

Chapter 7

Stillbirth education

7.1 The committee received evidence from many parents and family members who described the devastating emotional impact of being told that their baby would be stillborn.

7.2 The pain and grief may last a lifetime, compounded by inadequate information about the risks, the personal and financial implications, and the social stigma that continues to keep the tragedy of stillbirth in the shadows.¹

7.3 This chapter discusses the need for better stillbirth education of families, clinicians and other health professionals, hospitals, workplaces and the community generally.

A hidden tragedy

7.4 Mr Gavin Youngman, Director, Stillbirth Foundation Australia, described the contrast between public perceptions of pregnancy and the reality of those who experience stillbirth.

...it's not discussed, so I don't understand how we think we can go from having that lack of conversation even in those intimate circles to all of a sudden—when you're told, you feel completely alone.²

7.5 Several witnesses described how societal attitudes to death underpin the silence and stigma surrounding stillbirth:

We're not very good at talking about deaths in general in Australia and so the taboo around speaking about the death of a baby is a whole other element. Babies dying is somehow treated differently in all of our society including that coroners don't get to look in on that because they're not really seen as real people yet.³

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- 1 Jessica Longbottom, 'Decades after stillbirths, long-grieving parents find answers in mass graves', *ABC News*, 7 October 2018, <http://www.abc.net.au/news/2018-10-07/parents-stillborns-mass-graves-melbourne/10344252> (accessed 16 October 2018); V Flenady, AM Wojcieszek, P Middleton, et al, 'Stillbirths: Recall to Action in High-Income Countries', *The Lancet*, vol. 387, no. 10019, 13 February 2016, p. 691, [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(15\)01020-X/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(15)01020-X/fulltext) (accessed 12 November 2018).
 - 2 Mr Gavin Youngman, Director, Stillbirth Foundation Australia, *Committee Hansard*, 8 August 2018, p. 16.
 - 3 Mrs Jaime Yallup Farrant, *Committee Hansard*, 10 August 2018, p. 7.

Our society finds it very difficult to talk about death and finds it very difficult to talk about intense emotion, and the death of a little baby or a child is such a painful and confronting area for people.⁴

...

When I've spoken to friends of ours who are obstetricians and I've asked, 'Are you using the Still Aware stuff?' they have said, 'Well, you know, it doesn't happen that often.' That's not the answer we want to hear. How we get past that, how we deal with bereavement, how we deal with grief, how we deal with asking for help and how we deal with taking help on board is a stigma in Australia, and I think we need to look beyond it.⁵

7.6 One witness described how her stillbirth was met with silence and 'hushed condolences'.

Instead of feeling included, I felt a strong sense of being kept in the dark at arm's length. How can I trust a patriarchal healthcare system with a future pregnancy when it appears to prioritise silence over transparent communication?⁶

7.7 Ms Natasha Donnelly, a bereaved parent, researcher and advocate, argued that the 'paternalistic approach' to antenatal care contributes to a lack of awareness of stillbirth amongst women, and to feelings of shame and guilt amongst those who experience it. She urged clinicians and health professionals to be more open about stillbirth, citing the example of airline safety briefings that are presented to passengers on every flight, even though the risk of a crash occurring is extremely low.

Most passengers don't run off the plane screaming in fear that because it was discussed, it's going to happen. But we assume that women will do that if stillbirth is discussed. We desperately need a public awareness campaign and improvements to antenatal education to address this.⁷

7.8 One submitter expressed the importance of sharing the stories of families who have experienced stillbirth.

Learning how to be a mother to a child who never got to live is a horrible path to walk, but our children being acknowledged, and us being heard in the hope to help to make a change in their name and potentially save other babies and break the silence surrounding stillbirth is a small...piece of comfort.⁸

7.9 Dr Michael Gannon drew attention to the irony that women in developing countries with no organised maternity care are far more aware of the risk that they or their baby could die, whereas Australians tend to take their maternity care system for

4 Ms Deborah De Wilde, Volunteer, Stillbirth Foundation Australia, *Committee Hansard*, 8 August 2018, p. 15.

5 Mrs Rachele Martin, *Committee Hansard*, 10 August 2018, p. 9.

6 Mrs Clare Rannard, *Committee Hansard*, 8 August 2018, p. 3.

7 Ms Natasha Donnelly, *Committee Hansard*, 8 August 2018, p. 2.

8 Ms Zoe Marshall, *Submission 109*, [p. 8].

granted so that stillbirth or neonatal death is 'at least out of sight and potentially out of mind'.⁹

Public awareness campaigns

7.10 Public awareness campaigns such as Red Nose Day have been highly successful in raising public awareness, helping to reduce Sudden Infant Death Syndrome (SIDS) deaths by 85 per cent in Australia.¹⁰ However, even though stillbirth is statistically more common than SIDS, it is rarely discussed in public contexts.

7.11 Associate Professor Camille Raynes-Greenow, a public health specialist at the University of Sydney, cautioned that, whilst there is merit in a public awareness campaign, the emphasis should be on reducing the risk and not just providing information. She added that such a campaign should be evidence-based, inclusive, tailored to suit specific settings, and aimed at women who are likely to be at the greatest risk of stillbirth.¹¹

7.12 Nevertheless, as one bereaved parent noted, there is a widely-held perception that stillbirth only occurs in high-risk pregnancies, indicating that stillbirth education should be aimed at all women, regardless of risk.

Our naive understanding of stillbirth was that it was something that only happened in high-risk pregnancies, and that these families knew that there was a risk for their baby. We had researched many aspects of pregnancy and birth, but we had not researched stillbirth because we believed it was not a risk for us. As we have now learnt, many normal, healthy pregnancies like ours also end in stillbirth.¹²

7.13 Contrary to popular thinking, greater awareness is likely to reduce the incidence of stillbirth rather than create undue stress.

There is a feeling of not wanting to cause alarm or 'scare monger' women who are doing everything they can to bring a healthy child into the world. There is a feeling of not wanting to put too much responsibility on mothers since many cases are unavoidable. There is a fear of causing too much anxiety. My response to this is the example of SIDS. A terrifying thought for any new parent, however we are educated thoroughly and properly on the risk factors (from waiting room posters, to Parent Ed classes to midwife visits). The education on SIDS has not caused mass hysteria or anxiety, it has reduced rates.¹³

9 Dr Michael Gannon, *Committee Hansard*, 10 August 2018, p. 41.

10 Red Nose, *Submission 63*, p. 3.

11 Associate Professor Camille Raynes-Greenow, School of Public Health, University of Sydney, *Committee Hansard*, 8 August 2018, pp. 53–54.

