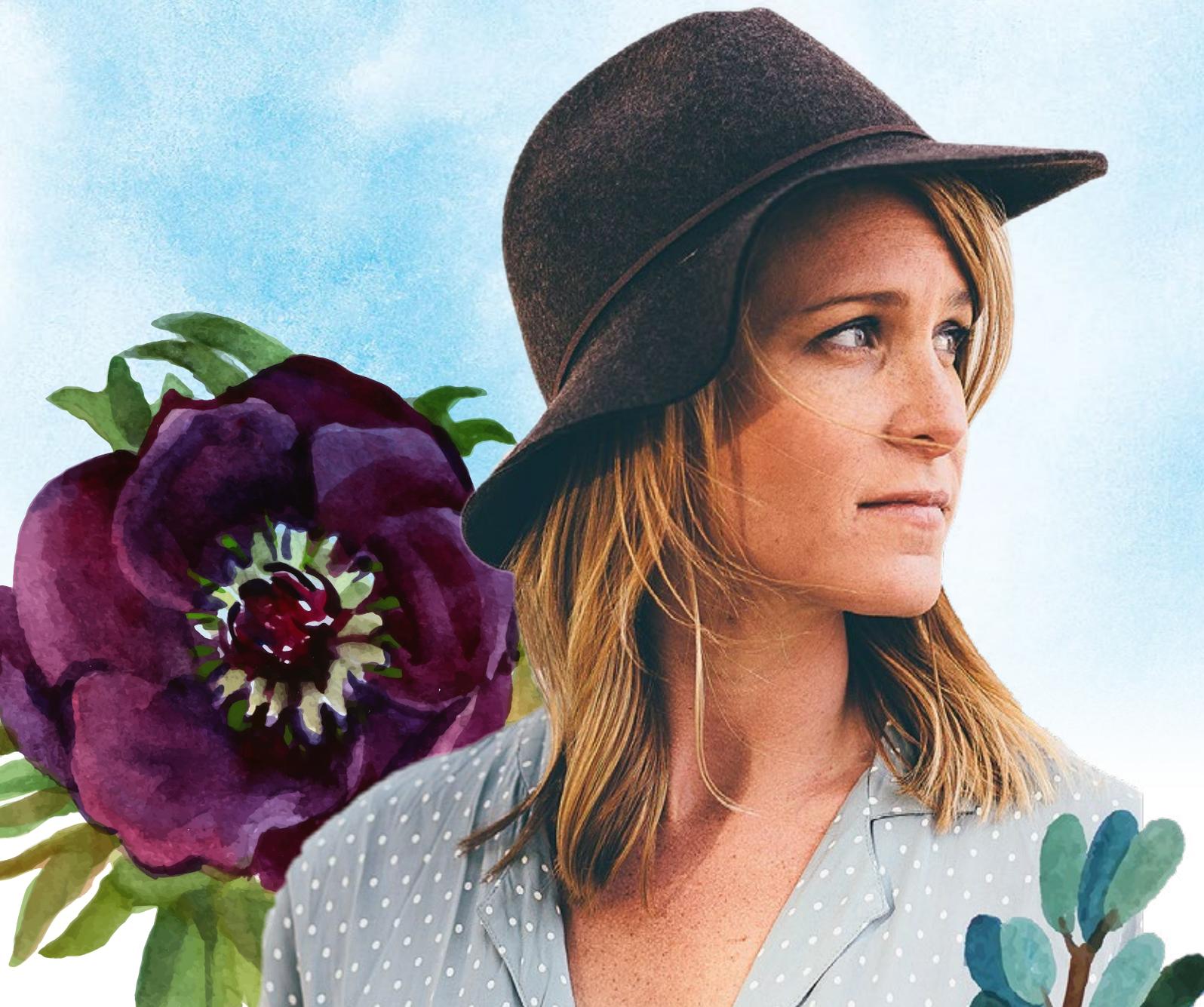




The State of Early Pregnancy Loss
in Australia 2022



A report prepared by The Pink Elephants Support Network

Executive Summary

The aim of this whitepaper is to outline the results of a survey whereby participants were asked 12 questions about their experiences of support following an early pregnancy loss. This would give way to a broader interpretation of the accessibility (or lack thereof) of the various avenues of support, and suggestions on how these can be improved.

