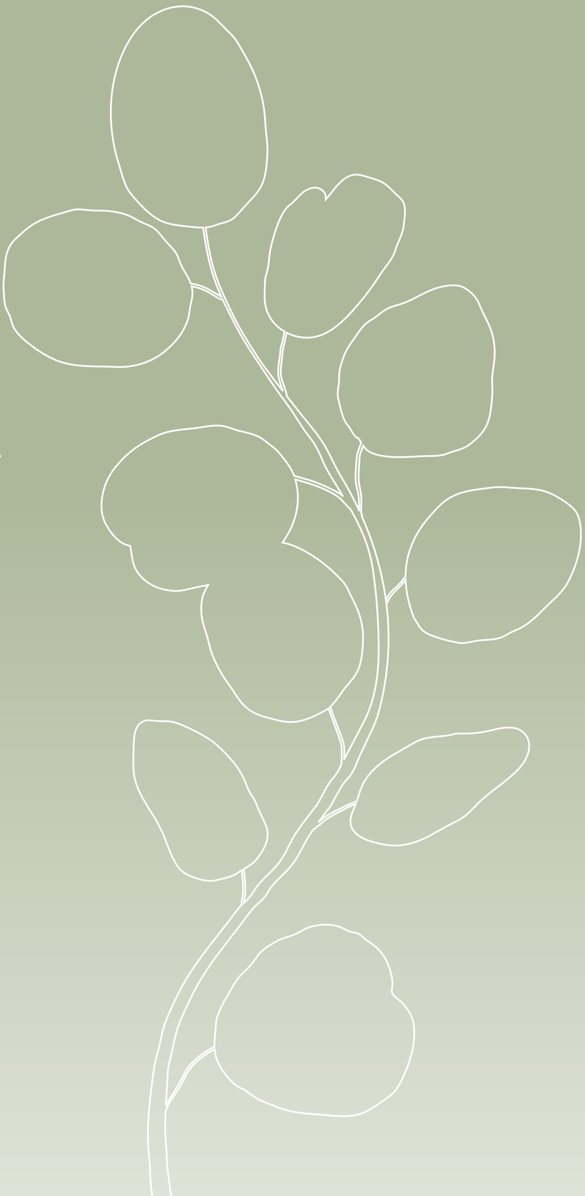
2024 NHMRC EDITION

Care Around Stillbirth and Neonatal Death

Clinical Practice Guideline

Executive summary and list of recommendations



The Centre of Research Excellence in Stillbirth (Stillbirth CRE) & Perinatal Society of Australia and New Zealand (PSANZ)

Stillbirth CENTRE OF RESEARCH EXCELLENCE

PERINATAL SOCIETY of Australia & New Zealand PSANZ

Introduction

The death of a baby during pregnancy or soon after birth is devastating for parents and families/whānau. Stillbirth and neonatal death have long-lasting social and emotional consequences that extend into subsequent pregnancies and beyond. There are also ongoing effects on healthcare professionals who care for parents around the time of loss, and economic impacts on health systems and society.

> **The time parents have with their baby can be very short and therefore very precious – if it is missed it is gone forever.**[1]

The care parents and families/whānau receive around the time of perinatal death is closely linked to their ongoing health and wellbeing. Best practice care can minimise additional emotional and psychological burden following the death of a baby and contribute to improved outcomes for parents and families/whānau in the short and long term, including in subsequent pregnancies. Best practice care around perinatal death is multifactorial, encompassing respectful and sensitive communication, information provision, and decision support for families/whānau – including those related to investigations to seek to identify cause(s) of death. It begins immediately following critical diagnoses (life-limiting condition and/or death of the baby) and spans follow-up care for parents and families/whānau after the baby's death, as well as in subsequent pregnancies. Broader institutional practices are essential. These include perinatal mortality audit and classification to facilitate national data reporting, understand causes of death, and identify how care can be improved.

Appropriate organisational practices also create the conditions and formal structures needed to enable effective health service delivery and support healthcare professionals to sustain high quality care.

This edition of the *Care Around Stillbirth and Neonatal Death Clinical Practice Guideline* was developed by a multidisciplinary working group led by the Centre of Research Excellence in Stillbirth (Stillbirth CRE) in partnership with the Perinatal Society of Australia and New Zealand (PSANZ).

This guideline includes 126 recommendations spanning seven major areas related to care around perinatal death:

- **Approach to care**
- **Perinatal loss care**
- **Perinatal palliative care**
- **Care in subsequent pregnancies**
- **Investigations for perinatal death**
- **Perinatal mortality audit and classification**
- **Organisational recommendations**

Resources for putting the recommendations in place include a parent version of the guideline, guidance for audit and research activities, and information to support decisions about investigations.

The aim of the guideline is to improve service provision and promote best practice care around perinatal death in Australia and Aotearoa New Zealand. Care begins at diagnosis, continues through pregnancy to birth, postnatal care and longer-term support including next pregnancies.

Six core goals for respectful and supportive care of bereaved parents and families/whānau underpin the guideline. These are:

- good communication defined by empathy and compassion
- recognition of parenthood and care practices that respect and honour the baby and affirm identity as a parent
- cultural safety where healthcare professionals respond to the diverse needs, beliefs, and practices that are important to parents and families/whānau
- effective support in the immediate and longer-term that includes physical, emotional, and social aspects
- parent-centred decision making where parents receive support and information to be involved in decisions and to explore different options
- organisational enablers where organisations support healthcare professionals to provide the best possible care.

Application of this guideline

This guideline is relevant for maternity and newborn care settings, as well as interfaces between hospital- and community-based services involved in the longer-term care of parents and families/whānau following perinatal death. The Australian Commission on Safety and Quality in Health Care (ACSQHC) *Stillbirth Clinical Care Standard* provides maternal and newborn services with a robust tool to help with implementation of the guideline.

Scope

This guideline addresses care around the time of perinatal death, including the following.

- **Stillbirth:** birth following the death of an unborn baby of 20 or more completed weeks of gestation or of 400 g or more birthweight. It is acknowledged that countries and organisations may use definitions that differ from this. Definitions of stillbirth using limits >20 weeks gestational age, OR >400 g weight at birth OR where the term ‘stillbirth’ is used to describe the birth outcomes were accepted for inclusion.[2,3]
- **Neonatal death:** a live born baby who dies within 28 days of life (regardless of gestation or weight at birth). For statistical purposes, the definition applied is the death of a live born baby of 20 or more completed weeks of gestation or of 400 g or more birthweight, within 28 days of birth. Early neonatal death is the death of a live born baby within 1–7 days of birth. Late neonatal death is the death of a live born baby within 8–28 days of birth.[2,3]

The definition of stillbirths and neonatal deaths includes those deaths which occur following a termination of pregnancy of 20 or more completed weeks of gestation or of 400 g or more birthweight.

