MATERNITY CONSUMER NETWORK
"Better outcomes for mothers and babies means better outcomes for the whole community"

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As a national organisation whose objectives are to advocate for improved maternity care, we strongly believe a preventative approach in the way we deliver maternity care will reduce stillbirth and support those families devasted by the loss of their baby. In the current system women rarely develop a relationship with their care provider, nor have anyone known to them for pregnancy, birth and postnatal care. There is fragmented education, or outdated information presented to women about stillbirth and decreased fetal movement which is contributing to consumers being left largely uneducated on signs of potential stillbirth.

a. **consistency and timeliness of data available to researchers across states, territories and federal jurisdictions;**
   All perinatal data reporting has a 2-year lag in this country, so we're only just able to access the 2015 data. The data reporting in this country is largely left to the individual primary health networks, who decide what system they are using to collect data. These systems don't "talk" across systems. It then ends up at the AIHW to be cleaned, sorted and reported. Streamlining the system collection would allow a faster reporting turn around, more accuracy in reporting and easier access for researchers, but importantly consumers, who are impacted by stillbirth. There has been debate on whether mortality data should be publicly available at facility level. This will improve transparency and the practice of care providers. There have been instances in this country (Bacchus Marsh, Victoria) where there have been many preventable baby deaths, and having a nationally available, transparent, easily accessible system would contribute to improved practice towards preventing stillbirth.
b. **communication of stillbirth research for Australian families, including culturally and linguistically appropriate advice for Indigenous and multicultural families, before and during a pregnancy;**
   Communicating stillbirth needs to be built on a foundation of a trusting relationship, communicating in a manner consumer will understand, rather than hand on pamphlets or rely on information posters in waiting rooms (as not everyone will see/understand them). We strongly believe having continuity of midwifery care and seeing a known care provider through pregnancy will enable better culturally appropriate dissemination of information and consider the 60% of consumers who have low health literacy (CHF, 2017).

g. **quantifying the impact of stillbirths on the Australian economy; and**

The Lancet, A UK medical journal, in 2017 published a series of papers titled "ending preventable stillbirth". One of these papers was a comprehensive literature review reporting there is a huge economic and psychological burden of stillbirth on society. Of particular notable mention from the paper:

- A stillbirth needs more resources than a livebirth, both soon after the death and also in the next pregnancy.
- There are usually indirect and intangible costs of stillbirth which are extensive and usually met by families alone.

There are many ongoing negative effects, particularly on parental mental health.

c. any related matters.

Overwhelmingly, this Inquiry needs to be broadened to include the whole maternity system in Australia. Our high preventable stillbirth rates reflect an out-dated, non-evidence based maternity system which is harming families. Stillbirth families are largely receiving fragmented care, little follow up support and often from care providers who are strangers. If information is to be disseminated about Stillbirth, families are to be supported in decreased fetal movement.

We invite the committee to accept the following insight into stillbirth care in Australia's maternity care system:

The Perinatal Deaths in Australia 1993 -2012 report shows the overall rate of perinatal deaths - stillbirths or neonatal deaths, that is death within the first four weeks of life - remained fairly stable over this 20 year period. During the same time period, the rate of induction of labour increased from 21% to 26% and caesarean section rates from 19% in 1993 to 32.4% in 2011 (AIHW). The figures simply do not add up that caesareans and inductions are saving babies.

The perinatal mortality rate for babies born to mothers who identified as Aboriginal or Torres Strait Islander has dropped by 20% to 17.1 deaths per 1000 births but is still almost double that of babies born to non-Indigenous mothers (9.6 deaths per 1,000 births) (AIHW).

Australia has the 15th lowest rate in the world, with 2.7 stillbirths for every 1000 births, behind countries like Iceland (1.3), Finland (1.8), Japan (2.1) and New Zealand (2.3) (Reinebrant, 2017). Australia ranked poorly in reducing its stillbirth rate over the past 15 years. It is worth noting, Nordic countries and New Zealand also have continuity of midwifery care as their dominant maternity care model. Currently only 8% of women can access midwifery continuity of care (Dawson et al., 2015). This involves seeing a known midwife (or a small group of midwives) for pregnancy, birth and postnatal care. Fragmented care is obviously the care most women receive- which involves visits to many different care providers, fragmented dissemination of information to women about the risks of stillbirth, often variances in opinion and not a lot of focus on building relationships.

As the rate of intervention in labour and birth has increased, the rate of preventable stillbirths has increased rather than decreased. Many women are routinely induced by 41 weeks gestation, as they have been told by their care provider it is due to "double the chance of stillbirth", yet the absolute risk remains small. Studies vary in their rates of stillbirth for gestation length, but women are rarely totally informed about the absolute risk versus relative risk, if the absolute risk of having a stillbirth at 41 weeks was 0.4 out of 1,000, then that means that 0.4 mothers out of 1,000 (or 4 out of 10,000) will experience a stillbirth. The statistics of having a still born baby at 42 weeks is still low at around 0.6%, and whilst it's 50% higher, the absolute risk is low.

Many women still report being embarrassed or dismissed when presenting to an emergency department with reduced foetal movement. Many women are still reporting being told to have a cold glass of water, change positions and, which is evident there is still a need for consistent education, evaluation of guidelines (as many aren't routinely followed) and continuity of care. There are still many women questioning what they need to look for regarding stillbirth and reduced fetal movement and there seems to be lack of communication to individual

women about it. This isn't surprising when in most maternity care settings women will see multiple obstetricians and up to 20 different midwives. The demonstrate a need for greater support for women throughout pregnancy, and for women to have access to midwifery continuity of care. The Cochrane Review into continuity of midwifery care found that women who have a midwife as their main carer throughout pregnancy and birth are around 19% less likely to lose their baby before 24 weeks' gestation, and 16% less likely to lose their baby at any gestation than women whose care is shared between different obstetricians, GPs and midwives. (Sandall, Soltani, Gates, & Devane, 2016)

It goes without saying that stillbirth is distressing for parents, and many are experiencing a range of negative psychological symptoms that often persist long after the death of their baby, including depression, PTSD and anxiety. How the woman and her family are cared for during this time plays a crucial role in how they recover from their loss. We strongly believe having continuity and familiarity in having a known midwife is crucial in supporting families, which much include ongoing support with appropriate consultation and referral.

In most continuity of midwifery care models, women are visited in the home for the first 6 weeks, which can include daily visits. Given the grief and psychological support stillbirth mothers experience, along with the physical recovery from birth- these women still need the same physical postpartum care, and appropriate support and education around milk supply, blood loss, hormones etc. Having continuity of midwifery care will also ensure the liaison and referral/consultation with appropriate supportive care providers such as psychologists and private stillbirth organisations is more consistent for ongoing support of families.

The ignorance in stillbirth education is coming from one of Australia's peak medical bodies, the AMA. Dr Michael Gannon, in 2017, said there was plenty of "anecdotal evidence" that if a mother had something to eat or drink "that will wake the baby", as reported in ABCs article "Have a cold drink, AMAs president tells mothers worried about stillbirth". This theme still carries with many care providers, with women who present to ED (emergency department) with decreased fetal movement report being made feel embarrassed, over-reactive and are often dismissed. Many women are also still told to have a drink of water, change positions etc. which is archaic and not in line with current guidelines, nor research.

References:

Australian Institute of Health and Welfare

Consumer Health Forum

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