EARLY PREGNANCY LOSS COALITION

Select Committee Inquiry into Reproductive, Maternal and Paediatric Health Services in Tasmania

Submission by the Early Pregnancy Loss Coalition
September 2024

The Secretary
Select Committee on Reproductive, Maternal and Paediatric Health Services in Tasmania
Via email: rmphs@parliament.tas.gov.au

Early Pregnancy Loss Coalition
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Dear Secretary,

Submission – Inquiry into Reproductive, Maternal and Paediatric Health Services in Tasmania

Please find attached the Early Pregnancy Loss Coalition (EPLC) submission to the Select Committee on Reproductive, Maternal and Paediatric Health Services in Tasmania.

The EPLC endorses publication of this submission by the Select Committee.

Members of the EPLC Board of Directors would be pleased to give evidence at a hearing should it assist the members of the Select Committee.

Yours faithfully,

[redacted]

Isabelle Oderberg
EPLC Chair (Assisted by Special Advisor To The Chair Karen Schlage and EPLC Policy Advisor Dr Sarah Simons)

EPLC's Organisational Members are:

- Australian Nursing and Midwifery Federation
- Australian College of Midwives
- Australasian Society for Ultrasound in Medicine
- Bears of Hope
- Centre for Perinatal Excellence
- Doctors for the Environment
- Early Pregnancy Network Victoria
- Miscarriage Information Support Service
- Mums Matter Psychology
- PANDA
- Pink Elephants Support Network
- Royal Australian and New Zealand College of Obstetricians and Gynaecologists
- Red Nose
- Your Fertility

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Who is the EPLC?

The Early Pregnancy Loss Coalition is a registered charity, founded in 2023 by author and journalist Isabelle Oderberg (Hard to Bear: Investigating the science and silence of miscarriage), Miscarriage Australia co-founder Dr Jade Bilardi (Monash University) and Associate Professor Dr Melanie Keep (University of Sydney). Our Mission is to work towards improved care, education and support for people affected by early pregnancy loss (miscarriage) and those close to them.

The Coalition is structured to ensure representation across all sectors and organisations with an interest in miscarriage care including pregnancy loss support organisations, medical professionals, researchers and academics, allied health professionals, mental health workers, economists, health policy experts and those with lived experience.

The Coalition has a four-tier management structure:

1) An executive Board of Directors who are responsible for the governance and administration of the EPLC
2) Organisational Members from organisations across all sectors with an interest in miscarriage[1] care
3) Expert Policy Advisory Group which provides advice and inform the EPLC's policies and platforms[2]
4) Public supporters

The four key goals of the Coalition are to improve:

- ★ Care
- ★ Communication
- ★ Data
- ★ Research

The EPLC provides a collective voice to Government and advocates for critical changes needed to address the current gaps in patient care, support and funding in Australia.

The EPLC applauds the Tasmanian House of Assembly for holding this Inquiry and acknowledges the bravery of the Tasmanian women and birthing people who have already made submissions or given evidence. The Inquiry will assist to remove some of the societal stigma and taboo regarding birth trauma, including early pregnancy loss. The EPLC anticipates significant positive change will also emerge from the Select Committee's findings and recommendations.

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Terms of Reference

This submission addresses Terms of Reference (a)(ii), (a)(iii) and (a)(vi).

In referencing "birth trauma" in the context of this Inquiry, we note that this is additional to the significant trauma experienced by the majority of birthing people and bereaved families impacted by miscarriage.

We also note that some birthing people do not experience pregnancy loss as trauma; it is therefore important for all care in the pregnancy loss space to be birthing person-led and individualised to that person's experience and needs, as an important aspect of the adequacy, accessibility and safety of maternal health services in Tasmania.

This submission refers to "baby", but the use of language by medical caregivers should always be led by the birthing person, reflecting each individual's personal terminology.

Background

Miscarriage or early pregnancy loss is sadly common in Australia, estimated to occur in anywhere from one in three to one in four known pregnancies, or anywhere from over 100,000 to 150,000 miscarriages per year. In Australia, a family experiences a miscarriage every five minutes[3].

Clinical levels of anxiety, depression and post-traumatic stress disorder following miscarriage are common[4]. Despite common assumptions, gestational age and other obstetric factors have little association with the level of psychological distress[5], with up to 40 per cent of patients who experience miscarriage also have grief of a similar intensity and duration to other major losses[6], including late or perinatal death[7].Future pregnancies are also often adversely affected due to heightened grief, fear, and anxiety during the pregnancy[8].

These psychosocial effects are significantly compounded by a lack of support and acknowledgement of this "unseen" loss in both healthcare[9] and social settings[10], leaving people alone and isolated in their grief.

Lack of support is especially concerning as it has been shown to be one of the major predisposing risk factors to psychological morbidity[11].

