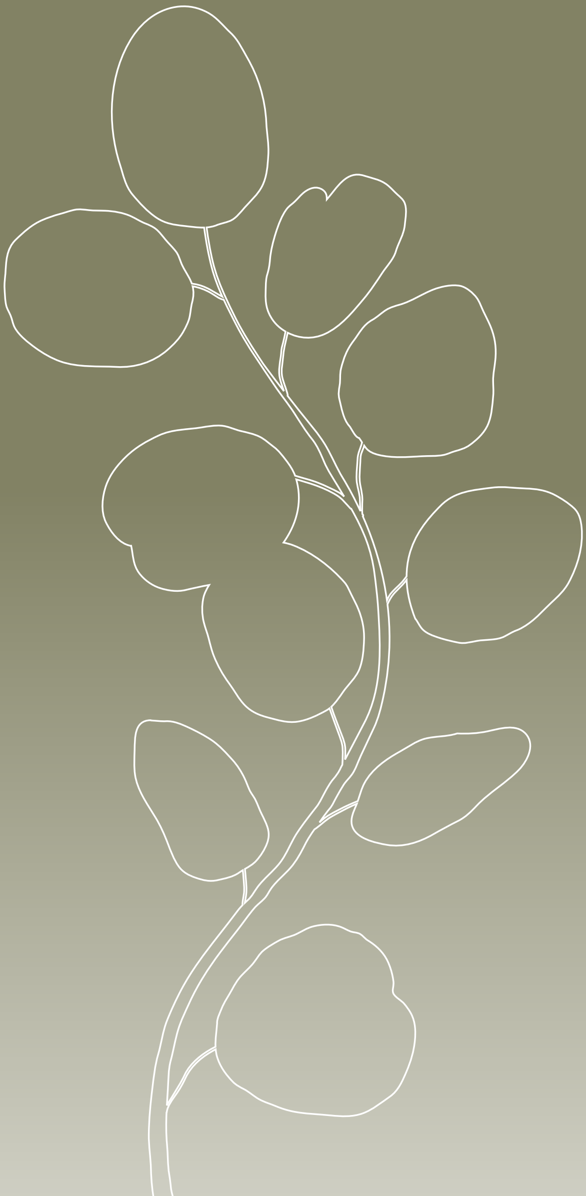
2024 EDITION

Care Around Stillbirth and Neonatal Death

Clinical Practice Guideline

Implementation and dissemination plan



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

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Introduction

Stillbirth and neonatal death are devastating pregnancy outcomes with long-lasting psychosocial consequences for parents and families/whānau, and wide-ranging economic impacts on health systems and society. Every year, 1 in every 100 pregnancies at or beyond 20 weeks' gestation ends with the death of a baby during pregnancy (stillbirth) or up to 28 days after birth (neonatal deaths). Stillbirths and neonatal deaths disproportionately affect Aboriginal and/or Torres Strait Islander women, Māori women, women living in remote settings, and women of migrant and refugee background, particularly those from countries in South Asia and Africa. Further, many parents will become pregnant again within a year of the death of their baby. Subsequent pregnancies present an increased risk of a range of obstetric complications and adverse pregnancy outcomes, and many parents will experience high levels of anxiety, depression, and fear during these pregnancies.

The quality of care that parents and family/whānau receive around the time a baby dies can have immediate and long-lasting consequences and extend into subsequent pregnancies and beyond. Respectful, supportive, and culturally responsive care should be provided to all parents and family/whānau who experience perinatal loss regardless of whether the loss occurs during pregnancy or after birth. Optimal perinatal loss care is based on the needs of parents rather than the type of loss.

For most families, perinatal bereavement care begins in maternity care settings. National guidelines and standards of recommended care exist, but widespread uptake and embedding of a consistent evidence-based approach is needed to ensure parents receive the best possible care regardless of where or when their loss occurs and to avoid a 'lottery of care'. Integrated care and support across maternity and community settings are vital for families following perinatal loss. The transition from hospital to community has long been recognised as a serious shortcoming in perinatal bereavement care with many parents feeling 'abandoned' and with few clear pathways to needed support. Strengthening services to ensure care follows parents from the maternity care setting to community is an important priority. It is also important to identify and implement the elements of care and support in subsequent pregnancies that lead to the best outcomes for parents, their babies, and families.

Best practice following stillbirth and neonatal death is clear – what is needed is a consistent national approach to implementation.

Understanding the causes and contributing factors for stillbirth and neonatal death through perinatal mortality audit is the essence of prevention and a crucial component of bereavement care to help parents recover and plan future pregnancies. However, many of these deaths are not appropriately investigated or understood and remain unexplained. The lack of a diagnosis adds to parents' distress, as they struggle to understand what went wrong and ask "will it happen again" in a subsequent pregnancy. Deficiencies in the quality of care are implicated in 20–30% of stillbirths, highlighting the importance of reviewing every perinatal death to identify the practice improvements necessary to reduce the numbers of these tragic deaths. In our recent work, we found significant gaps in the use of evidence-based clinical care guidelines, training and education of care providers in the delivery of best practice bereavement care, and providing parents the opportunity to engage and be involved in the perinatal mortality review process.