12 Britt Jacobsen and Samuel Haldane, *Submission 82*, [p. 2].

13 Caroline Campbell and Kirk von Mollendorf, *Submission 80*, [p. 2].

7.14 Several witnesses and submitters called for a government-funded public campaign aimed at pregnant women so that they can be better educated about the risk of stillbirth and techniques for identifying and monitoring potential issues. Suggestions included:

- advice that pregnant women know their baby's movements, sleep on their side, trust their instincts and expect to be listened to when they have concerns;
- the distribution of pamphlets about stillbirth at antenatal appointments and classes such as the information provided by the organisation Still Aware, using clear, non-technical language in information and guidelines and avoiding medical terms such as 'fetal demise' and acronyms that most people will not understand; and
- information about mobile apps that enable pregnant mothers to monitor their babies' movements similar to the Australian government's 'Quit for You—Quit for Two' App released in 2013.¹⁴

7.15 Still Aware highlighted the importance of using clear terminology and language in educational materials, rather than acronyms and technical language which serve to perpetuate the lack of awareness and discussion about stillbirth.¹⁵

7.16 Mr Terry Slevin, Chief Executive Officer of the Public Health Association of Australia, drew on his extensive experience to outline the elements of conducting an effective national public health campaign but noted that, whilst Australia is internationally recognised for its public health campaigns, the financial investment in these programs is generally inadequate to meet the costs.¹⁶

7.17 Mr Slevin advised that such a campaign should be not only properly researched and implemented, but also appropriately funded over the longer term, in order to have a societal impact:

...if you think about any of those campaigns, whether in the skin cancer area, with Slip! Slop! Slap! or in HIV and the famous Grim Reaper campaign, those got attention to the issue; but there's been an awful lot of hard graft that's followed those things, and it's the hard graft that makes the difference.¹⁷

14 See for example, Ms Nerida Box, *Submission 105*, [p. 1]; Rebecca and Paul Dixon, *Submission 74*, [p. 2]; Name withheld, *Submission 252*, [p. 3]; Name withheld, *Submission 140*, [p. 1]; Meg and Shane Keating, *Submission 249*, [p. 2]; Mrs Rhonda Jeavons, *Submission 106*, [pp. 1–2]; Ms Kirsten Willis, *Submission 251*, [p. 2]; Ms Rebecca Barclay, *Submission 86*, [p. 2]; Ms Alex Lowes, *Submission 78*, [p. 1]; Ms Sarah Matheson, *Submission 237*, [p. 4]; Ms Caitlin Cvitkovic, *Submission 97*, [p. 2]; Mrs Claire Foord, Chief Executive Officer and Founder, Still Aware, *Committee Hansard*, 8 August 2018, p. 42; Mrs Bree Amer Wilkes, *Submission 22*, [p. 2].

15 Mrs Foord, Still Aware, *Committee Hansard*, 8 August 2018, p. 42.

16 Mr Terry Slevin, Chief Executive Officer, Public Health Association of Australia (PHAA), *Committee Hansard*, 7 September 2018, p. 46.

17 Mr Slevin, PHAA, *Committee Hansard*, 7 September 2018, p. 50.

7.18 Mr Slevin stressed that a public awareness campaign focusing on stillbirth is more likely to be effective if it not only identifies the problem but also offers the solution. It should also be delivered through different channels so that it will target particular audiences.

When it comes to issues of stillbirth, it is a really powerful and highly emotive issue. I think that with the right demographic it has the impact of having an emotional, and therefore likely, behavioural response that makes people more prepared to take up the practical advice you provide as to how they tackle obesity, or smoking cessation, or alcohol consumption or whatever it might be. So the issue gets embedded into the call for influencing people's behaviour in a healthy way.¹⁸

Education for families

7.19 Recent Australian and international research has shown that many stillbirths are preventable and that the number of deaths can be reduced through greater awareness and improved quality of care.¹⁹

7.20 Antenatal education is provided in a variety of ways and by a range of organisations and individuals, often on a fee-paying basis, and there is currently no standardised curriculum or content guidelines meaning that such education is generally not accessible to those without the means to pay.

7.21 Ms Victoria Bowring, Chief Executive Officer, Stillbirth Foundation Australia, described how the silence surrounding stillbirth during pregnancy poses challenges for educating families.

I would say it's probably the biggest hurdle that we face at the moment in regard to the issue. In the time that I've been with the Stillbirth Foundation, the very first thing that nine out of 10 families that come to us ask is, 'Why wasn't I ever told this was a possibility?' As was referred to before, we are told not to eat soft cheese and all of these different things, yet the issues arising from those particular behaviours are far less common than stillbirth. One in every 135 pregnancies in Australia will end in stillbirth. It's not spoken about. For nine out of 10 families to not even know that that is a possibility is astounding.²⁰

7.22 Ms Bowring estimated that the rate of stillbirth in Australia could be reduced by one-third if two of the biggest risk factors were common knowledge amongst pregnant women, clinicians and other health professionals.

Research indicates that, if two of the stillbirth risk factors that we are currently aware of—decreased fetal movement and maternal sleep position—were common knowledge among the pregnant population and health clinicians there is potential to reduce the number of stillbirths by up

18 Mr Slevin, PHAA, *Committee Hansard*, 7 September 2018, p. 50.

19 Centre of Research Excellence in Stillbirth (Stillbirth CRE), *Submission 56*, p. 4.

20 Ms Victoria Bowring, Chief Executive Officer, Stillbirth Foundation Australia, *Committee Hansard*, 8 August 2018, p. 13.

to 30 per cent...The sleep position, particularly, which we're working on at the moment through a public health campaign, has the potential to reduce that risk by up to 10 per cent, and just in Australia alone that's 200 babies a year.²¹

7.23 Dr Gannon, who reflected on his extensive experience in the area of stillbirth prevention, noted that he tended to avoid directly mentioning stillbirth to his patients, unless the discussion was 'remote from the delivery date'.

I will usually talk to them at 36 weeks about the increased frequency of visits, about the importance of reporting decreased fetal movements and the reasons why I will want them to give permission for them to be scheduled for induction of labour not long after 40 completed weeks or sometimes before 40 weeks. I will refer in bleak terms to it being safer for the baby. So even someone like myself who understands the issue and possibly should call [it] out is reluctant to use the word. There remains a taboo about it.²²

7.24 Similarly Professor Steve Robson, President, Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG), found it difficult to discuss the issue of stillbirth with his patients.

There's an increasing recognition that perhaps people have been afraid to tell pregnant people certain things, and stillbirth would be key among them. Even I don't like directly bringing it up. If I'm seeing somebody and we're talking about things and they talk about movements or I do a scan, it's very difficult to say, 'I'm worried that your baby will die.' I often will phrase it: 'I'm anxious here. I would do something. I wouldn't want something to go wrong.' It's very difficult to say that.²³

7.25 Recent international research has shown the value of preconception care in improving pregnancy outcomes. Professor Craig Pennell, Senior Researcher, Hunter Medical Research Institute (HMRI) noted that the outcomes of a pregnancy are often good if conditions associated with adverse outcomes, such as low folate, Zinc, vitamin D and iron, are addressed before pregnancy. In the Hunter region, for example, the HMRI team meets each week with every family who has experienced a preterm birth or a stillbirth, and offers them an evaluation and assistance with planning for the future.

Also there is an offer available for preconception care for anyone who wants to have it in pregnancy through the referral system through GPs. That partly encourages GPs to do it, because they can do a lot of it, but for people with more complex issues they need to be referred in.²⁴

21 Ms Bowring, Stillbirth Foundation Australia, *Committee Hansard*, 8 August 2018, p. 12.

22 Dr Gannon, *Committee Hansard*, 10 August 2018, p. 41.

23 Professor Steve Robson, President, Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG), *Committee Hansard*, 9 August 2018, pp. 41–42.

24 Professor Craig Pennell, Senior Researcher, Hunter Medical Research Institute (HMRI), *Committee Hansard*, 8 August 2018, p. 21.