The guideline does not specifically address or provide best practice recommendations for the care of parents who experience early pregnancy loss/miscarriage (including ectopic or molar pregnancy). In Australia, **Miscarriage Australia** and **Pink Elephants Support Network** provide tailored information and support. In Aotearoa New Zealand, **Miscarriage Support** and **Miscarriage Matters** provides online resources and best practice recommendations.

The IMPROVE 2.0 education program for maternity services and healthcare professionals is currently being expanded to address care of parents who experience early pregnancy loss (miscarriage) across maternity services in Australia. The national perinatal loss care pathway in Australia will also address early pregnancy loss.

Target audience

Primary audience: This guideline is for all healthcare professionals who care for parents and families/whānau in maternal and newborn care services in Australia and Aotearoa New Zealand. This may include doctors, midwives, nurses, social workers, psychologists, Aboriginal and Torres Strait Islander health workers and practitioners as well as Aboriginal liaison officers, and community-based healthcare professionals including community first responder organisations (for example ambulance services). This guideline is also for healthcare professionals who care for families/whānau in the transition from hospital to community and provide longer-term ongoing support. Other healthcare professionals such as sonographers, pathologists, and radiologists may also find this guideline helpful in identifying the cause of a baby's death. Healthcare professionals will apply this guideline according to their knowledge, skills, and role, as well as the geographical and cultural setting in which they provide care. Strong multidisciplinary partnerships are essential to ensure optimal care for parents and families/whānau.

Secondary audience: The guideline may also be used by policy makers, health system administrators, and others involved in implementation of maternal, newborn and child health programmes. In addition, the guide may be useful for parents, families/whānau and their support people, including those who have been affected by stillbirth or neonatal death and/or are involved in advocacy related to maternal and newborn health.

> **Healthcare professionals play a central role across the continuum of care from the moment of bad news, through birth and the postnatal period, and into future pregnancies.[4]**

A note about terminology

This guideline uses parent-centred language that is intended to be inclusive of all affected by loss. We use the term 'woman' throughout the guideline to refer to the person who is pregnant and gives birth.[5] We acknowledge diverse gender identities and that not all individuals who become pregnant and give birth identify as a woman. The term 'parent' is used to refer to expectant and bereaved mothers, fathers, and partners. It is important to recognise individuals who identify themselves as parents. However, we also acknowledge that not all individuals who experience perinatal loss consider themselves to be parents.[6]

This guideline uses 'baby' when referring to stillbirth and neonatal death because these terms are preferred by many bereaved parents. Terms such as 'fetus' may add to parents' distress because this language denies personhood[7] and is inconsistent with recognition of parenthood that is crucial to providing respectful and supportive care.

This guideline uses 'healthcare professional' to denote all those working with bereaved parents and family/whānau (see Glossary).

A note about the evidence

Care of parents and babies after perinatal death is an area of practice that is complex, multifaceted, not well defined, and largely informed by observational and qualitative evidence.

Four Cochrane reviews that have addressed aspects of care after perinatal death found limited trial evidence to support clinical practice.[8-11] The review assessing the effectiveness of interventions intended to provide psychological support or counselling to mothers, fathers or families/whānau after perinatal loss, found no eligible randomised controlled trials (RCTs).[8] The review on approaches to investigations for stillbirth also found no RCTs.[11] The reviews on subsequent pregnancy care[10] and autopsy consent found very limited evidence from RCTs.[9] The review authors acknowledge the challenge of conducting experimental study designs in this area and the need to rely on non-randomised and observational studies to guide practice.

There is a growing body of qualitative and non-randomised evidence with consistent findings, which helps to inform best practice care around stillbirth and neonatal death. We have drawn on this body of research evidence and the insights from an experienced multidisciplinary team as part of the Development Committee and its specialised subcommittees in developing the recommendations in this guideline. Further, when cross referencing our findings against all relevant international guidelines we found consistency in interpretation of the evidence and recommendations.

Many recommendations are consensus-based drawing on the available literature and expert knowledge and experience of the committee members and the wider audience through public consultation. For many of the evidence-based recommendations the evidence was rated as low to moderate quality. The recommendations have been developed so that maternal and newborn services can strive to meet best practice care to improve outcomes for families around the time of stillbirth or neonatal death.

Implementation

In Australia, the National Stillbirth Action and Implementation Plan[12] highlights the need for all families/whānau who experience stillbirth to receive personalised, respectful, supportive and holistic clinical and community care.

A co-designed national care pathway is currently under development by the Stillbirth CRE in Australia, and in Aotearoa New Zealand. These national pathways aim to ensure that high-quality, appropriate, and equitable care is available to all parents and families/whānau across the continuum of care and different settings.

The *Implementation and dissemination plan* outlines 21 key recommendations that have been identified by the Guideline Development Committee as most likely to lead to improvements in quality of care and outcomes for families/whānau. The development and implementation of the national perinatal loss care pathway in Australia and care pathway in Aotearoa New Zealand will be instrumental in ensuring uptake of key recommendations across services in Australia and Aotearoa New Zealand. The national pathway in Australia will be linked with the Stillbirth Clinical Care Standard to maximise effective uptake.

Methods

Key research questions for each of the seven major areas were developed by the Guideline Development Committee. The Technical Working Group carried out database searches between April and August 2022, with top-up searches completed in September 2023.

Records were assessed for eligibility by at least two independent reviewers, in accordance with the applied PICO (population, intervention, comparator, outcome) criteria. Eligible studies were evaluated using critical appraisal checklist tools from the Joanna Briggs Institute and the available evidence was synthesised by the Technical Working Group. An overall rating of confidence in the body of evidence for each recommendation was applied using GRADE-CERQual (Confidence in the Evidence from Reviews of Qualitative research). Recommendations were classified as either evidence-based recommendations (EBR) or consensus-based recommendations (CBR). The latter were formulated by the Guideline

Development Committee and Expert Working Groups based on expert opinion where there was low confidence in the evidence, or the evidence was limited or lacking.

Iterations of the evidence synthesis and recommendations were circulated to the Guideline Development Committee between September 2022 and October 2023 for feedback and consensus on the recommendations. Public consultation was conducted in August and September 2023 and feedback was incorporated prior to finalising the guideline.