Best practice following stillbirth and neonatal death is clear – what is needed is a consistent national approach to implementation to ensure all affected parents in Australia are provided with respectful and supportive care including high quality investigations to help understand what went wrong and inform prevention strategies to reduce these deaths.

In Australia, the National Stillbirth Action and Implementation Plan1 highlights the need for all families who experience stillbirth to receive personalised, respectful, supportive and holistic clinical and community care. As the national Centre of Research Excellence in care for bereaved parents and families around perinatal death, we will provide leadership and collaborate with partners to support and promote the implementation of this edition of the guideline with the Perinatal Society of Australia and New Zealand (PSANZ). This includes improving care for all bereaved parents and families who experience the death of a baby during pregnancy or soon after birth and are cared for in maternal and newborn settings – regardless of where a baby dies in Australia or Aotearoa New Zealand.

Objective

The purpose of the 2024 edition of the *Care around Stillbirth and Neonatal Death (CASaND) Clinical Practice Guideline* is to promote best practice across Australia and Aotearoa New Zealand for stillbirth and neonatal deaths. Maternal and newborn care settings are the primary focus, as well as interfaces between hospital-based services, the community and the longer-term support needs of parents and families/whānau.

This implementation and dissemination plan describes the approach for dissemination of the guideline and for a national approach to implementation. The specific objectives of this dissemination and implementation plan are to:

- Outline a multi-faceted and efficient strategy to raise awareness about the guideline and increase its reach across a range of targeted end-users and stakeholders
- Outline the approach for evaluating the effectiveness of guideline dissemination
- Describe a national approach for implementation and evaluation of the guideline
- Present the key guideline recommendation most likely to lead to improvement.

The Australian Commission on Safety and Quality in Health Care The Australian Commission on Safety and Quality in Health Care (ACSQHC) released the *Stillbirth Clinical Care Standard* in November 2022. The Standard aims to reduce variation in the prevention and investigation of stillbirth, and to support best practice in bereavement care after any perinatal loss. This Standard provides maternal and newborn services with a robust tool to help with implementation of the guideline.

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 (e.g. 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 policymakers, health systems administrators, and others involved in implementation of maternal, newborn and child health programs. In addition, the Guideline 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.

Dissemination strategies

The 2024 edition of the CASaND guideline will be promoted and disseminated using a multifaceted approach, catering to all the guideline's target audience as outlined in Table 1 and further described below.

Table 1: Dissemination approach and target audience

DISSEMINATION APPROACH	TARGET AUDIENCE			
	HEALTHCARE PROFESSIONALS	IMPLEMENTERS OF MATERNAL, NEWBORN AND CHILD HEALTH PROGRAMMES	PARENTS, FAMILIES/ WHĀNAU, SUPPORT PEOPLE	OTHER STAKEHOLDERS
Launch activities				
Launch event	✓	✓	✓	✓
Media release and media engagement				✓
Social media and communications kit	✓	✓	✓	✓
Post-launch dissemination				
Email distribution (newsletter)	✓	✓	✓	✓
Federal Parliamentarians "introduction kit" to enable local connections		✓	✓	✓
Blog	✓	✓	✓	✓
Plain language summary			✓	✓
Web-based tool	✓	✓	✓	✓
Face-to-face activities				
Workshop/seminar/ meeting	✓	✓	✓	✓
Webinar	✓	✓	✓	✓
Conference	✓	✓	✓	✓
Scientific outlets				
Registration on guideline databases	✓			✓
Journal publications	✓	✓		✓

Launch activities

Launch event

The guideline will be officially launched on Tuesday 9 April 2024 at the PSANZ annual congress to be held in Christchurch from 7–10 April 2024. PSANZ is a multidisciplinary society promoting communication and collaboration among those involved in perinatal research and care to develop professional, political, administrative, and educational advice. Membership includes neonatologists, neonatal nurses, obstetricians, midwives, pathologists, epidemiologists, social scientists, and others involved in research and care of women, babies, and families during pregnancy, birth, and the postnatal period.

Media release

The Stillbirth CRE will engage communications agency 89 Degrees East to develop a media release announcing the launch of the guideline and its significance. 89 Degrees East specialises in strategic advice, policy, and communications and has a long-standing relationship with the Stillbirth CRE. It is anticipated that the release will yield media coverage the form of print, online and radio, which will then be further disseminated via the Stillbirth CRE website and social media channels. We will also explore opportunities to disseminate the information through targeted podcasts – especially those popular among priority populations.

