mayonnaise on it. I thought, in my naivety—because how does stillbirth actually occur? It's medieval. I thought that my action of mistakenly biting into a burger that had mayonnaise on it caused my baby's death, because no-one told me any different. I was totally isolated. She died when she was born. It is the two inevitabilities of life colliding, and it should not happen.

Still Aware was forged because there is great research out there around ways to prevent the loss of a baby. In my case, I had a baby born at 40 weeks with no illness and no abnormality, who did have a change in movements, who was screaming for help in the only way she knew how, which was through her movements, but nobody asked me the right question, nobody told me what to look for and nobody checked whether she was okay. They checked if I was and if I was in danger. If I had stopped breathing, if I had stopped moving, they would have paid more attention to my child; they didn't.

I know I have drastically gone over time, but I do want to say that that is the reason Still Aware exists, not because I actually wanted to start a charity. In fact, if somebody else had already done this we wouldn't be here today, because what we do at Still Aware is life-saving, translating research into easily measurable tools and communication to create awareness in pregnancy, so that women, families and expectant parents can feel empowered, empowered to speak up and to know what to look for so that they can save their baby's life, so they have the best opportunity of taking their baby home, just as they always intended.

We need to take away an assumption that people just know, that everyone knows about stillbirth. In fact, they don't. The chances of listeria are one in over 200,000, and I was scared about taking a bite of a burger—impossible, but that's what I did. The chances of me losing my daughter to stillbirth were one in 135—six babies every day. That is not okay. That is not rare, which is what I was told. I was not unlucky, but I was not cared for appropriately.

I was not given the tools in pregnancy to protect my baby and myself. That needs to change, and that is why Still Aware exists. That is what we have been doing for the last 11 years and what I have just realised today is that it actually takes a lot of strength and it is now time for me to actually work through the trauma, because it is seriously a trauma that you live with. I am proud of my scars now, that the hole I live with is her. I don't have to try to fill it with something else. She is my daughter. She is my firstborn. I am so proud of her and I am proud to be her mother. With that, before I become even more of a blubbering mess—and I do sincerely apologise for not being able to hold it together—

385 The CHAIRPERSON: Never.

Ms FOORD: —I do pass on to Tracey, who probably can speak more to what we have been doing in the realm of our community space. Thank you very much for listening.

386 The CHAIRPERSON: Thank you, Claire. I will, just for the record, acknowledge Alfie. I know when I spoke to my mum about the possibility of doing this inquiry the first thing she said to me was, 'I never thought that my son would get to have a legacy.' I would like to thank you for letting this be Alfie's legacy and for the work that you have done in memory of her. Turning your grief into something so powerful is something that will have an impact, that already has had an impact on so many, so we do want to thank you for that.

Ms FOORD: Thank you, Olivia.

Ms CLARK: Baby Ben's legacy. That is a very hard act to follow, my goodness—sorry.

387 The CHAIRPERSON: Also, we don't apologise in this room. Emotions are what we want. We want real stories. We are so, so pleased to be a safe space for you all to share your stories. Be as emotional as you need to be. We absolutely understand and we value it.

Ms FOORD: Beautiful footage on there for people to watch.

Ms CLARK: I just wish I had gone first. I just wanted to thank you for this opportunity today; it is an absolute honour. For those of you who don't know, I have been with Still Aware for six years but I have known the Foord family for over 20. I am just going to read this out and it is going to seem a little emotionless but I will have a little cry again I am sure.

The model of Still Aware is evidence based, community led and clinically supported, centred around the Still Aware empowered care timeline. This resource empowers parents to have a safe, timely and culturally appropriate conversation about pregnancy and loss. I speak with thousands of parents nationally. Every single month, I leave my own family behind and I educate parents at Pregnancy Babies & Children's Expos. Time and time again, they want to know how to keep their baby safe—and it is simple.

This timeline helps mothers understand their baby's movements, recognise their normal, empower pregnant women and their partners to trust their instincts and advocate for themselves when they feel like something is off. We at Still Aware define clinicians very broadly; it is doctors, midwives, doulas, OBs, partners and any family member who plays a crucial role in every single pregnancy. When everyone is involved, babies are safer.

Still Aware provides practical resources for open, informed conversations about stillbirth without the fear of stigma. Many parents ask me at expos, 'Why haven't we heard this before? Why wasn't this mentioned? I am nine months pregnant. No-one has ever mentioned the word 'stillbirth' to me.' Some people almost see my signage at a PBC Expo and look to get away from me. Obviously, they are the people I hunt down and give a brochure to anyway, because this information is so important.