The Centre of Research Excellence in Stillbirth (Stillbirth CRE) and the Perinatal Society of Australia and New Zealand (PSANZ) developed the guideline with extensive input from bereaved parents, healthcare professionals, researchers, and policy makers.

> **"When my baby died, I had no idea what I needed to know, or what was possible. It was such an overwhelming time. What I really needed was to know the options I had so that we could make decisions that were right for us."**
>
> Parent quote from the *Guiding Conversations* booklet.

Summary of recommendations

Section 2 – Approach to care

#	TYPE	RECOMMENDATION
2.1	CBR	A multidisciplinary team should oversee care across the continuum from diagnosis through birth and death planning to transition from hospital to community. The team should: • provide continuity of care and carer • hold regular meetings with parents and family/whānau • ensure medical records include a care plan (for example a perinatal palliative care plan) that has been developed with the parents and the plan is accessible to all team members, parents and family/whānau • consider supports that may be required to meet the cultural, religious, and/or spiritual needs of parents and family/whānau • engage other relevant healthcare workers and interpreters, where needed.
2.2	CBR	To ensure continuity of carer, designate a lead contact person with training in perinatal loss care, ideally a bereavement midwife to be a known point of contact for parents, family/whānau and other members of the care team (including hospital volunteers).
2.3	CBR	Use an identifier in medical records to show there is a perinatal loss care plan in place outlining parents' values, preferences, and wishes for care and support. • Ensure care plans are accessible to all members of the multidisciplinary team and available to parents and family/whānau.
2.4	EBR	Use respectful and sensitive language and terminology that is honest, realistic, and understandable. • Take the lead from parents regarding preferred language for their baby. • Use the word 'baby' or 'bub' if acceptable to parents. • Ask parents if they have named their baby and, if so, seek permission to use the name **Evidence quality:** moderate confidence
2.5	EBR	Be aware that stress and grief can greatly affect how people absorb, retain, and respond to information. Tailor information by: • using open-ended questions • repeating information and checking with parents that they understand • offering parents culturally and linguistically appropriate parent-facing information and resources about perinatal grief and what to expect • allowing parents time and space to read information and resources when they are ready. **Evidence quality:** moderate confidence
2.6	CBR	Acknowledge the specific care and support needs of parents who experience a termination of pregnancy and ensure perinatal loss care planning is across the continuum of care.
2.7	CBR	Normalise and validate parents' individual experience of grief and loss. Support parents to express their concerns by confirming their feelings and having open discussions about their needs. • Be aware of potential differences in how partners and family/whānau members express grief.
2.8	CBR	Acknowledge father/partner's experience of loss and their identity as a parent. Provide tailored support services for fathers/partners including both formal and informal support options and referral to parent support organisations as required.

#	TYPE	RECOMMENDATION
2.9	CBR	Acknowledge the grief and loss of other family/whānau members, especially grandparents and other children (siblings), and offer appropriate support options.
2.10	CBR	Offer parents culturally and linguistically appropriate information about perinatal grief and what to expect, to review when they are ready.
2.11	CBR	Provide parents and family/whānau members with information and opportunities for social and emotional support including peer support, professional counselling and psychology services, and other bereavement support services.
2.12	CBR	Establish and use referral pathways to ensure appropriate ongoing professional support for parents who may be at risk of developing mental health problems (for example post-traumatic stress), particularly parents who have pre-existing mental health conditions.
2.13	EBR	Care must be appropriate to parents' cultural, religious and/or spiritual needs. Healthcare professionals should: • recognise that parents and family/whānau come from a wide range of backgrounds and acknowledge diversity within and between cultural groups • avoid cultural stereotypes and culture-based assumptions • be aware of and responsive to individual, cultural, religious and/or spiritual approaches to death and expressions of grief and loss • be aware of and respond appropriately to families with a history of trauma and loss and previous negative experiences with health services particularly: – intergenerational trauma among Aboriginal and Torres Strait Islander families – complex trauma among women of refugee background • acknowledge the importance of each cultural group's vital support systems such as kinship and community care for Aboriginal and Torres Strait Islander families and Māori families/whānau. • seek advice and support from experienced health workers and engage cultural support services where required. **Evidence quality:** moderate confidence

Section 3 – Perinatal loss care

#	TYPE	RECOMMENDATION
3.1	CBR	The option of ultrasound should always be available and used to diagnose death or other conditions in an unborn baby. A second opinion should be considered where appropriate. • Ensure sonographers are considered as part of the multidisciplinary team and are aware of the clinical context and receive relevant information when caring for parents in the context of perinatal loss. • Advise parents that there may be periods of silence during procedures such as scanning. • Adverse findings should be communicated by an experienced and empathic healthcare professional.
3.2	CBR	Prior to breaking bad news, ensure that you are well-placed to answer parents' questions by gathering relevant information and consulting with colleagues, where needed. If you are uncertain of an answer or information is unavailable, assure parents that you will seek the information they need.

#	TYPE	RECOMMENDATION
3.3	CBR	When breaking bad news: • communicate the news in a safe and private space to both parents together; if this is not possible, communicate to the woman first, before others • use thoughtful and clear communication and sensitive terminology when referring to the baby (for example ask parents if they have a name for the baby and ask permission to call the baby by name) • acknowledge parents' distress, feelings, and concerns • assure parents that everything possible is being done to ascertain the baby's condition and offer to stay for support or to answer questions • inform parents of expected time delays between investigations and results and keep parents updated.
3.4	CBR	Do not leave parents on their own without information. If a woman has attended alone, offer to contact her partner or other support person, and ensure that she is supported by a healthcare professional and not left alone until that person arrives.
3.5	CBR	Advise parents of the possibility of passive movement of the unborn baby following diagnosis of death. If parents report movements after the scan, offer support and a repeat scan.
3.6	CBR	Arrange a formal consultation with parents to discuss their understanding of the diagnosis and options available. Ensure that parents have clear information and time to consider all available options where they need to make decisions. Provide culturally and linguistically appropriate information in a range of formats. • Refer to *Guiding Conversations booklet* and *Jiba Pepeny: Star Baby* booklet for Aboriginal and Torres Strait Islander families.
3.7	CBR	Develop a detailed care plan across the phases of care including: • pregnancy care plan, including individualised preparation and support for labour and birth • maternal birth care plan including timing and mode of birth • newborn care plan • perinatal loss care plan • discharge plan and ongoing support. Discussions around care planning should: • identify who parents want involved in decision making (for example family/whānau members, other support persons, community Elders or spiritual leaders, or other specialists) • acknowledge parents' (or their chosen support person's) role as primary decision maker and carer of their baby • incorporate parents' values, preferences, wishes and needs.
3.8	CBR	Provide multiple opportunities for parents to ask questions and explore their concerns with the same informed, experienced, and trusted healthcare professional. • Provide opportunities for parents to revisit their decisions but inform them of time critical issues (for example mode of birth, how the baby's condition may change, time to autopsy).
3.9	EBR	Engage with parents to develop a detailed care plan that considers their values, preferences, wishes, and concerns. • Discuss advantages and disadvantages of options with parents and accompanying family/whānau or support person. • Provide appropriate information so that parents know what to expect and can make informed decisions about their care. • Ensure care plans are filed in medical records to ensure good communication between all healthcare professionals and members of the multidisciplinary team. **Evidence quality:** moderate confidence