Social media and communications kit

Working with PSANZ, the Stillbirth CRE will use its existing social media platforms (LinkedIn, Twitter, Facebook) and branding to launch and promote the guideline including a paid socials campaign. A social media and communications kit will be developed, including suggested copy, social media graphics/tiles, and links for further information. This kit will be shared with partner organisations to increase reach.

Post-launch dissemination

Stillbirth CRE and PSANZ email lists and newsletters

Previous editions of the **Stillbirth CRE newsletter** have included progress updates on the guideline and calls for public consultation. In continuing with this engagement, the launch of the completed guideline will be featured in the newsletter, which is emailed to 9,892 subscribers and is also available on the Centre website. The PSANZ newsletter will also share details of the launch of the guideline. Subscribers will be asked to forward the email to their networks and any other interested parties.

Engaging local MPs and Senators to encourage local dissemination of the materials

Local MPs play an important role in bringing their community together. The Stillbirth CRE will create an "introductory pack" for each Federal MP and Senator. The pack will highlight the challenge, the CRE's role, the importance of the new guidelines and provide tips on how MPs can support their community by sharing the resources with local parent groups, maternity and newborn care settings and a range of priority populations — such as First Nations, Migrant and Refugee, as well as rural and remote communities. The introductory pack will also provide information on how the local MP can continue to keep their community informed through the social networks in place and the blog outlined below.

Blog

The parent voice remains critical to emphasising the impact of stillbirth and neonatal death and the importance of putting the guideline recommendations into practice. The Stillbirth CRE will partner with a bereaved parent who is willing to share their experience of perinatal death in blog form and what impact they feel the guideline can have for improving outcomes for families. We will also engage with existing parent-led Blogs.

Plain language summary

A summary of the guideline will describe the recommendations in plain language and be targeted primarily at parents and families/whānau. It is anticipated that this summary will be packaged together with the blog described above.

Web-based tool

A web-based version of the guideline will be created to aid usability for those using the guideline via computer or handheld device. The web-based tool will aid navigation around guideline sections via clickable links, hide/show content, and pop-up boxes with definitions of key terms and phrases.

Face-to-face activities

Workshop/seminar/meeting

As a chief dissemination and education strategy, in partnership with PSANZ, the Stillbirth CRE proposes to enhance and expand the existing IMproving Perinatal Mortality Review and Outcomes Via Education (IMPROVE) program to ensure direct alignment with the revised guideline. IMPROVE is available as a face-to-face workshop and eLearning resource and has already been completed by over 6,000 healthcare professionals in Australia, which demonstrates its acceptability and effectiveness.

In addition, the guideline will be promoted at ongoing Stillbirth CRE and PSANZ events including the Annual National Stillbirth Forum and outreach face-to-face educational programs (roadshows). This will ensure prioritisation of dissemination in rural and remote services across Australia. Stillbirth CRE advisory groups (listed below) will also promote the guideline among their networks and via dedicated meetings and events, particularly aspects of the guideline that pertain to their specific areas of work.

- Education committee
- Indigenous advisory group
- Migrant and refugee advisory group
- Rural and remote advisory group
- Safer Baby Bundle Operational committee
- Safer Baby Bundle Steering committee

Webinar

With PSANZ, the Stillbirth CRE will host a live, open webinar for guideline stakeholders to summarise the guideline devolvement and content. The key recommendations will be emphasised, and the evaluation strategy described. The webinar will be recorded and available to view via the Stillbirth CRE website for any interested stakeholders who cannot attend live. We will also develop and tailor webinars and resource packs specific to target audience groups such as General Practitioners (GP).

Conference presentations

Stillbirth CRE staff and collaborators will submit abstracts to present aspects of the guideline development and (future) evaluation at relevant scientific conferences and meetings. Such conferences may include the PSANZ annual congress, the Australian College of Midwives national conference, the International Conference on Stillbirth, SIDS and Baby Survival, and others.

Via networks

With PSANZ, the Stillbirth CRE will ask partner organisations in Australia and Aotearoa New Zealand to promote the guideline, including at the time of its launch by use of the social media kit. The Department of Health and Aged Care will promote the Guideline in the **Chief Nursing and Midwifery Officer (CNMO) newsletter**. NHMRC will publish a notice in the **Tracker newsletter** to advise that the guideline has been approved.

Partner organisations include academic and research institutions, member organisations for healthcare professionals, and parent support organisations.