Why isn't this information discussed at antenatal classes? That must change. We must challenge the outdated notion that stillbirth is a taboo subject. It should be discussed as commonly and confidently as listeria risk in pregnancy. Every single expectant mother, even teenagers who aren't pregnant yet, know to not eat sushi, soft cheese, salad buffets, ham, salami. I have done presentations in high school where you go around the room and you say, 'What can't you

eat in pregnancy?' High school kids know what not to eat in pregnancy. And yet I say, 'Does anyone know anything about stillbirth?' and the room is silent.

The risk of getting listeria in pregnancy is one in 220,000, and everyone knows about it. The risk of delivering a stillborn baby in Australia is one in 135 and no-one discusses stillbirth. With the support of the government and our community, we are hoping to have the ability to distribute more stillbirth prevention kits to all pregnant women and their partners in South Australia, and deliver culturally and linguistically sensitive training across all South Australian pregnancies and care providers.

We are really hoping to translate Still Aware's resources into the top three commonly spoken languages in Australia after English. We are hoping to launch a public awareness campaign statewide, to create dedicated resources for male partners to advocate for themselves and their unborn child, and to introduce perinatal mortality review processes to include the voices of parents, based on a UK model so we know this works. Thank you so much for your time; I have also gone over. I would love to pass you onto our beautiful chair, aunty of precious Alfie and our beautiful work colleague, Gemma Foord.

Ms ANTUNES: Antunes.

Ms CLARK: You will always be Foord to me.

Ms ANTUNES: Both are appropriate. Still Aware has four part-time employees. We have five interns, a dedicated board of directors, a clinical advisory committee, and a consumer advisory committee. We have 20 weekly volunteers and 150 volunteers nationwide. We do a lot with a little. We work with the power of people and the purpose of meaningful conversations. Our mission to end preventable stillbirth through education and awareness is possible if every pregnant woman receives our vital information. Unfortunately, there are a lot of people who are missing out on that information. We are doing what we can. Stillbirth is not rare, but it is often preventable.

We have distributed over a million safe pregnancy kits to families, hospitals, GPs and clinicians. When we refer to a 'clinician', we include everybody—from a doula to a father to an expectant mother, an aunty, a midwife, a doctor—so it is not just through the hospital route that this information needs to be delivered. Everyone has a different pregnancy plan and we want to make sure that everybody receives this information. We deliver clinical training sessions through midwives who are learning their profession. We want to make sure that no midwife in training is missing this information. There is a big gap there, one that we want to fill.

We have very proudly now been extended on a very successful campaign that Professor Jane Warland has led on behalf of Still Aware working with Indigenous communities called WINDS, where we have collaborated with local communities: yarning with them, delivering workshops, delivering information that they vitally need in the way that they would like to receive it. There is still a lot of work to be done there also.

Thank you, Olivia. Thank you to this wonderful, honourable and passionate parliamentary committee. We are honoured to be part of this instrumental moment for South Australia in preventing and reducing stillbirth rates around the country, and we would hope that we can continue to work with you in creating this vital and needed change. Thank you.

388 The CHAIRPERSON: Thanks, Gemma; thank you, ladies. We very much appreciate everything that you have provided to us today but also, of course, everything that you do every day in your mission. It is very much valued by each and every one of us and by a number of the parents who we have heard mention Still Aware throughout our work so far. It is always lovely to hear the work that you are doing in practice.

We will move now to some questions, if you don't mind. First of all, I might just start with a question with respect to your safe pregnancy and safe bubba kits. We have a figure here on the first page of your submission: it says that in 2024 you distributed more than 25,000 safe pregnancy and safe bubba kits directly to expectant families. Can I have a rough indication of the spread of that—so is that nationwide, is it South Australia-specific—and perhaps the ratio of that to expectant parents, if you have a rough figure of how many babies are being born per year?

Ms CLARK: I can answer that; I would love to. I do all the distribution nationally from orders online, but I also hand-deliver to every single expectant parent at Pregnancy Babies and Children's Expos. Depending on the state, I would say a majority of our Safe Pregnancy Kits probably go to New South Wales, and then probably Victoria, Queensland, South Australia, WA and then Tasmania and ACT in there somewhere, and Northern Territory, of course.

