

**Submission to Australian Senate Select inquiry into Stillbirth Research and Education**

**Paula Dillon**

**June 27, 2018**

Dear Committee Members,

Thank you for the opportunity to provide a submission to the Select Committee on Stillbirth Research and Education on the future of stillbirth research and education in Australia.

I provide this submission as both a Registered Midwife / Childbirth and Perinatal Loss Educator, and also as a bereaved mother. My daughter Annabelle was stillborn 13 years ago.

**Background**

Please find below the prologue to my Master of Midwifery minor thesis, titled “Decreased fetal movements: Exploring practices in maternity care”, as a background to my involvement in education about stillbirth awareness, prevention, and care of bereaved families.

On the 21st of May 2005 my world changed forever. Our precious daughter, Annabelle Lucy, was stillborn at 41 weeks 6 days gestation, weighing 3780g and the spitting image of her big sister Grace. The cause of Annabelle’s death was found to be a result of a massive idiopathic feto-maternal transfusion. That is, spontaneous loss of Annabelle’s blood into my circulation, the cause of which remains unknown.

As soon as I was told there “was no fetal heartbeat”, two questions seemed to be on everyone’s lips: “when did you last feel baby move?” and “did you notice a decrease in baby’s movements over the last day or two?” There seemed to be a great emphasis on pinpointing the last fetal movement/s and whether I could have been alerted to something being awry in the days preceding the diagnosis of fetal death in utero. Prior to this point, I could not recall a time during my pregnancy where there was any discussion about fetal movements at all! Perhaps there hadn’t been such a discussion because I was a midwife and ‘should know’ when to report decreased or absent fetal movements. Perhaps that discussion had occurred and I had been oblivious to it because ‘babies don’t die in Australia or the rest of the developed world.’ Or so I naively thought at the time.

Following the stillbirth of Annabelle, feelings of guilt and failure as a mother, and also as a midwife, racked my brain. I couldn’t help but wonder if I had been more attuned to her movements during my pregnancy, would I have noticed a reduction, and if so, would I have contacted my obstetrician? On reflection, sadly the simple answer was “no”.

I believed the notion that a reduction in fetal movements towards the end of pregnancy was normal due to the increased size of the baby, and subsequent reduced uterine space for baby to move. This made sense to me from an anatomical perspective, and so it was a belief I had never questioned. I also recall hearing at some point early in my midwifery career that “fetal movements decrease prior to labour in an attempt to conserve oxygen reserves in preparation for the rigours of labour”, the source of which was an experienced and reputable midwife. I also accepted this belief unquestioningly. I had no reason to do otherwise.

After Annabelle’s death, I became acutely aware that I was not alone in my acceptance that “decreased fetal movements towards the end of pregnancy were normal”. After discussions with friends, family, colleagues and other midwives, I found that this was a commonly held belief.

Hence, I began looking for research to either support or refute this notion. I found a plethora of literature relating to fetal movements, and more significantly decreased fetal movements. But why,

## Submission to Australian Senate Select inquiry into Stillbirth Research and Education

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as a midwife, did I not know this information existed? Why, as a mother, did I not 'listen' to my baby and seek advice earlier, when I suspected my baby had not moved for some time? Why did I think it was okay to wait until the next day? Why didn't I know just how significant decreased fetal movements were? Why hadn't anyone told me that my baby could die? Do we even know how to broach the topic of decreased fetal movements with women during their pregnancy? One day I was going to seek answers to some of these questions.

My curiosity around current information and communication regarding decreased fetal movements subsequently set the scene for this research project. I wanted to find out what midwives know already about fetal movements and decreased fetal movements, and what they would like to know about this topic. This, combined with my passion for education (of parents-to-be and also other health professionals) led to this study, which will constitute a Masters of Midwifery minor thesis. It is my greatest hope that by my undertaking this study, midwives will be alerted to the significance of decreased fetal movements, and have a raised awareness of clinical practice guidelines in this area. Fundamentally, the aim is to provide best evidence care and ensure that women are well-informed about the risks of decreased fetal movements, and ultimately help prevent stillbirth.

Annabelle's death cannot be in vain.....

Subsequent to the stillbirth of Annabelle, for several years I provided perinatal loss education to undergraduate and post-graduate midwifery and maternal and child health nursing students across four universities in Victoria. I continue to do the same for midwifery and paramedicine students at two universities in Queensland. I also facilitate workshops on perinatal grief and loss for health care professionals through CAPERS Bookstore. I have previously been a Parent Supporter with SIDS & Kids Victoria (now Red Nose Grief and Loss), and parent support group facilitator. I am also an Executive Volunteer and Queensland Educator for Still Aware – the first Australian charity solely dedicated to raising awareness of stillbirth pre-conception and during pregnancy.

