

Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death

Section 3

Respectful and Supportive Perinatal Bereavement Care

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Endorsed by:



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The Perinatal and Infant Mortality Committee of Western Australia

SECTION 3

RESPECTFUL AND SUPPORTIVE PERINATAL BEREAVEMENT CARE

3.1 Introduction

The death of a baby is a highly distressing event for parents and families. Initial feelings of shock, disbelief, confusion and guilt can be overwhelming and may have lasting psychological and social consequences¹⁻⁵. This section of the guideline aims to improve the quality of bereavement care for parents who experience stillbirth or neonatal death. Earlier pregnancy losses can have a similar impact but are not within the scope of this guideline.

Caring for parents who experience perinatal loss can be extremely challenging for health care professionals. It also can be seen as a privilege to provide compassionate care for families at such an important time in their lives⁶⁻⁹. The quality of care can have immediate and long-term consequences for families, both beneficial and otherwise^{1,10,11}.

The update of this section of the guideline has been undertaken through a partnership between the [Perinatal Society of Australia and New Zealand \(PSANZ\)](#) and the [NHMRC Stillbirth Centre of Research Excellence \(Stillbirth CRE\)](#). [Sands Australia](#) and [Women's Healthcare Australasia](#) were also key partners. A guideline update group comprising more than 50 members who represented bereaved parent support organisations, clinicians from a variety of relevant disciplines, policy makers and researchers provided expert input and advice based on their experience of perinatal bereavement care.

The content of this section of the guideline aligns with the *Principles of Bereavement Care* developed by Sands Australia¹², which embody a core set of expectations for bereavement care based on wide consultation with parents who have experienced perinatal death. The *Principles of Bereavement Care* outline the care bereaved parents need, while this section of the guideline provides the foundations and best evidence to guide clinicians in the delivery of that care.

The content of this section of the guideline aligns with and draws on recent key international initiatives, including:

- [Respectful Maternity Care Charter: The Universal Rights of Childbearing Women](#)¹³;
- [National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death](#)¹⁴; and
- the Research of Evidence based Stillbirth care Principles to Establish global Consensus on respectful Treatment (RESPECT) working group.

3.2 What has changed in this update?

Since the last version of this section of the guidelines, a number of systematic reviews of bereavement research associated with perinatal death have been published and their findings

have been incorporated into this update. We have introduced a framework for care based on four core goals of care, revised the formatting, and reduced duplication.

3.3 Objective of this section

The main objective of section 3 of the PSANZ Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death is to assist health care professionals and maternity services provide the best possible care for women and families faced with the death of a baby before or soon after birth.

The recommendations for respectful and supportive perinatal bereavement care are based on 10 foundations for care and an organising framework that sets out four overarching goals of care¹⁵:

- Good communication
- Shared decision making
- Recognition of parenthood
- Effective support

These goals of care are distinct but inter-related. A fifth goal of the framework – Organisational response – acknowledges the wider systems context in which care is provided.

Each of the five goals encompasses specific practices and actions that can be implemented in maternity care settings. These practices and actions are presented as 49 recommendations (41 for health care professionals and 8 for use by maternity services).

The first part of this section presents the foundations for care and introduces the organising framework. The second part presents the recommendations and more detailed guidance.

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.

A Cochrane review to assess the effectiveness of interventions intended to provide psychological support or counselling to mothers, fathers or families after perinatal loss, found no eligible randomised controlled trials¹⁶. The review authors acknowledged 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 research which helps to inform best practice care around stillbirth and neonatal deaths. We have drawn on this body of research evidence and the insights from an experienced multidisciplinary team in developing the recommendations in this section.

3.4 Understanding perinatal grief

Grief is a normal response following the death of a baby and high levels of distress are a normal part of the grieving process¹⁻⁵. Parents grieve the loss of their baby, as well as hopes and dreams for the future. The death of a baby challenges the natural order of life and raises uncertainties about the future, including expectations of pregnancy and parenthood. For some parents, their baby's death may be their first experience of the death of a close family

member. Parents usually have little or no preparation for what to expect or how to manage the intensity of their grief.

Perinatal loss is often poorly understood and may be associated with stigma and misperceptions^{1,4,17,18}. Parents may feel blamed, or blame themselves, for their baby's death and feel a sense of failure, shame or guilt that their baby died^{1,5,19}. Lack of acknowledgement of their baby, the extent of their loss, and their identity as bereaved parents can lead to disenfranchised grief²⁰ where parents feel their grief is not legitimate or socially acceptable. Validating perinatal loss is an essential part of improving support and reducing the sense of isolation that is commonly described by parents^{1,11,21}.

No single approach will meet the needs of all parents and perinatal bereavement care cannot be reduced to a checklist of activities²². Respectful and supportive care is personalised and takes account of the needs, preferences, circumstances and cultural context of each bereaved parent^{10,23}. Grief is a uniquely individual experience and it is important to avoid making assumptions about how parents will grieve or the support they will need. For example, gestational age of the baby, the type of loss or the presence of surviving children are not good predictors of the intensity of parental grief^{5,17,24}.

Many theories and models of loss and grief have been developed and refined over time to help explain the grieving process and to guide practice in bereavement care.

(A short overview of current theoretical perspectives that are relevant to perinatal bereavement care is provided as an appendix to this document.)

3.5 Role of health care professionals

Health care professionals from many disciplines are typically involved with bereaved parents during and immediately following the death of a baby. At every stage, the actions of health care professionals, and their timing, are critical to high quality care^{10,25}.

Health care professionals have a major role in helping parents to make decisions that minimise regret and avoid missed opportunities^{11,25}. Inappropriate or insensitive care can disempower parents. This can make an already potentially traumatic event worse for bereaved parents¹¹. Health care professionals must be prepared for a wide range of responses that may not reflect their own values or expectations²⁶.

Providing perinatal bereavement care is a stressful and challenging area of practice for many health care professionals. Health professionals require skills to support parents and this includes knowing where and how to seek their own support and the ability to develop resilience to ensure the longevity of their career and to avoid burnout.

Studies show that health care professionals commonly report feelings of guilt, frustration and helplessness, alongside feelings of sadness and distress when supporting parents who experience perinatal death⁷⁻⁹. Unless acknowledged and addressed, these emotional impacts can lead health care professionals to feel overwhelmed, to distance themselves from grieving parents, and to experience burnout.

Health care professionals may also be affected by grief and loss in their own lives. These personal experiences can affect the quality of care given to families in a positive way but can

also increase the vulnerability of health care professionals. Supporting health care professionals experiencing their own loss is necessary for the optimal care of parents.

However, health care professionals also describe positive aspects of caring for bereaved parents^{9,10}. These include the knowledge that they had provided best possible care and supported families at a time of great need.

Education, training, resources and support are identified as critical enablers for best practice care following perinatal death. These include both formal educational initiatives and informal debriefing and sharing of experiences with colleagues. Organisational responses are important to support health care professionals and to prevent burnout among those working in highly emotionally demanding roles, including those who deal regularly with perinatal loss⁷⁻⁹.

3.6 Foundations for care

This section of the guideline is based on 10 broad foundations for care. These are themes that are prominent and consistent in the published literature^{5,10,17,23,27-29}, and widely perceived as essential for perinatal bereavement care that is respectful and supportive.

Respectful and supportive perinatal bereavement care:

- Addresses the psychosocial, physical and practical needs of parents and families with consideration of parent preferences, circumstances and cultural context. Care begins with the first signs of concern about a baby, continues through pregnancy to birth, postnatal care and longer-term support including subsequent pregnancies.
- Acknowledges the baby and the impact of the baby's death on parents.
- Recognises that perinatal bereavement may be associated with intense grief and may include high levels of anxiety, depression, guilt, anger and self-blame.
- Understands that perinatal deaths can profoundly affect health care professionals and that support for health care professionals is essential for the optimal care of parents.
- Involves empathic and compassionate communication, appropriate non-verbal communication and respect for privacy. Both spoken and written communication needs to be understandable and to avoid euphemisms (e.g., "lost the baby") and other terms that may be ambiguous or unfamiliar to parents (e.g., "fetal demise").
- Recognises that parents come from a wide range of cultural and spiritual backgrounds, so it is important to check with parents to gain understanding of their needs, and not make assumptions.
- Includes shared decision making by:
 - Recognising the many difficult and complex decisions faced by parents
 - Respecting different approaches to making decisions
 - Understanding that parents' concerns, preferences, goals and wishes may change
 - Adequate time, information and support from health care professionals.
- Ensures care practices and approaches that respect all babies and acknowledge parenthood are integral to perinatal bereavement care.
- Recognises parenthood by offering and supporting options for parents to create memories from spending time with their baby and collecting mementoes of their baby to the extent that they wish.