Despite a global evidence base showing that positive support experiences at the time of healthcare contact with pregnancy loss leads to better psychosocial outcomes[12], further data (including research undertaken by EPLC) has shown that people undergoing pregnancy loss continue to have significantly negative experiences relating to the level and quality of emotional support offered by healthcare professionals.

Issues commonly cited include:

- Focus on physical but not emotional needs
- A lack of sensitivity, empathy, and acknowledgement of the loss
- Use of medicalised terminology
- Lack of and clarity pertaining to follow-up care, including referral to support services
- Lack of information provision around causes, physical symptoms, recovery, and subsequent pregnancy prospects
- An expectation that recovery from grief should occur quickly[13].

According to a 2020 survey, nearly two-thirds of female participants reported they were not offered any information about miscarriage or pregnancy loss support organisations or referral/access to counselling services at the time of miscarriage, despite almost all reporting they would have liked further support[14].

EPLC's research has shown that consumers and clinicians are often unaware of the miscarriage support services available in Australia[15]. Research shows clinicians often do not consider themselves responsible for patients' emotional care following miscarriage, citing time, lack of resources, desensitisation to women's losses, and a need for self-protection as restricting their ability to provide this[16].

Indeed, many of our organisational members have recognised and responded to the need for support services, including Red Nose Australia, Pink Elephants Support Network, Miscarriage Information Support Service, Bears of Hope, Perinatal Anxiety and Depression Australia and Mums Matter Psychology.

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Specific geographical, socio-cultural and public health considerations in Tasmania

Tasmania is Australia's smallest state with a population of 57,571 according to the 2021 census[17]. The Tasmanian landscape challenges its health system with a number of considerations encompassing distance, landscape and significant decentralisation of the Tasmanian population[18]. According to a 2021 report exploring the trajectory of Tasmania's future health needs, only 44% of the state's population live in or in proximity to Hobart, the capital city, compared to the 68% of Australians overall who reside in their state's metropolitan capital city. As a further important consideration, First Nations people comprise 5.7% of the Tasmanian population[19] compared to 3.2% of the overall Australian population.

Studies and data describing reproductive healthcare in the non-metropolitan Australian setting have long identified higher rates of substandard antenatal and postnatal healthcare in rural, regional and remote areas of Australia; this specifically affects the 309,000 people who live outside Greater Hobart[20] who comprise nearly two thirds of the Tasmanian population.

Though the Tasmanian Department of Health manages four major hospitals; Royal Hobart Hospital, Launceston General Hospital, North West Regional Hospital and Mersey Community Hospital, only the Royal Hobart Hospital is a tertiary referral centre. Early pregnancy assessment services[21] are available in all four hospitals but care remains predominantly centralised in more metropolitan areas. Therefore, people experiencing pregnancy loss in non-metropolitan areas often have to travel further to access healthcare and are unable to access specialist services including EPAS or ultrasonography closer to home due to a lack of staff with the prerequisite specialist skillset[22].

Furthermore, the most recent Tasmanian Population Health Survey[23] released in 2022 cited a number of significant health concerns relevant to the context of miscarriage and early pregnancy loss; 58% of women included in the survey had a BMI meeting overweight or obese criteria and just over a third of respondents (37%) reported that they had previously been diagnosed with depression or anxiety. Respondents were also asked about their perceptions of "social connectedness" and were asked specifically about whether they would be able to receive help and support from friends, family or a local community if needed; 71% of females reported that they could definitely get help compared to 68% of males overall.

However, only 58% of First Nations Tasmanians reported that they could definitely get help when needed. This is particularly pertinent in the context of early pregnancy loss and the significant psychological impact as discussed above, though the survey did not ask questions relating specifically to reproductive healthcare, pregnancy or pregnancy loss.

Additionally, in terms of accessing timely healthcare, the survey also identified difficulties for Tasmanians to see a GP when they felt unwell. 32 % of Tasmanians reported that they were unable to access a General Practitioner in the last year when they felt they needed to; this disproportionately affected 37% of female Tasmanian respondents compared to 27% of male respondents.

Drivers of birth trauma associated with early pregnancy loss in the Australian healthcare context

Terminology

Birth trauma can be generated through the use of terminology that is deemed to be medically correct, but is often deeply offensive and upsetting to the birthing person and bereaved family. This includes terminology such as “spontaneous abortion”, “products of conception”, “incompetent cervix” and “failed pregnancy”.

Location of care

Birthing people and their families also report significant levels of birth trauma due to the location of their care during pregnancy loss. This is particularly prevalent amongst people cared for in hospital Emergency Departments (EDs), Early Pregnancy Assessment Services (EPAS) and maternity units in both the private and public system, as opposed to those cared for in the community.

Emergency Departments in particular are frequently cited as environments where people experiencing pregnancy loss have suboptimal experiences. Pregnancy loss presentations are typically treated as lower acuity emergency cases because the majority of birthing people remain clinically and physiologically stable during miscarriage, despite the birthing person usually experiencing significant grief, emotional distress and anxiety.