In April 2022, The Pink Elephants Support Network (herein referred to as Pink Elephants) released a short, online survey to understand the types of support available to, and accessed by, people following early pregnancy loss. The survey was developed in collaboration with researchers Dr Jane Carland and Dr Melanie Keep, and surveyed individuals who had specific lived experience of early pregnancy loss.

The survey consisted of 12 questions, a combination of fixed choice and open-ended questions. Participants were asked about their use of Pink Elephants resources, and their experiences of accessing support after early pregnancy loss, both immediately and in the general aftermath. The data captures survey answers from 407 participants residing in Australia or overseas (n=13, 3.2%) at the time of survey completion.

Key findings include that Respondents were almost equally as interested in information about the emotional aspects of loss (64%) as they were about the physical aspects of loss (67%). Half of Respondents (51%) indicated they wanted to talk to another individual who had experienced an early pregnancy loss following their own loss (i.e. peer support). 40% of Respondents reported experiencing barriers to accessing support following their early pregnancy loss.

It is the hope of Pink Elephants that through highlighting the many barriers to accessing support experienced by people following their early pregnancy loss, that more can be done to remove barriers to access support services, providing much-needed empathy and validation to grieving families. This can lead to better long-term mental health outcomes and reduced likelihood of anxiety, depression and post-traumatic stress for these families. If early pregnancy loss services continue to be underfunded, the poor mental health outcomes associated with early pregnancy loss will not improve, and many families will continue to navigate their pain and grief in silence and confusion.

A note on terminology used

For the purposes of this whitepaper, we use the terms early pregnancy loss and miscarriage interchangeably, though there are scientific differences. We define early pregnancy loss as spontaneous pregnancy loss occurring before 20 weeks' gestation, and include termination for medical reasons (TFMR) in this definition.



The State of Early Pregnancy Loss in Australia 2022

Early pregnancy loss (defined in Australia as spontaneous pregnancy loss occurring before 20 weeks' gestation) is the most common adverse outcome of pregnancy¹. It is estimated that around 300 Australians and their partners experience early pregnancy loss every day – around 103,000 people a year. It is estimated that one in four pregnancies end in loss.²

Early pregnancy loss, or miscarriage, is often fraught with unknowns, silence, shame and stigma. Many families carry the experience alone because of outdated social practices such as the '12 week rule' (the social practice of not disclosing a pregnancy until the second trimester when the perceived risk of pregnancy loss is reduced). This exacerbates the sense of isolation and disenfranchised grief felt by parents.

Despite the high incidence of miscarriage, and its impact on the health of tens of thousands of Australians each year, early pregnancy loss continues to be sidelined and ignored when it comes to ongoing government funding, research, and formal support pathways. The end result is poor mental health outcomes for those who are left to navigate their grief, confusion, and disappointment alone. A recent study showed women experience high levels of post traumatic stress, anxiety, and depression after early pregnancy loss. Distress declines over time, but remains at clinically important levels even nine months after the loss³.

¹ Jurkovic D, Overton C, Bender-Atik R. Diagnosis and management of first trimester miscarriage BMJ 2013; 346 :f3676 doi:10.1136/bmj.f3676

² Collins, C., Riggs, D. W., & Due, C. (2014). The impact of pregnancy loss on women's adult relationships. *Grief Matters: The Australian Journal of Grief and Bereavement*, 17(2), 44-50.