- Recognises that organisational support and financial commitment is required to create the necessary conditions and structures to enable the implementation, monitoring and evaluation of best practice perinatal bereavement care.

3.7 Framework for respectful and supportive care

The organising framework developed by PSANZ and the Stillbirth CRE (Figure 1) addresses four core goals of care:

- Good communication
- Shared decision making
- Recognition of parenthood
- Effective support

These inter-related goals of care are relevant to all interactions with bereaved parents. The fifth goal of the framework – Organisational response – acknowledges the wider systems context in which care is provided. Each of the goals has associated practices and actions that are reflected in the following guidance and recommendations.



Figure 1 Framework for the practice of respectful and supportive care after perinatal loss¹⁵

Good communication is a core component of respectful and supportive perinatal bereavement care and is the issue most often raised in studies of parents' experiences of care^{10,11,30}. Good communication involves finding the right words, the right approach, and attention both to what is said and how it is said. Health care professionals cannot take away parents' emotional pain

and distress, but by communicating in a sensitive and compassionate manner they can provide comfort and avoid adding further distress

Shared decision making is “an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences”³¹. A systematic review found decisional conflict, limited information, and less involvement in decision making predicted regret about medical decisions³². In the context of perinatal loss, the value parents place on supported and informed decision making is well-documented^{10,33}.

Recognition of parenthood begins by acknowledging the deceased baby, the relationship that parents may already have established with the baby, and the enormity of the loss that has occurred. Care practices that honour their baby and acknowledge parenthood are central to the respectful and supportive care of parents^{17,27,28}. Treating the baby with the care and respect that would be accorded to a living baby may help to validate and normalise parents’ experiences. Some actions are easy for health care professionals to implement and are impactful, such as calling the baby by name, talking to the baby and dressing the baby. Health care professionals play an important role in empowering parents to engage in normal parenting activities. A culturally sensitive approach and appropriate discussions with all parents are essential to ensuring parents’ preferences and concerns are understood and met.

Effective support addresses the short and long-term needs of parents and other family members. Support should be based on the recognition that parents have experienced the birth and death of a baby with consideration to psychological, physical health and practical support needs¹⁰. Parents require immediate support to be able to manage the initial stage of their grief and pathways to support in their community once they have left hospital^{10,34}.

Organisational response is necessary to create the conditions and formal structures that support and enable health care professionals in the provision of high quality perinatal bereavement care¹⁰. Acknowledging that respectful and supportive perinatal bereavement care is a responsibility shared between the organisation and individual health care providers is critical to developing an environment that enables and supports sustainable best practice care.

3.8 Good communication

Good communication involves finding the right words and the right approach with attention to what is said and how. Studies of parents’ experiences of perinatal bereavement care repeatedly highlight three critical elements of good communication: sensitivity and compassion; clear understandable information; and respect for individual needs and preferences^{10,11,17,28,35}.

Information about a baby’s diagnosis and prognosis is often complex and uncertain¹⁷. Parents want health care professionals to communicate with honesty and compassion³⁶ and to show emotion, empathy and human reactions²⁸.

Where appropriate it is important to involve both parents in communication, information provision and decision making to ensure the loss of partners is recognised^{28,30}. Studies of fathers’ reactions to perinatal death highlight what is often a strong need to protect their partner. It is important to assist partners to find ways to do this and to express their own needs^{5,10,37}. The death of a baby affects families and the needs of siblings, grandparents and other family members should be considered^{28,37}.

Family structures and dynamics differ and health care professionals need to establish who is to be involved in communication and decision making. Children may be conceived in different ways (e.g., use of reproductive technologies, surrogacy arrangements) with implications for who is affected by the death. A sensitive approach is needed based on recognition of the added difficulties that may be experienced by some groups of parents including single mothers, same-sex parents and those from other marginalised groups who may experience added difficulties, including stigma and lack of recognition of their loss³⁸.

Careful consideration should be given to wording and terminology used when communicating with parents and families. When referring to the baby it is preferable to use the word “baby” instead of using words such as “fetus”, “miscarriage” or “it”, or terms such as “23- weeker”²². Asking parents if they have a name for the baby and for permission to call the baby by name acknowledges parenthood and use of the baby’s name creates identity and conveys respect to the baby and parents^{11,22,39,40}.

A systematic review of 28 studies placed high confidence in the finding that the timing, amount and quality of information provided have a considerable impact on the wellbeing of parents facing a severe or life-limiting prenatal diagnosis and on their understanding of the situation¹⁷. Parents wanted specific and detailed information about diagnosis, prognosis and options presented in clear and comprehensible language. Following stillbirth, clear, easily understandable and structured information given sensitively at appropriate times is consistently shown to help parents through their experience¹⁰.

In all communication with parents, it is important to remember that stress and grief can greatly reduce people’s ability to absorb, process and retain information^{28,30}. Extreme emotional distress combined with sudden exposure to complex and unfamiliar medical information can leave parents overwhelmed and with limited capacity to process and make sense of information⁴¹.

Parents may need information to be given more than once and supporting verbal information with written or electronic resources, including reliable internet sites, is widely shown to be of benefit for parents^{17,28,39}. Written resources enable parents to revisit information when ready and as needed, reinforce information given by health care professionals, and can be used as discussion initiators with care providers and others⁴¹. Many parents will turn to the internet for additional information and having appropriate information from health care providers may help reduce confusion and distress that may arise from online information¹⁷. Written information should be clearly and sensitively written with medical terms explained in understandable language⁴¹.

Most parents want to be kept informed and to be given as much information as possible⁴¹, but how much information to give and how to convey it must be guided by parents’ needs. The goal for health care professionals is to establish the level of detail and complexity desired by families and adapt to their needs³⁶.

Cues from parents regarding their emotional state should guide the timing and delivery of information²⁸. Pausing to ask questions to check what parents have understood and how the information is being processed or perceived, both cognitively and emotionally can guide health care professionals in tailoring information^{22,30,36}. Specific techniques for establishing parents’ informational needs include using open questions to ask parents what they understand the

situation to be, what it means, what they want to know, and what concerns them most at this time^{17,22}.

No parent is prepared for the news of the death, or possible death, of their baby and intense shock and grief are to be expected. Health care professionals need to be prepared for a wide range of grief responses and avoid assumptions about parents' responses. It is important that health care providers do not impose their own views or values, but support parents to express their emotions and concerns¹⁰. Parents' responses include shock and disbelief, distress, anger, blame, guilt. The raw emotions of grief may be accompanied by crying and other intense responses. Health care professionals may feel powerless to 'solve' the situation, but parents will value staff members who remain calm and supportive and allow them to express their thoughts and feelings. It is important for health care providers to be able to acknowledge emotions such as anger as valid and natural parent responses²⁸.

Recommendations for good communication

- 1** Be empathic, factual and responsive. Answer parents' questions, acknowledge when something is unknown or uncertain and undertake to obtain information that parents may need.
- 2** Include both parents in communication and decision making, if appropriate, and ask if they wish to have a support person present. Acknowledge different grief responses and support parents to express their emotions and concerns.
- 3** Use the word "baby" and ask the parents if they have a name for their baby. If so, ask for permission to call the baby by that name. Do not refer to the baby as a "fetus" or "it" or using terms such as "23-weeker".
- 4** Give parents clear information in a sensitive and timely manner using understandable and non-technical language.
- 5** Be aware that stress and grief can greatly affect how people absorb, retain and respond to information:
 - Repeat information and check with parents their understanding and need for further information
 - Use open questions (e.g., "What concerns you most right now?" or "What would be most helpful to know?") to assist in tailoring information
 - Give parents time to process information at their own pace and allow time for parents to ask questions
 - Anticipate intense emotional responses, including anger. Be able to support parents in their grief and consider including an experienced colleague who has understanding of the parents' circumstances.
- 6** Support verbal information with accurate and parent-centred written or electronic information that parents can read when they are ready.