While the non-urgent status is relative to the context of critical and immediately life-threatening emergencies managed in EDs, this can inadvertently cause further birth trauma for the birthing person and bereaved family. This may occur through delayed and sometimes substandard definitive care that is often very clinically focussed and may be perceived to lack social and emotional support.

There are also reported instances of birthing people miscarrying in ED waiting room toilets and then needing to decide whether to flush or retrieve their baby, causing additional birth trauma.

Emergency Departments remain ill-equipped to provide optimal holistic care to people and families experiencing pregnancy loss for a multitude of reasons, including preconceived clinician attitudes[24] or lack of knowledge pertaining to pregnancy loss as well as structural issues such as busy bed-blocked departments and long waits to be seen.

Pregnant people who are treated in EPAS units for pregnancy loss report birth trauma from sitting in waiting areas alongside pregnant people who are not experiencing complications or loss.

Inadequate information sharing, communication, follow up and data collection

This birth trauma is compounded when medical caregivers are unaware the pregnant person is miscarrying, due to issues such as medical files not being updated appropriately, the pregnancy loss not being prominently identified in the file or caregivers not having time to read the file. When caregivers subsequently engage with the pregnant person erroneously presuming their baby is still alive or healthy, this causes further trauma and distress

The EPLC was pleased to note the creation and deployment of guidelines for parent-centred communication in obstetric ultrasound by its Organisational Member, the Australasian Society for Ultrasound in Medicine[25].

The EPLC advocates for similar guidelines to be created across all areas of care, including in EDs, with guidelines for specific minority groups, such as parents who are Aboriginal or Torres Strait Islander, LGBTIQ+, disabled, Culturally or Linguistically Diverse (CALD) or any combination of these demographics or others.

Birthing people who have been admitted to maternity units during pregnancy loss express distress at the birth trauma caused when they are inadvertently exposed to the sights and sounds of living babies, such as cardiotocography (CTG) monitors, babies crying and family celebrations.

For birthing people who choose or are medically required to have surgical management, surgical delays cause birth trauma. Pregnant people are often required to continue carrying their deceased child for days and weeks beyond the diagnosis of their miscarriage.

Further birth trauma can be caused to a birthing person when plans are not put into place for follow-up and their primary health care professionals are not informed of their pregnancy loss. Birthing people have been contacted weeks later by the same hospital where they miscarried, with an appointment reminder for a twenty-week scan that is no longer required. Plans for follow-up post-loss must be clearly recorded, and a system must be put in place to ensure primary health care professionals are advised of the pregnancy loss.

The EPLC also notes that while early pregnancy loss is thought to affect between 100,000 to 150,000 Australian families per year[26], Australia does not collect miscarriage statistics. The EPLC considers that all state governments – including in Tasmania – must move to collect/collate this data as a matter of urgency.

Lived experiences of early pregnancy loss and areas for improvement

Fourteen years ago, Jana Horska had a horrifying miscarriage in the emergency department toilets at Sydney's Royal North Shore hospital. Despite an inquiry and promises that miscarriage care would change, there are still far too many documented cases of these instances and many others in the media[27].

EPAS were rolled out at all public, tertiary hospitals but media reports indicate that some of these services operate in name only. When asked how many EPAS clinics are running in the state, how many patients they see and who has oversight, NSW Health couldn't offer an answer[28].

Both current literature and research shows women commonly experience poor healthcare support experiences at the time of miscarriage, only serving to exacerbate the trauma associated with it. Issues in care consistently reported include:

- Focus on physical but not emotional needs

- A lack of sensitivity, empathy, and acknowledgement of the loss
- Use of medicalised terminology; lack of follow-up care, including referral to support services
- Lack of information provision around causes, physical symptoms, recovery, and subsequent pregnancy prospects
- An expectation that recovery from grief should occur quickly (14, 16).

This needs to change.

The challenge facing birthing parents whose pregnancies end in miscarriage or termination for medical reasons is an endemic, national issue. Tasmania is not immune from these challenges, and despite the uproar over Jana Horska's loss 14 years ago and a Parliamentary Inquiry that led to significant intended change, cases of sub-standard care or practices are not difficult to find[29].

In 2021 Hannah (name changed) attended a hospital emergency department in Sydney after repeatedly calling the hospital's EPAS with no response[30].

"So we went to the emergency department, they gave me the painkillers and said call the clinic again [because] 'they're the ones that know what they're doing'," she says. Finally, after continuing to phone repeatedly, Hannah got a call back from the clinic.
"[The nurse from the EPAS] was like, 'What's going on?' And I said, 'I'm having all of this pain.' Basically, what I wanted to ask her was, if my husband leaves the house, is he going to come home and find me dead in the bathroom? That was where my brain was at because I'd never experienced anything like that … And she said to me, 'Darling, it's just a miscarriage.'"

Another patient, Rose (name changed), experienced a miscarriage earlier this year. After her GP in coastal NSW confirmed the loss via an ultrasound, he referred her to the local EPAS, which took three days to get back to her[31].