³ Farren J, Jalmbrant M, Falconieri N, Mitchell-Jones N, Bobdiwala S, Al-Memar M, Tapp S, Van Calster B, Wynants L, Timmerman D, Bourne T. Posttraumatic stress, anxiety and depression following miscarriage and ectopic pregnancy: a multicenter, prospective, cohort study. *Am J Obstet Gynecol*. 2020 Apr;222(4):367.e1-367.e22. doi: 10.1016/j.ajog.2019.10.102. Epub 2019 Dec 13. PMID: 31953115.

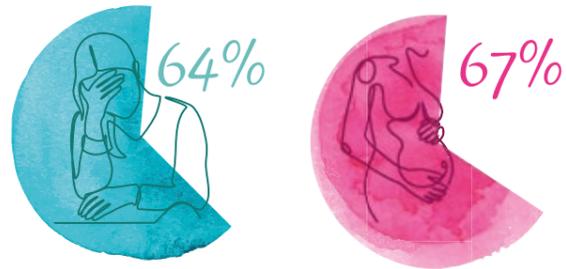
Why Pink Elephants?

The Pink Elephants Support Network is Australia's leading early pregnancy loss support charity, providing up-to-date resources such as information for bereaved parents, their families and friends, and their workplaces, and a range of peer support options for anyone impacted by the emotional, physical, and mental health effects of early pregnancy loss. Pink Elephants receives no ongoing government support.

Yet, through the mobilisation of its incredible community and five years of intense government lobbying, Pink Elephants' Leave for Loss campaign resulted in an amendment to the Fair Work Act (2009) in September 2021, extending its paid bereavement leave provisions to include people who experience miscarriage and their partners. These people can now receive two days of paid bereavement leave following their loss.



Here are some of the key findings of our recent survey:

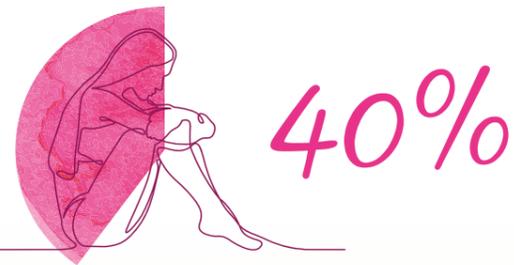


Respondents were almost equally as interested in information about the *emotional* aspects of loss (64%) as they were about the *physical* aspects of loss (67%).

More than half



More than half of Respondents indicated they wanted to talk to another individual who had experienced an early pregnancy loss following their own loss.



40% of Respondents reported experiencing barriers to accessing support following their early pregnancy loss.



An overwhelming majority accessed support from their personal networks immediately following early pregnancy loss, with only half (55%) accessing support from health and medical professionals.

Survey finding:

The type of early pregnancy loss experienced

According to the survey results, the most common type of early pregnancy loss was *missed miscarriage* (42%). This is where the baby has died or failed to develop but is still in the uterus. As a result, the pregnant person is unaware that their baby has died since they still have symptoms of pregnancy.

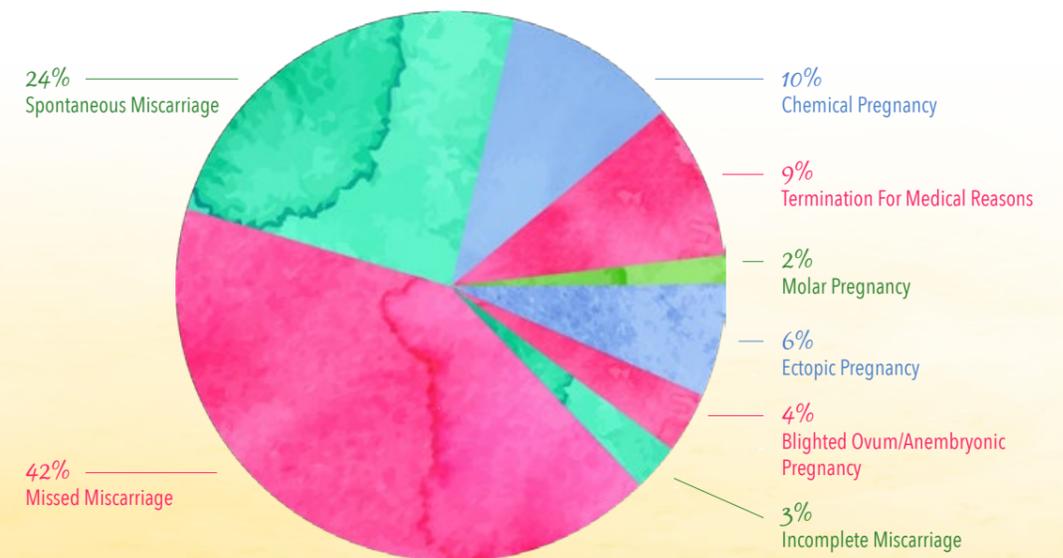
The type of miscarriage can affect how much care is provided to the parent after their loss.