Breaking bad news

Respectful and supportive perinatal bereavement care begins at the point of diagnosis of a baby's death or life-limiting condition and the health care professionals involved will depend on the setting. Being told of a baby's death or life-limiting condition is a life-changing moment for parents. A review of 25 qualitative studies concluded that the way the diagnosis of stillbirth is conveyed impacts on parents' experience of care and their psychological wellbeing²⁸.

How news is communicated to parents has both immediate and lasting impacts. Parents often recall in detail many years later the circumstances in which they were told of their baby's death, the words used and the actions and attitudes of those involved^{11,30,42}.

Verbal and nonverbal communication that conveys care, empathy, and understanding is essential at the time of diagnosis. Words, signs and gestures from clinicians are noticed and interpreted by parents and expressions of empathy and acknowledgement of the parents' feelings were valued^{11,17}. As in all communication, health care professionals should use clear and comprehensible language and avoid medical terms that parents may not understand^{28,41}.

Delays in receiving information are worrying and distressing for parents. Signs of a problem may first be discovered by sonographers or other health care professionals who may not be empowered or authorised to communicate their observations to parents^{42,43}. Parents may be extremely sensitive to verbal and non-verbal messages, such as sudden silence or concerned tone¹⁷. Advising parents that there may be periods of silence during scanning and other procedures is recommended^{29,44}.

Parents want health care professionals to be transparent, even when the situation is uncertain, and to be assured that all possible is being done³⁹. When left without information, parents may feel health care professionals are withholding information from them or are using "diversionary or avoidance tactics" which can lead to feelings of mistrust^{11,28,42}.

When a problem is suspected, it may be advisable to use a transition, such as "I have a few concerns about what I am seeing. I'd like to call the doctor in for another opinion"⁴⁵.

Thoughtful communication is essential throughout the diagnostic process, using an approach such as the following⁴⁵: (a) acknowledge the parents' feelings, perhaps saying, "I can see you are concerned" or "I can imagine that this might feel stressful"; (b) assure the parents that everything is being done to ascertain the baby's condition by saying something like, "I'm going to get another technician/doctor here to help me interpret what I'm seeing" or "I need to get another machine to get a better look"; (c) confirm that the parents will get the information as soon as it is possible, perhaps saying, "I'm going to step out and talk with the doctor who will back here in just a few minutes to talk with you and answer any questions you have"; and (d) support the parents by asking if anything is needed while waiting to get the results of the exam. A mother should not be left alone, and another staff member should be called to stay with her if her partner or other support person is not present.

In an integrative review of 33 studies of parents' experiences of prenatal diagnosis, an almost universal finding related to the need for immediate and detailed information when an anomaly is detected or suspected³⁹. Communicating detailed information and giving answers to parents' initial questions may increase parents' confidence in health care professionals³⁹. Accordingly, it is essential that parents have quick access to an appropriately trained health care professional who is equipped to provide information when an anomaly is suspected, or diagnosis of stillbirth

needs confirmation. Parents should be kept updated even if health care professionals are waiting for confirmation or further details³⁹. When a diagnosis of stillbirth has been confirmed it is vital that parents are informed without delay and are supported so they do not feel abandoned, or that their care has been de-prioritised^{10,23,29}.

Balancing the provision of immediate and detailed information may present a challenge if the mother has attended alone. Asking if she would like to have another support person present before discussing the findings may provide her with some control over the situation and help to alleviate distress and anxiety^{28,39}. When bad news is delivered, it is important that health care professionals check with parents whether they would like them to stay for support or to answer questions before leaving the room. When left alone, parents should feel assured that they have access to health care professionals and know when to expect a health care professional to return.

Recommendations breaking bad news

- 7 When breaking bad news, communicate clearly, sensitively and honestly. Advise parents that there may be periods of silence during procedures, such as scanning. Prioritise access to a health care professional who is able to discuss findings with parents.
- 8 Minimise delays and keep parents informed. Do not leave parents on their own without information. If a mother has attended alone, offer to contact her partner or other support person and ensure she is supported until that person arrives. Advise parents if uncertainty exists, assure parents that everything possible is being done to ascertain the baby's condition and offer to stay for support or to answer questions.

Cultural safety

Providing care in a culturally diverse population requires health care professionals to acknowledge and address a wide range of beliefs and practices that may be important to parents and families around the time of a baby's death. Health care professionals should take care not to impose western or other mainstream perspectives of grief and bereavement on parents. Cultural stereotypes and culture-based assumptions should also be avoided as diversity exists within all cultural groups. For all parents, it is important not to make assumptions, but to ask about their needs and seek further guidance where appropriate.

Rituals, customs and beliefs can help parents as they grieve for their baby. These may be important during the birth, at the time of death, or at a later time and might include speaking to baby in their own language, or performing other cultural, spiritual or religious rituals while in hospital^{28,40}.

The key task for health care professionals is to establish what families want. This involves asking parents whether there are rituals or practices that are important to their culture or belief system and that they wish to see happen^{28,37}. Open questions help to explore with families their needs

and preferences and to identify appropriate actions, which may include contacting appropriate spiritual, religious or cultural support services or engaging an accredited interpreter.

Recommendation for cultural safety

- 9** Provide culturally safe care by:
- Avoiding cultural stereotypes and culture-based assumptions and recognising that diversity exists within cultural groups and between individuals
 - Asking all parents whether they have any religious, cultural or spiritual needs and facilitating requests where possible
 - Offering to contact appropriate support services to assist with cultural needs if the parents wish
 - Determining with the parents whether an interpreter is needed and, if so, engage an accredited interpreter (some women may not wish to have a male interpreter)
 - Being aware of particular needs of vulnerable groups who may have a history of trauma and loss

Spaces and surroundings

The physical environment for the care of bereaved parents will depend on the timing of the perinatal death and the setting and model of care. Regardless of the circumstances, physical spaces and surroundings are essential to support good communication. The physical environment for the care of bereaved parents should provide “privacy not abandonment” in the form of spaces that balance the family’s need for privacy and comfort with their need for access to appropriately trained health care professionals¹⁰.

Appropriate spaces need to be available for conducting difficult conversations across the full spectrum of care²². This includes breaking bad news and all subsequent discussions as well as maternity care. Seeing and hearing other mothers and babies may add greatly to parents’ distress and parents may find it distressing to return to the unit where their baby was born for follow-up meetings^{10,11,28}. This should be considered when choosing the location of all meetings with parents.

Around the time of birth, a designated bereavement suite for parents is considered the ideal for parents experiencing stillbirth¹⁰. This should be a purpose-built room, separate from busy birth suites and wards, but with access to staff for necessary physical and emotional care. Some mothers may prefer the option of care away from the maternity ward, but this should not be assumed suitable for all. For some mothers, being away from the maternity ward may be experienced as isolating or reinforce a sense of failure from a lack of recognition of status as a mother^{11,28}. It is therefore important to establish what parents would prefer.

In settings where a designated bereavement suite is not available, suitable areas must be made available to ensure parents have privacy to support each other. Capacity for extended family members and other support persons to gather should also be considered.

In cases where a baby is dying, a room connected to the nursery, or a perinatal loss unit, can ensure the family is well supported during the difficult time of the baby's impending death and afterwards. It may be possible for some parents to take their baby home and thought should be given to the option of perinatal palliative care in the family home, if desired by the family. Perinatal palliative care is associated with positive outcomes and is well-received by many parents when appropriate support and resources are available to make this a feasible choice for parents^{5,37,40}. Parents may understandably feel apprehensive about taking their baby home to die. Exploring with parents their concerns and ensuring practical and psychosocial support including access to suitable community palliative care services.

When a baby has died, parents should be given the option to take their baby to their family home, or to another place that holds meaning for the family, if they wish. Health care professionals should discuss this option with parents and provide accurate information about care of the baby's body, changes to expect, transportation issues and associated legal matters.