7.26 Professor Robson also observed that every hospital has a different antenatal education program, and those that do operate do not necessarily provide for culturally and linguistically diverse families.²⁵

International models

7.27 Several witnesses and submitters drew attention to the success of the Scottish education program, Maternity Care Quality Improvement Collaborative, which has created a 'cultural change' in Scotland's medical system around the issue of stillbirth.²⁶ Scotland had one of the highest rates of stillbirth in Europe. In 2011 the Scottish government invested \$7.1 million over four years to implement a package that has seen a 22 per cent reduction in stillbirths in a population of 60 000 births.²⁷

7.28 Ms Danielle Pollock, Stillbirth Researcher and Bereaved Parent representative, Global Stillbirth Advocacy Network, summarised the reason for its success:

It actually seems so simple when you break it down. It was just educating pregnant women. It was not being afraid to mention the word 'stillbirth'. They got rid of the anxiety myth, which has absolutely no evidence for it.²⁸

7.29 The initiative was based on the successful program implemented in the Netherlands in 2001, which resulted in a 55 per cent reduction in stillbirths over 14 years. It is based on the concept that, whilst the risks of stillbirth are well known, 70 per cent of mothers of stillborn babies have no significant medical condition. The stillbirth prevention package includes five elements:

- a tailored patient education campaign with clear messaging that stillbirth can happen to anyone and some are preventable;
- implementation of a new package to reduce smoking in pregnancy across all maternity units in Scotland;
- raise awareness for reduced fetal movement;
- risk assessment and fetal surveillance for fetal growth restriction (FGR); and
- implementing a new Perinatal Mortality Review Tool.²⁹

7.30 Red Nose noted that it has been offered the new Perinatal Mortality Review Tool, developed for the Scottish Program and recently adopted by the United

25 Professor Robson, RANZCOG, *Committee Hansard*, 9 August 2018, p. 41.

26 Mrs Yallup Farrant, *Committee Hansard*, 10 August 2018, p. 7; Red Nose, *Submission 63*, p. 4; Ms Danielle Pollock, Stillbirth Researcher and Bereaved Parent representative, Global Stillbirth Advocacy Network (GSAN), *Committee Hansard*, 8 August 2018, pp. 63–64.

27 Red Nose, *Submission 63*, p. 1.

28 Ms Danielle Pollock, GSAN, *Committee Hansard*, 8 August 2018, pp. 63–64.

29 Red Nose, *Submission 63*, p. 4.

Kingdom (UK), for evaluation in a clinical setting as part of the Red Nose Stillbirth Prevention Program.³⁰

7.31 Red Nose estimated that the cost of rolling out the Scottish package in Australia would cost \$37 million over four years (\$9.3 million annually), resulting in 1218 fewer stillbirths during implementation, and 500 babies' lives saved per year thereafter.³¹

Education for clinicians and other health professionals

7.32 Ms Donnelly noted that clinicians are required to stay up-to-date on a wide range of issues, and may have limited time to discuss research on stillbirth with pregnant women during their appointments.³² However, while FGR is widely understood to be a major risk factor for stillbirth, there is still a need for clinicians to educate women in this area.

Most pregnant women can recite the foods they should avoid during pregnancy and that they should avoid alcohol but most women have no idea that their baby's movements shouldn't slow down at the end of pregnancy or that they should avoid sleeping on their back. Most women have no idea that their baby is far more likely to be stillborn than to die of SIDS, but most know to sleep their baby on their backs with no head covering or toys in the bed.³³

Antenatal monitoring

7.33 Several witnesses drew attention to the need for better education and training of sonographers to enable them to identify potential health issues during routine scans in pregnancy. Some reported discrepancies in the way that test results were reported by sonographers and clinicians.³⁴

7.34 Mrs Doshni Stewart, for example, received conflicting information about her baby's measurements from the sonographer and the obstetrician. She also noted that medical staff involved in her care seemed unaware of research from other countries that revealed how people from certain ethnic backgrounds had a shorter gestation period, even though the information was readily available on the internet.³⁵

7.35 Mrs Tiffany McIntosh experienced severe itchiness at 32 weeks, and was told that it was hormonal. After losing her baby, she discovered an online fact sheet about cholestasis of pregnancy identifying what action should have been taken. However,

30 Red Nose, *Submission 63*, p. 10.

31 Red Nose, *Submission 63*, p. 7.

32 Ms Donnelly, *Committee Hansard*, 8 August 2018, p. 6.

33 Ms Natasha Donnelly, *Submission 116*, p. 5.

34 See for example, Ms Jasmine Prowse, *Submission 256*, p. 4; Mrs Doshni Stewart, *Committee Hansard*, 9 August 2018, p. 11; Mrs Tiffany McIntosh, *Committee Hansard*, 9 August 2018, p. 12; Mrs Lyndy Bowden, Caretaker Chief Executive Officer, Sands Australia, *Committee Hansard*, 9 August 2018, p. 6.

35 Mrs Stewart, *Committee Hansard*, 9 August 2018, p. 11.

she claimed that the clinicians involved in her care were unaware of the diagnostic tests that were required at the time.

No medical professionals around me spoke about the fact that your baby could die before it's born. And even in the birthing class I attended they tell you to look out for symptoms like swelling, high blood pressure, reduced movement—nothing about itching, but furthermore, nothing about the fact that some of these symptoms can lead to stillbirth. So I think we still have a lot of people who haven't started a family yet that are simply unaware that that could happen to them, and when they're told about these symptoms in pregnancy have no idea of exactly what the adverse outcome can be.³⁶

7.36 One witness suggested that this problem could be addressed by establishing an online stillbirth research and education 'clearinghouse', bringing together domestic and international research in an accessible way for clinicians, health professionals and the general public.³⁷

7.37 The National Health and Medical Research Council (NHMRC) noted that the Centre of Research Excellence in Stillbirth (Stillbirth CRE) has been developing a Fetal Growth Restriction Program, a clinical face-to-face training program for health professionals designed to improve detection and management of women at risk.³⁸

7.38 The HMRI noted that Professor Craig Pennell is currently developing a pre-conception program in Newcastle for every pregnant woman, or a woman planning to have a baby. The program aims to reduce child mortality by improving the health of women before and during pregnancy.³⁹

Bereavement care

7.39 Witnesses who had experienced the trauma of stillbirth described responses from clinicians and other health professionals ranging from empathetic to unhelpful, and highlighted the need for better education about stillbirth amongst those who care for the bereaved parents and their families.⁴⁰

7.40 Ms Deborah De Wilde, Volunteer, Stillbirth Foundation Australia, stated that there are significant issues around the care of bereaved parents that need to be addressed, including the bedside manner and language used by clinicians and other health professionals at a time when bereaved parents are in a state of profound shock and disbelief.

We need to throw a ring of care and support around these people. We need to provide them with service providers who have a high level of communication. We need them to feel that we can give them, as we should, all the time in the world. We need to have people raise those important

36 Mrs McIntosh, *Committee Hansard*, 9 August 2018, p. 12.

37 Name withheld, *Submission 145*, pp. 3–4.

38 National Health and Medical Research Council (NHMRC), *Submission 27*, p. 3.

39 HMRI, *Submission 36*, [p. 7].

40 Ms Michelle Cullen, *Submission 111*, p. 5.

issues about seeing their baby, spending time with the baby, what delivering a baby who has died before it's birth might be like, how that little baby is going to feel in your arm, a parameter for how long you might be with your baby and who else might be invited into what, for me, becomes a sacred site.⁴¹

7.41 One witness noted an obvious lack of empathy and knowledge of basic administrative processes relating to stillbirth amongst some of the medical staff she encountered, both in hospital and at home following the stillbirth.⁴² Another highlighted the long-term impact of stillbirth when appropriate counselling is not provided:

In 14 hours from learning our baby was dead, we were never offered counselling. The midwife tried her best taking ink prints of Nina's hands and feet. She took photographs the best she could. But we needed more and should have been provided with much more. A grief counsellor should have supported us throughout those 14 hours. The guilt I carry with me for not picking her up could have been eased with a grief counsellor.⁴³

7.42 The review undertaken into the unusually high number of perinatal deaths at the Bacchus Marsh Hospital in 2013–14 found that death may have been preventable in seven of the 11 cases. The Wallace Report found that the workforce was inadequately skilled, and recommendations included improved staff education.⁴⁴

7.43 One witness, whose daughter was stillborn during a homebirth, expressed concern that homebirth midwives downplay the risks of stillbirth, and that parents do not have sufficient information about the stillbirth risks associated with homebirth.