A missed miscarriage is usually not diagnosed until a routine scan. This means that the parent/s are in the presence of a health professional such as a sonographer or obstetrician when they receive the news of their loss. This provides an opportunity for the parent to be offered support in a coordinated way. Examples include, providing on-the-spot referrals to services, or provision of pamphlets and support phone numbers.

Conversely, a spontaneous miscarriage where the pregnancy loss occurs with symptoms (at 24%, the second most common amongst Respondents) could happen when a person is alone at home, or in the workplace, and therefore the outcome of post-care is less controlled.

Question:

What type of early pregnancy loss have you most recently experienced?



Survey finding:

Emotional support is just as important as physical support

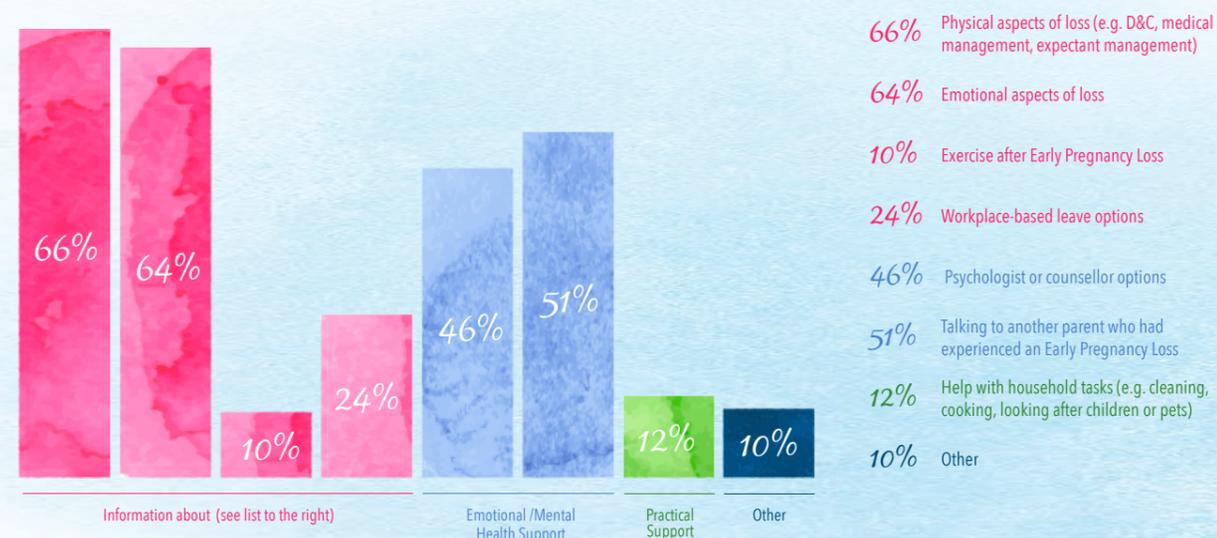
When asked to indicate what types of support they were interested in following early pregnancy loss, Respondents were almost equally as interested in information about the emotional aspects of loss (64%) as they were about the physical aspects of loss (67%). Practical support, such as help with household tasks or finding out how to safely exercise after a loss, were less of a priority (12%).