Recommendations for space and surroundings

- 10** Identify an appropriate space for breaking bad news and all subsequent discussions with parents. Ideally, these spaces should be:
 - Private and quiet
 - Conducive to unrushed and uninterrupted time
 - Separate from other pregnant women and newborn babies
 - Suitable for extended family to gather
 - Free of items or equipment that could be confronting or upsetting to bereaved parents
- 11** Establish what parents want for their care around the time of birth, including whether they would prefer to be away from the maternity ward if this is possible. Make provision for the mother's partner or other support person to stay in her room if she wishes.
- 12** Enable parents 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 home:
 - For a baby who has died, discuss practical matters with parents when they are ready, including care and transport of the baby's body, 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

Communication between health care professionals

Continuity of care and carer is valued by parents who feel reassured by meeting with familiar staff throughout their care^{10,11,28}. Continuity of staff and appropriate handover and documentation processes should be in place to reduce the burden for parents of having to repeat their story.

Appropriate documentation is also necessary to ensure all staff are aware that a loss has occurred. A universal bereavement symbol, such as a teardrop or butterfly sticker, may be placed in the mother's room and displayed on all medical records and charts to communicate the occurrence of perinatal death²⁷. It is essential that all staff who come into contact with the mother are aware of the meaning of the symbol so that they can act in a thoughtful and responsive manner²⁷. Door signs and stickers should be used discreetly and with the mother's agreement as their use may distress some parents²⁸.

Timely communication with relevant care providers is essential to ensure appropriate support is activated. Communication between hospital- and community-based health care providers is an important part of continuity of care and this needs to occur in a streamlined and standardised way^{10,14,34}. While some mothers may appreciate the cancellation of existing antenatal appointments, it is important to discuss this with mothers as some may prefer to contact providers themselves.

Recommendations for good communication between health care professionals

- 13** Designate a lead contact person with training in bereavement care to be available to the parents and other members of the care team to promote continuity of care. Ensure that more than one person is trained for this role to avoid compassion fatigue.
- 14** With the mother's agreement, use a universal bereavement symbol that can be placed discreetly in the woman's room and on her medical records to indicate a baby has died or is expected to die and ensure the symbol is recognised and understood by all staff who interact with the parents.
- 15** With the mother's agreement, advise relevant health care professionals involved in her care (including general practitioner, child health and other community services) of the baby's death or impending death so that existing appointments are cancelled, and other types of appropriate follow-up are activated. Where possible, this should occur prior to hospital discharge.

Complex circumstances

Many circumstances can add to the complexity of parents' grief experiences and heighten the need for sensitivity and understanding from health care professionals.

Multiple births: Parents of twins or higher order births may experience conflicting emotions when one or more of their babies die and one or more survive. Common emotions may include

guilt relating to the amount of time spent with a deceased baby, or for not devoting enough time to a surviving baby because they are grieving; fear of a surviving baby also dying; and feeling torn between spending time with their living and deceased babies.

Acknowledging such conflicting feelings is important, to validate both the baby who has died and the parents' grief for that child, particularly when the response of others may be to focus on the surviving baby.

Maternal illness: Provisions should be made in the event that the mother is unwell following the birth. In instances where a mother is admitted to Intensive Care Unit or transferred to another hospital, every effort must be made to ensure appropriate and timely communication to ensure she is kept informed and involved in decision making³⁷. Opportunities for her to have access to her baby and to delay decisions where possible need to be considered and discussed with the mother, her partner and other family members as appropriate.

Perinatal death usually refers only to the death of a baby. However, maternal death, while rare in Australia, has a devastating impact on families, with an increased incidence of previous experience of maternal death in refugee and some immigrant populations, impacting on their care requirements. Early referral to relevant family support teams is imperative and will be explored further in future PSANZ guidelines.

Previous loss experiences: Parental response to the death of a baby may be intensified by a previous perinatal or child death or other pregnancy-related losses, including miscarriage or difficulties conceiving⁴⁶. Parents may experience resurgence of previous loss and grief, which can complicate their current loss. Some parents may have clear ideas regarding the way in which they choose to manage the death of their baby due to their past experience. It is important for health care professionals to respect parents' wishes, provide appropriate support and information and to be guided by the parent's response.

3.9 Shared decision making

Parents face many difficult and emotionally-charged decisions when their unborn child has died or is diagnosed with a life-limiting condition. Social stigma and complex medical, ethical and legal dimensions may add to parents' distress around decisions such as whether to terminate or continue a pregnancy or whether to initiate or withdraw treatment^{5,17,37,40}. Decisions will often need to be made about the mode and timing of the baby's birth along with decisions about end-of-life care. Decisions after a baby has died include those relating to seeing and holding the baby, autopsy and other investigations, and funeral arrangements.

While the decisions faced will vary according to the baby's diagnosis, all will require information and non-judgemental support⁴⁰. Expressing understanding, normalising and validating parents' decisions is important. For example, parents appreciated confirmation by health care professionals that it was normal to have ambivalent feelings about whether to continue or terminate a pregnancy for fetal anomaly¹⁷.

Conventional best practice in Australia and New Zealand assumes autonomy in decision making, where parents are seen as the primary decision makers, best qualified to speak for their child. However, for many parents the approach to decision making may be relational, where relationships with family, including the impact of decisions on other family members are strong

considerations^{22,40}. Personal values, extended family, societal norms, religious beliefs, and legal issues are just some of the factors that will influence each parents' decision making⁴⁰. For some parents the locus of decision making and support may rest with extended family, with particular family members, or with input from religious or community advisers. Cultural and religious beliefs may have much bearing on decision making. For example, discussion about cessation or limitation of treatment may not be an option in some parents' belief systems.

Supporting parents in decision making requires more than a one-off conversation. Giving parents options, time to consider those options, and opportunities to discuss and revisit their decisions is essential¹⁰. Providing options is critical as parents are often not in a position to recognise what is possible and what ultimately might be important to them.

Exploring with parents their decision making styles, their values and preferences promotes the tailoring of information and approaches to suit their individual needs^{22,28}. This involves asking parents what they want to know and how they want to make decisions. Questions such as the following may be helpful to explore with parents their decision making needs²²: "Some parents want to know all the numbers and statistics while others want the big picture, what kind of parent are you?" "Some parents want doctors to give them all the information and make these decisions on their own, other parents want to take these decisions with doctors. Other parents want doctors to give them recommendations. What kind of parent are you?" It is also important to recognise that there may be differences between partners and that ways of making decisions may change over time or depending on the decision to be made.

Recommendations for shared decision making

- 16** Support parents to make their own decisions and take care to avoid assumptions about what parents will choose. Ask parents what is important to them and what concerns they have. Keep in mind that parents may not yet know what their needs are and provide guidance and support as they absorb information.
- 17** Consult parents about all decisions, with the understanding that they may not be ready to make decisions and may need more information and time
- 18** Acknowledge that parents may feel uncertain or uncomfortable about their decisions. Use "other people" framing (e.g., "Other parents have sometimes found it helpful to ...") to help normalise decisions and help parents explore options and clarify what is important to them.
- 19** Ask whether parents want others to be involved in decision making (e.g., family members, other support persons, community elders or spiritual leaders) while also letting parents have time to themselves.
- 20** Provide opportunities for parents to ask questions and explore their concerns more than once with an informed, experienced and trusted health care professional. Provide opportunities for parents to revisit their decisions, but inform them of time critical issues (e.g., time to autopsy; how baby's condition may change).

Decisions about timing, mode and place of birth

If the baby has died before labour has started, then including parents in decision making about the timing, mode and place of birth may increase their sense of empowerment and control¹⁷. Ideally, discussions about birth should take place before labour commences to enable both practical and emotional planning.

A systematic review of 29 studies focused on the care of parents who continued pregnancy following prenatal diagnosis of a baby's life-limiting condition found consensus in the literature that a birth plan should be created⁴⁰. Equally important is planning for the baby's death³⁷. At a suitable time, sensitive discussion should take place to explore parents' needs and wishes in relation to relevant issues including: how and where the birth will occur; the involvement of other family members, including siblings; care for the baby, including end-of-life care; care of the family, including spiritual and social support and interactions with the baby; and organ donation where appropriate^{17,28,37,40}.