#	TYPE	RECOMMENDATION
3.10	EBR	For labour and birth, parents should be given as much time as they need to make decisions about options offered. • Advise parents that labour and vaginal birth may provide physical and emotional benefit, compared to a caesarean birth without obstetric indication. However, parents' values, preferences, and wishes need to be respected. • Ensure parents understand what usually happens when labouring with a baby who has died and what their baby may look and feel like following birth (for example physical appearance, size, tone, and temperature). • Advise parents that the full range of pharmacological and non-pharmacological pain relief options are available for them. • Offer strong pain relief/sedation with caution as this may interfere with opportunities for spending time with the baby. **Evidence quality:** moderate confidence
3.11	CBR	Validate parenthood and support memory making by: • discussing options and exploring parents' concerns and preferences around parenting activities • offering all parents the opportunity to see and hold their baby immediately after birth, including skin-to-skin contact with their baby and supporting them through the process • normalising and supporting parenting activities such as bathing and dressing their baby • using gentle and caring language and actions when interacting with the baby • asking parents how they would like you to refer to their baby (for example by name) • providing parents information about their baby (for example weight, length, hair colour) using the same tenderness and respect afforded to any baby • providing opportunities to involve siblings, grandparents, and other family/whānau members • offering parents and family/whānau the opportunity to engage in parenting activities and memory making more than once, while remaining respectful of their decisions.
3.12	CBR	Ask parents and family/whānau throughout care about cultural needs regarding perinatal loss practices and handling of their baby's body. • Always ask parents and family/whānau permission before handling their baby.
3.13	CBR	Prepare parents for seeing and holding their baby by giving information about the baby's physical appearance, size, tone, and temperature. • Sensitively answer parents and family/whānau members questions and explore concerns. • Discuss preferences for seeing their baby, including use of special blankets, hats, or clothing.
3.14	EBR	Enable parents and family/whānau to spend as much time as they wish in private with their baby who is dying or who has died, including the option to take their baby outside into the natural environment, home, or to another place important to the family. • For a baby who has died, discuss practical matters with parents when they are ready, including care and transport of the baby's body, use of 'cold cots', and relevant legal issues. • For a baby with a life-limiting condition, consider and offer the option of perinatal palliative care in the family home, involving palliative care teams if available and ensuring parents have the support they need. **Evidence quality:** moderate confidence

#	TYPE	RECOMMENDATION
3.15	CBR	For parents of twins, triplets, or other multiple births: • provide parents with opportunities to spend time with and make memories with their baby or babies that have died • support parents in their decision making and acknowledge that there may be mixed feelings around spending time with a baby who has died, while also caring for and spending time with the surviving baby or babies • provide parents with culturally and linguistically appropriate resources and support options for the loss of a baby or babies from a multiple pregnancy.
3.16	CBR	Offer and facilitate opportunities to gather tangible mementos of the baby (for example photographs, identification tags, cot cards, locks of hair, handprints, and footprints). Memory making should be an option that is offered more than once to parents/family/whānau.
3.17	CBR	Be aware of local processes for supporting parents and family/whānau who initially choose not to keep mementos. Ensure mementos are stored securely and labelled appropriately in maternal or neonatal records for future access.
3.18	CBR	Support and facilitate parents to take a mix of photographs and videos of their baby, including with family/whānau. • Ensure photos are taken with sensitivity and are of highest possible quality. • Facilitate access to a professional photographer who has experience in compassionate bereavement photography, if desired by parents.
3.19	EBR	Offer and facilitate opportunities for commemorative rituals and acknowledge cultural, religious, and spiritual customs important to families/whānau. **Evidence quality:** moderate confidence
3.20	CBR	Sensitively discuss with parents and family/whānau that burial or cremation is a legal requirement for a baby who dies at greater than 20 weeks gestation or weight of 400 g. Provide parents with: • information (including written) that includes the range of available options for burial, cremation, and funeral, and support parents/family/whānau in their decision making • contact details for relevant services • information about available financial support.
3.21	CBR	Discuss expectations for postnatal care including lactation, vaginal bleeding, wound care, contraception, and physical activity. Provide all women with information about postnatal physical changes, postpartum care and potential complications that could occur, including when to seek medical advice and support.
3.22	CBR	Provide information on the full scope of lactation management options to women and ask open ended and nondirective questions to understand and explore perspectives, while also considering cultural and individual variations.
3.23	CBR	Discuss with parents prior to hospital discharge, their preferences for advising relevant healthcare professionals involved in their care (for example general practitioner [GP], other community-based services) of the baby's death or impending death so that existing appointments are cancelled, and other types of appropriate follow-up are activated. • Document processes and decisions to ensure handover is contemporaneous and accurate.

#	TYPE	RECOMMENDATION
3.24	CBR	Discuss the birth and death registration process with parents and family/whānau prior to their leaving hospital and ensure parents understand what is required of them. • Provide parents with written information about the registration process, including where, how, and when parents are required to register their baby's birth and death. • Ensure parents are aware that there is no fee to register, and they can choose to purchase a birth certificate at the time, or later.
3.25	CBR	Ensure parents are supported as they physically leave the hospital setting. For example, a healthcare professional or other support person should be available to accompany parents from the hospital to their mode of transport.
3.26	CBR	Ensure parents leave hospital with contact details for 24-hour follow-up support and are provided with culturally and linguistically appropriate information about ongoing sources of support including parent support organisations.
3.27	EBR	Ensure parents receive follow-up calls or visits, as required, from an appropriately skilled healthcare professional. **Evidence quality:** moderate confidence
3.28	EBR	Ask parents about their social and emotional wellbeing at all postnatal care appointments and appropriately refer to support services where needed. • Ensure sufficient time is available in all follow-up appointments with bereaved parents to enquire about their social and emotional wellbeing. • Provide information about future pregnancy planning and reproductive health at appropriate time points throughout their care and follow-up, including family planning if desired. See Section 5: Care in subsequent pregnancies **Evidence quality:** moderate confidence