Academic and research institutions

- The University of Queensland (Stillbirth CRE host institution)
- Mater Research Institute (Stillbirth CRE host institution)
- Griffith University
- Monash University
- The University of Sydney
- The University of Melbourne
- South Australian Health and Medical Research Institute
- Mercy Perinatal
- Kolling Institute of Medical Research
- Hudson Institute of Medical Research
- Burnet Institute
- National Perinatal Epidemiology and Statistics Unit
- Murdoch Children’s Research Institute (MCRI)

Professional and health services organisations

- Australasian Society of Ultrasound in Medicine (ASUM) (Australia)
- Australasian Sonographers Association (ASA) (Australia)
- Australian and New Zealand Neonatal Network (ANZNN) (Australia and Aotearoa New Zealand)
- Australian Association of Social Workers (AASW) (Australia)
- Australian College of Midwives (ACM) (Australia)
- Australian College of Rural and Remote Medicine (ACRRM) (Australia)
- Australian Commission on Safety and Quality in Health Care (the Commission) (Australia)
- Australian Private Hospitals Association (Australia)
- Australian State and Territory Health Departments (including the Woman-centred Care Senior Officials Groups) (Australia)
- Baby Loss New Zealand (Aotearoa New Zealand)
- Catholic Health Australia (Australia)
- Centre of Perinatal Psychology (Australia)
- Congress of Aboriginal and Torres Strait Islander Nurses and Midwives (CATSINaM) (Australia)
- CRANAPlus (Australia)
- Health New Zealand (Aotearoa New Zealand)
- International Stillbirth Alliance (ISA)
- Multicultural Centre for Women’s Health (WCWH) (Australia)
- National Aboriginal Community Controlled Health Organisation (NACCHO) (Australia)
- New Zealand College of Midwives (NZCOM) (Aotearoa New Zealand)
- Royal Australasian College of Physicians (RACP) (Australia)

- Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG) (Australia and Aotearoa New Zealand)
- Royal Australian College of General Practitioners (RACGP) (Australia)
- Royal Australian and New Zealand College of Psychiatrists (Australia and Aotearoa New Zealand)
- Royal College of Pathologists Australasia (RCPA) (Australia)
- Royal Australian and New Zealand College of Radiologists (RANZCR) (Australia and Aotearoa New Zealand)
- Royal New Zealand College of General Practitioners (RNZCGP) (Aotearoa New Zealand)
- Women's Healthcare Australasia (WHA) (Australia)
- Vicki Culling Associates (Aotearoa New Zealand)

Parent support organisations

- Bears of Hope (Australia)
- Centre of Perinatal Excellence (COPE) (Australia)
- Miracle Babies Foundation (Australia)
- Multicultural Centre for Women's Health (WCWH) (Australia)
- Perinatal Loss Centre (PLC) (Australia)
- Pink Elephants Support Network (PESN) (Australia)
- Raising Children Network (RCN) (Australia)
- Red Nose Australia (Australia)
- Remembering Riley (Australia)
- Stillbirth Foundation Australia (SFA) (Australia)
- Sands New Zealand (Aotearoa New Zealand)
- Still Aware (Australia)
- Heartfelt (Australia)

Scientific outlets

Registration on guideline databases

The Stillbirth CRE will register the guideline in the **International Guidelines Library** of the Guidelines International Network. This library is free to access and contains guidelines in development and published from across the world.

Journal publications

The Stillbirth CRE will publish articles about the guideline in peer reviewed academic journals. This may include commentaries on the development process and key recommendations, as well as on the importance of guideline expansion to address:

- cultural safety and inclusiveness for culturally and ethnically diverse populations
- perinatal palliative care
- care in subsequent pregnancies.

In addition, the Stillbirth CRE and its international collaborators intends to propose a follow-up series on stillbirths to The Lancet, based on the success of previous special stillbirth series in 2011 and 2016. Papers relating to the guideline may be included in a special issue accompanying this series.

Accessibility considerations

The guideline and all supporting documents and resources will be available via the **Stillbirth CRE website**. The guideline will be available as a web-based tool and as a printable text document (e.g., PDF format). Accessibility issues such as compatibility with digital devices (e.g., smart phones, iPads) and offline access will be considered in the design of the digital infrastructure.

The guideline has the following features to enhance accessibility:

- available free of charge (no paywall)
- accompanying plain language statement
- clearly structured with colour coding to delineate guideline sections and to distinguish between the two types of recommendations in the guideline
- hyperlinks to relevant resources.

Evaluation of effectiveness of dissemination

A dissemination and impact log will be developed to track the guideline's reach and impact. This log will comprise information and metrics including:

- details of presentations related to the guideline (e.g., scientific conferences, congresses, meetings, webinars, other) and any feedback received
- social media engagement (posts, likes, shares, and comments and impressions) related to the guideline and/or its launch materials
- guideline views and downloads via the Stillbirth CRE website (assessed via Google Analytics)
- citations of journal articles about the guideline
- formal written feedback received via the Stillbirth CRE website or email address
- expressions of interest for individuals who wish to be involved in future updates of the guideline.