"When I went into the EPAS, I was in the waiting room and I was seeing pregnant women everywhere, which was kind of shit," she says.

Once Rose got into the clinic she says she "broke down", but the service was good.

"The nurse was fantastic and so was the obstetrician," she explains.

Rose opted for a surgical procedure to end the pregnancy. Usually, she would have to wait up to two weeks, but by luck they were able to fit her in two days later. This still meant a total 10-day wait from the

first confirmation of the miscarriage to bringing the pregnancy to a close. Rose appeared grateful her case was treated in two days whereas most would be required to wait up to 14 days for their preferred method of management, which is in itself unacceptable.

In a study conducted in 2020 with nearly 400 women, many from Tasmania, exploring women's access to healthcare services and support at the time of miscarriage, more than half of women were not offered any information from healthcare providers about miscarriage or pregnancy loss support organisations or referral/access to counselling services at the time of miscarriage, despite almost all reporting they would have liked various forms of support.

Less than a quarter of women received information about miscarriage or pregnancy loss support organisations and far fewer received referral or access to counselling services (private counselling, social worker or pastoral care).

When asked about a list of potential support items, nearly all women reported they would have liked to be asked how they were coping emotionally, to receive referral for counselling and to receive leaflets for support organisations either at the time of miscarriage or in a follow up appointment.

As stated earlier in this submission, clinical levels of anxiety, depression and post-traumatic stress disorder following miscarriage are common[32]. Gestational age and other obstetric factors have little association with the level of psychological distress[33], with up to 40 per cent of women experiencing grief of a similar intensity and duration to other major losses[34], including late or perinatal death[35].

Male partners and LGBTIQA+ people often feel their role and loss is devalued and their grief is unacknowledged in the same way, if at all, as women[36].

While best practice care includes the ability of the patient to select their method of miscarriage management (surgical, expectant or medical) this choice is rarely extended to rural and regional services due to high stress on medical professionals and services, or indeed, a lack of those services at all.

Birthing persons experiencing pregnancy loss in Tasmania are not consistently provided with the full range of options for miscarriage management, which causes birth trauma when (for example) they choose surgical management without being aware they had an option to labour and give birth or pass pregnancy tissue with medication. Or vice versa.

Bereaved families have also not been provided with complete information (and sometimes are not provided with any information) about their options regarding memory-making and/or funeral arrangements, which also contributes to birth trauma and prevents families from fully experiencing memory-making, bonding with and paying tribute to their baby.

In some instances, the lack of options regarding funeral arrangements has prevented families from following their religious faith or culture, layering further birth trauma.

Any care that does not provide birthing persons with their full options cannot possibly comply with the legal, ethical and professional requirements for health care providers to ensure that an informed choice has been made and that therefore "informed consent" has been given.

Legislative reform

Tasmanian legislation should be amended to require research to be undertaken and programs to be established or expanded in support of pregnancy loss and infant death, consistent with legislation introduced in Ontario, Canada in 2015. The *Pregnancy and Infant Loss Awareness, Research and Care Act 2015* amended the *Ministry of Health and Long-Term Care Act 1990* to include the following as a function and duty of the Ontario Minister for Health: to undertake research and analysis on pregnancy loss and infant death that assists those, including [parents] and families, who experience such loss and that informs the establishment or expansion of programs related to such loss".

The societal impacts and costs of early pregnancy loss are enormous; the costs and numbers of Tasmanian citizens impacted every year by miscarriage and related birth trauma are too significant to ignore. Legislative change such as this would enable Tasmania to lead the way in Australia by preventing birth trauma associated with miscarriage through the funding of research and analysis, and the provision of appropriate support for bereaved families.

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Recommendations

The experience of birth trauma associated with miscarriage can be significantly reduced and ultimately eliminated in the following ways:

Care

1. Birthing persons experiencing pregnancy complications or pregnancy loss should be cared for in dedicated pregnancy complication/pregnancy loss units. The EPLC notes the opening of the ACT's recent dedicated unit[37] and calls on the Select Committee to recommend the inclusion of such a unit in each Tasmanian public hospital offering maternity services whenever any construction, renovation or relocation of public maternity service facilities occurs throughout Tasmania.

2. At a minimum, EPAS clinics must be located away from maternity services and discrete waiting areas must be offered to pregnant people experiencing complications or loss, so they are not accommodated with pregnant people who are not experiencing complications or loss.

3. Medical caregivers must inform pregnant people of the three methods of management for miscarriage and pregnant people must have the ability (subject to the pregnant person's individual situation, preference and medical advice) to select any of those options.