Section 4 – Perinatal palliative care

#	TYPE	RECOMMENDATION
4.1	CBR	When a life-limiting perinatal condition is diagnosed in pregnancy, arrange a formal consultation with parents and family/whānau and the lead healthcare professionals to openly discuss the diagnosis and available options and begin to develop a detailed palliative care plan. A follow-up meeting should be held once parents have had the opportunity to consider and discuss with others the information received.
4.2	CBR	Parallel planning related to potential outcomes should be considered to provide comprehensive information to parents and family/whānau (for example antepartum stillbirth, intrapartum stillbirth, very early neonatal death, survival). Develop a detailed perinatal palliative care plan that includes all phases and transitions of care: • antenatal care plan • birth care plan • newborn care plan • perinatal loss care plan.
4.3	EBR	Provide perinatal palliative care within a parent-centred decision-making framework involving parents and family/whānau and the multidisciplinary care team. **Evidence quality:** Moderate confidence

#	TYPE	RECOMMENDATION
4.4	EBR	Discuss the option of community-based perinatal palliative care and ensure community-based practical, social, and emotional support is available, including care at home, outreach, hospice, generalist palliative care services with support from the multidisciplinary team so they can accommodate babies. **Evidence quality:** Moderate confidence
4.5	CBR	Discuss and provide all required documentation to the parents, family/whānau and community care team members when a baby is to be transferred to community-based care including care at home, outreach, hospice, or generalist palliative services (for example birth registration, letters for transport).
4.6	CBR	When a baby has died, provide parents with the option to take their baby home or to cultural, religious, or spiritual places that hold meaning for their family/whānau. Discuss these options with parents and provide accurate information about caring for the deceased baby at home.

Section 5 – Care in subsequent pregnancies

#	TYPE	RECOMMENDATION
5.1	EBR	Offer bereaved parents postpartum/preconception consultation(s) to discuss future pregnancy planning. • Provide information about the types of specialised care and support available that may benefit parents in a subsequent pregnancy. **Evidence quality:** Moderate confidence
5.2	EBR	Support parents to plan the timing of a subsequent pregnancy, taking into consideration physical and emotional recovery and the circumstances of the previous birth. **Evidence quality:** Moderate confidence
5.3	EBR	Provide care in a subsequent pregnancy within a continuity of care and carer model with a multidisciplinary focus and appropriate to cultural, religious, and spiritual needs of each family/whānau. **Evidence quality:** Moderate confidence
5.4	EBR	Acknowledge parents' previous loss, including if and how they would like healthcare professionals to refer to their previous baby (for example by name). **Evidence quality:** Moderate confidence
5.5	EBR	Ensure effective referral pathways and appropriate handover and documentation processes are in place, with previous loss identifiable in medical records. **Evidence quality:** Moderate confidence
5.6	EBR	Review maternal risk factors and results of investigations from the previous pregnancy, with detailed clinical history and information from parents, to identify risks and opportunities to improve outcomes. • Be aware of and respectful of cultural, religious, and spiritual-based decisions around care following the death of their previous baby including (if any) postmortem investigations. **Evidence quality:** Moderate confidence

#	TYPE	RECOMMENDATION
5.7	EBR	At the initial antenatal care visit, explore parents' expectations, concerns, and support needs including: • risk of recurrent perinatal death • number and timing of appointments • availability of support outside appointments and out of hours • need for and access to additional ultrasound scans, investigations, and monitoring • pregnancy milestones and settings that may evoke a heightened emotional response and require additional support • parents' discomfort being around other pregnant women • options relating to timing and mode of birth. **Evidence quality:** High confidence
5.8	CBR	Consider early screening for gestational diabetes mellitus (GDM) in addition to routine screening at 26–28 weeks for women with a previous unexplained stillbirth.
5.9	CBR	Determine fetal monitoring frequency based on obstetric history, the circumstances surrounding the index stillbirth or neonatal death, screening findings, and parental preferences. • Consider fetal biometry, amniotic fluid, and fetal Doppler every 4 weeks from 24 weeks' gestation. • Consider additional support requirements for parents at significant milestones.
5.10	CBR	Consider the use of low dose aspirin (LDA) prophylaxis in a pregnancy following loss if preterm pre-eclampsia, or other forms of placental dysfunction, was evident. • Suitable LDA dose is 100–150 mg from 12–36 weeks gestation. • LDA prophylaxis is not recommended for preventing early pregnancy loss, spontaneous preterm birth or in the context of prior unexplained stillbirth.
5.11	CBR	It is not recommended to routinely offer women low-molecular-weight heparin (LMWH) in pregnancies following stillbirth, unless there are other medical considerations or thrombophilia is present.
5.12	EBR	To support parent-centred decision making, discuss timing and mode of birth and consider the circumstances of the previous stillbirth or neonatal death, current pregnancy, and emotional state of parents: • individualise counselling concerning timing and mode of birth • discuss planned birth from 39 weeks' gestation • discuss the potential harm of early planned birth (such as increased chance of neonatal and longer-term adverse outcomes) before 39 weeks' gestation. **Evidence quality:** Moderate confidence
5.13	EBR	Offer parents individualised preparation for birth including: • a birth plan that details the likely location of the birth (for example avoiding birthing rooms where the previous baby died) • antenatal classes specific to pregnancy after loss including tailored education (such as on fetal movement) and support • an identifier in medical records to indicate parents have experienced a previous stillbirth or neonatal death. **Evidence quality:** Moderate confidence

#	TYPE	RECOMMENDATION
5.14	EBR	Engage parents in open discussions about the challenges of pregnancy and parenting after loss by: • anticipating and supporting parents through points in pregnancy and after birth that may be particularly distressing, such as pregnancy milestones and certain settings • acknowledging the mixed emotions relating to the joy or having a baby and the ongoing grief of previous loss • asking about preparations for the baby to help identify and support parents who may experience impediments to parenting such as delayed attachment and bonding. **Evidence quality:** Moderate confidence
5.15	EBR	Ask parents about their social and emotional wellbeing and support needs at all antenatal and postnatal care appointments, in addition to routine mental health screening. Appropriately refer to support services where needed. • Provide information on how to access outpatient peer support, professional counselling and psychology services and other local and national perinatal mental health and parenting support services. **Evidence quality:** Moderate confidence