Governance strategies

The evidence base underpinning any guideline must be monitored in order the recommendations to remain valid and useful. As part of core business, the Stillbirth CRE will monitor new publications and reports which may be relevant to the Guidelines. In addition, the guideline will be updated based on a comprehensive literature review every three years. Where new evidence is identified, the Guideline Development Committee will consider whether the evidence could potentially impact the evidence base for the associated recommendation(s). If so, the relevant recommendation(s) will be re-evaluated. In addition, any formally communicated concern about the validity of any recommendation will be reviewed by the Guideline Development Committee and plans will be made to update the recommendation where required. Any such feedback will also be recorded in the dissemination and impact log.

To maintain document version control and guideline integrity, a document management protocol will be employed, ensuring standardised record keeping of:

- any approved changes to the guideline
- the document version number associated with the change
- notification to stakeholders of changes to the guideline.

These strategies will facilitate the transition of the guideline to a living guideline platform, when available.

A national approach to implementation

Parents who experience the death of a baby consistently link their grief with the quality of care they received in maternity settings. There is large variation in knowledge and clinical practice, with healthcare professionals often ill-equipped to provide respectful and supportive bereavement care, including breaking bad news and supporting grieving parents through complex and difficult decisions. Tailored support for culturally diverse populations is essential.

A co-designed national care pathway is currently under development by the Stillbirth CRE to ensure best practice care is provided across the continuum of care and different settings (see Figure 1), and for all parents and families/whãnau that experience a perinatal loss. This includes early pregnancy loss. This package will focus on increasing the uptake of best practice to meet national standards including undertaking high-quality investigation and audit with feedback to close the audit loop. We will adapt and tailor existing clinician and parent-facing resources to form a support package for each stage of the pathway. This aims to meet the needs of diverse communities through co-design. The package includes bereavement outreach to parents and families, and providing training and real-time support to smaller services using telehealth (e.g. network of experienced in how to chair audit meetings).

This national approach to implementation aligns with the planned update to the national education program ‘IMPROVE 2.0’. With PSANZ, the Stillbirth CRE is working with healthcare professionals and bereaved parents to expand the existing education program to support and sustain evidence-based care and address care inequities in maternity and newborn care settings. This update will focus on enhancing the existing content to align with this edition of the clinical practice guideline and incorporate other training priorities identified by healthcare professionals and parents for bereavement care. We will also co-design additional training and education components for:

- cultural safety and inclusiveness for Aboriginal and Torres Strait Islander families, South Asian and African-born families
- early pregnancy loss (miscarriage)
- care in subsequent pregnancies
- supporting the emotional wellbeing of healthcare professionals.

Evaluation

We will monitor engagement and impact of the national care pathway through in-built data collection methods. We will evaluate the effectiveness and acceptability of the care pathway using mixed-methods approaches including a pre-post-trial with maternal and newborn care services. Nested studies are planned and include:

- cross-sectional surveys of healthcare professionals to determine the acceptability and usefulness of the care pathway in delivering best practice perinatal bereavement care around the time of stillbirth and neonatal death (in maternity settings) and continued care (in community settings). Surveys will also elicit clinician knowledge and confidence in using the toolkit and resources, including parent-facing resources to encourage shared decision-making.
- surveys will be undertaken to examine parent care experiences and psychosocial outcomes including acceptability of parent-facing resources.

We will also assess the impact of the intervention on hospital resource use, level of implementation and the influence of leadership, governance, and workforce culture on implementation. An economic evaluation will be undertaken. The co-design of a national care pathway and evaluation is a 4-year program of work that requires more than $8 million in national funding.