New South Wales is always a really big baby expo. They also have three every year. They have three expos in New South Wales, so it is no surprise that we distribute more Safe Pregnancy Kits there. They also have three in Queensland and they have three in Victoria, so they are our top three states, but I go there more often. We actually don't do a baby expo in the Northern Territory. They are looking at doing one there, but Professor Jane Warland does do a lot of WINDS stuff in the Northern Territory and WA, so we do distribute WINDS, the safe bubba brochures and 'your pregnancy' kits nationally all over.

Ms ANTUNES: Tracey, sorry: do you mind just elaborating on how many—that's obviously direct to consumer. Can you give a little bit more information on going to hospitals, clinics, etc.?

Ms CLARK: Yes. Do we have the—

Ms SHAHIN: I have the figures.

Ms CLARK: In 2024, we sent out 58,000 kits—Your Pregnancy and Safe Bubba kits—to hospitals and antenatal clinics across Australia.

Ms SHAHIN: I would just like to mention there were 120,000 kits distributed last year around Australia.

Ms FOORD: To clinics—the figure you are referring to may actually be more related to the Safe Bubba kits. A lot of them were actually hand-delivered either by Professor Warland herself. Even Tracey, whilst on leave, actually went to a community and delivered very vital information that they needed that couldn't be posted. We also get lot of orders directly from clinician-based hospitals. Like Gemma alluded to earlier, we also distribute to other clinician-based areas. So they may not be hospital-heavy, but most of our orders are going out in a large bulk sense to hospitals and clinics, but we also have GP, shared care, allied health and other clinics as well, including that of osteopaths or sonographers, doulas and doctors, but, yes, also places like IVF clinics.

But, really, what is unfortunate is it's totally up to the individual. There is no mandated information anywhere that says, 'Everybody needs this information.' It is totally up to the people who often have attended our clinical training sessions, who then go and deliver that information, or people who have sought us out because we have connected to them in some way.

389 The CHAIRPERSON: I might ask—and perhaps this might be something that, if you have the opportunity, someone could prepare on notice for us—what we would like would be a breakdown in South Australia specifically of where the information is going, but, more importantly, where it is not going. Obviously, I accept that a lot of your model, if it is at a PBC expo, is people choosing to take the information, which again we see an issue with, and the gap that you have just mentioned.

Ms FOORD: Absolutely.

390 The CHAIRPERSON: So we would like an indication of where it is going in South Australia, who is asking for it, who is agreeing to have the information and providing it, and, I guess, for our courses—

Ms FOORD: I can tell you absolutely people who have said no to it, which is incredibly disappointing. Ashford Hospital refuse to have the information, and I am happy to put that on *Hansard*.

391 Ms HOOD: Did they provide a reason?

Ms FOORD: It is purely up to the nursing unit manager, and that is a real problem. If you have a NUM who does not want to deliver the information and they don't think that it is needed—'I don't want to scare people,' or, 'Your information is fear-filled.' However, the information we have and the data we have is actually that it is not fearful, that the person who has the fear associated with giving the information is actually the deliverer of the information, not the receiver, so that is also interesting.

We can give you those statistics as well, because we have actually done, I suppose, training as well as community-led conversations and workshops to find out how best to have this conversation. So that is the other thing. I know Gemma mentioned we work with our consumers as well as our clinicians. Nothing that we deliver is done so without the advice of our consumer advisers and our clinical advisers. Not only do we know that everything that we are giving the information on is accurate and is fact-based and is also crosschecked and referenced for the purpose of doctors and midwives particularly but also it is delivered in a way that is appropriately and carefully constructed and delivered in a way that actually says, 'This is how you have the conversation.'

We have an empowered care timeline that can easily be followed. Our model also has been adopted in other countries, and it is proving to reduce stillbirth in their areas where they have taken it on board. Other hospitals that do take it are the likes of Calvary in North Adelaide. Burnside used to take our information. Again, the nursing unit manager changes, and then it means that the information changes.

As you can see, I think there is a real issue here in terms of mandating information. Without the mandated tool of 'You have to have this conversation in pregnancy', it is totally up to the individual doctor, the individual midwife, the individual pregnancy care provider, but also there is no reason, unless they personally feel like they don't have that fear-induced discussion, that they would give the information out. Again, that misconception that it is rare is really driving that.