Close to one quarter of Respondents were interested in obtaining information about the type of leave they could access within their workplace (24%). Thanks in part to the continued advocacy of Pink Elephants, this type of leave is now protected by the Fair Work Act (2009) but may require additional support and resourcing to be successfully implemented in workplaces formally and informally.

Half of the Respondents (51%) indicated they wanted to talk to another parent who had experienced an early pregnancy loss following their own loss. This further underscores the need for Pink Elephants' Peer Support services, which include LiveChat Peer Support and Personalised Peer Support phone calls. These free services are run by trained volunteer Peer Support Companions who have all experienced early pregnancy loss.

Question:

What type of support were you interested in following your early pregnancy loss?



Survey finding:

Personal networks are the first port of call

When asked to identify the types of support accessed immediately after early pregnancy loss, participants primarily accessed support via their personal networks, specifically partners, family and friends (85%).

This far exceeds those who accessed support from health professionals such as GPs, hospital workers, and obstetricians (57%).

In spite of 46% of Respondents saying they would have appreciated having access to a counsellor after their loss (Question 9), few individuals (1%) reported accessing a counsellor immediately. One potential explanation for this discrepancy is access to mental health services (either generally or with psychologists, psychiatrists or counsellors trained in perinatal loss). Eighteen per cent reported immediately accessing support via online support communities.

Organisations like Pink Elephants are under-resourced, reducing their ability to meet the demands for their services or to deliver the types of services people and their partners need immediately following a loss. A lack of ongoing funding affects the ability of Pink Elephants to reach the many people who have experienced early pregnancy loss and should be aware of the no-cost services available to them.

People explored different resources in the general aftermath, when compared with the immediate aftermath of early pregnancy loss.

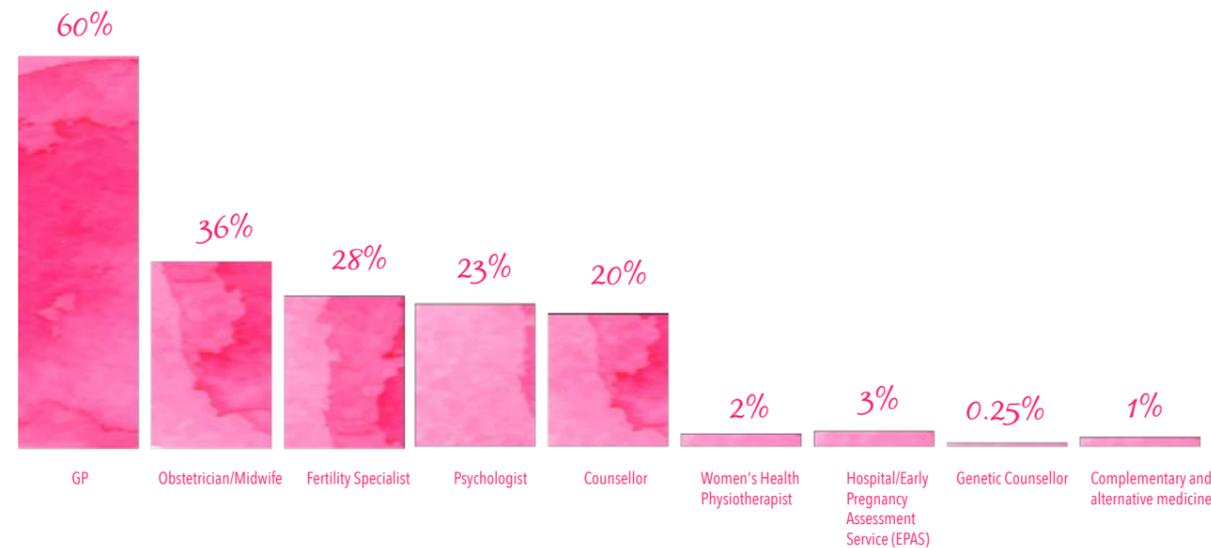
Even though health professionals weren't the resource most commonly accessed immediately after an early pregnancy loss, GPs were by far the resource accessed the most in the general aftermath of early pregnancy loss (60%).