Little information is available about the birth planning needs of parents who chose to terminate their pregnancy but the limited evidence available suggests that, as for all parents, they may appreciate being presented with options and being able to make their own decisions about them¹⁷.

Clear information about birth options should be given to parents and the risks and benefits of each should be explained²³. Unless clinically indicated, vaginal birth is the recommended mode of birth for most women to reduce risks related to morbidity and future pregnancy⁴⁷. Psychological benefits may also be associated with vaginal birth¹⁰. Parents of a stillborn baby may not expect to have to go through labour and vaginal birth and may assume that their baby will be delivered by caesarean section^{10,11}. It is important that health care professionals seek to understand the various reasons why parents may request a caesarean birth rather than a vaginal birth, so as to provide effective counselling that addresses parents' concerns and assists them in making an informed decision^{23,29}. Support and information from health care professionals may help parents who feel emotionally unprepared for a vaginal birth¹⁰.

When a baby is not expected to survive for long after birth, decisions may need to centre on the desire of parents to meet their baby while alive. The majority of authors consider that, in such instances, caesarean section should be provided as an option for women together with appropriate discussion to ensure they are aware of the risks of the procedure⁴⁰.

Decisions about the length of time between diagnosis and the induction of labour and birthing may need to be made and sufficient time for discussion and decision making is important^{11,17,28}. Some parents may wish to consider whether the birth occurs straight away or whether to go home for a period of time before the birth. This can give parents time to consider the information they have been given, to share the news with extended family and/or other children, and gather support²⁸.

Sedation and pain relief options

Options for pain relief should be available and the advantages and disadvantages of each should be discussed with all parents^{10,23}. Careful consideration needs to be given to the potential for sedation to lead to later regrets about lost opportunities for interacting and spending time with the baby.

Recommendations for decisions about timing, mode and place of birth

- 21** Provide clear and understandable information about options for timing, mode and place of birth, and pain relief options that take into account parents' wishes, goals and concerns. Advise parents that a labour and vaginal birth may provide physical and emotional benefit, compared to a caesarean section without indication
- 22** If parents wish, develop with them a birth plan that incorporates planning for the baby's death, including the type of care to be delivered to a baby born alive, interactions with the baby, and any cultural, spiritual or other rituals.

Decisions about autopsy and other investigations

Parents should be assured that everything possible will be done to understand the cause of their baby's death and that this will include standard investigations and a review of the care provided to facilitate improvements to future care. It should be explained that the hospital has a clinical meeting where all the results of the investigations are reviewed by a team of experienced clinicians and that the findings of that meeting will be discussed with parents at a follow-up visit.^{23,29}

Clear information should be given regarding how and when parents will receive results of investigations that take place. Uncertainty around timeframes and lengthy waiting times for results are a commonly reported source of distress for many parents^{29,48,49}. It is important that parents are assured that they will receive results as soon as they are available and that preliminary results may be available within days but that others may take longer.

Autopsy remains the gold standard investigation for perinatal deaths⁵⁰ and should be offered to parents in all cases of perinatal death by a health care professional who is trained in consent, understands the parents' situation and is able to answer parents' immediate questions^{23,50}. Parents usually want an explanation for why their baby died and also to help planning with future pregnancies^{28,51} but there are many influences on parents' decisions about consent for autopsy^{10,49,50,52}. Barriers to autopsy may be perceived differently by health care professionals and parents and assumptions should not be made about what is important to parents.

When approaching decision making about autopsy for their baby, parents may feel strongly for or against, or somewhere in between and many will feel overwhelmed⁴⁹. Finding out where parents are on the decision spectrum and exploring with them their views and concerns can assist health care professionals to provide information and support that matches parents' needs. Parents who choose not to have an autopsy for their baby may experience later regret¹⁰. Ensuring parents feel fully informed and adequately involved in the decision making process may minimise regret, regardless of the decision made⁴⁹.

Where individual, religious and cultural beliefs make autopsy unacceptable to parents, these beliefs and the decision against autopsy should be respected²³. Less invasive approaches may be more acceptable to those who decline autopsy and these options should be discussed with parents⁵⁰. Less invasive approaches may include limited autopsies that take an organ-specific approach, minimally invasive autopsies that use a laparoscopic or keyhole approach to obtain

organ samples, or non-invasive autopsies that use detailed external, placental and umbilical cord examinations and external measurements, skin/needle blood sampling, clinical photography, and radiological investigations.

The way in which autopsy is discussed is a major influence on parents' decision making. Discussion about autopsy should involve a trusted and knowledgeable health care professional who is empathic to the parents' situation and able to provide the information needed to assist them in reaching their decision⁵⁰. Sufficient time must be allocated to explain the options available, including less invasive and stepwise examinations, and to explore concerns and answer questions^{48,50}.

Parents should be assured that decisions are not required immediately and discussions should take place on multiple occasions to enable parents to consider the information they have received and to follow-up on matters of concern to them^{10,50}. Cues from parents should be used to guide the timing and amount of detail presented and it may be helpful to provide information in an incremental manner^{10,28}. Information provided verbally should be supported by parent-centred information in written or electronic formats⁵⁰.

Health care professionals should be mindful of their influence on parents' decision making. Ambivalence about the value of the procedure on the part of health care professionals can be one of the most common barriers to autopsy consent following stillbirth⁵⁰. It is important to convey to parents an understanding of the value of autopsy and that it is useful and respectful²⁹.

Parents should be assured that their baby will be treated with respect and dignity. Health care professionals should discuss practical matters and concerns that are commonly held by parents. These include issues relating to the length of time parents can have with the baby without the autopsy results being affected, where the baby will be and for how long, the method of transport for the baby, whether they can see and hold their baby after the autopsy, and possible implications for funeral arrangements. Where possible personal contact with the perinatal pathologist undertaking the examination, may assist to address questions and concerns.

Recommendations for decisions about investigations after death

- 23** Discuss the value of an autopsy with parents in all cases of perinatal death and offer them the option of the procedure. Explain the various autopsy options, including less invasive and stepwise examinations. Where possible, the discussion should be led by a senior clinician who has established a rapport and understanding with the parents.
- 24** Provide written or electronic information to supplement and support discussions with parents about autopsy to help in their decision about autopsy for their baby.
- 25** Assure parents that their baby will be treated with care and respect at all times and that everything possible will be done to understand the cause of the death, including standard investigations and review of the care provided.

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| 26 | Address issues that may be important to parents including knowing where the baby is, whether they can accompany the baby to the mortuary, and whether they can see the baby again. |
| 27 | Provide parents with a preliminary plain language report of the autopsy examination as soon as possible after the examination. The report should be carefully explained to the parents by a senior clinician who has established a rapport and understanding with the parents. |
| 28 | Establish clear processes and timelines for informing parents of investigation results beyond hospital discharge. |
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3.10 Recognition of parenthood

Actions that validate the baby's existence and recognise parenthood are highly valued by many parents. Being the parent of a baby who is stillborn, or unlikely to survive, does not diminish the identity of parenthood and parents want their baby to be acknowledged as their child^{17,27,28,35}.

Recognising parenthood requires actions by health care professionals that support the creation of lasting memories. These actions enable parents to meet and get to know their baby, to have contact with their baby and engage in parenting activities, and to collect tangible mementoes of their baby.

Among the parenting activities that parents may value are:

- Creating memories and getting to know the baby through information about the baby
- Seeing and holding the baby and spending time with the baby
- Dressing and taking care of the baby
- Taking photos and collecting mementoes
- Arranging a commemorative service, funeral or other mourning rituals.

Giving parents options and supporting them to explore what is appropriate and meaningful for them is critical. Parents generally appreciate supportive suggestions and guidance about how they might engage in parenting activities with their baby²⁸. Health care professionals need to "ask the family what they want while realizing that they may not know"³⁷. Regardless of the type of loss, parents generally appreciate being presented with options and support to help them make their own decisions about parenting activities^{11,17}.

Conveying to parents the value of memory creation starts with the actions of health care professionals. These actions include showing respect to the baby by using the same tenderness and respect afforded to any baby. Sensitive conversation about their baby and their experience may help normalise and validate parents' feelings and wishes to engage in parenting activity^{11,28}. Actions that are easy to implement but impactful include: calling the baby by name; dressing the baby; and giving parents information about the baby.