392 The CHAIRPERSON: I might just say, further to that, that I don't think it would be inappropriate to say that all of the bereaved parents we have spoken to have said that they wished they were better prepared, and all of the researchers and experts that we have heard from have said that a less anxious mum is an empowered mum. But, again, in the same vein, all of the conversations seem to be that the old-school, perhaps, way of treating an expectant parent would be 'We don't want to scare them into all showing up in the emergency room' type of behaviour.

Ms FOORD: I can answer that very carefully and clearly, knowing that that is actually not what happens. If the information is given based on the Still Aware empowered timeline and empowered care timeline, the way in which they are encouraged to come in and what they need to say, versus 'We're just going to scare women and everyone is going to rock up'—that actually doesn't happen. It is proven not to happen. If you look at the UK-based data that actually has worked, where the conversation is delivered appropriately, carefully and with the right wording, it doesn't actually occur that way.

To be honest, though, if we were going to be talking about—let's take it outside of pregnancy for a minute here. If you were talking about a young boy, let's call him Tom—because we know that in the case of pregnancy you are at higher risk of stillbirth if you have a male pregnancy, and you are at higher risk of stillbirth if you are a first-time mum. What often comes with being a first-time parent is a lot of misinformation but also a lot of information, but also fear anyway, because you don't want to get it wrong. What does reduce anxiety is information. If you talk to any clinical psychologist or psychologist or doctor, you will find that the more information they give to somebody who is anxious, it generally does reduce their anxiety because information breeds knowledge, which then breeds empowerment.

If we go back to Tom, who I am talking about, he is a toddler. Tom is a really active kid, he loves to jump, he loves to climb just like every other little boy. But one day Tom is not reacting in the same way that he normally does. He is really docile on the couch, but I say, 'I'm not going to take him to see the GP because he is still moving, his foot is moving, he's fine.' So I ring the GP and say, 'Tom's usually really active. He is breathing, he is lying on the couch and he is kicking his foot.'

The GP, the doctor, the midwife or whoever is on the phone says, 'That's okay. Bang a drum next to him. Give him a poke. Did he respond?' 'Yes, his leg moved.' 'Great, that's fine, don't worry about it. In fact, how about you try giving him an orange juice. Give him an orange juice, or throw a bucket of water on him.' That is the information we are giving to expectant mums in pregnancy—old-school information. 'Have an orange juice. Maybe the sugar will make the baby move. Poke it. Did it respond?' 'Yes.' 'Then you're fine.'

They are taking any movement as gold. Then what happens? Someone has an at-home doppler. What does a doppler do? A doppler simply reads a heartbeat, and sometimes not even the baby's, it may be the mum's. 'Okay, but does Tom have a heartbeat?' 'Yes, but he is still not moving.' 'It's fine, just bang a drum, give him a poke, throw some water on him, and if he is still reacting just leave him there until he's not moving. Once he has completely passed out, and he is no longer responsive—in fact, let's wait until he's not breathing and has no heartbeat, and then bring him in.'

Can you imagine the uproar that would happen in South Australia, in Australia, globally, in response to that if that is how we dealt with children? We don't, because that is neglect. That is not okay, but for some reason, that is what's happening in pregnancy. So for fear of wanting somebody to not bother us or come in, because their baby might be moving a little, the fact is if a mum says, 'I am concerned, something doesn't feel right,' even if their baby is moving, we have a duty of care to make sure that baby is okay, not just that they have a heartbeat; not just that they are responding to movement, but that everything is okay.

There are also studies around a mum being concerned: if a mum is concerned, the doctor should be concerned, the midwife should be concerned in pregnancy. You would never leave Tom on the couch to wait until he passed out, wasn't breathing, didn't have a heartbeat, before you took him in. You would be absolutely out of your mind, and you would race him straight to the hospital or call an ambulance, and we don't dispute that.

393 The CHAIRPERSON: Can I ask you a question further to that. Accepting that a clinician mentioning stillbirth is dependent on the day and dependent on the clinician, which I have my thoughts on, do you have an idea of what standardised information is given about foetal movements and also about safe sleeping for mum whilst pregnant?