This was followed by peer support, such as Pink Elephants Online Communities, LiveChat, Phone Call support, and downloadable resources, which was accessed by 46% of people.

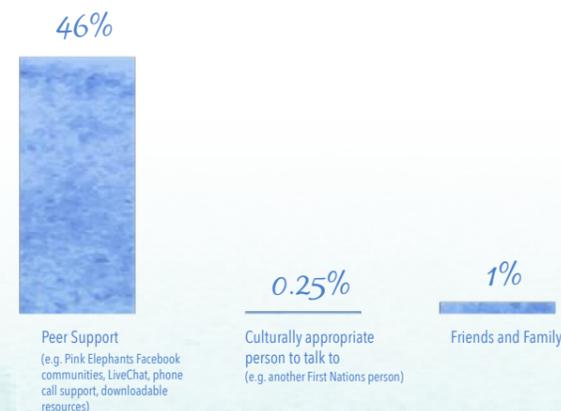
Question:

What support was provided or accessed following your early pregnancy loss? (Not immediate)

Health Professionals



Peer Support



Other



Survey finding:

Parents want access to specialised peer support following their loss

Forty-four per cent of people experiencing early pregnancy loss would have appreciated access to a peer support service (such as those provided by Pink Elephants). Survey participants also indicated a preference for in-person peer support in the open-ended responses while acknowledging the benefits of digital support in the context of COVID-19 concerns.

Why could this be?

Research has shown that early pregnancy loss can be extremely isolating, and access to peers who have also experienced loss can provide unique support to parents. In Australia, early pregnancy loss support (with the exception of Pink Elephants) is usually provided by organisations who also provide stillbirth support services (stillbirth is defined as loss at or following 20 weeks' gestation). This means that if someone who had experienced a miscarriage accessed these support services, they may speak with someone who had experienced stillbirth or infant loss, rather than miscarriage.

Informal feedback from members of the Pink Elephants community shows that many people experiencing early pregnancy loss hesitate to contact stillbirth support services, or even organisations which offer support for both types of loss. This is because they often feel they need to justify their grief in comparison to those who had lost their baby through stillbirth. They do not want to take up space. They do not feel confident. They may feel their loss is 'less important,' and this contributes to a feeling of isolation and their grief not being validated.

That is why dedicated early pregnancy loss services are so important.

Survey participants also highlighted their experiences of having to navigate the health and not-for-profit systems to find their own support, and instead, would have preferred to be directed to early pregnancy loss support from their health professionals.

Conclusion:

The current barriers to access are unacceptable and must be overcome

40% of respondents reported experiencing barriers to accessing support following their early pregnancy loss.

Of the 40% of Respondents who reported experiencing barriers to accessing support following their early pregnancy loss, many shared their specific experiences, which Pink Elephants has grouped accordingly into four categories:

- **Challenges in navigating health services without guidance.** Participants mentioned having to research information about pregnancy loss management themselves, citing a need to be proactive in chasing professional follow ups, and a lack of clarity about what was available. A lack of referral pathways was also highlighted as a barrier.
- **Isolation was a common theme identified in responses, especially for those living outside metropolitan areas.** The isolation cited was twofold: the ongoing sense of isolation brought about by feelings of grief, and COVID-19 and its related restrictions prohibiting the type of in-person support that might otherwise be desired. Here, the overwhelming need for digital-first services is clear.
- **Hesitation in accessing support via social media.** Respondents brought up the limitations of Facebook as a key platform for accessing peer support. Their specific concerns included privacy (i.e. can Facebook friends view their membership in support groups), not having a Facebook account, bullies, and not fitting the criteria for certain groups.
- **Lack of access to counselling services,** prohibited by factors such as financial barriers, wait times for free services, and finding mental health professionals with expertise in perinatal loss.