Homebirth midwives need to be under stricter onus to correctly communicate the risks of stillbirth to their clients, as well as the limitations of their practice in the home. It is an absolute must, to counter-act the incredible amount of misinformation that is propagated by homebirth advocates.⁴⁵

7.44 Stillbirth CRE noted the need for more resources to support clinicians and other health professionals in caring for bereaved parents:

Providing care after stillbirth is a challenging area of practice for many health care professionals. Education, training, resources and support are critical enablers and organisational support and financial commitment are both required to create the conditions and structures for the implementation,

41 Ms De Wilde, Stillbirth Foundation Australia, *Committee Hansard*, 8 August 2018, p. 15.

42 Ms Marshall, *Submission 109*, [p. 7].

43 Ms Terri Ryan, *Submission 124*, [p. 2].

44 Maurice Blackburn Lawyers, *Submission 69*, p. 7. The report was prepared by Professor Euan Wallace, Carl Wood Professor and Head, Department of Obstetrics and Gynaecology, Monash University.

45 Ms Willis, *Submission 251*, [p. 1].

monitoring and evaluation of best practice care. Training for clinicians in the care of women and families after stillbirth is urgently needed.⁴⁶

7.45 Stillbirth CRE drew attention to the Improving Perinatal Mortality Review and Outcomes Via Education (IMPROVE) program developed by the Perinatal Society of Australia and New Zealand Stillbirth and Neonatal Death Alliance (PSANZ-SANDA) to provide clinicians and health professionals with appropriate training in managing a stillbirth or neonatal death including investigations, counselling for autopsy, and examining the baby.⁴⁷

7.46 Professor Vicki Flenady, Director of Stillbirth CRE, noted that the IMPROVE program has been well received by clinicians and midwives. The training comprises a half-day workshop conducted in hospitals, community centres or conference venues, and includes all aspects of care, including how to have a conversation about stillbirth. However, she noted that there is no funding provided for this training, and that the educators involved often provide it in their own time.

The only state that's actually putting in money for hospitals to avail themselves of this course is Queensland at the moment. We've had recurrent funding in Queensland for a few years to offset the cost for clinicians to attend. It's quite an expensive workshop, really, for hospitals with limited resources, but that's something we really need upscaled.⁴⁸

7.47 Dr Glenn Gardener, Director of Maternal Fetal Medicine, Mater Health endorsed the IMPROVE program, noting that it has been successful in increasing confidence and knowledge of participants and is being made available internationally.⁴⁹ Dr Adrienne Gordon, Neonatal and Perinatal Medicine Specialist, Royal Australasian College of Physicians (RACP) proposed that the program could be expanded to provide practical guidance on communicating with bereaved families.⁵⁰

Clinical practice guidelines

7.48 The committee noted that there are currently multiple guidelines to guide clinical practice in relation to pregnancy, stillbirth and neonatal death. None of these guidelines are mandated, so their application is ad hoc and there is little information

46 Stillbirth CRE, *Submission 56*, p. 12.

47 Stillbirth CRE, *Submission 56*, p. 7. IMPROVE was developed to provide training for clinicians and health professionals in using the *Clinical Practice Guideline for Care around Stillbirth and Neonatal Death*.

48 Professor Vicki Flenady, Director, Stillbirth CRE, *Committee Hansard*, 6 September 2018, pp. 16–17.

49 Dr Glenn Gardener, Director of Maternal Fetal Medicine, Mater Health, *Committee Hansard*, 6 September 2018, p. 27.

50 Dr Adrienne Gordon, Neonatal and Perinatal Medicine Specialist, Royal Australasian College of Physicians (RACP), *Committee Hansard*, 8 August 2018, p. 49; see also Perinatal Society of Australia and New Zealand Stillbirth and Neonatal Death Alliance (PSANZ-SANDA), *IMPROVE*, <https://sanda.psanz.com.au/improve/> (accessed 9 October 2018).

on how to implement them.⁵¹ As one witness observed: 'some do it extremely well; others don't'.⁵²

7.49 As noted in Chapter 4, PSANZ-SANDA updated its *Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death* in March 2018. It aims to:

...ensure best practice across Australia and New Zealand around the time of a perinatal death to improve maternity and newborn care for bereaved parents and families and to improve the quality of data on causes of stillbirth and neonatal deaths through appropriate investigation, audit and classification.⁵³

7.50 The PSANZ Guideline provides information for effective monitoring to reduce perinatal deaths; increased understanding of causes to further reduce perinatal deaths; better care and outcomes in future pregnancies; and improved psychosocial outcome for parents and families. There are also specific guidelines relating to aspects of antenatal care, including decreased fetal movement.

7.51 Professor David Ellwood, Co-Director of the Stillbirth CRE noted that, whilst there is 'a plethora of guidelines about everything', there are no nationally consistent guidelines.⁵⁴

Guidelines for antenatal care

7.52 In 2005 the Department of Health developed *Clinical Practice Guidelines: Pregnancy Care*, a series of national evidence-based antenatal care guidelines as one of four projects approved by the Australian Health Ministers Conference and Community and Disability Services Ministers Conference. The guidelines, updated in 2018, cover a range of topics including stillbirth, and are intended to assist health professionals who provide antenatal care to healthy pregnant women.⁵⁵

7.53 Professor Susan Walker, Head, Department of Obstetrics and Gynaecology and Chair, Women's and Newborn Health Network, Melbourne Academic Centre for Health, The University of Melbourne, reported on the success of live-streaming education events to 200 rural and remote sites to enable maternity care providers to be kept informed and connected with current practices and knowledge in relation to stillbirth risk and prevention.

51 Dr Warland, *Committee Hansard*, 8 August 2018, p. 41.

52 Ms Bowring, Stillbirth Foundation Australia, *Committee Hansard*, 8 August 2018, p. 12; also see Mrs Foord, Still Aware, *Committee Hansard*, 8 August 2018, p. 41.

53 PSANZ-SANDA, *Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death*, <https://sanda.psanz.com.au/clinical-practice/clinical-guidelines/> (accessed 14 November 2018).

54 Professor David Ellwood, Co-Director, Stillbirth CRE, *Committee Hansard*, 6 September 2018, p. 12.

55 NHMRC, *Clinical Practice Guidelines: Pregnancy Care*, 2018 Edition, updated 12 February 2018, <https://www.clinicalguidelines.gov.au/portal/2589/clinical-practice-guidelines-pregnancy-care-2018-edition> (accessed 17 October 2018).