4. Once the pregnant person chooses an option for management of their miscarriage, this must be undertaken within a reasonable timeframe, avoiding situations where a patient is for instance:
    - Required to deliver a deceased or dying baby outside a clinical setting (for instance in an ED waiting area or toilets)
    - Required to return numerous times to hospital for treatment
    - Subjected to long waiting periods before surgical resolution of a miscarriage

5. Additional education and training specific to pregnancy loss and bereavement care must be provided to all Tasmanian healthcare professionals who provide obstetric and related services, to ensure appropriate behaviour and birthing person-led language is used at all times. This includes both medical and ancillary health care providers, such as sonographers and social workers.

Communication

6. There continues to be use of inappropriate terminology by Tasmanian healthcare providers that causes birth trauma during pregnancy loss. Tasmanian healthcare providers must be directed to immediately cease the use of offensive and upsetting terms, including but not limited to "spontaneous abortion", "products of conception", "incompetent cervix" and "failed pregnancy".

7. The language used by Tasmanian healthcare providers in the context of pregnancy loss must be birthing person-led language and healthcare providers must also be directed to use alternative phrasing for any terms or language the birthing person and bereaved family find to be offensive, inappropriate or traumatic.

8. Where pregnant or birthing people cannot be medically treated within a reasonable period of time, printed resources and information must be provided that includes appropriate support service information, with additional information specifically tailored to marginalised groups including but not limited to:

    - Aboriginal and Torres Strait Islander people;
    - People with disability
    - LGBTQIA+ and gender diverse people
    - People whose first language is not English
    - Those from diverse cultural groups ?culturally and linguistically diverse communities

9. There should not be undue reliance on online resources and information to support people experiencing pregnancy loss, as people in regional, rural and remote Tasmania do not always have reliable connection to online resources and this may further marginalise people living in lower socio-economic circumstances. Telephone and printed support, resources and information should always be available in a variety of languages appropriate to the diverse cultures living in Tasmania.

Data

10. Tasmania has the opportunity with this Inquiry to play a significant and groundbreaking role in instigating a national effort to collect and collate miscarriage data. This would help identify whether rates are increasing, whether there are key demographics or geographic areas in which miscarriage is more common and identify where emergency care measures must be taken.

11. In addition, the EPLC would like to see Tasmania Health:

- Establish how many EPAS clinics are running in Tasmania (and compare this number to other states)
- Establish their locations
- Establish their funding
- Establish the model of care for each clinic
- Quantify how many patients they are seeing annually
- Conduct qualitative research on the services provided and whether they are fit for purpose
- Provide audit records for miscarriage numbers/management

Research

The EPLC is currently raising funds to commission Health Economists at the University of Melbourne to undertake a study into the economic cost of miscarriage, using the framework of the same research done by a cross-institutional range of medical researchers based in the United Kingdom.

Select Committee hearing

Members of the EPLC Board of Directors would be pleased to give evidence should it assist the members of the Select Committee. The Board of Directors can extend invitations to EPLC member organisations, but the decision of whether or not to attend would be made by each organisation alone.

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Glossary of Terms

- **Abortion** Also known as termination, abortion is the intentional ending of a pregnancy using surgical or medical intervention.
- **Australian Bureau of Statistics (ABS)** Australia's independent statutory body responsible for national data collection, collation and analysis.
- **Australian Institute of Health and Welfare (AIHW)** The national agency responsible for information and statistics on the country's health and welfare.
- **D&C (dilation and curettage)** A procedure to remove pregnancy tissue or uterine lining. This procedure is commonly used for pregnancies under 14 weeks gestation.
- **D&E (dilation and evacuation)** Similar to a D&C, but the tissue is removed using a suction device, as well as other instruments such forceps. This procedure is generally used at gestations over 14 weeks.
- **Early pregnancy assessment service or centre (EPAS/EPAC)** Outpatient clinics in hospitals designed to support patients who have bleeding or other issues during the first 12 to 15 weeks of pregnancy.
- **Ectopic pregnancy** This occurs when an embryo implants outside of the uterus, often in a fallopian tube. There are a variety of possible treatments and outcomes for ectopic pregnancy, ranging from having to take medication to bring on a miscarriage all the way through to the condition being life threatening and requiring urgent surgery.
- **Expectant management** This is the 'wait and see' strategy of miscarriage care, where you wait to see if the body will miscarry naturally.
- **Fetal monitoring unit** The FMU takes over the care of high-risk patients and babies who need monitoring after the cut-off for the EPAS (which is around 12 to 15 weeks).
- **LGBTIQA+** An acronym standing for lesbian, gay, bisexual, trans and gender diverse, intersex, Queer, asexual and aromantic, and a range of other identities and experiences. Some communities also see the + as representing people who are HIV+.
- **Miscarriage** is the loss of a pregnancy before reaching 20 weeks gestation, including but not limited to the experiences of:

- **Blighted ovum** An out-dated term that is still commonly used, this is the name of a pregnancy that has a gestational sac but no fetus. It can also be called an 'anembryonic pregnancy' because there's no embryo.
- **Chemical pregnancy** A pregnancy that ends before reaching five weeks of gestation.
- **Complete miscarriage** This means the entire pregnancy has left your body. An incomplete miscarriage means that there may be some tissue left in the uterus.
- **Idiopathic miscarriage** This is early pregnancy loss in which no cause has been identified.
- **Missed or delayed miscarriage** This is when a pregnancy has stopped growing or an embryo has failed to develop and your body hasn't realised yet. That means that the body doesn't trigger the process of ending the pregnancy and pregnancy tissue has not been passed.
- **Molar pregnancy (hydatidiform mole)** A non-viable pregnancy that results in a placenta developing in an irregular way, with little sacs of fluid, a bit like a bunch of grapes. Molar pregnancies are surgically removed. In some cases the placenta can become malignant and develop into a rare form of cancer called choriocarcinoma.
- **Recurrent miscarriage** Either two or three consecutive miscarriages. The Royal Women's Hospital in Melbourne defines it as three losses, but the Australian Journal of General Practice defines it as two.
- **Termination for medical reasons (TFMR)** An abortion due to a fetal abnormality or because a pregnancy threatens the life of the birth parent.
- **Threatened miscarriage** A threatened miscarriage usually occurs in the context of vaginal bleeding in a confirmed pregnancy before 20 weeks gestation, where the cervix is closed.

- **Medical management** The strategy of treating miscarriage where either misoprostol or a combination of misoprostol and mifepristone are given trigger to the miscarriage process and pass the pregnancy tissue.

- **Medicare codes** All medical services subsidised by the Australian government are given a unique code to identify them. These codes are subject to regular revision and expansion.

- **Mifepristone** A drug used in abortion and D&Cs, which blocks the production of progesterone and causes uterine contractions.

- **Misoprostol** A drug also used in abortion and D&Cs; misoprostol causes the cervix to dilate.

- **Non-binary** People who identify as living outside the prescribed gender binaries of male and female.

- **Pregnancy tissue** Tissue that develops as part of pregnancy, including but not limited to fetal tissue and the placenta.

- **Products of conception** The 'formal' medical terminology for pregnancy tissue. "Pregnancy tissue" is now becoming more widely used as a more compassionate and delicate alternative.

- **Spontaneous abortion** The formal medical terminology for a miscarriage or early pregnancy loss. Its usage was formally abandoned in the UK, but it is still used in the Australian context.

- **Stillbirth** The death of a baby after 20 weeks of gestation either before or during labour.

- **Surgical management** One of the three options for miscarriage management, surgical management of a miscarriage is a procedure to end the pregnancy, usually a D&C or a D&E (see above).

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References

[1] Our use of the term “miscarriage” includes all forms of early pregnancy loss (under 20 weeks gestation), including termination for medical reasons.

[2] EPLC.au/members

[3] Khan RA, Drudy L, Sheehan J, Harrison RF, Geary M. Early pregnancy loss: how do men feel?. Irish Medical Journal. 2004 Jul 1;97(7):217-8

[4] -Farren J, Jalmbrant M, Falconieri N, Mitchell-Jones N, Bobdiwala S, Al-Memar M, et al. Posttraumatic stress, anxiety and depression following miscarriage and ectopic pregnancy: a multicenter, prospective, cohort study. American journal of obstetrics and gynecology. 2020;222(4):367. e1-. e22.

-Lok IH, Neugebauer R. Psychological morbidity following miscarriage. Best Practice & Research Clinical Obstetrics & Gynaecology. 2007;21(2):229-47.

-Quenby S, Gallos ID, Dhillon-Smith RK, Podesek M, Stephenson MD, Fisher J, et al. Miscarriage matters: the epidemiological, physical, psychological, and economic costs of early pregnancy loss. The Lancet. 2021;397(10285):1658-67

[5] -Collins C, Riggs DW, Due C. The impact of pregnancy loss on women's adult relationships. Grief Matters: The Australian Journal of Grief and Bereavement. 2014;17(2):44.

- Jackman C, McGee HM, Turner M. The experience and psychological impact of early miscarriage. The Irish Journal of Psychology. 1991;12(2):108-20.

-Neugebauer R, Kline J, O'Connor P, Shrout P, Johnson J, Skodol A, et al. Determinants of depressive symptoms in the early weeks after miscarriage. American Journal of Public Health. 1992;82(10):1332-9.

- Prettyman R, Cordle C, Cook G. A three-month follow-up of psychological morbidity after early miscarriage. British Journal of Medical Psychology. 1993;66(4):363-72.

[6] Brier N. Grief following miscarriage: a comprehensive review of the literature. Journal of Women's Health. 2008;17(3):451-64

[7] Toedter J LJ, Janssen H,. International comparison of studies using the perinatal grief scale: a decade of research on pregnancy loss. Death Studies. 2001;25(3):205-28

[8] - Hunter A, Tussis L, MacBeth A. The presence of anxiety, depression and stress in women and their partners during pregnancies following perinatal loss: A meta-analysis. Journal of Affective Disorders. 2017;223:153-64.