Pink Elephants' view:

What can be done to further support and offer access to services for those experiencing early pregnancy loss?

A message from Pink Elephants' Co-Founder and CEO.

Despite over 100,000 Australians experiencing this profound physical and emotional health issue each year, early pregnancy loss is continually minimised and ignored when it comes to ongoing government funding, research, and formal support pathways. This can result in poor mental health outcomes for so many who are left to navigate their grief, confusion, and disappointment alone.

At Pink Elephants we see far too many bereaved parents struggling to come to terms with their pregnancy loss, feeling unsupported and isolated. This adversely affects their mental health and their ability to participate meaningfully in their daily lives. It is clear from this research that more funding is urgently needed to increase capacity of support programs and to ensure every person is given a clear referral pathway to support services that provide specific early pregnancy loss support.

Not providing ongoing funding for early pregnancy loss support services, at either a national or state level, is a serious error. It disenfranchises the grief that comes with early pregnancy loss. It tells a person their grief is unjustified or unimportant, and ignores the broader issue of poor mental health outcomes for people experiencing early pregnancy loss. For too long aspects of women's health and the emotional trauma from early pregnancy loss has been overlooked and under funded.

Pink Elephants is calling for change during International Pregnancy and Infant Loss Awareness Month 2022.



"It's part of the reason why we took matters into our own hands, and conducted a survey to examine the current avenues and accessibility of support available after early pregnancy loss, in the hopes of bringing to light some serious barriers to access."

-Samantha Payne, October 2022

A message from The Australian Medical Association (South Australia)

"Miscarriage is so often a 'hidden' loss, with many women and their partners experiencing early pregnancy loss unable to share or discuss their loss in the midst of their grief and confusion. Despite all they know to the contrary, some women feel shame and disappointment in themselves; they may also feel isolated and alone.

The Australian Medical Association in South Australia recognises and appreciates the very valuable work of Pink Elephants in helping these women and all who experience early pregnancy loss in Australia.

We congratulate Pink Elephants for the emphatic advocacy that led to the passing of Australia's 'Leave for Loss' legislation in 2021, and hope to continue working with you to improve the care and emotional and physical support for all experiencing early pregnancy loss."

– Australian Medical Association (SA) President, Dr. Michelle Atchison



Disclaimer: This white paper contains information collected by The Pink Elephants Support Network quality improvement initiative to understand the types of support available to, and used by, people following early pregnancy loss. As the survey was not conducted for the purpose of academic research it was not subject to an ethics approval process. No identifiable information was collected and survey participants provided implied consent on submitting the survey.

About Pink Elephants

Pregnancy loss may be an individual journey but no one should have to walk it alone. Pink Elephants provides the latest resources, information and peer-support for anyone impacted by early pregnancy loss. Using evidence, empathy and connection, our unique digital-first approach offers a single source of specialist support, whenever and wherever it's needed – for anyone who has directly experienced it, for family and friends, corporate partners or healthcare professionals seeking proven ways to help.

With so much of the current experience of miscarriage based on old science, outdated perceptions, social anxiety and mistruths, Pink Elephants aims to right the story of early pregnancy loss by smashing the stigma and leading a new narrative, creating a healthier experience for all. Founded in Sydney, Australia, in 2016, Pink Elephants is a registered not-for-profit. For support, or to learn more, please visit: pinkelephantssupport.org.au

Access all Pink Elephants support materials, resources, and peer support programs here: pinkelephants.org.au/page/65/find-support

To contact us, please email contact@pinkelephantssupport.com



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