They are the ones delivering prepregnancy care and, indeed, they're delivering much of the first half of antenatal care, as many of our public hospitals do not book patients until perhaps 16 to 18 weeks.⁵⁶

7.54 Some state jurisdictions have also produced clinical guidelines. Queensland Health, for example, has a guideline for 'Stillbirth care' as part of its *Maternity and Neonatal Clinical Guidelines*.⁵⁷

Guidelines for bereavement care

7.55 Stillbirth CRE noted that *Respectful and Supportive Perinatal Bereavement Care Guidelines* form part of the larger *Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death*, and are designed to improve the quality of bereavement care for parents who experience stillbirth or neonatal death.⁵⁸

7.56 Stillbirth CRE also drew attention to the 'Sands Australian Principles of Bereavement Care', and recommended that all major maternity hospitals should establish specialist bereavement care, with outreach services to smaller and regional/rural hospitals.⁵⁹

Support for health professionals

7.57 Several witnesses and submitters discussed the emotional impact that a stillbirth can have on the clinicians and other health professionals involved, noting that there is a need for strategies to care for health professionals and, where necessary, to guide them in handling their grief in the presence of the bereaved families.⁶⁰

7.58 Professor Pennell noted that staff might take leave, or occasionally even leave the profession, after having been involved in an unexpected stillbirth, and reflected on how he had developed his own ways of dealing with the situation.

If I feel like crying, I cry. I have no shame about giving the husbands hugs, sitting there holding their hand while their wife's pushing out their dead baby. But the implications are huge, and to do it repeatedly and see it repeatedly and not to see it change is frustrating, and it drives me into doing what we're doing.⁶¹

56 Professor Susan Walker, Head, Department of Obstetrics and Gynaecology and Chair, Women's and Newborn Health Network, Melbourne Academic Centre for Health, The University of Melbourne, *Committee Hansard*, 9 August 2018, p. 26. Also see Department of Obstetrics and Gynaecology, The University of Melbourne, *Submission 45*, p. 15.

57 'Stillbirth care', *Maternity and Neonatal Clinical Guidelines*, Queensland Health, March 2018, <https://www.health.qld.gov.au/qcg/publications#neonatal> (accessed 18 October 2018).

58 Stillbirth CRE, *Submission 56.1*, [p. 1].

59 Stillbirth CRE, *Submission 56*, pp. 2 and 12.

60 Mr Timothy Smith, Delegate, Public Service Association of New South Wales (PSA NSW), Community and Public Sector Union New South Wales (CPSU NSW), *Committee Hansard*, 8 August 2018, p. 61; Ms Marshall, *Submission 109*, pp. 2–3.

61 Professor Pennell, HMRI, *Committee Hansard*, 8 August 2018, p. 26.

7.59 Professor Caroline Homer, Distinguished Professor of Midwifery at the Centre for Midwifery, Child and Family Health, University of Technology Sydney, noted the stresses for those who care for a woman giving birth to a stillborn baby, and recommended education programs that help to build resilience in those involved.

One obstetrician told me about scars on his soul. He says, 'Every time something goes wrong, there's like a little scar on my soul. But I have to pick myself up and do it again tomorrow.' But how many scars can you do over time and still provide exemplary care? So I don't think we look after people well enough.⁶²

...

I know that as a midwife, standing outside a door going into a room where there is a woman who is going to give birth to a stillborn baby, you have to take a big breath and think, 'I've got to get this right.' That's quite stressful. You can't rewind it, really. So I think there is silence in the community and also in the professions, and we need to talk about it more, both at an undergraduate level and at the clinical coalface.⁶³

Autopsies and other port-mortem investigations

7.60 For bereaved parents, making a decision about whether to allow an autopsy following stillbirth is a harrowing and unexpected experience. A number of submissions pointed to the difficulties that face parents, families and healthcare providers in approaching the subject of autopsy.⁶⁴

Bereaved parents

7.61 Whilst information brochures are available that may help bereaved families decide whether or not to consent to an autopsy, many families will fear making such a decision or are unwilling to proceed with an autopsy for religious, cultural or other reasons. In one instance, the bereaved parents decided against an autopsy of their baby daughter because they were told it would 'rip her little body apart and probably never find out why'.⁶⁵ In some cases, a baby may need to be transferred to another hospital for the autopsy to be conducted, adding to the stress of the bereaved parents.⁶⁶

7.62 The bereaved parents may also be confronted with the cost of an autopsy or other post-mortem investigation costs associated with the autopsy process, including transporting the baby to the autopsy, travel and accommodation for the parents, and the cost of the autopsy itself (see Chapter 3 for further discussion of the financial

62 Professor Caroline Homer, Distinguished Professor of Midwifery, Centre for Midwifery, Child and Family Health, University of Technology Sydney (UTS), *Committee Hansard*, 8 August 2018, p. 35.

63 Professor Homer, UTS, *Committee Hansard*, 8 August 2018, p. 38.

64 Ms Britt Jacobsen, *Committee Hansard*, 8 August 2018, p. 4; Ms Donnelly, *Committee Hansard*, 8 August 2018, p. 2.

65 Ms Terri Ryan, *Submission 124*, [p. 2].

66 Ms Christine Prosser, *Submission 6*, p. 2.

implications of stillbirth for families). Stillbirth CRE recommended that all parents should have access to a high-quality autopsy service without charge.⁶⁷

7.63 The autopsy process itself can also add to the uncertainty and stress of bereaved parents, particularly where parents are given incomplete information.⁶⁸

Our experience with the autopsy process was also a nightmare. We continually had to chase up the progress and status of the results. Eventually a meeting was scheduled with one of the doctors at the hospital we delivered Evelyn (we had not had any interaction or involvement with this particular doctor until the meeting). The meeting was brief and brutal. The doctor basically said that there was no clear cause of death and then went on to say, “better luck next time”. I was an emotional mess—it was such a cold, quick and heartless delivery of results and I was left full of questions and fears for the future...A few weeks later we were left even more confused when we received a call from ANOTHER hospital to say our autopsy results were ready and they would like to schedule a meeting. Apparently the first meeting we had attended, and the results delivered were based on an incomplete report.⁶⁹

...

We had to go back to the hospital when the autopsy results were completed. It was horrible to sit there with my husband and the ob and a nurse while they talked to us about it. To be honest I wasn't expecting any answers. I think the results took about 7 weeks. I had googled hydrops a lot and there were a lot of causes. I was expecting them to say that it was my fault and I could have done something better. That was how I felt. I felt like it was my fault for whatever reason there was, it didn't matter what had happened but it was my fault. They told us that they found a valve in the heart that hadn't developed properly so the blood wasn't going back through, it was pooling in his heart. This is what caused the hydrops and that i[s] why he died. As much as I try, I can't remember the medical term, I think one day I will ask for records so I can find out what it was called. I did call the hospital to ask but it was really hard to get the information released so I gave up.⁷⁰

7.64 Professor Walker noted that the discussion with parents should not just be about the surgical procedure involved, but it should also convey the importance of obtaining as much information as possible about why the baby died.

