# The silence around miscarriage hurts health care and bereaved parents

We need to talk about miscarriage, to provide sensitive, patient-centred, evidence-based continuity of care

After years of trying to conceive, my husband and I were ecstatic to see the double lines on our home pregnancy test — overjoyed to be parents, relieved that the hardest part of that journey was over. Even the nausea seemed a gift. Months later, he put his head next to mine as I lay on a hospital bed waiting for a dilation and curettage procedure to remove "the products of conception". We had a missed miscarriage, and for two blissful months we started dreaming about and planning for our family of three. In the days, weeks and now years after our loss, I feel the silence of miscarriage reverberating through my life. This silence limits our ability as family, friends, colleagues, and health professionals to support women and their partners to reconfigure their lives after early pregnancy loss.

In Australia, miscarriage is defined as spontaneous pregnancy loss occurring before 20 weeks' gestation. It is the most common adverse pregnancy outcome, occurring in up to 20% of clinically confirmed pregnancies, and has been linked to depression, anxiety, grief and trauma even 3 months following the loss.[1] The 12-week rule is a social practice of not disclosing a pregnancy until after the first trimester, when pregnancies are more likely to be carried to term. This rule exacerbates the silence around miscarriage, and permeates many Australian health and medical guidelines and legislation where miscarriage is not explicitly mentioned or acknowledged. In this article, I reflect on the absence of miscarriage and why we need to stop the deafening silence.

## Talking about miscarriage: knowing what to say, especially as health professionals

The sonographer who said they "[could not] find a baby" during my ultrasound did not seem to have the words to explain my loss to me. As I left the room, heavy with the weight of the confirmed miscarriage, they reflexively said, "Have a good day!" I know they meant to support me more than their words suggested, but they too were unsupported. It was only in 2020 that consensus guidelines were published for delivering unexpected news via obstetric ultrasound in the United Kingdom.[2] These guidelines acknowledge the unique context of obstetric ultrasound where unexpected findings are identified while the patient is present and so there is little time for preparing to communicate bad news. The formal, explicit advice in these guidelines provides reassurance and support to ultrasound practitioners and, through this support, patient-centred and sensitive communication. To date, no such guidelines exist for sonographers in Australia.

## Testing our assumptions about miscarriage and providing evidence-based care

After my miscarriage, I felt broken. My heart hurt, and the changes to my body during pregnancy made it feel like something I no longer understood. I wanted the mental health benefits of exercise and the sense of control over my body that it could give me, but I did not know where to start. Scholarly research on miscarriage and exercise focused on whether exercise caused miscarriage,[3] and the Australian physical activity and sedentary behaviour guidelines for adults[4] had no mention of pregnancy loss.

It could be argued that the physical impact of a miscarriage is limited because the common methods for managing miscarriage, even the most invasive, the dilation and curettage procedure, does not require incision or percutaneous puncture. Therefore, exercise advice would not need to be modified for women following miscarriage — they can just use the general advice. However, this is a claim or assumption that can be empirically tested. Further, even if it is true that the physical impact of an early pregnancy loss on a person's body does not warrant adjustments to exercise or physical activity advice, miscarriage can still be acknowledged in physical activity guidelines. Such guidelines can highlight the benefits of exercise for the mental health of women and explain that modifications are not required. Explicitly addressing exercise following miscarriage provides guidance, reassurance, safety and validation not only for women but also for general practitioners, physiotherapists, exercise physiologists, exercise scientists and other health professionals.

## Providing continuity of care to all bereaved parents

I was admitted to a public hospital in a low socio-economic and culturally diverse part of Sydney. The gynaecologists and nurses who treated me acknowledged my loss, provided information and reassurance, and gave me the best possible care. Then, I left the hospital. I had a discharge summary with clear instructions to see my GP in 7 days and the well wishes of the staff, but no sense of who might look after me next. My body was sorted, but what about my grief? What do I do now?

Our health service cannot be everything to everyone. It should, however, be supported to be able to refer patients onto other resources that are relevant to the next step in their healing or recovery. Australia has a number of consumer-led services that provide support to women and their partners following miscarriage.

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These include the Sands 24-hour telephone and in person peer support services (www.sands.org.au) and the online information sheets and support groups of the Pink Elephants Support Network (www.pinkelephants.org.au). From here, bereaved parents may be referred onto health professional support, such as counselling or physiotherapy, as required. Conversations about miscarriage, sharing these resources, enable health services to provide support in sustainable ways.

## The effects of miscarriage on every part of life

As an academic in health, it is perhaps unsurprising that my workplace was supportive when I requested leave following my loss. Although I was physically capable of responding to emails, designing a curriculum and completing research tasks (and needed some of it to distract myself), I did not have the cognitive or emotional capacity to work at the pace at which I had previously worked. I was, am, grieving. In September 2021, the Parliament of Australia passed the Sex Discrimination and Fair Work (Respect at Work) Amendment Bill 2021,[5] which extends the bereavement leave provisions (2 days of paid leave) to include parents who have experienced miscarriage. This amendment is significant in the acknowledgement it provides. Bereavement leave is partly about the time, partly about the financial support, and a lot about validation. It is also only the start of workplace-based support for parents.

The absence of miscarriage in Australian health guidelines described above is true at the time of writing. It is also true that there are pockets of advocacy aiming to change this. A community of sonographers are building on the success in the United Kingdom to create guidelines for communicating unexpected findings in the Australian health care context, and the Pink Elephants Support Network is developing resources to support managers and colleagues to support bereaved parents. The purpose of this reflection is to draw attention to the absence of miscarriage in the health and medical discourse and the implications for the care received by bereaved parents. The silence is deafening to those of us to have lost our children. At every turn, there is missing or insufficient information for our health practitioners, our support network, and for us to make decisions about our care in a way that is sensitive to our loss.

I write this still without a living child, keenly aware that, if we were able to conceive again, we may not be able to keep our next baby either. I am hopeful, however, that between my losses, medicine and health would have listened beyond the silence, that ultrasound practitioners are supported to have conversations about miscarriage, that research has explored best practice for exercise following early pregnancy loss, and that health and medical guidelines mention me and acknowledge my baby in the way that recent legislative change has: she was here, she mattered and her loss matters.

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References are available online.

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5 Sex Discrimination and Fair Work (Respect at Work) Amendment Bill 2021 (Cth). ■