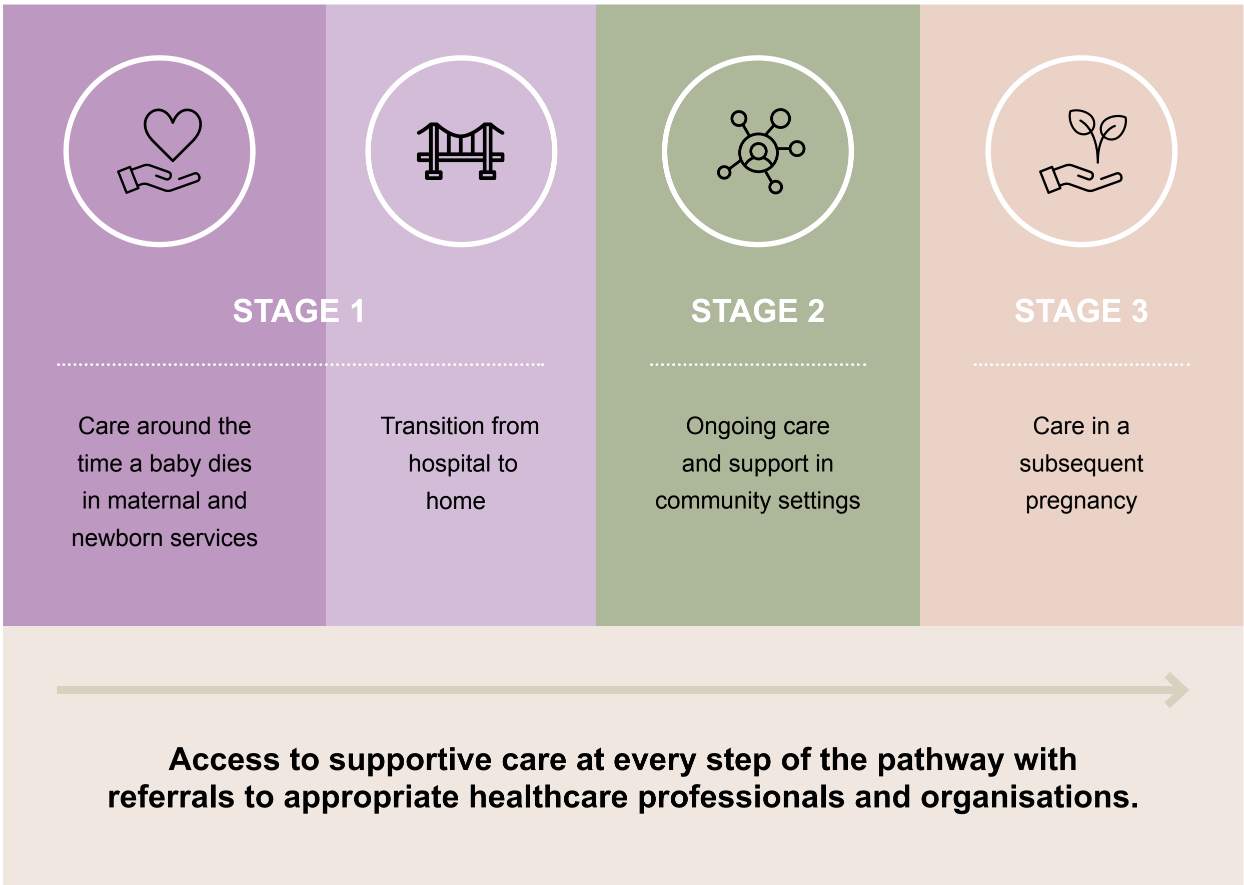

Figure 1. Illustration of a national care pathway across phases and settings to ensure parents receive best possible care around stillbirth and neonatal death.

A national care pathway is also under development in Aotearoa New Zealand.

Key recommendations

The CASaND guideline is a comprehensive clinical practice resource describing 127 recommendations spanning seven major areas. Table 2 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 maximize effective uptake.

Recommendations with potential resource implications for healthcare providers and institutions were identified by the Guideline Development Committee and are highlighted with this icon followed by a brief description of resource requirements. While the guideline aims to provide best practice evidence-based guidance - local context, location, and budgetary limitations may affect implementation of key recommendations in some settings.

In a survey of maternity services, we identified variation in implementation of recommendations of the previous guidelines[2] in Australia. Services in rural and remote regions and non-tertiary centres were less likely to report optimal care practices. As many of the recommendations in this update are similar in terms of respectful supportive care with a strengthening of the focus on culturally appropriate care, education of healthcare professionals and continuity of care there is likely to be variation in resource requirements for implementing or upscaling based on type and place of service.

By acknowledging and addressing resource implications we aim to contribute to the sustainable implementation of clinical recommendations to improve care for families/whānau. In these situations, we hope these guidelines may be used as an advocacy tool for services to use in planning care provision for families who experience stillbirth or neonatal death.

Table 2. Key recommendations and rationale

RECOMMENDATION	NUMBER	GUIDELINE SECTION	RATIONALE
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.	CBR 2.1	Section 2 – Approach to care	The care parents receive around the time of a perinatal death has a major influence on their recovery. There are multiple points of care starting from the time of a baby's death through to subsequent pregnancy and beyond. The national care pathway will bring together all services and care providers to ensure all parents and families/whānau are provided with best possible care. The resource implications for a national care pathway in Australia and Aotearoa New Zealand include implementation and data systems for ongoing evaluation to ensure high-quality, appropriate, and equitable care for all.
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).	CBR 2.2	Section 2 – Approach to care	Continuity of carer provides parents and families/whānau with a sense of familiarity and lessens the need for parents to retell their story to healthcare professionals. With continuity of carer, families/whānau may be more likely to receive care that is individualised to their needs, preferences, circumstances, and cultural context. Resource implication includes workforce planning. These may mean reallocation and training of existing staff or employment of new staff to fulfil such a role.