I often ask those families, 'Can I spend a little bit of time to try to ascertain what I can about why your baby might have died?' If we had a minimum dataset that recorded biometry, amniotic fluid volume, whether there was any evidence of fetal hydrops—that is, excess fluid accumulation within the baby's body—if there were calcifications noted in the liver or the brain,

67 Stillbirth CRE, *Submission 56*, p. 3.

68 See for example, Ms Donnelly, *Submission 116*, pp. 1–2; Ms Julieanne Carmichael, *Submission 123*, [p. 1].

69 Samantha and Aaron Isfahani, *Submission 121*, p. 3.

70 Name withheld, *Submission 129*, [p. 4].

then these are things whereby, if a family does not have autopsy, at least we might have some signal of why the baby died.⁷¹

7.65 Nevertheless, even an autopsy may never provide an answer for bereaved families, as one witness explained:

Ultimately, it showed that they found nothing, which to me seemed unfathomable. I had given birth to a four-kilogram baby. He looked absolutely perfect. It seemed insane that nobody could tell me, after everything I'd been through—that this had all happened for no apparent reason. In the months that followed after that I think we tried to contact a pathologist to give us some sort of explanation as to what had gone wrong. At the end of the day they couldn't really find anything.⁷²

7.66 These issues highlight the need for bereaved families to be better informed about autopsies, and to be given the opportunity to meet the pathologist performing the autopsy. Nevertheless, parents should also have other options available to them.⁷³

Discussing autopsy after stillbirth

7.67 Educating clinicians and other health professionals about how to have a conversation about a stillbirth autopsy may help bereaved parents to make an informed decision.

7.68 Mr Brad Farrant highlighted the need for clinicians to be better trained to discuss the importance of an autopsy with bereaved parents. He reported that he and his wife were cared for by 'well trained and understanding midwives' who gave them time with their baby and information about the autopsy and review process.⁷⁴ Nevertheless, the cause of the stillbirth could not be determined, highlighting the need for more research. As Mrs Jaime Yallup Farrant observed:

...it's almost like there's an acceptance and a total toleration that this just happens sometimes. People even said that to us: 'It just happens sometimes, and we don't know why'—as if that's okay. And yet in our society we would never accept that for AIDS, for example, or for cancer. If people were dying of cancer and, as clinicians, politicians and a community, we just went, 'You know, it just kind of happens sometimes; sorry and all,' there'd be an uproar. I think that's part of what really needs to shift in this conversation: the toleration that it just happens. Life happens, yes. Death happens, yes. But lots of these cases are actually preventable if we do the work.⁷⁵

7.69 However, the trauma of an unexpected stillbirth may make it especially difficult for a clinician to discuss the issue of autopsy with the bereaved parents.

71 Professor Walker, The University of Melbourne, *Committee Hansard*, 9 August 2018, p. 28.

72 Mrs Martin, *Committee Hansard*, 10 August 2018, p. 7.

73 Professor Walker, The University of Melbourne, *Committee Hansard*, 9 August 2018, p. 28.

74 Mr Brad Farrant, *Committee Hansard*, 10 August 2018, p. 8.

75 Mrs Yallup Farrant, *Committee Hansard*, 10 August 2018, p. 8.

Deciding whether to undertake an autopsy is a harrowing decision for any parent to make at the time of their child's birth, and not something that any of us expected to be doing. So this decision is not made lightly, and it is made in the hope that answers can be found for the child's death, and in the hope that others may also benefit from information identified. It is therefore a travesty when this information is not used as part of perinatal mortality audit, and lessons are not being learnt about how maternity care can be improved to prevent stillbirth.⁷⁶

7.70 Even in cases where the bereaved parents consent to an autopsy, the decision may still be fraught with uncertainty or the results may leave parents with more questions than answers. This situation demonstrates the need for more research into unexplained stillbirths.

I cannot explain why she is dead and I have no way to prevent this from happening again in any future pregnancies. I don't know if anything more than the autopsy and placenta analysis could have been done to try and identify the causes of Hannah's death. I wish that more were done to find out about the causes of stillbirth, about understanding why it happens and about finding ways to prevent this happening to other families. It is inconceivable that for the last two decades there has been no improvement in the rate of stillborn babies, and that in more than 40% of cases the cause of death is unknown. I am not aware of anything I could have done to prevent Hannah's death. I would have done anything in my power to prevent my daughter's death. Had there been more research and investigation into stillbirths, she might still be alive today.⁷⁷

...

We owed it to ourselves, because we would have to live with not knowing, if we didn't pursue that, whether there was perhaps something genetic or something that could affect our future children. We felt not that we didn't have a choice, but that from a medical sense that was something important we needed to pursue. I know that we were very lucky that we did get an answer, but we had a six-week wait to receive that answer. I really struggled with that wait. I'm thinking medically: 'Oh my God; is it this? Is it that?' It was building my anxiety, because I just wanted to know why this had happened. It's also very difficult, when you put your child in their coffin, and you go to re-dress them, to see that they had been cut. Obviously that is done with the utmost respect, but it's very difficult to see your child like that, and I can understand that many parents just can't do it. But, in moving forward, we need to talk to parents about how important it is to do these post-mortems and to do more research. That way we can figure out why this is happening. There are so many people that just don't get an answer. There have to be answers out there; we just don't know what they are yet.⁷⁸

76 Ms Donnelly, *Committee Hansard*, 8 August 2018, pp. 2–3.

77 Name withheld, *Submission 12*, [p. 2].

78 Mrs Shannon Cook, *Committee Hansard*, 10 August 2018, pp. 7–8.

7.71 Bereaved parents need to be confident that the information gathered in an autopsy will be available to stillbirth researchers so that, ultimately, the results might help prevent future stillbirths.

[Had I] had more time to take every ounce of my experience into consideration, and to understand the real value in proceeding with an autopsy, my decision would have been different...it is absolutely necessary and paramount that medical professionals engaged in this type of scenario are equipped enough to navigate parents and families to really raise awareness as to why conducting autopsies and examinations is so important.⁷⁹

7.72 One witness expressed concern that bereaved parents were not asked for information about their own observations and experiences in the lead up to the stillbirth, noting that such information may help to inform the results of the investigation. In her own situation, Ms Britt Jacobsen and her partner had consented to an autopsy because they not only wanted answers but also hoped that the information yielded might help other families.⁸⁰

7.73 Professor Euan Wallace, Carl Wood Professor and Head, Department of Obstetrics and Gynaecology, Monash University noted that, following the inquiry into perinatal deaths at Bacchus Marsh, Victoria had established a dedicated perinatal autopsy service. However, he also noted that there are a limited number of sites where such autopsies are undertaken, meaning that a stillborn baby may have to be taken to another hospital for autopsy before being returned to the bereaved parents, adding to the trauma and cost for parents.⁸¹

7.74 Dr Gordon pointed out that a perinatal autopsy service in Victoria included a skilled coordinator as the first point of contact for a bereaved family in the hospital, and offered a useful model for how an autopsy might be discussed with bereaved families in a culturally and linguistically sensitive manner.⁸²

7.75 Still Aware, Australia's only not-for-profit organisation dedicated to raising awareness of stillbirth, provides information for clinicians and parents about stillbirth both online and at public events, promoting open dialogue about the realities of loss 'in order to break the silence and taboo surrounding stillbirth' and empowering parents to be actively involved in monitoring their pregnancy. Contrary to being confronted by autopsy information, Still Aware found that women and their partners were generally grateful to receive it.⁸³

They know that they will get a full report. They know will go through what happened. If we have done any sort of clinical investigations or root cause

79 Ms Michelle Cullen, *Submission 111*, p. 4.

80 Ms Jacobsen, *Committee Hansard*, 8 August 2018, p. 9.

81 Professor Euan Wallace, Monash University, *Committee Hansard*, 9 August 2018, p. 28.

82 Dr Gordon, RACP, *Committee Hansard*, 8 August 2018, p. 48.

83 Still Aware website, <http://stillaware.org/about-us/> (accessed 27 September 2018); Mrs Foord, Still Aware, *Committee Hansard*, 8 August 2018, p. 40.