Ms FOORD: There is none. To me, that would sit in the same space as stillbirth. In the same way that we need to have a conversation, it is a bit like—let's use another example of something we do very, very well, which is I would say a bit fear-inducing, which is about wearing your seatbelt. In South Australia, we have those signs that say: 'Drink drive—you're a bloody idiot'—sorry, Hansard. There's a sign on the way home to where I live in the McLaren Vale region, which actually has a corpse with a toe tag on it. I would say that's pretty scary for a kid to look at: 'What's that, mum?' 'Oh, that's okay. That's just a dead man on a screen because he decided not to wear his seatbelt.' So is that fear-inducing? I would say a little bit.

The *Grim Reaper* ads—they were fear-inducing. There is an element of shock that has to happen to make people listen. We are not proposing that that is what we do in the space of stillbirth, but what I am saying is that when you have a conversation around wearing a seatbelt, you don't just say, 'Hey, wear a seatbelt because I told you to,' you say, 'Wear a seatbelt because it helps to prevent a fatal accident and it might just save your life.' The 'why' is really important.

If a doctor, midwife, doula, antenatal carer, masseuse, mother, father, grandparent, child, is saying, 'Hey, is your baby moving?' the question should not be, 'Is your baby moving?' it should be, 'How is your baby moving? Have you noticed a pattern in their movement? Has that pattern remained the same? Great—because the reason I am asking you this is if that pattern changes, that could be a sign that your baby may be in distress. I am not saying this to worry you; in fact, you don't need to be worried. Just get to know that little bump inside you. However, if something doesn't feel right, or your baby's pattern of movement has changed, it's really important that you tell me because I care about you, I care about your baby, and I want to keep your baby safe and help prevent the possibility of stillbirth happening to you. I want to help save your baby's life, stop your baby from being stillborn. This is a possible sign that a baby is in distress.'

You need the 'why' as well as the 'how', in the same way that when we say, 'Settle to sleep on your side,' we don't just say, 'Oh, by the way, sleep on your side,' or 'By the way, don't put soft pillows around a crib.' 'Why?' 'I'm not going to tell you; it's too scary. I don't want to tell you that SIDS is a thing.' 'I don't want to tell you that you might have a car accident, but just wear your seatbelt because I said so.' It doesn't work.

Ms ANTUNES: Sleeping on your side, I believe, is a piece of information that has been—

Ms FOORD: It's not mandated.

Ms ANTUNES: It's not mandated.

Ms FOORD: No, nothing is mandated around these things. There is information, there are best practice guidelines. But guidelines are just that: guidelines. Still Aware has been calling for mandated guidelines around pregnancy, particularly relating to foetal movements and discussion of stillbirth, and you have to say that it is a discussion of stillbirth. That has to be mandated, because if you don't write that, they will just talk about the foetal movements and not tell you why. Without the 'why', the 'how' is irrelevant.

394 The CHAIRPERSON: I might just ask quickly: Lucy and Dana, do you have questions on this topic before I move to the review topic? Yes. Ms Hood.

395 Ms HOOD: For context, I am wearing a Fletch t-shirt today. Fletch was the son of Sarah and Mike and he was born still. We are raising funds at the moment.

Ms FOORD: I love that. Are those t-shirts for sale?

396 Ms HOOD: They are, yes. I think they're doing a last round.

Ms FOORD: I would love to buy one. That's awesome.

397 Ms HOOD: Just for context.

398 The CHAIRPERSON: That was Fletch, for the record, today as well.

399 Ms HOOD: I find quite fascinating the conversation around mandating. As an example and as a comparison, I am also a marriage celebrant and I am actually mandated to legally provide a couple with a flyer about marriage counselling and having conversations around a successful marriage. I am actually mandated to do that so it is often quite strange to think that there hasn't been that kind of conversation around mandating that information.

Having had two babies myself, I know that I wasn't provided with that information. Have there ever been conversations around where that information could easily be slotted in to information already being provided to women, for example, the orange book—

Ms FOORD: Absolutely.

400 Ms HOOD: —that we receive when we first go through prenatal care?

Ms FOORD: With regard to the Women's and Children's Hospital, for example, years ago we talked about—in fact, the nursing unit manager and also the midwives were very keen to have it put into the book. However, it was rejected. Why? Because you have to have everybody on the panel agree and there was one person on the panel who didn't agree. I think it would stem back to that old-school mentality of, 'Oh, we don't need it. Everyone knows.'

Ms ANTUNES: 'We don't want a paranoid mother.'