Health care professionals should take time to explore with parents their concerns and preferences and areas of uncertainty or apprehension regarding parenting activities. Recounting what other parents have found beneficial may help parents in their decision making. Follow-up

on initial refusals to engage in parenting activities is important to give parents the chance to change their decisions.

Some parents may choose not to engage in parenting activities or memory creation. While this may be difficult for health care professionals, it is important to acknowledge that cultural, religious and personal values may influence parents' decisions about interactions with their baby. Some widely accepted activities that are valued by many parents may not be acceptable in some cultures or for some parents³⁷. As for so many aspects of perinatal bereavement care, the role of the health care professional is always to ask and facilitate, rather than to expect or impose a particular course of action.

Seeing and holding the baby

One of the most important decisions facing parents around the time of stillbirth or following a baby's death is whether or not they will see and hold the baby. A review of research on the consequences for parents of seeing and holding their stillborn baby shows mixed findings and little clear guidance for parents or clinicians⁵³. While several studies have addressed the question of whether parents should see and hold their stillborn baby, others have argued that the more important question relates to how health care professionals can best inform and support parents in their decision^{25,54}.

Above all, skilled and compassionate care that prepares, guides and supports parents is essential^{25,55}. The way contact is offered may greatly affect parents' decisions and experiences of time with their baby. Parents may initially be hesitant or fearful of seeing their deceased baby, and will look to staff for advice and support²⁵. Where parents are uncertain, normalising and offering contact as a routine practice may be helpful to parents. Open-ended questions and sensitive discussion is likely to be more appropriate than a closed-ended question such as "*Do you want to see your baby?*" that could unintentionally lead parents to decline. Parents who decline initially should be assured that they can change their decision and continuing sensitive conversation about the baby is important regardless of the decision made²⁸.

A review of 11 studies of the impact of seeing and holding on mental health and wellbeing confirmed that, for many parents, seeing and holding the baby is a positive and highly valued experience⁵³. Another review of studies of parents' experiences found parents were more likely to regret not seeing than seeing their baby and to wish that they had been able to spend more time with their baby¹¹. Health care professionals need to ensure that parents feel adequately supported and prepared to meet their baby and to engage in parenting activities that are meaningful to them. Supportive actions include: preparing parents to meet their baby with sensitive discussion about issues of temperature, appearance and feel of the baby²⁵; allowing parents and other family members as much time with their baby as they wish; and using cues from parents to achieve the right balance between privacy and access to health care professionals⁵⁵. Health professionals can also support parents to integrate siblings (or other family members) and help them "to be a family for a little while"²².

Mementoes and photographs

Supporting parents in creating memories through collecting mementoes such as photographs, hand and footprints, baby identification bracelet and a range of other tangible items is widely supported in the literature^{23,27,28,40,55-57}. Systematic reviews conclude that memory-making

should be an option for parents that is offered more than once¹⁰ and that health professionals' involvement and commitment to memory making is an essential component of appropriate and compassionate care²⁵.

High quality photographs provide lasting and valuable memories for many parents^{58,59} and every effort should be made to ensure there is opportunity for photographs to be taken. Health care professionals should support parents in taking photos and should be prepared to assist parents by taking photos for them.

A range of photographs should be considered including:

- The baby individually, as well as with parents (and extended family if suitable);
- Images of babies together if the death is one or more of a multiple pregnancy (this may necessitate discussion with staff in critical care nurseries if one or more baby is born alive);
- Photos with mementoes such as quilt, teddy, special clothes;
- Photographs during the birth (if appropriate).

Photos should be taken with sensitivity. Where possible parents should be offered the service of a professional photographer, including local volunteer services that provide compassionate bereavement photography, to ensure images are of the highest possible quality⁵⁸. Photos should capture the baby in natural positions, including being held and wherever possible, disfigurements concealed.

Photographs are greatly valued by many parents and should always be offered. Where parents refuse or are uncertain, sensitive enquiry is important to establish and explore parents' concerns. A minority of parents may refuse photos due to cultural beliefs or personal preference and this decision must be respected⁵⁸.

Parents who initially choose not to gather mementoes or photos should be given the option of revisiting this decision at a later time. The option for safe storage of mementoes and photographs of the baby for collection when they are ready should be made available to parents^{11,28,58}.

Commemorative rituals

All parents should be supported in arranging bereavement rituals that meet their spiritual, religious and cultural needs³⁷. These rituals may include blessings, naming services, or baptism. Health care professionals have an important role in opening conversations and providing options and information to enable parents to participate in decisions about funeral and other memorial options^{37,59}.

Parents should be informed in a sensitive way that burial or cremation is a legal requirement for a baby who dies at greater than 20 weeks gestation or weight of 400 grams. In most instances these arrangements need to be made with a registered funeral or cremation service. Staff should be able to discuss information about options for funeral arrangements in a clear and empathic way and provide written information that includes the range of available options and contact details for relevant services^{10,37}. Information about financial support should also be offered to parents where available⁵⁹.

It is important to assure parents that there is no urgency for decisions to be made regarding funeral arrangements. Parents should be given adequate time to consider the available options¹¹, to spend further time with their baby prior to the funeral if they wish, and to prepare aspects of the funeral service itself.

Recommendations for recognition of parenthood

- 29** Validate parenthood and support memory making by:
 - Assuring parents that their baby will be treated with care and respect at all times
 - Using gentle and caring language and actions when interacting with the baby
 - Providing information about the baby (e.g., weight, length, hair colour)
 - Supporting parenting activities such as holding, bathing, dressing, and undressing the baby
 - Offering all parents the opportunity to see and hold their baby immediately after birth, including skin-to-skin contact with their baby
- 30** Support parents' decisions to see and hold or not see and hold their baby recognising that either option is valid and that parents may also change an initial decision.
- 31** Prepare parents for seeing and holding their baby by giving relevant information about the baby's physical appearance, size, tone and temperature.
- 32** Ensure that all parents are offered (on more than one occasion):
 - Opportunities to spend time with their baby, including taking the baby home or to another place important to the family.
 - Photographs that tell the story of their baby, including: the labour and birth; photographs of their baby, themselves and others with their baby; and, in the case of a multiple birth, photographs of the babies together (including any surviving babies). Advise parents of any free photography service for bereaved parents.
 - Tangible mementoes of the baby (e.g., identification tags, cot cards, lock of hair, hand and footprints).
 - Opportunities to involve siblings and other family members.
 - Opportunities for commemorative rituals such as naming ceremony, blessing or baptism.
- 33** Discuss with parents options for storing mementoes of their baby with their hospital records, for possible collection at a later date, if they choose not to take these items home.
- 34** Provide parents with information about burial, cremation, and funeral options that are available for babies and support them in making an unhurried decision.

3.11 Effective support

Effective support involves facilitating immediate and ongoing emotional, informational and practical support to assist parents and other family members. The care provided needs to acknowledge that parents have experienced the birth and death of a baby and to address the psychosocial, practical and physical aspects of postnatal support¹⁰.

Emotional and psychological support

Few parents will be prepared for the intensity of grief that can accompany the death of a baby. Anticipatory guidance regarding the grieving process should begin as soon as a diagnosis is confirmed^{34,37}. It may also be helpful to prepare parents for interactions with others by: offering support to tell siblings and other family members²⁸; discussing how mothers, fathers and other family members may express grief differently; and that family and friends may find it difficult to know how to respond^{5,17,37}.

When a baby dies, and where parents have had to make the difficult decision of whether or not to continue a pregnancy, there may be a fear of stigma and judgement from others. Providing support and guidance in managing the responses of others, including selective disclosure of information, may be helpful to some parents^{5,17}.

All parents should receive information that addresses psychological and practical aspects of support. This information should be provided verbally and supported in written or electronic form for parents to take home and use as needed and when they are ready. Supporting parents requires a family-centred approach that also considers the support needs of siblings, grandparents and other family members^{34,37}.

A “flexible menu of support offerings” that recognises a continuum of support needs and the importance of collaboration between hospital, community and families should be made available to all parents^{34,55}. Little evidence exists to indicate who is most likely to benefit from different types of psychological support^{23,60} and not all parents will require formal interventions³⁴. Some parents may find the support they need in their natural support networks while others may benefit from specific supportive interventions or a combination of supports that will meet their needs at different times³⁴.