- Hutti MH, Armstrong DS, Myers JA, Hall LA. Grief intensity, psychological well-being, and the intimate partner relationship in the subsequent pregnancy after a perinatal loss. Journal of Obstetric, Gynecologic & Neonatal Nursing. 2015;44(1):42-50

[9] Bellhouse C, Temple-Smith M, Watson S, Bilardi J. "The loss was traumatic… some healthcare providers added to that": Women's experiences of miscarriage. Women and Birth. 2019;32(2):137-46.

-Geller PA, Psaros C, Kornfield SL. Satisfaction with pregnancy loss aftercare: are women getting what they want? Archives of Women's Mental Health. 2010;13(2):111-24.

-Lee L, Ma W, Davies S, Kammers M. Toward optimal emotional care during the experience of miscarriage: an integrative review of the perspectives of women, partners, and health care providers. Journal of Midwifery & Women's Health. 2023;68(1):52-61.

-Robinson J. Provision of information and support to women who have suffered an early miscarriage. British Journal of Midwifery. 2014;22(3):175-80.

-Rowlands IJ, Lee C. 'The silence was deafening': social and health service support after miscarriage. Journal of reproductive and infant psychology. 2010;28(3):274-86.

-Sejourne N, Callahan S, Chabrol H. Support following miscarriage: what women want. Journal of reproductive and infant psychology. 2010;28(4):403-11.

-Stratton K, Lloyd L. Hospital-based interventions at and following miscarriage: Literature to inform a research-practice initiative. Australian and New Zealand Journal of Obstetrics and Gynaecology. 2008;48(1):5-11.

[10]-Collins C, Riggs DW, Due C. The impact of pregnancy loss on women's adult relationships. Grief Matters: The Australian Journal of Grief and Bereavement. 2014;17(2):44

-Rowlands IJ, Lee C. 'The silence was deafening': social and health service support after miscarriage. Journal of reproductive and infant psychology. 2010;28(3):274-86

-Bellhouse C, Temple-Smith MJ, Bilardi JE. "It's just one of those things people don't seem to talk about..." women's experiences of social support following miscarriage: a qualitative study. BMC women's health. 2018;18(1):176.

-Kavanaugh K, Trier D, Korzec M. Social support following perinatal loss. Journal of family nursing. 2004;10(1):70-92.

-Rajan L, Oakley A. No pills for heartache: The importance of social support for women who suffer pregnancy loss. Journal of Reproductive and Infant Psychology. 1993;11(2):75-87.

[11] -Lok IH, Neugebauer R. Psychological morbidity following miscarriage. Best Practice & Research Clinical Obstetrics & Gynaecology. 2007;21(2):229-47.

-Lee C, Slade P. Miscarriage as a traumatic event: a review of the literature and new implications for intervention. Journal of psychosomatic research. 1996;40(3):235-44

[12]-Toedter J LJ, Janssen H,. International comparison of studies using the perinatal grief scale: a decade of research on pregnancy loss. Death Studies. 2001;25(3):205-28

-Stratton K, Lloyd L. Hospital-based interventions at and following miscarriage: Literature to inform a research-practice initiative. Australian and New Zealand Journal of Obstetrics and Gynaecology. 2008;48(1):5-11

[13]-Bellhouse C, Temple-Smith M, Watson S, Bilardi J. "The loss was traumatic… some healthcare providers added to that": Women's experiences of miscarriage. Women and Birth. 2019;32(2):137-46.

-Lee L, Ma W, Davies S, Kammers M. Toward optimal emotional care during the experience of miscarriage: an integrative review of the perspectives of women, partners, and health care providers. Journal of Midwifery & Women's Health. 2023;68(1):52-61.

[14]Bilardi JE, Sharp G, Payne S, Temple-Smith MJ. The need for improved emotional support: A pilot online survey of Australian women's access to healthcare services and support at the time of miscarriage. Women and Birth. 2021;34(4):362-9

[15]Jensen KL, Temple-Smith MJ, Bilardi JE. Health professionals' roles and practices in supporting women experiencing miscarriage: A qualitative study. Australian and New Zealand Journal of Obstetrics and Gynaecology. 2019;59(4):508-13.

[16]-Jensen KL, Temple-Smith MJ, Bilardi JE. Health professionals' roles and practices in supporting women experiencing miscarriage: A qualitative study. Australian and New Zealand Journal of Obstetrics and Gynaecology. 2019;59(4):508-13.

-Sumarno V, Temple-Smith MJ, Bilardi JE. Whose role is it? Primary care and the provision of emotional support for women experiencing miscarriage: a pilot qualitative Australian study. Australian Journal of Primary Health. 2020;26(5):388-95.