Ms FOORD: That assumption that everybody already knows about it. Yes, we did talk about putting it in the orange booklet. It is really important. If you look at, say, the people who do use it properly, we have an empowered care timeline that has been created alongside this information. When Still Aware does our clinician training, we start off by saying, 'When do you talk about stillbirth?' The majority of people in the room when we start the training will say, 'Never.'

'When do you talk about foetal movements?' Some people say, 'Oh, sometimes.' 'When do you talk about not smoking?' 'All the time.' When do you talk about not drinking?' 'All the

time.' 'When do you talk about listeria?' 'All the time.' We ask them when they actually have that conversation in pregnancy. On the care pathway or the empowered care timeline, we actually have the main areas of when an antenatal visit will occur.

There is a continuity of care issue, and the continuity of care issue that we face is that, in the public system, you are not always seeing the same midwife or care provider, or even the same obstetrician. Sometimes even in private practice you will see a co-obstetrician when you are actually delivering the baby. I have people who say, 'I always give your information out after somebody experiences loss,' and I am like, 'Well, that's too late. Thanks for that, but it's too late.' How offensive to say, 'Hey, I could have prepared you for this,' because that is the other thing: support happens prior to the effect. Support for after care can happen before.

In answer to your question, there is never a time that is too early. There is always a time that is too late, and that is after the fact of stillbirth occurring. We have advice based on how to have the conversation at the first appointment, the 20-week appointment, even the 12-week check-up and scan. We have information around the conversation that needs to happen at that third trimester visit or even every subsequent visit.

Our advice is there is never a time that it shouldn't be discussed, that it must be questioned. Because there are questions around, 'Is your baby moving?' that most doctors, midwives and care providers do ask, particularly in that third trimester, but it's the way in which they ask the question. I was invited to speak to doctors and midwives, but predominantly doctors, at the RANZCOG conference.

I stood up in front of this audience of let's say 300-plus obstetricians and I said, 'Who here asks, "Is your baby moving?" in pregnancy?' to which most of the people put their hand up, and they were so proud of themselves. I said, 'Great. Who asks a question that isn't a yes or no answer? Because the answer to that is yes or no.' They had this sudden realisation that they had been missing the information. They had been missing the opportunity; they had just been ticking a box.

You can't just say, 'Here's a brochure; it goes inside the orange booklet,' without the discussion that goes with it. We actually know from research—and there is data out there that says giving a brochure doesn't work, and I have to be very honest about that—that the problem sometimes with research is that they don't actually mind what the outcome is, because it's just: get an outcome, whether it's good or bad.

The problem that happened with that particular case is that there was no discussion around the way in which the pamphlet or the tool was given to people. In some cases it was just popped in an orange book, for example, and in some cases it was just available on the table and at other times it was just passed—but unless the conversation went with it, it didn't actually make a change. But for the hospitals where the conversation occurred around why it was important and what they needed to do, they saw a massive reduction in stillbirth in those clinical settings. So the conversation has to go with the care provision of information.

I do urge the government to talk to our medical professionals and to our Minister for Health and request that there be a further conversation that needs to happen around mandated care, particularly. We could trial it here in South Australia—we don't have to make it a competition but, gee, they are very competitive in the medical field—within the public system and with the private system and urge them to practise or trial a mandated pregnancy care plan, one that we already know works, and give it a shot and let's see what happens. I actually encourage you to trial that over a three to five-year period, and you will be very surprised that, if they do follow a not-tickbox process, you will see a reduction in stillbirths in South Australia.

401 The CHAIRPERSON: Thank you, Claire. Do you have a question, Ms Wortley?

402 Ms WORTLEY: Yes, I have. Can I first of all just say thank you to everyone at the table here and to the people in the gallery there who are making the time to come today. This is a really important issue and we know that; that is why we are all here. Claire, thank you for establishing Still Aware in Alfie's honour. I think that there is a long way to go still.

Something that I am interested in is that we have stillbirth and we have avoidable stillbirth. You were saying, Tracey, about when you were at expos and how some people detour. I am wondering how you advertise avoidable stillbirth. We are talking about empowering people, and when you empower someone it means that they can play a role in ensuring that something happens or doesn't happen, and I want to know a little bit about that.

Ms CLARK: Absolutely. Generally, the people who say, 'Oh my goodness, I'm so worried about this happening to me,' are the people I really love talking to. At the last expo, literally on the weekend just gone, I had a mum and a daughter come up to me, and the mum said, 'Please don't mention stillbirth,' and the daughter said, 'No, I want the information. Tell me what I can do.' I empowered her with the tools that our empower timeline says to do: monitor movements, get to know your baby in pregnancy, sleep on your side from 28 weeks, and advocate for yourself. At the end of it they both hugged me and said, 'This is amazing. I actually feel like I'm going to be okay because I've stopped and asked the right questions.'