analyses they know they'll get feedback from those. Our hope is that in the future we'll also be able to engage families in the review of their baby's death, as well as be feeding back the information about the review. That's one of the things that have happened in the UK. The Each Baby Counts program has very much tried to involve parents in the death review process—not just giving them the results in a coordinated fashion, but getting their story to add to the events that surrounded the baby's death. If that happens, that would be amazing.⁸⁴

7.76 Professor Flenady noted that the IMPROVE program includes a 'whole station...about how to have that conversation and the importance of the autopsy examination', although the lack of funding for the program has restricted its application.⁸⁵

7.77 Dr Gordon stated that there are other options available to clinicians and parents, apart from full autopsies. These include minimally invasive autopsies, a post-mortem MRI scan, an external examination by a skilled perinatal pathologist, in addition to a placental examination which is considered vital for every stillbirth.⁸⁶

7.78 Where an autopsy is not conducted, placental investigation can still yield important information about the stillbirth. As Dr Diane Payton, Chair, Paediatric Advisory Committee, Royal College of Pathologists of Australasia stated:

A detailed knowledge of placental pathology is also required, as the placenta is vital for the wellbeing of the infant during intrauterine life and placental pathology is being increasingly correlated with intrauterine deaths.⁸⁷

7.79 Associate Professor Kerry Ireland-Jenkin, Head of Unit, Victorian Perinatal Autopsy Service (VPAS) described the placenta as the 'black box flight recorder' of pregnancy. She argued that a placental examination should be undertaken in all perinatal autopsies following stillbirth, and noted that VPAS had recently conducted a course to update pathologists and pathology registrars from Australia and New Zealand on the guidelines for placental pathology.⁸⁸

84 Dr Gordon, RACP, *Committee Hansard*, 8 August 2018, p. 47.

85 Professor Flenady, Stillbirth CRE, *Committee Hansard*, 6 September 2018, p. 19.

86 Dr Gordon, RACP, *Committee Hansard*, 8 August 2018, p. 48.

87 Dr Diane Payton, Chair, Paediatric Advisory Committee, Royal College of Pathologists of Australasia, *Committee Hansard*, 6 September 2018, p. 38.

88 Associate Professor Kerry Ireland-Jenkin, Head of Unit, Victorian Perinatal Autopsy Service (VPAS), *Committee Hansard*, 7 September 2018, pp. 16–17.

Protocols for stillborn babies held in hospital morgues

7.80 The committee heard disturbing evidence about six stillborn babies of Aboriginal descent who had remained in the morgue at the Katherine Hospital, Northern Territory, for a number of years.⁸⁹

7.81 Ms Sara Potter, Clinical Nursing Midwife, Maternity Ward, Katherine Hospital, noted that the mothers may be transient or live hundreds of kilometres from the health service, and the difficulty for hospital staff in knowing how to manage these circumstances, even when the families were able to be contacted.⁹⁰

7.82 Ms Potter highlighted the lack of resources available for locating and working with bereaved Aboriginal and Torres Strait Islander parents, and noted that there may also be financial issues for the parents themselves. Until recently there was only one funeral service provider in the Katherine area, and they charged \$4000 for a service.⁹¹

7.83 However, the Stillborn Baby Payment was inadequate to cover the high cost of a funeral service in Katherine, and there were no other funeral services operating in the town at that time.⁹²

7.84 Ms Belinda Jennings, Senior Midwifery Advisor, Policy and Practice, Katherine Hospital, reported that a baby might remain in the morgue for several months while culturally appropriate arrangements are made for a funeral service. She described how a model of 'satellite care' can be used in cases of perinatal loss, where a midwife will arrange for care of the family to be transferred to a primary health care provider, although she acknowledged that this is difficult where the parents live in remote communities.⁹³

7.85 State and territory policies relating to babies held in morgues vary across jurisdictions. In the Australian Capital Territory and Queensland, for example, there is no legislation governing storage time for bodies held in a hospital morgue, although in the ACT a social worker is required to follow up with families if no communication has been received concerning the release of a body after three business days from the date of admission.⁹⁴ There is no time limit for holding a body in Tasmanian or South

89 Ms Sara Potter, Clinical Nursing Midwife, Maternity Ward, Katherine Hospital, *Committee Hansard*, 5 September 2018, p. 10.

90 Ms Potter, Katherine Hospital, *Committee Hansard*, 5 September 2018, p. 10.

91 Ms Potter, Katherine Hospital, *Committee Hansard*, 5 September 2018, p. 10. See Chapter 3 for further discussion of costs associated with bereavement services.

92 Ms Potter, Katherine Hospital, *Committee Hansard*, 5 September 2018, p. 10.

93 Ms Belinda Jennings, Senior Midwifery Advisor, Policy and Practice, Katherine Hospital, *Committee Hansard*, 5 September 2018, pp. 13–14.

94 Australian Capital Territory government, answers to written questions on notice, 24 September 2018 (received 22 October 2018); Queensland government, answers to written questions on notice, 21 September 2018 (received 19 November 2018).

Australian morgues, although provision is made in Tasmania for a basic funeral service under the Unclaimed Deceased Person Policy.⁹⁵

Culturally appropriate education

7.86 Inclusive, culturally appropriate education is important, particularly for families from culturally and linguistically diverse backgrounds including migrants and refugees. The NHMRC has stated that:

All Australians have the right to access health care that meets their needs. In our culturally and linguistically diverse society, this right can only be upheld if cultural issues are core business at every level of the health system-systemic, organisational, professional and individual.⁹⁶

7.87 Drawing on his experience as a member of the Western Australian (WA) Perinatal and Infant Mortality Committee, Dr Gannon noted that there was a need to address the particular circumstances of the diverse groups affected by stillbirth, and argued that the current PSANZ guidelines are inadequate and should be reviewed in the light of recent research into perinatal mortality.

Gaps do exist between women having their babies in rural areas and metropolitan areas. Gaps exist between Aboriginal and Torres Strait Islander women and non-Indigenous women. Gaps exist between culturally and linguistically diverse women and non-CALD women. And there are very real gaps between public and private hospitals. The greatest opportunity would be to construct a prospective study of women who have suffered a stillbirth and measure the perinatal maternal and psychological outcomes in their subsequent pregnancy.⁹⁷

7.88 The Multicultural Centre for Women's Health recommended that educational materials on stillbirth be delivered to migrant and refugee women via:

- bilingual peer support and education initiatives, particularly for newly-arrived women;
- culturally appropriate multilingual resources and education materials developed in consultation with communities and migrant women who have experienced stillbirth; and

95 Tasmanian government, answers to written questions on notice, 24 September 2018 (received 9 October 2018); South Australian government, answers to written questions on notice, 24 September 2018 (received 19 October 2018). See also Northern Territory government, answers to written questions on notice, 21 September 2018 (received 5 October 2018); Western Australian government, answers to written questions on notice, 24 September 2018 (received 26 October 2018); New South Wales government, answers to written questions on notice, 21 September 2018 (received 28 November 2018).

96 NHMRC, *Cultural Competence in Health: A Guide for Policy, Partnerships and Participation*, 2006, cited in Western Health, *Submission 48*, p. 2.