Parent support groups and the support of those who have had similar experiences will be helpful for many parents^{10,60}. A list of parent support organisations and their range of services should be provided together with an offer to make a direct referral. Key organisations include [Sands Australia](#), [Sands New Zealand](#), [Bears of Hope](#) and [RedNose](#).

Information about referrals to psychologists, social workers or counsellors with specialist experience and expertise in perinatal loss and grief should also be provided for parents to take up if and when desired¹¹. Direct referral pathways should be in place for women who require immediate support or who may be at risk of complicated grief due to aspects of the loss or social circumstances^{34,35,60}.

Practical support

Parents should be given easy access to reliable and current sources of information to manage practical issues such as registration of the baby's birth or other paperwork that may be required¹¹. Costs associated with funeral or burial and time away from work may be substantial¹ and avenues for government assistance or entitlements, including parental leave, should be broached sensitively with parents¹⁰. Parents who are away from their local home environments will have particular practical support needs that may need to be addressed.

Preparing parents for how to manage public interactions, including responding to questions about the baby from those unaware of the baby's death may be helpful. So too may be suggestions regarding timing of appointments with health care providers, such as making the appointment last in the day to avoid other pregnant women in waiting rooms.

Physical support

Maternal physical recovery and what to expect postnatally should be addressed with all women¹⁰. Providing information about lactation, vaginal bleeding and wound care is critical as not all women will be prepared for these experiences, which can be both physically painful and emotionally distressing for mothers whose baby has died. Verbal and written information should be provided and care taken to ensure the information is appropriate for mothers who have experienced the death of a baby. Generic information about these issues may be distressing for bereaved mothers^{11,28}. All women should be offered lactation suppression in the absence of contraindications²³, comfort measures and consultation with a lactation specialist if available. Women should also be advised of the importance of a post-natal check with their general practitioner or obstetrician at six weeks following the birth and encouraged to maintain contact with their primary care provider (e.g., community midwife, community health nurse, general practitioner).

A limited amount of evidence has suggested that different forms of physical activity may appeal to and be a helpful coping strategy for women following stillbirth^{11,28,60}.

Parents describe a reduction in their sense of isolation, improved coping and personal growth when cared for and supported by staff in the transition from hospital to community³⁴. Parents may appreciate individual follow-up contact with the attending maternity care providers to ask further questions and to talk about their experiences. Both outreach to parents from health care providers and the availability of a single point of contact for parents in the follow-up period is recommended^{10,28,37}.

A meta-synthesis of 20 findings pertaining to care after stillbirth parents' support needs may be ongoing and continue well beyond hospital discharge through to subsequent pregnancies¹¹. This should be reflected in clear care pathways that support the transition from hospital to community^{10,29,34}.

Follow-up appointment

A follow-up appointment to address clinical and emotional aspects of care should be offered to all families who experience perinatal death to help parents understand what happened to their baby, to resolve uncertainty and to assist the grieving process^{10,34,37}. Within six to ten weeks of the death is common practice¹⁰. Where the availability of results influences timing, parents

should be kept informed of any delays and the meeting should occur no later than 12 weeks after the death.

The meeting with parents should be led by a health care professional with experience in perinatal bereavement care and involve members of the multidisciplinary care team, including those known to the family where appropriate^{10,23}.

The critical importance of the meeting for many parents should be acknowledged. Good preparation and structure for the appointment is an essential requirement to support parents¹⁰. Parents should be aware of the meeting purpose and process and kept informed of any delays with investigation results. The venue for the meeting should be carefully considered to avoid unnecessary distress that may be caused by returning to the hospital and the sights and sounds of a maternity care setting. Timing the appointment for either the beginning or end of the day may help to avoid such distress.

Elements of the follow up appointment should include:

- discussion of events leading up to the baby's death;
- discussion regarding decisions and interventions provided during the mother's care;
- results of maternal clinical investigations and perinatal post-mortem investigations;
- implications for future pregnancies;
- referral for further testing or consultation if needed; and
- discussion of parents' grief and coping and recommendations or referral for on-going support if necessary.

Subsequent pregnancy

The vast majority of couples who experience a perinatal loss will consider a subsequent pregnancy at some time in the future. Decisions about embarking on a new pregnancy and the subsequent pregnancy itself presents a range of issues and challenges for parents. Heightened levels of anxiety, fear, worry and uncertainty are common among parents who have experienced perinatal death^{61,62}

Acknowledging and conveying an understanding of the fears and concerns held by parents in relation to a new pregnancy is part of ongoing perinatal bereavement care, as is providing parents with access to advice and support when needed^{11,28}.

Currently, there is little clear evidence to guide the provision of psychosocial support in a subsequent pregnancy. A separate guideline to improve the quality of both clinical and psychosocial care in subsequent pregnancies is being developed by PSANZ and the Stillbirth CRE.

Recommendations for effective support

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| 35 | Provide parents with guidance about common perinatal grief responses and what to expect, including written or electronic information to review when they are ready. |
| 36 | Sensitively address mothers' postnatal physical care needs, including lactation, vaginal bleeding, wound care, contraception, and physical activity. |

- 37** Address practical support needs including sources of financial support, options for accommodation and assistance if parents are away from their local home environment, birth and death certificates, birth registration, and medical certificates for employers.
- 38** Ensure parents leave hospital with contact details for 24-hour follow-up support and written information about ongoing sources of support (telephone, online and face-to-face), including parent support organisations. Recognise that parent support needs and preferences vary and that written information complements, but does not replace, empathic face-to-face communication.
- 39** Ensure mothers receive at least one follow-up call or visit from an appropriately skilled health care professional after their discharge from hospital.
- 40** Offer all parents a follow-up review meeting held within 12 weeks of the baby's death, led by a health care professional who is experienced in providing feedback to parents, known to the parents where relevant, and able to address the clinical and emotional aspects of their baby's death. Recognise the importance of follow-up meetings for parents:
 - Provide parents with clear verbal and written details of the process for follow-up appointments
 - Ensure all available results are assembled and provide information about any delays or interim results
 - Address implications for future pregnancies, including recommendations for pre-conception and maternity care
- 41** Establish and use referral pathways for parents who may be at risk of complicated bereavement due to factors relating to the death, medical or personal history, social circumstances or other stressors.

3.12 Organisational response

The final recommendations in this section of the guideline are directed at the organisational level and are intended to support maternity care services in developing a service-wide approach to the provision of respectful and supportive perinatal bereavement care.

Organisational support drives the quality of perinatal bereavement care by creating the conditions and formal structures that enable health care professionals to provide optimal care. Policies that reflect current evidence in perinatal bereavement care should be in place and easily accessible to all staff to achieve optimal standards of care for all parents^{10,11,28,37}.

Best practice care relies on building a culture that values bereavement care and recognises the importance of institutional support for health care professionals who work in this challenging area⁷⁻⁹. Acknowledging that respectful and supportive perinatal bereavement care is a

responsibility shared between the organisation and individual health care providers is critical to developing an environment that enables and supports sustainable best practice care.

Recognising and finding ways to manage the impacts of perinatal death on health care professionals is essential for the optimal care of parents and for the wellbeing of care providers. Systematic reviews identify education, training and support as critical enablers for best practice care following perinatal death⁷⁻¹⁰. These include both formal educational initiatives and informal debriefing and sharing of experiences with colleagues.

Studies highlight the importance of a dual focus for health care professional training^{7-9,28,37}. As well as addressing the delivery of emotional and practical aspects of care for bereaved parents, training should address the emotional impacts of perinatal death on health care providers and strategies to promote self-care and build resilience among staff.

Organisational-level measures have been shown to be beneficial in preventing burnout, compassion fatigue or secondary traumatic stress in the context of perinatal loss^{9,37}. These include: ready access to debriefing and support; clinical supervision and mentoring with more experienced senior colleagues^{9,34}; and flexibility to enable rotation of health care professionals to avoid repeated exposure and to build confidence and experience across staff^{7,34}.