We know that this information works. I have been at an expo where a mother has come up to me and said, 'Tracey, oh my God, I am so pleased to see you here. I just want to introduce you to my baby, Oliver. You are the only reason he is here with us today.' I got goosebumps and I gave her a big hug and I looked at this perfect little baby, and she said, 'I knew something was wrong, but as a first-time mum we get told to stay home as long as we can. Don't come in. Don't come in, you're hours away from labour. Babe, have a sugary drink and a lie-down; that will get baby moving.' All these things we know are myths: have a cold drink—by the time it gets past here it's not cold; and by the time the sugar gets through to the placenta it's not sugar.

Ms FOORD: It shouldn't get through to the placenta, by the way, if the placenta is doing its job. If the baby jumps around, isn't that a sign that something might actually be wrong with the placenta? Is it functioning properly? The myths are really outdated.

Ms CLARK: That's right. So she went to bed, and she said, 'All I could hear'—she had been to the expo a couple of weeks before—'was your voice saying, "If you're worried, go in and get checked."' So she woke her husband and said, 'I haven't felt baby move much today. I have been putting it out of my head but now all I can hear is that girl at the expo.' He said, 'I'm sure it's fine'—as we all get told—'I'm sure it's fine, go back to bed. I'm sure it's fine.' She said, 'No, babe, I'm really worried,' so he said, 'I'm sure it's fine but we will ring the obstetrician.' They rang the obstetrician, who obviously was amazing and said, 'If you are worried, I'm worried. I'll meet you in hospital.'

They went into hospital. The blood pressure of the baby was up and they could see the baby was in distress. Her blood pressure was through the roof. They did an emergency caesarean, and the umbilical cord was wrapped around his neck three times. At her post appointment, he said, 'I'm not saying you would have given birth to a stillborn baby, but I am saying you most likely would have—the severity with which that was tied around the baby's neck, I genuinely think he was hours from death. So well done on advocating for yourself.'

It really gives me a pep in my step, because at every single expo I try to get that empowered care timeline into every bag I can. Often I just pop it in their bag and say, 'Read it later and get back to me if you have any questions. Keeping baby safe, keeping baby safe.'

Ms FOORD: In answer to your question, Dana, I think that is the way in which we can empower care. There are multiple different slogans, I suppose, that we have tested with our consumer advisers and our clinicians. One of them is 'Keeping your baby safe in pregnancy'.

In one of the talks we run often at expos and things—there might be 100 people in the room or there might be a thousand or there might be five; it doesn't really matter how many people you are speaking to—we have a conversation about getting to know your baby in pregnancy. In that time, we have the conversation and we end with the 'why' it is important.

It is really interesting how many people go, 'Wow, that's really helpful. I now have the tools I need to help keep my baby safe, to give me the best chance of helping my baby be born well and alive and knowing what I need to do to advocate for myself. I am not a bother. I am not wasting anybody's time. My child is important, I am important and it's important that I stand up for my baby in pregnancy, just as I would post delivery.'

403 Ms WORTLEY: I have one follow-up question; I know we are running out of time here and we have other people to see, too. In relation to one in 135, has there been any research done as to how many of those losses are avoidable?

Ms FOORD: I think the other thing that we need to talk about, and what Tracey alluded to there, is we don't report on near misses. One of the things that Tracey mentioned, about having the parent voice included in the perinatal review committee, is incredibly important. Not necessarily from a Still Aware perspective but personally, I have said that we need to be reporting numbers of stillbirths. It shouldn't be shameful; it is not about shaming people but actually saying that we are checking whether it is working better in the public system or the private system and recording who, what, how and when—and also those near misses.

It is really hard; sometimes they do get re-categorised. That would be a question for the perinatal mortality review committee, which I know can give you that information. The unfortunately retired but very educated Professor Gustaaf Dekker would be a very good person to discuss this with, if you are open to that.

Ms ANTUNES: Professor Jane Warland unfortunately couldn't be here today, but she also may have some extra information around those specific numbers. She is the chair of our clinical advisory committee.