Section 6 – Investigations for perinatal death

#	TYPE	RECOMMENDATION
6.1	CBR	Counselling parents about options for investigations (including the option of a full autopsy or less invasive options) should be conducted within a parent-centred decision-making framework by an experienced healthcare professional who has established rapport with the parents. • Discussions should include the value and limitations of the investigations in their circumstances. Parents should be given multiple opportunities to discuss their options according to their needs.
6.2	CBR	Ideally, counselling parents on their options for investigations (including autopsy) is informed by a clinical case review by a multidisciplinary team, including a perinatal/paediatric pathologist, the lead obstetrician or paediatrician, and radiologist.
6.3	EBR	Information (written and verbal) and counselling for parents about all investigations, including autopsy, should include: • the possibility that the cause of death may not be determined despite all investigations being undertaken • that, while a cause may not be found, excluding some potential causes of death may be helpful • a full investigation, including autopsy, provides the best possible information to help understand why the baby died and to plan future pregnancies • when and how they will be provided with the outcome of the investigations undertaken • whether the baby will need to be transported to another centre for the investigations, how the transport is organised, when the baby will be returned to them. • how their baby will look after the autopsy • any costs to them related to investigations **Evidence quality:** High confidence
6.4	CBR	Assure parents that, throughout the process of autopsy and other investigations, their baby will be cared for by highly trained healthcare professionals who will treat their baby with respect as they do all possible to understand the cause of death.
6.5	CBR	Explain to parents that the placenta can be returned to them following examination by the pathologist. The pathology service should be notified of the parents' wishes when the placental examination is requested. Advice should be given to families/whānau about any relevant health and safety precautions when handling the placenta.

#	TYPE	RECOMMENDATION
6.6	EBR	Healthcare professionals must respectfully ask parents and family/whānau throughout their care if they have cultural, religious, or spiritual care needs including preferences for discussing and making decisions about investigations to understand why their baby died. • Healthcare professionals should avoid making assumptions and must work in partnership with families/whānau to ensure care is individualised and that their needs are met, seeking further guidance where needed. **Evidence quality:** Moderate confidence
6.7	EBR	Provide parents with a clear timeline for receiving results of investigations and reports prior to discharge. The timeline should be made in conjunction with the multidisciplinary care team, including pathologists. **Evidence quality:** Moderate confidence
6.8	EBR	The recommended core set of investigations, with further investigations based on the clinical circumstances, should be considered routine practice for all perinatal deaths. • In some circumstances it may not be appropriate to undertake all core investigations (for example where cause has been unequivocally determined antenatally). • Ideally, an individualised approach should be developed through multidisciplinary team discussion including the lead obstetrician, neonatologist/paediatrician, pathologist, radiologist, and geneticist, considering the clinical circumstances and the parents' wishes. Refer to *Appendix 6A: Stillbirth investigations flowchart and Appendix 6B: Neonatal death investigations flowchart.* **Evidence quality:** Moderate confidence
6.9	EBR	A comprehensive clinical summary should be completed for all perinatal deaths to inform the investigations required. This summary should be completed as soon as possible after the death and include the following: • medical, social, family, and pregnancy history • antenatal ultrasound results • antenatal testing • initial findings of maternal, baby, and placental examination • parent's summary of the events surrounding the death. **Evidence quality:** High confidence
6.10	CBR	A formal ultrasound for fetal anomalies, biometry and amniotic fluid index may be considered. The ultrasound should be carried out by an appropriately trained healthcare professional as soon as possible following diagnosis of a fetal death if not recently performed (within the past 4 weeks) and especially if there has been no second trimester morphology scan.
6.11	EBR	A Kleihauer–Betke test to detect feto-maternal haemorrhage (with follow-up flow cytometry for quantification if any feto-maternal haemorrhage is detected) should be performed following the death of an unborn baby, preferably prior to birth. **Evidence quality:** High confidence
6.12	CBR	External examination of the baby should be undertaken by an appropriately trained healthcare professional using *Appendix 6E: Examination of baby checklist.*
6.13	CBR	Clinical photographs, following consent from parents, should be taken for later review, particularly for births that occur in non-tertiary hospital settings and where an autopsy is declined or delayed. • These photos are additional to the bereavement photographs and should not be given to the parents. • They should be clearly labelled and filed in the medical record.

#	TYPE	RECOMMENDATION
6.14	CBR	Examination of the placenta and cord should be undertaken by the attending healthcare professional at the time of birth following the *Indications for placental examination (Appendix 6L); Placental examination for healthcare professionals (Appendix 6D).* • If offered locally (and after parental consent), sample placenta for cytogenetic testing, including request to extract and store DNA for subsequent investigations. *Appendix 6D: Placental examination for healthcare professionals.*
6.15	CBR	Full body X-ray imaging of the baby (also known as a 'babygram') should be included in the routine investigations for perinatal deaths.
6.16	EBR	Histopathology of the placenta and umbilical cord should be undertaken for all perinatal deaths by a perinatal pathologist. Microbiological culture may be required as directed by pathologist. **Evidence quality:** High confidence
6.17	EBR	Following a stillbirth or birth of a high-risk newborn, the placenta, membranes, and cord should be kept refrigerated and sent fresh to the laboratory and unfixed for macroscopic and histological examination by a perinatal pathologist as soon as possible (ideally within 48 hours of the birth). **Evidence quality:** Moderate confidence
6.18	EBR	Cytogenetic testing should be performed for all perinatal deaths by either conventional karyotyping or by chromosome microarray. • Snap freezing a piece of chorionic plate or muscle (if baby is not very macerated) is worth considering for all cases should a genetic condition need to be investigated). **Evidence quality:** High confidence
6.19	CBR	In perinatal deaths where there may be a genetic cause, parents should be referred to a multidisciplinary team with expertise in clinical genetics to discuss the option of genomic sequencing where this option is available.
6.20	EBR	Autopsy should be offered to all parents with an explanation of the likely value of the examination, including any limitations, in their specific circumstances. **Evidence quality:** High confidence
6.21	CBR	Consent for autopsy must clearly outline the extent of the investigations to be undertaken and should be recorded on an approved consent form, relevant to the jurisdiction.
6.22	CBR	When consent is obtained for specific organ/s to be retained for further examination at autopsy, parents should be offered the option of either delaying the funeral until the organs can be returned to the body or specifying their preference for how their baby's retained organs are to be taken care of and their preferred method of organ disposal.
6.23	EBR	A comprehensive clinical summary should accompany the baby for autopsy and imaging to guide the procedure, including maternal, medical, social, family and pregnancy history, and results of antenatal investigations and imaging. Ideally, the cord and placenta should be sent with the baby for autopsy examination. Complete the following documents: • *Appendix 6D: Placental examination for healthcare professionals* • *Appendix 6E: Examination of baby checklist* • *Appendix 6G: Autopsy clinical summary form* • *Appendix 6K: Exemplar placental histopathology request form* **Evidence quality:** Moderate confidence
6.24	EBR	A perinatal/paediatric pathologist should perform or supervise all perinatal postmortem examinations. **Evidence quality:** High confidence