RECOMMENDATION	NUMBER	GUIDELINE SECTION	RATIONALE
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 Appendix 1B: *Guiding Conversations* booklet and Appendix 1C: *Jiba Pepeny (Star Baby)* booklet for Aboriginal and Torres Strait Islander families.	CBR 3.6	Section 3 – Perinatal loss care	Decisions faced by parents around the time of perinatal loss are highly sensitive to personal values and preferences; there is rarely one “right” decision. Active partnership between parents and healthcare professionals is essential to keep parents’ values and preferences at the centre of care.
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.	CBR 3.26	Section 3 – Perinatal loss care	Leaving hospital without their baby is highly distressing for parents and families/whānau. Ensuring that they are aware of available support services can minimise feelings of abandonment in the transition from the hospital to the home.
Ensure parents receive follow-up calls or visits, as required, from an appropriately skilled healthcare professional.	EBR 3.27	Section 3 – Perinatal loss care	Lack of follow-up care and support for bereaved parents is consistently reported following perinatal death and is likely to compound the grieving process and contribute to feelings of isolation and loneliness.
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.	CBR 4.1	Section 4 – Perinatal palliative care	Perinatal palliative care is a right for all babies with a life-threatening or life-limiting illness and their parents and families/whānau. Palliative care providers need to partner with parents and families/whānau to develop individualised, seamless, and compassionate care plans that address the physical, emotional, and cultural needs.
Provide perinatal palliative care within a parent-centred decision-making framework involving parents and family/whānau and the multidisciplinary care team.	EBR 4.3	Section 4 – Perinatal palliative care	Healthcare professionals can provide individualised palliative care by acknowledging parents as the primary carers and as equal partners in decision making with the multidisciplinary team.

RECOMMENDATION	NUMBER	GUIDELINE SECTION	RATIONALE
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.	EBR 5.1	Section 5 – Care in subsequent pregnancies	Most parents who experience perinatal death conceive again within 12 months. Pre-conception counselling can support parents and assist to manage increased psychosocial and obstetric risks. Resource implications include infrastructure to support specialised multidisciplinary care including continuity of care/carer from the time of the initial loss to pregnancy planning through to all subsequent pregnancies. Ideally care will be managed and led by a skilled midwife as part of a multidisciplinary team including effective management of the interface between hospital-based and community services.
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.	EBR 5.3	Section 5 – Care in subsequent pregnancies	Multidisciplinary models of continuity of care and carer (midwifery led) are associated with improved clinical outcomes for parents in a pregnancy following loss, including more positive experiences for the woman. Resource implication includes workforce development (appropriate staffing or training) and infrastructure (appropriate area for provision of subsequent pregnancy care). Ideally a network of services is needed to implement best practice care with ongoing evaluation using agreed outcome measures (iCHOOSE core outcome set).[3]

RECOMMENDATION	NUMBER	GUIDELINE SECTION	RATIONALE
Counselling parents about options for investigations (including the option of a full autopsy or less invasive options) should be conducted within a shared 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.	CBR 6.1	Section 6 – Investigations for perinatal death	Ensuring that parents are fully informed and adequately involved in the decision-making process around diagnostic investigations may help to minimise regret, regardless of the decision made. Transparent information around diagnostic investigations is part of quality, respectful care.
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 parents' wishes.	EBR 6.8	Section 6 – Investigations for perinatal death	Parents need the best possible information to help understand why their baby died and to guide care in subsequent pregnancies. Accurate information on the cause of death is also necessary to inform effective prevention strategies at the population level. $ Core investigations should be possible in all settings in Australia and Aotearoa New Zealand. Selective investigations based on the clinical circumstances may have resource implications in terms of staffing, funding and availability e.g. magnetic resonance imaging, genomic/genetic testing.
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.	CBR 6.26	Section 6 – Investigations for perinatal death	All parents and families/whānau are entitled to the highest standard of care possible, regardless of where they reside. Any available information, service, or expertise may help to understand cause of death, counsel parents, and facilitate care in subsequent pregnancies. $ Resource implications include the coordination of multidisciplinary team to communicate with family. This should not have significant cost implications but would require staff time to organise.

RECOMMENDATION	NUMBER	GUIDELINE SECTION	RATIONALE
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.	CBR 6.27	Section 6 – Investigations for perinatal death	Untimely reporting of autopsy examinations may increase distress among parents and families/whānau. Timely reporting is necessary to process grief and aid psychological closure and for future pregnancy planning. 💲 Additional perinatal pathologists are needed bi-nationally to perform autopsies and deliver reports in a timely manner. Additional administrative staff to compile reports may also be required. Current resource limitations mean that this timeline is seldom met for full reports. Significant investment into growing and sustaining this discipline needs to be planned and supported.
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.	CBR 7.4	Section 7 – Perinatal mortality audit and classifications	The perinatal mortality audit committee must be supported for the audit process to be effective. This includes supporting the committee through appropriate training, workload, staffing, resources, reporting procedures, indemnification, and authority to implement and evaluate ensuing practice change. Minimum resource implications for perinatal mortality audit includes regular protected non-clinical time for clinicians to participate in audits and training in the process through the IMPROVE program. This also includes funding a dedicated secretariat, ideally led by a bereavement midwife to ensure all administrative processes, including communication with parents, are carried out effectively. In addition, maternity services require effective data systems to ensure timely review and reporting particularly with respect to contributing factors relating to care to enable timely action when required to reduce the risk of future adverse events. 💲