97 Dr Gannon, *Committee Hansard*, 10 August 2018, p. 37.

- referrals to antenatal care provided by an appropriately qualified workforce trained to deliver culturally responsive care.⁹⁸

Educational materials for Aboriginal and Torres Strait Islander communities

7.89 The WA Reducing the Risk of SIDS and Sleep Accidents in Aboriginal Communities program, introduced in 2005, is a culturally appropriate campaign in language. A similar pilot campaign has been undertaken in Victoria in English.⁹⁹

7.90 Red Nose made a decision not to translate its education materials into every First Nation language, on the basis that there are over 250 language groups in Australia. Instead, the organisation decided to translate them into the four most prevalent languages apart from English, and to develop education programs in more meaningful ways, in consultation with senior community health professionals and Indigenous elders who participated in the advisory group. The material is pictorial based and culturally appropriate.¹⁰⁰

7.91 Stillbirth Foundation Australia reported that it had moved to writing and distributing stillbirth research findings for Aboriginal and Torres Strait Islanders in a culturally appropriate manner and ensuring the correct use of language.¹⁰¹

Education for employers and work colleagues

7.92 Some submitters and witnesses drew attention to the need for better education designed for employers and work colleagues, particularly to provide information and guide them in supporting an employee who is returning to work after experiencing the trauma of stillbirth.¹⁰²

7.93 Mrs Jackie Barreau reported on her experience of returning to work, and noted a campaign being conducted by Sands (Stillbirth and Neonatal Death Charity) in the UK called *Finding the Words*, which seeks to assist employers to talk with a bereaved employee following a stillbirth.

My experience of workplace support by my employer was adequate and empathetic, but I was not prepared for the overwhelming grief that I experienced most days. My fellow work colleagues were supportive, although some were not sure what to say or what to do.¹⁰³

98 Multicultural Centre for Women's Health, *Submission 70*, pp. 4–5.

99 Mrs Jane Wiggill, Manager, Health and Advocacy, Red Nose, *Committee Hansard*, 9 August 2018, p. 23; Red Nose, *Keeping Bub Safe*, https://rednose.com.au/downloads/RROSIAC_brochure.pdf (accessed 2 October 2018).

100 Red Nose, answers to questions on notice, 9 August 2018 (received 14 September 2018).

101 Ms Bowring, Stillbirth Foundation Australia, *Committee Hansard*, 8 August 2018, p. 16.

102 See for example, Ms Alex Lowes, *Submission 78*, [p. 2]; Name withheld, *Submission 145*, p. 4; Ms Jennifer Thomas, *Submission 168*, [p. 2].

103 Mrs Jackie Barreau, *Submission 215*, [p. 2]; Sands (UK), *Finding the Words*, <https://www.sands.org.uk/get-involved/sands-campaigns/finding-words> (accessed 23 October 2018).

Committee view

7.94 Efforts to reduce the rate of stillbirth in Australia must begin with Australians being better informed about stillbirth and encouraged to acknowledge stillbirth in public conversations. There is no doubt that the culture of silence that surrounds stillbirth in Australia significantly adds to the emotional trauma experienced by bereaved families.

7.95 This silence reflects a broader lack of public awareness about the incidence and impact of stillbirth, and results in extended families, friends, work colleagues as well as people in the wider community being unprepared or unable to talk about stillbirth. In turn, this reinforces the profound grief and sense of social isolation experienced by bereaved parents. The issue is exacerbated by the fact that the current model of care for pregnancy and birth tends to normalise birth and seeks to reduce fears about the risks involved. Indeed, there appears to be a greater fear about stillbirth relative to other risk factors in pregnancy and birth that are, statistically, less likely to occur.

7.96 The committee agrees that better public education about stillbirth may reduce the rate of stillbirths in Australia by helping to demystify the risk of stillbirth and removing the stigma that inhibits clinicians and other health professionals from discussing the risk with pregnant women because they fear that it will cause them unnecessary anxiety.

Recommendation 10

7.97 The committee recommends that the Australian government develops and implements a national stillbirth public awareness campaign, similar to the successful SIDS campaign, which aims to demystify stillbirth, educates parents and the general public about the risks of stillbirth, and encourages public conversations about stillbirth as a public health issue.

7.98 The committee commends the IMPROVE training workshops designed to assist clinicians and health professionals in managing a stillbirth or neonatal death including investigations, counselling for autopsy and examining the baby.

7.99 Stillbirth also exacts an emotional toll on clinicians and other health professionals who care for bereaved parents, and the committee recognises that they too should have access to counselling and support services when they need it during the course of their employment.¹⁰⁴

Recommendation 11

7.100 The committee recommends that the Australian government develops and implements a national best-practice, culturally appropriate education kit that equips current and future health professionals to:

104 Mr Smith, PSA NSW/CPSU NSW, *Committee Hansard*, 8 August 2018, p. 61; Ms Marshall, *Submission 109*, pp. 2–3.

- **discuss risks of and strategies for preventing stillbirth with pregnant women; and**
- **provide culturally and linguistically appropriate information about counselling and support services to assist them with emotional support whilst caring for parents following a stillbirth.**

7.101 The committee considers that protocols need to be developed to guide public hospitals and health centres in managing autopsies or other investigations into stillbirths and providing culturally appropriate counselling for autopsy and other medical investigations.

7.102 The committee is also concerned that there is no nationally consistent approach in public hospitals and community health services as to how they care for stillborn babies held in morgues; how they communicate with the parents of those babies, particularly for parents who may live long distances away from the hospital where their baby was stillborn; and how they assist those parents who may find the cost of a funeral service prohibitive and require advice on other options.

7.103 The committee sought data compiled by public health authorities in the states and territories relating to unclaimed stillborn babies left in morgues. Whilst not all jurisdictions responded within the committee's timeframe, it is clear to the committee that the situation varies across jurisdictions and requires a nationally consistent approach.

Recommendation 12

7.104 The committee recommends that the Australian government develops and implements culturally and linguistically appropriate protocols for public hospitals and community health services in all jurisdictions, to guide them in:

- **managing autopsies or other investigations into stillbirths;**
- **counselling for autopsy and other medical investigations;**
- **care of stillborn babies held in morgues; and**
- **communicating with bereaved parents.**

7.105 The success of public health education campaigns depends in part on being informed by high quality research. The committee is concerned that there is no central point of access to the growing body of research and clinical guidelines regarding stillbirth. As a result, this important resource is fragmented and difficult to access for researchers, clinicians and other health professionals, support and advocacy groups, and members of the general public.

7.106 As a starting point, the committee considers that an Australian online register, similar to the International Society for the Study and Prevention of Perinatal Infant Death, would help to reduce fragmentation and duplication of effort across the jurisdictions, and provide greater access and education for those involved in stillbirth

research as well as care providers and families who wish to undertake their own research.¹⁰⁵

Recommendation 13

7.107 The committee recommends that the Australian government creates an online register of current international and Australian research and clinical guidelines relating to stillbirth, accessible to all interested stakeholders including the public.

7.108 The committee recognises that better community education about stillbirth is a high priority, and urges the Australian government to develop culturally appropriate educational materials—informed by international best-practice models such as the UK program *Finding the Words*—that offer information about stillbirth, practical guidance on how to talk about stillbirth, and strategies for supporting a person who has experienced the trauma of stillbirth.

7.109 Such educational materials need to be culturally appropriate and aimed at a wide range of people in the community including extended family members, friends, employers, work colleagues, and anyone who may know or encounter a bereaved parent.

Recommendation 14

7.110 The committee recommends that the Australian government develops and implements a best-practice, culturally appropriate public education kit that assists families, friends, employers, work colleagues and people in the wider community to understand stillbirth and to offer support to a bereaved parent or family member following a stillbirth.

105 International Society for the Study and Prevention of Perinatal Infant Death, <https://www.ispid.org/index/> (accessed 18 October 2018).