#	TYPE	RECOMMENDATION
6.25	EBR	If local autopsy is unavailable, transport for the baby to a centre with appropriate expertise should be arranged as per local procedures. **Evidence quality:** Moderate confidence
6.26	CBR	In remote settings, where autopsy is unavailable, communication with a multidisciplinary team (obstetrician and/or neonatologist/paediatrician, perinatal pathologists, and geneticist) at tertiary centres should be established to ensure that any opportunities to gather information or investigations that can be performed locally are not missed.
6.27	CBR	Ideally, the final autopsy report should be forwarded to the referring healthcare professional within six weeks of the autopsy where the brain is not examined or 14 weeks if the brain is examined. (This is an aspirational target noting that reports may take longer due to resource limitations.) Healthcare professionals should consult with the perinatal pathology service available in each jurisdiction to obtain estimates of time to completion of autopsy (and release of body) and completion of report.
6.28	CBR	A copy of the autopsy report (including the plain language summary, if available) of any stillbirth or neonatal death should be sent to the requesting healthcare professional and woman's general practitioner (GP).
6.29	CBR	Maternal and newborn services should ensure appropriate education on the local coronial process for perinatal deaths is provided for all healthcare professionals. Healthcare professionals should seek advice from the coroner if any doubt exists as to whether a death should be referred to the coroner.
6.30	EBR	Where a full autopsy is declined by the parents, alternative options of less or minimally invasive investigations should be offered and an explanation provided of the value in their circumstances following a multidisciplinary discussion including the obstetrician, and neonatologist/paediatrician pathologist, radiologist, and geneticist as required. In addition to all core investigations, the following should be offered to parents who decline a full autopsy: • limited autopsy or minimally invasive tissue sampling (where available) • external examination by the pathologist • full body X-ray imaging of the baby (also known as a 'babygram') • postmortem MRI (where available). **Evidence quality:** Moderate confidence
6.31	CBR	A postmortem MRI, where available, should be offered to parents as an adjunct to autopsy or in place of an autopsy where this is declined. • Ideally, MRI should be performed within 24 hours of stillbirth. • MRI has been shown to be helpful in identifying brain and spinal cord anomalies, particularly in macerated stillborn babies.

Section 7 – Perinatal mortality audit and classifications

#	TYPE	RECOMMENDATION
7.1	EBR	All maternal and newborn services should implement a formal process for perinatal mortality audit, including identification of causes, associated conditions, and contributing factors relating to care. **Evidence quality:** Moderate confidence
7.2	CBR	Smaller services, including those in rural and remote regions, are encouraged to participate in combined perinatal audit meetings with other experienced maternal and newborn services to ensure high-quality audit.

#	TYPE	RECOMMENDATION
7.3	CBR	If a baby dies outside the hospital of birth, the audit should ideally be carried out by the hospital where the baby was born. Communication between hospitals that provided care is needed to ensure the perinatal mortality audit committee has access to all relevant details.
7.4	CBR	All maternal and newborn services should ensure that appropriate systems for undertaking perinatal mortality audit, reporting of findings, and implementation of recommendations are in place and that the perinatal mortality audit committee is adequately supported to ensure perinatal mortality audit is conducted effectively.
7.5	CBR	The Perinatal Mortality Audit Committee should arrange for review of perinatal death to occur in a timely manner, aiming to have results in time for the initial follow-up visit with parents. • If test results are delayed, it may be necessary to re-review and arrange additional follow-up meetings with the parents to provide final results.
7.6	CBR	Discuss the audit process with parents including how parents may be involved, and when, and how the results of the audit will be provided. • This should be conducted by an experienced healthcare professional, ideally the lead healthcare professional involved in the parents' care or the known point of contact for each family/whānau (such as a bereavement midwife).
7.7	CBR	Offer parents the option of providing a summary of events for presentation at the audit meeting either through a written summary using the Australian Perinatal Mortality Audit Tool, or local equivalent, and/or a healthcare professional presenting information on their behalf.
7.8	EBR	Perinatal mortality audit committees should ensure the classification of causes and associated factors for stillbirths and neonatal deaths use the best available information from a comprehensive history and appropriate investigation (see Section 6: Investigations for perinatal death). **Evidence quality:** High confidence
7.9	CBR	The Australian Perinatal Mortality Audit Tool (or local equivalent) or the New Zealand Mother and Baby Rapid Reporting Forms for a Perinatal Death should be completed for each perinatal death in Australia and Aotearoa New Zealand, respectively, for purposes of committee review of the death and for relevant local and jurisdictional reporting requirements.
7.10	CBR	The Medical Certificate of Perinatal Death should be completed by (or supervised by) the lead/experienced healthcare professional responsible for care around the time of the death in accordance with local requirements.
7.11	EBR	The perinatal mortality audit process should be overseen by a multidisciplinary committee including medical staff (obstetric and neonatal), midwives, nurses, a perinatal pathologist (where possible), and parent advocate. **Evidence quality:** High confidence
7.12	EBR	The perinatal mortality committee chair must ensure audits are conducted in a no-blame environment. **Evidence quality:** Moderate confidence
7.13	EBR	Perinatal mortality audit committees should use the PSANZ Classification system to assign the underlying cause of death and up to two associated conditions for every perinatal death after consideration of all relevant clinical information. **Evidence quality:** High confidence