RECOMMENDATION	NUMBER	GUIDELINE SECTION	RATIONALE
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).	CBR 7.6	Section 7 – Perinatal mortality audit and classifications	Parents indicate a desire to know about audits of care and a willing to participate in the process. Existing research provides a model for how parents may be successfully involved in perinatal mortality audit.
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 healthcare team.	EBR 7.17	Section 7 – Perinatal mortality audit and classifications	Parents generally place a high value on information about the causes of, and contributing factors related to, their baby's death. This information aids understanding and planning for subsequent pregnancies. Dedicated experienced clinical and administrative staff are required to prepare the plain language summaries and to communicate the results to parents. This activity should be incorporated into an appropriately supported perinatal mortality audit process as outlined in Recommendation 7.4 and ideally led by a bereavement midwife.

RECOMMENDATION	NUMBER	GUIDELINE SECTION	RATIONALE
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.	EBR 7.20	Section 7 – Perinatal mortality audit and classifications	Comprehensive and transparent reporting of data is necessary to inform the high-level changes in national policy and clinical practice needed to improve outcomes for parents and families/whānau. Ideally perinatal mortality causes and contributing factors should be transparently reported using a National coordinated approach. Countries such as the UK, Netherlands and Aotearoa New Zealand have clinician driven national entities to enable training and support maternity services in undertaking audit and to improve national reporting and action. In Australia, resources are needed for a national committee to enable standardised perinatal mortality audit including local and national reporting and implementation of practice improvements. This includes a dedicated secretariat, including protected time for the chair, and experienced educators to provide support and training for local and jurisdictional committees.
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.	CBR 8.2	Section 8 – Organisational recommendations	Lack of a single point of contact adds to distress among parents. Parents are often comforted by a familiar face and by knowing they will not need to repeat their story to multiple healthcare professionals. Support for a cadre of experienced bereavement midwives/ midwifery teams providing continuity of care across maternity care settings is needed, ideally into a subsequent pregnancy, Resource implication includes workforce planning. These may mean reallocation, training and support of existing staff or employment of new staff to fulfil such a role.

RECOMMENDATION	NUMBER	GUIDELINE SECTION	RATIONALE
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.	EBR 8.5	Section 8 – Organisational recommendations	Poor coordination of care and lack of healthcare professional knowledge or skill in managing care or in interactions with parents can exacerbate family/whānau trauma and add to healthcare professional stress. A dedicated and appropriate space is essential for provision of best practice care. 💲 Resource implication relates to infrastructure and physical space. In any new building with maternity/newborn services, these spaces should be considered and planned for. In existing services where these do not yet exist consideration should be given to whether existing spaces are suitable for this purpose.
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.	EBR 8.9	Section 8 – Organisational recommendations	Lack of or insufficient training for healthcare professionals is consistently reported as a major barrier to the provision of quality perinatal loss care. 💲 The IMPROVE program for perinatal health care providers is available as e-learning and face-to-face workshops. Additional funding would ensure the sustainability of this program across the country. Maternity services could consider attendance every 2–3 years for staff involved in maternal and newborn care.

References

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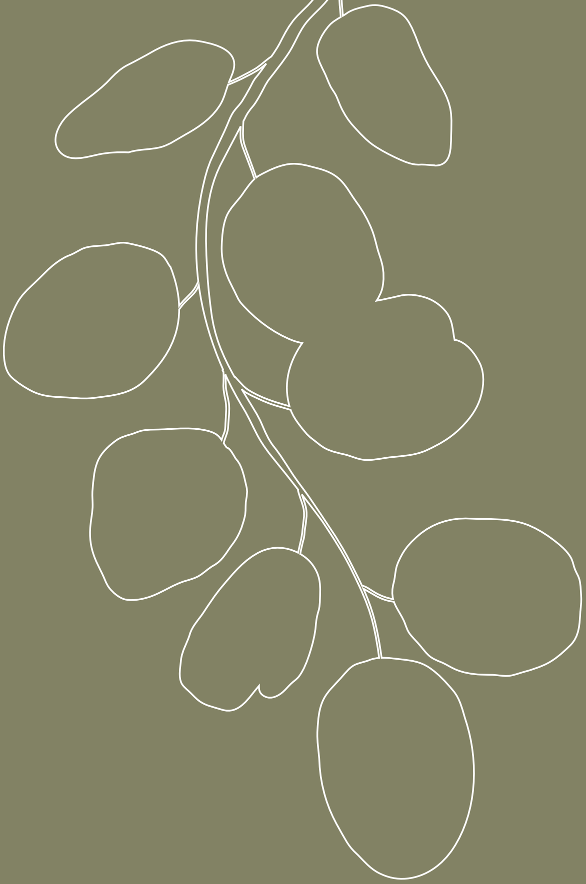

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