### **Response to Terms of Reference**

In this submission I address the committee's terms of reference c), f) and h).

#### ***c). partnerships with the corporate sector, including use of innovative new technology***

- There is very little in the way of partnerships with the corporate sector in undertaking research and development activities.

- It is also imperative that technology is appropriately and carefully used. As stated in the current Clinical Practice Guidelines for Care of Women with Decreased Fetal Movements, listening to women's experience and intuition should be considered above any technology. At present, the risk is that clinicians tend to concentrate on the technology (the machines that say baby and mother are ok, or that things are going wrong), and often forget to prioritise what the woman feels or is experiencing. The literature supports women who say that 'they knew something was wrong' but that all the tests they had showed no problems and she was sent home<sup>1</sup>. Listening to women should be the first technology applied in this area.

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<sup>1</sup> Warland, J., Heazell, A.E.P., Stacey, T., Coomarasamy, C., Budd, J., Mitchell, E.A., & O'Brien, L.M. (2018). "They told me all mothers have worries", stillborn mother's experiences of having a 'gut instinct' that something is wrong in pregnancy: Findings from an international case-control study. *Midwifery* 62 (2018) 171-176.

## Submission to Australian Senate Select inquiry into Stillbirth Research and Education

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June 27, 2018

- No funding of wearable devices developed to externally monitor fetal movements. Wearable device technology has the potential to detract from the pregnant woman and her own connection with her baby. They take away a mother's intuition of her baby's movements, or lack thereof. My concern is that women will trust technology more than her own knowledge of her baby, and may not seek medical advice if she has concerns about her baby's wellbeing because "the machine said that everything was ok". I have heard of this happening already with hand held fetal heart rate monitors (Dopplers), where a woman had concerns about her baby's wellbeing, however did not seek care because she was sure she heard baby's heart rate with her Doppler. Sadly, her baby was subsequently stillborn. Funding would be best re-directed at educating women about getting to know her baby during pregnancy.

### ***f). communication of stillbirth research for Australian families, including culturally and linguistically appropriate advice for Indigenous and multicultural families, before and during a pregnancy;***

- mandated education and training for midwives, antenatal educators, obstetricians and GPs providing antenatal care, around how to raise the conversation with pregnant women about risk factors and preventative measures for stillbirth, and discussion of how a pregnant woman can get to know her baby in utero.

- discussion around stillbirth and preventable measures is a must in ALL antenatal care settings. To see a reduction in stillbirth, there is a requirement to raise public awareness. Not for profit charity organisation Still Aware is working tirelessly in this area, but just like any public safety initiative, without government funding the message has limited reach, and preventable deaths continue.

- ALL pregnant women need to know about stillbirth, and steps that they can take to potentially reduce their risk. I was already a Registered Midwife and a mother when I was pregnant with Annabelle. To this day, I cannot recollect any information provided to me about stillbirth risks during my Postgraduate Diploma of Midwifery, pre-conception of my children (I saw a GP for pre-conception health check and advice prior to my first pregnancy), nor during my pregnancies.

- I encourage a public health awareness campaign around stillbirth awareness and risk reduction similar to the 'Reducing the Risk of SIDS' program introduced in Australia in 1991<sup>2</sup>, and the ongoing Safe Sleeping campaign by Red Nose, which has seen a dramatic reduction in the incidence of SIDS over the last 25+ years. This campaign will help ensure ALL Australians are aware of the risks of stillbirth, and hence support pregnant women to keep baby safe.

### ***h). any related matters***

- Care in a subsequent pregnancy after stillbirth – the need for specialist subsequent care facilities in each state in Australia for women with a previous stillbirth.

- Women who have experienced stillbirth, are at an increased risk for subsequent stillbirth. A successful model like the "Rainbow Clinic"<sup>3</sup> run by the Mercy Hospital for Women in Melbourne and

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<sup>2</sup> [https://www.health.qld.gov.au/\\_data/assets/pdf\\_file/0029/144686/info35.pdf](https://www.health.qld.gov.au/_data/assets/pdf_file/0029/144686/info35.pdf)

<sup>3</sup> <https://mercyperinatal.com/clinic/rainbow-clinic>

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Tommy's<sup>4</sup> in the UK, where they have a zero repeat stillbirth rate, could be instituted in more healthcare sites in Australia. These clinics should provide care from midwives, obstetricians, pastoral care workers, psychologists, and neonatology specialists; bearing in mind the proven positive health outcome benefits of continuity of care models.

Thankyou again for the opportunity to make this submission.

Yours sincerely,

Paula Dillon (RN, RM, BN, PostGradDip Mid, MMid)

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<sup>4</sup> <https://www.tommys.org/our-organisation/our-research/research-cause/stillbirth-research/rainbow-clinic>