#	TYPE	RECOMMENDATION
7.14	CBR	The maternity service (ideally through a designated bereavement service) should ensure the death certificate is revised, when necessary, based on the outcome of the perinatal mortality audit meeting and ensure a revised copy is sent to the parents. • Parents should be informed by the lead carer (ideally a bereavement midwife) that they will receive a revised death certificate including the reasons for the revision.
7.15	CBR	The perinatal mortality audit committee should consider areas for practice improvement in relation to every perinatal death and develop recommendations and an accompanying implementation plan where relevant. This should also include any recommendations for care of the woman in a subsequent pregnancy.
7.16	CBR	A follow-up meeting with the parents, ideally with the lead healthcare professional involved in the woman's care and the healthcare professional managing the perinatal mortality audit process (for example bereavement midwife or nurse), should be offered to discuss the outcome of the review by the perinatal mortality audit committee. More than one follow-up meeting may be required, depending on when the final results of investigations become available, and the audit committee finalises the review.
7.17	EBR	Parents should be offered a plain language summary of the outcome of the review of their baby's case by the perinatal mortality audit committee. Ideally, this should occur during a face-to-face follow-up meeting with the lead healthcare provider, the bereavement midwife, and other relevant members of the health care team. **Evidence quality:** Moderate confidence
7.18	CBR	A comprehensive clinical summary should be sent to the woman's general practitioner and all care providers nominated to the parents after review by the perinatal mortality committee.
7.19	EBR	Following the completion of the review by the perinatal mortality audit committee, the chair of the perinatal mortality audit committee or delegate should ensure a summary of the classification of causes and contributing factors relating to care is provided to the jurisdictional perinatal mortality committees for regional and national reporting. **Evidence quality**: Moderate confidence
7.20	EBR	The assigned classifications for causes and contributing factors relating to care should be included in the routine perinatal data collections across jurisdictions for every perinatal death to enable comprehensive reporting of perinatal deaths. **Evidence quality:** Moderate confidence
7.21	CBR	National definitions for statistical reporting of perinatal deaths should be used to ensure consistency and comparability in perinatal death data across Australia and Aotearoa New Zealand. Reports of perinatal deaths should present data with and without the inclusion of perinatal deaths resulting from termination of pregnancy.

Section 8 – Organisational recommendations

#	TYPE	RECOMMENDATION
8.1	CBR	Each maternal and newborn service should establish and support a multidisciplinary team approach across the continuum of care to meet the physical, social, and emotional, cultural, religious, and spiritual needs of bereaved parents and family/whānau. • Ensure processes are established for cultural support services including interpreters. • Use a recognisable marker that designates perinatal loss in all physical spaces where bereaved parents are cared for, to ensure all clinical and non-clinical staff are aware of loss.

#	TYPE	RECOMMENDATION
8.2	CBR	Ensure a coordinated and informed approach to care across the continuum through a dedicated role within the service, ideally a bereavement midwife, to be a known point of contact (that is, contact details of a named healthcare professional) for bereaved parents and family/whānau. • This requires appropriate rostering of staff to provide high quality care.
8.3	CBR	Maternal and newborn services should have established protocols in place to access appropriate expertise where not available locally for all aspects of care around the time of a perinatal death and in subsequent pregnancies (such as team-to-team or telehealth consultations). • This is particularly important to ensure families/whānau who live in regional or remote areas have access to appropriate clinical, social, and emotional supports.
8.4	CBR	Ensure culturally and linguistically appropriate information and resources are available in multiple formats (print, audio, digital) and languages for bereaved parents and family/whānau.
8.5	EBR	Ensure a designated private and safe place is available for bereaved parents and family/whānau whose baby has died or is receiving palliative care. This includes capacity and resources to support: • parents to spend time with and create memories with their baby including mementos and other keepsakes • family/whānau members and other support people to gather • cultural, religious, and/or spiritual rituals or ceremonies. **Evidence quality:** Moderate confidence
8.6	CBR	Establish a local process for storing mementos for parents who initially choose not to take them, including how to store securely and label appropriately in medical records for future access.
8.7	EBR	Establish relationships and partnerships with parent support organisations to ensure appropriate commemorative rituals are available to parents, such as an annual remembrance service for parents whose babies have died. **Evidence quality:** Moderate confidence
8.8	CBR	All healthcare professionals should be aware of and familiar with the law, policy, practices, and clinical care standards related to reporting stillbirths and neonatal deaths.
8.9	EBR	Maternal and newborn services should make available specific professional development opportunities in care around stillbirth and neonatal death to all staff. The Improving Perinatal Mortality Review and Outcomes Via Education (IMPROVE) educational program has been well received by healthcare professionals across Australia. **Evidence quality:** Moderate confidence
8.10	CBR	Organisations must provide and maintain effective cultural education for all healthcare professionals particularly non-Indigenous health professionals. Education must include: • cultural awareness and understanding of diversity within and between cultural groups • understanding of implicit biases and ongoing racism for some population groups • impact of colonisation for some populations, particularly Aboriginal and Torres Strait Islander communities in Australia and Māori communities in Aotearoa New Zealand • awareness of history of trauma and loss, and previous negative experiences with health services particularly: – intergenerational trauma among Aboriginal and Torres Strait Islander families – complex trauma among women of refugee background • acknowledge the importance of each cultural group's vital support systems such as kinship and community care for Aboriginal and Torres Strait Islander families.

#	TYPE	RECOMMENDATION
8.11	CBR	Maternal and newborns services should ensure that healthcare professionals who provide care around stillbirth and neonatal death have access to formal and peer support and are encouraged to prioritise their social and emotional wellbeing.
8.12	CBR	All maternal and newborn services should implement a perinatal mortality audit program that is integrated into quality improvement activities to ensure practice improvement in the provision of care around stillbirth and neonatal death. The audit program should include parent experiences of care.

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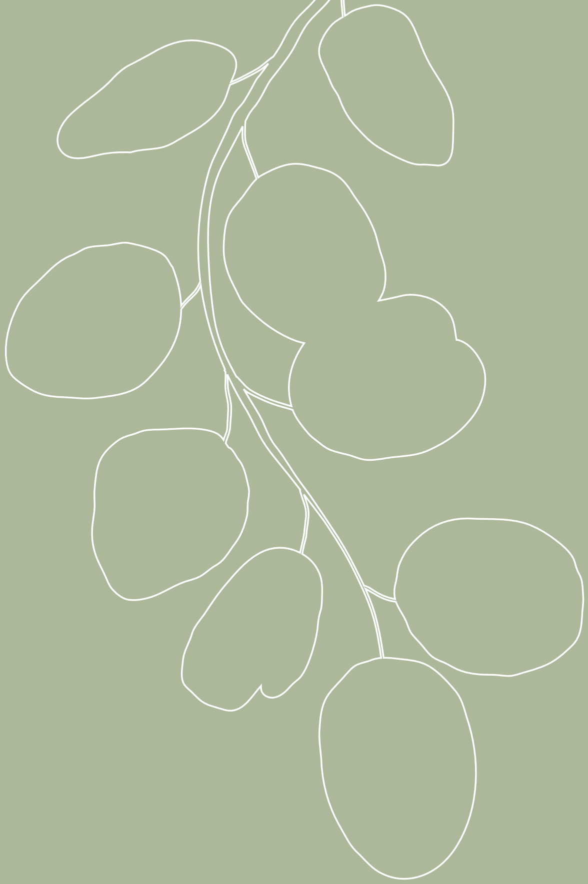

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