[17]https://www.abs.gov.au/census/find-census-data/quickstats/2021/6

[18]https://www.health.tas.gov.au/sites/default/files/2022-06/Drivers%20of%20Tasmania%27s%20Future%20Population%20Health%20Needs_0.pdf

[19]https://www.abs.gov.au/statistics/people/aboriginal-and-torres-strait-islander-peoples/census-population-and-housing-counts-aboriginal-and-torres-strait-islander-australians/latest-release#:~:text=In%202021%3A,2016%20and%202.5%25%20in%202011

[20]https://www.abs.gov.au/articles/snapshot-tas-2021

[21]https://www.health.tas.gov.au/hospitals/outpatients/clinic-directory/obstetrics/early-pregnancy-assessment-service

[22]Breaking the sound barrier—innovations in the Rural Women's GP Service, S Downes, A Sippi National Rural Health Conference, 2011•ruralhealth.org.au

https://ruralhealth.org.au/11nrhc/papers/11th%20NRHC%20Downes_Susan_D5.pdf

[23]https://www.health.tas.gov.au/sites/default/files/2024-01/report_on_the_tasmanian_population_health_survey_2022.pdf

[24]-Bellhouse C, Temple-Smith M, Watson S, Bilardi J. "The loss was traumatic… some healthcare providers added to that": Women's experiences of miscarriage. Women Birth. 2019;32(2):137-146. doi:10.1016/j.wombi.2018.06.006

-https://www.sciencedirect.com/science/article/abs/pii/S1871519217304791?via%3Dihub

[25]Australasian Society for Ultrasound in Medicine. Parent-centred communication in obstetric ultrasound. ASUM Guidelines. 2022; http://www.asum.com.au/files/public/SoP/curver/Obs-Gynae/Parent-centred-communication-in-obstetric-ultrasound.pdf

[26]Oderberg I, 2023, Hard to Bear: Investigating the science and silence of miscarriage, Ultimo Press

[27]https://www.theguardian.com/society/2021/sep/26/just-a-miscarriage-has-anything-improved-in-nsw-since-jana-horskas-shocking-experience-in-2007

[28]Oderberg I, 2023, Hard to Bear: Investigating the science and silence of miscarriage, Ultimo Press

[29]Oderberg I, 2023, Hard to Bear: Investigating the science and silence of miscarriage, Ultimo Press

[30]Oderberg I, 2023, Hard to Bear: Investigating the science and silence of miscarriage, Ultimo Press

[31]Oderberg I, 2023, Hard to Bear: Investigating the science and silence of miscarriage, Ultimo Press

[32]-Farren J, Jalmbrant M, Falconieri N, Mitchell-Jones N, Bobdiwala S, Al-Memar M, et al. Posttraumatic stress, anxiety and depression following miscarriage and ectopic pregnancy: a multicenter, prospective, cohort study. American journal of obstetrics and gynecology. 2020;222(4):367. e1-. e22.

-Lok IH, Neugebauer R. Psychological morbidity following miscarriage. Best Practice & Research Clinical Obstetrics & Gynaecology. 2007;21(2):229-47.

-Quenby S, Gallos ID, Dhillon-Smith RK, Podesek M, Stephenson MD, Fisher J, et al. Miscarriage matters: the epidemiological, physical, psychological, and economic costs of early pregnancy loss. The Lancet. 2021;397(10285):1658-67

[33]Collins C, Riggs DW, Due C. The impact of pregnancy loss on women's adult relationships. Grief Matters: The Australian Journal of Grief and Bereavement. 2014;17(2):44.

-Jackman C, McGee HM, Turner M. The experience and psychological impact of early miscarriage. The Irish Journal of Psychology. 1991;12(2):108-20.

-Neugebauer R, Kline J, O'Connor P, Shrout P, Johnson J, Skodol A, et al. Determinants of depressive symptoms in the early weeks after miscarriage. American Journal of Public Health. 1992;82(10):1332-9.

-Prettyman R, Cordle C, Cook G. A three-month follow-up of psychological morbidity after early miscarriage. British Journal of Medical Psychology. 1993;66(4):363-72

[34]Brier N. Grief following miscarriage: a comprehensive review of the literature. Journal of Women's Health. 2008;17(3):451-64

[35]Toedter J LJ, Janssen H,. International comparison of studies using the perinatal grief scale: a decade of research on pregnancy loss. Death Studies. 2001;25(3):205-28

[36]Khan RA, Drudy L, Sheehan J, Harrison RF, Geary M. Early pregnancy loss: how do men feel?. Irish Medical Journal. 2004 Jul 1;97(7):217-8.

-McCreight BS. A grief ignored: narratives of pregnancy loss from a male perspective. Sociology of Health & Illness. 2004 Apr;26(3):326-50.

-Miller EJ, Temple-Smith MJ, Bilardi JE. 'There was just no-one there to acknowledge that it happened to me as well': A qualitative study of male partner's experience of miscarriage. PloS One. 2019 May 28;14(5):e0217395

[37]https://www.cmtedd.act.gov.au/open_government/inform/act_government_media_releases/rachel-stephen-smith-mla-media-releases/2023/new-dedicated-unit-for-early-pregnancy-service