404 The CHAIRPERSON: I believe the figure that Jane presented is 20 per cent being avoidable; I believe that is the figure that she has used in most of her research.

Ms FOORD: In terms of what they say in terms of what can be preventable stillbirth, it is actually 50 per cent; that is what they are reporting on. What they are saying with this information, based on the research that is international, is that hospitals have shown a 20 per cent reduction. If we are using Scotland for an example, which might be what she is referring to particularly in that case, they saw a 20 per cent reduction in stillbirth based on mandating and discussion.

405 The CHAIRPERSON: Jane will correct me if I am wrong; that was just off the top of my head.

Ms FOORD: No, but that is absolutely accurate. Look at Professor Vicki Flenady's work from years and years ago around monitoring fetal movements and talk to Jane, who has done some amazing research through her Stellar Research program. But in terms of South Australian statistics, Professor Gus Dekker can give you the right contact for the perinatal review committee and how they actually either recategorise or categorise stillbirth here in South Australia.

406 The CHAIRPERSON: We have only got time for one more question. I am going to turn quickly to the perinatal autopsy question. We have heard from a number of bereaved parents that they didn't even know a review was occurring. Can you give us a top-line summary of what the benefit is of having a parent involved in that process, whether that be from a medical perspective or from an emotional and a grief perspective?

Ms FOORD: From my perspective, as a mother of a stillborn daughter, I would have loved to have been given the opportunity to speak up for myself and my daughter. You are sent home without a child. Your milk comes in, despite the fact they give you a pill that says it won't. It's horrific.

The people who have the best information on the impact of stillbirth are the parents themselves and I commend you for how you are doing this, in terms of hearing from and actively and properly engaging with the community, because too many people don't. That is why the perinatal mortality review does require a parent voice. Not everybody will want to speak up, but to be given the option of an exit interview to say, 'Is there anything that you feel?' 'How did we do?' 'Give us your feedback.' 'How was the food?' 'You liked the sandwich.' When you are delivering, or have delivered a stillborn baby, you are tarnished with this, 'There's something wrong with you.'

In hospital, even though they hadn't told me I was going to have a stillborn baby, they put me in a wheelchair all of a sudden and started wheeling me around like there was something wrong with me. I was like, 'I don’t understand why I'm in a wheelchair?' 'Oh, well, you're not going to cope now.' You are suddenly this weak little person and they talked about me in the third person.

Things like, 'She'll need this' and 'She'll need that' and 'She won't cope with this' and 'She won't cope with that.' I never had a choice. I never got an opportunity to speak up.

The shock and the horror was what drove everything. The pain I felt was not physical pain, but just the pain of an absolute broken heart. There were things I did not get offered personally in the hospital that are available freely to people, that everybody deserves the right to have. They didn't get offered to me and don't get offered to so many parents who have experienced stillbirth. It is totally up to that individual to get that support post loss.

The discussion with parents around their experience—everybody's experience is unique, because everybody is unique. Just as every pregnancy is unique, every delivery is unique. The trauma—not only the birth trauma, but also the same things can still occur after you deliver a baby who is stillborn: you can bleed out, you can haemorrhage, you still have this urge, you still feel phantom movements, but you are totally alone.

Having an opportunity to be included with a perinatal mortality review, would allow parents a chance to feel heard and would give them a sliver of being able to parent that baby they never got to take home.

Ms CLARK: The reason that our community really empower us to do what we do is because they want to be heard. While we have got a consumer advisory committee helping us, guiding us, educate us—and look, I am not a bereaved parent, but they help Still Aware guide our way. Their voice and the babies' voices are just so incredibly important.

407 The CHAIRPERSON: We continually hear about what it does for a grieving parent to allow them parenthood and that is something that has come through as really significant for all the parents we have spoken to.

We are going to have to close up there. We will give you a copy of the transcript for your review and we will also get you a copy perhaps of some specific questions with respect to the dissemination of material in South Australia. We will send an email with that information. Thank you all for coming and thank you for sharing with us. It has been such a privilege to have you here.

Ms FOORD: We will make sure we give you some additional notes from today, so there could be some other data there. I would also like to submit within that something else for you to potentially review, which is further information around what we have done and my personal story which I chose not to submit. It's an audio file, which is totally fine to share if you see fit.

408 The CHAIRPERSON: I ask that someone note additional information from Still Aware.

Moved by Ms Wortley.

Carried.

THE WITNESSES WITHDREW