Students and newly graduated health care professionals should be included in training, education and mentoring opportunities. Gaining experience at an early stage is important for preparing health care professionals to provide best possible care when they are confronted with perinatal death^{63,64}.

All major maternity hospitals should consider developing specialist bereavement support services and employing staff with specific training in bereavement care¹⁰. These staff have an important role in the ongoing training and support of all health care professionals who have contact with bereaved parents. Outreach to smaller hospitals might also be considered an extension of that role, including use of telehealth, to address issues of access for smaller facilities or those located in rural or remote areas.

Organisational responses include developing and implementing local protocols and policies that are consistent with current evidence. Attention should be given to issues that have been highlighted in earlier parts of this section of the guideline with arrangements made to suit the local contexts and conditions of different maternity services.

At a minimum, local policies should address: planning and action at hospital level to ensure the availability of best possible spaces and surroundings to meet the needs of parents and their health care professionals across the full spectrum of bereavement care^{10,40}; the use of a universal symbol to indicate that a baby has died or has a life-limiting condition^{27,28}; the safe and reliable storage of images and mementoes for parents who may request these at a later time^{11,28,58}; and the availability and consistent use of up-to-date parent-centred informational resources¹⁰. Appropriate linkages should be made with other local services for perinatal palliative care and post-hospital care and support, including parent support organisations^{34,55}.

Better collaborative care at the interface between hospital and community is essential to addressing the ongoing support needs of bereaved parents^{10,34}. Standard and consistent approaches to managing the transition following hospital discharge and the continuity and transition across caregivers are required²⁹.

Recognition and honouring of the baby by hospital staff is a source of comfort for many parents. Commemorative rituals such as remembrance books and memorial services serve an important purpose by offering a permanent and formal reminder of the baby who has died and should be made available to all bereaved parents^{14,34}.

Information should routinely be sought from parents about their views and experiences of care, ideally using a set of standardised questions to promote comparison and benchmarking across different maternity services⁶⁵. Results from the recent PARENTS 1 study (Parents' Active Role and Engagement in The review of their Stillbirth/perinatal death) highlights the importance of including a parent summary of events as part of the formal perinatal mortality review process and making feedback from the review process available to parents⁴⁴. Information received from parents can help to identify and address areas that may need attention and to develop local services as part of ongoing quality improvement in perinatal bereavement care. A future update of this guideline will incorporate recommendations on how to engage parents in this process following consultation with parents and their care providers in Australia and New Zealand.

Recommendations for organisational response

- 42** Each maternity facility should establish and foster a commitment to delivering best practice perinatal bereavement care. Evidence-based policy and guidelines should be available to and used by all relevant staff.
- 43** Training and support of staff is critical for the delivery of best practice perinatal bereavement care:
 - All health care professionals in maternity settings should complete the IMproving Perinatal Mortality Review and Outcomes Via Education (IMPROVE) Workshops educational program or other training in perinatal bereavement care that meets appropriate standards, reflects current evidence, and addresses relevant local policies
 - Formal and peer support should be readily available for health care professionals working with perinatal death
 - Mentoring, supervision and specialist training should be supported to build capacity, sustainability and excellence in perinatal bereavement care
 - Opportunities should be provided for students and new graduates to gain appropriate training and mentoring in perinatal bereavement care
- 44** Each maternity facility should establish and implement local protocols and policies relating to:
 - The use of a universal symbol for recognition by all staff who interact with parents to indicate that a baby has died or has a life-limiting condition
 - Options for perinatal palliative care when a baby has a life-limiting condition
 - The management of mementoes, including their storage on behalf of parents
 - Resources for perinatal bereavement care, including accurate and up-to-date written informational resources that are offered to all parents

- Contact details for health care professionals trained in high-risk pregnancies available at all times to provide advice (e.g., when an anomaly is suspected, or diagnosis of stillbirth needs confirmation)
 - Referral pathways for parents who may be at risk for complicated bereavement
 - Use of appropriate communication technology such as telehealth services for facilities in rural and remote locations
- 45** Make available appropriate spaces and surroundings, including accommodation, for parents whose baby has died or requires end-of-life care.
 - 46** Ensure all health care professionals who support bereaved families are familiar with the processes and arrangements for conducting perinatal autopsy, including the baby's care.
 - 47** Establish commemorative rituals, such as an annual Remembrance Service, for parents whose babies have died.
 - 48** Develop links and partnerships with relevant local services for perinatal palliative care and post-hospital bereavement care and support, including parent support organisations
 - 49** Establish data collection processes to routinely monitor and evaluate quality of bereavement care from parent and health care professional perspectives and regularly report on outcomes.

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3.16 Appendix

Theoretical Perspectives on Perinatal Bereavement

Many theories and models of loss and grief have been developed and refined over time to help explain the grieving process. These can be useful in helping to understand parents' responses to perinatal loss and in guiding practice. However, it is important to remember that theories make general statements which are open to testing and are not meant to be applied in a rigid way. No theory or model will fully account for the individuality and diversity of parents' grief. It is also important to note that theories of loss and grief are usually based on a Western worldview and that the experience and expression of grief and the needs of parents may differ greatly across cultures.

Three current theoretical perspectives that may help guide practice in perinatal bereavement care are: attachment theory; the continuing bonds perspective; and the dual process model.

Attachment theory provides an explanation of the nature of human relationships and of grief and mourning. Bowlby's theory of attachment⁶⁶⁻⁶⁹ centres on the emotional bonds between parents and their children. The loss, or threatened loss, of these bonds is at the core of parental grief.

Maternal attachment has been shown to begin well before birth and to be strengthened through interactions between the mother and unborn child during pregnancy and following the birth. These interactions include planning a pregnancy, confirming and accepting the pregnancy, feeling the baby move, accepting the baby as an individual, giving birth, seeing and touching the baby, and taking care of the baby. Fathers and other family members may also form close bonds and attachments with the baby both prior to and following the birth.

Applied to perinatal bereavement care practice, recognising that parents may have formed high levels of attachment long before the birth of their baby is critical to understanding and acknowledging the depth of loss that parents may experience when a baby dies⁷⁰.

The **Continuing Bonds** perspective⁷¹ stems from attachment theory and supports the idea that attachments do not end when a loved one dies. People often maintain ongoing, but redefined, relationships with those who have died. The concept of continuing bonds challenges the once widely held notion that relinquishing attachment is necessary for grief resolution. The continuing bonds perspective suggests that parental attachment does not end with a baby's death. This perspective is supported by numerous studies that show the high value placed by many bereaved parents on creating memories of their baby and their strong desire to maintain a lifelong connection with their child^{27,57,58}.

Applied to perinatal bereavement care practice, health care professionals can enable continuing bonds by giving parents opportunities to connect with their baby and create lasting and meaningful memories. This may include giving information about the baby, using the baby's name, enabling engagement in normal parenting activities, and the gathering of mementoes.

The **Dual Process Model (DPM)** of bereavement^{72,73} describes two categories of stressors associated with major loss. *Loss-oriented stressors* relate directly to the loss and, in the context of perinatal bereavement, include high levels of distress, pain and yearning as parents grieve for

their lost child. *Restoration-oriented stressors* relate to managing the loss and include the practical issues, problem-solving and decision making that accompany any major loss. The DPM views oscillation between loss-oriented stressors and restoration-oriented stressors as integral to coping by enabling balance between confronting the reality of the loss and engagement in more practical activities⁷². The DPM helps account for different expressions of grief, including gender and cultural differences, by describing both instrumental (“doing something”) and intuitive (“expressing emotions”) styles of grieving⁷⁴.

Applied to perinatal bereavement care practice, the DPM can guide approaches to supporting bereaved parents by recognising that that grief responses and support needs may differ for each individual parent and for the same parent over time. Emotional and practical issues may each take precedence at different times.

A further perspective on loss and grief emphasises people’s capacity for resilience following major bereavement^{75,76}. Much remains to be understood about how to promote resilience following loss, but supportive and respectful care and the attitudes and communication skills of health care professionals are important factors for long-term wellbeing^{10,27}. A review of research into grief support around the time of perinatal death, identified three consistent themes in providing care for bereaved parents: a deep respect for the individuality and diversity of grief; respect for the deceased baby; and recognition of the healing power and resilience of the human spirit¹⁶.