

Thank you for your email and for the opportunity to participate in the committee's hearing in Brisbane on the 6th September. Please find attached the corrections from the Stillbirth CRE to the *Hansard* transcript (page 14 of *Attachment 1*). A hardcopy of this document will be provided by post before the 8th October.

The Senate Select Committee has requested supplementary information from the Stillbirth CRE. This includes:

1. Access to the Respectful and Supportive Perinatal Bereavement Care Guidelines (outlined on page 15 of the *Hansard* transcript).

This clinical guideline aims to improve the quality of bereavement care for parents who experience stillbirth or neonatal death, and is part of the larger Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death. Within these guidelines, we would like to draw the committee's attention to the impact of stillbirth on health care professionals (outlined in Section 3.5 of the Guideline) and the importance of organisational-level recommendations to enable health care professionals to provide the best possible care for bereaved families. (Section 3.12) This document (*Attachment 2*), along with the full Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death (*Attachment 3 and 4*), has been attached for the Senate Select Committee.

2. Request from the Senate Select Chair for additional information on the Stillbirth CRE Indigenous Advisory Group (page 18 of the *Hansard* transcript).

The specific questions from the select committee, and the response from the Stillbirth CRE are outlined below.

a) How was the Stillbirth CRE Indigenous Advisory Group (IAG) established?

- The Stillbirth CRE IAG includes representatives from the Indigenous Advisory Group established for the My Baby's Movements RCT in 2014.
- Membership expanded to include individuals who had expressed an interest in participating, particularly from States and Territories not already represented
- Other individuals known to have an interest in preventing stillbirth in Indigenous communities e.g. through CATSINAM and research projects in Indigenous maternal and child health were invited to join

b) Outline the IAG terms of reference (ToR) are in relation to the Stillbirth CRE

The ToR have not yet been finalised but were discussed at the meeting on 8/8/2018. The scope of the IAG would include strategies to prevent stillbirth; better information about choices, and better support, for women and families experiencing stillbirth, and culturally appropriate models of care. The importance of better understanding the journeys of Indigenous women and families who have experienced stillbirth was also raised.

c) Clarify the Stillbirth CRE expectations from the IAG

The Stillbirth CRE expectations include that:

- the IAG will have Indigenous leadership, and work in a partnership model.
- the IAG will facilitate capacity building of Indigenous staff in maternity care
- the IAG will advise what culturally appropriate models of care need to include
- the IAG will work with other parts of the CRE to prevent stillbirth.

Again, on behalf of the Stillbirth CRE, I would like to thank the committee for the opportunity to assist with this inquiry.

Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death

Section 3

Respectful and Supportive Perinatal Bereavement Care

Version 3.2, August 2018

Endorsed by

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 parent 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 Bereavement Care Global Expert Consensus Group, now called RESPECT: *Research of Evidence based Stillbirth care Principles to Establish global Consensus on respectful Treatment*

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 associated with stigma and misperceptions^{1,4,17}. 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^{1,5,18}. Lack of acknowledgement of their baby, the extent of their loss, and their identity as bereaved parents can lead to disenfranchised grief¹⁹ where

parents feel their grief is not legitimate or socially acceptable. Validating perinatal loss is an essential part of improving support and reducing the stigma and sense of isolation that is commonly described by parents^{1,11,20}.

No single approach will meet the needs of all parents and perinatal bereavement care cannot be reduced to a checklist of activities²¹. Respectful and supportive care is personalised and takes account of the needs, preferences, circumstances and cultural context of each bereaved parent^{10,22}. 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^{5,17,23}.

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.

(Appendix Z provides a short overview of current theoretical perspectives that are relevant to perinatal bereavement care.)

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^{10,24}.

Health care professionals have a major role in helping parents to make decisions that minimise regret and avoid missed opportunities^{11,24}. 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 expectations²⁵.

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^{5,10,17,22,26-28}, 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 is essential to supporting parents and reducing the stigma and sense of isolation often experienced by 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^{10,11,29}. 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”³⁰. A systematic review found decisional conflict, limited information, and less involvement in decision making predicted patient regret about medical decisions³¹. In the context of perinatal loss, the value parents place on supported and informed decision making is well-documented^{10,32}.

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^{17,26,27}. 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^{10,33}.

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^{10,11,17,27,34}.

Information about a baby’s diagnosis and prognosis is often complex and uncertain¹⁷. Parents want health care professionals to communicate with honesty and compassion³⁵ and to show emotion, empathy and human reactions²⁷.

Where appropriate it is important to involve both parents in communication and decision making. Including fathers in communication and information-giving is essential to ensuring their loss is recognised^{27,29}. Responses to grief differ and fathers may have a strong need to protect and support their partner. It is important to assist them to find ways to do this and to express their own needs^{5,10,36}. The death of a baby affects families and the needs of siblings, grandparents and other family members should be considered^{27,36}.

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 loss³⁷.

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 the baby’s condition (e.g., “23-weeker”)²¹. 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^{11,21,38,39}.

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^{27,29}. Extreme emotional distress combined with sudden exposure to complex and unfamiliar medical information can leave parents overwhelmed and with limited capacity to processing and make sense of information⁴⁰.

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^{17,27,38}. 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 others⁴⁰. 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 language⁴⁰.

Parents want to be kept informed and to be given as much information as possible⁴⁰, 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 needs³⁵.

Cues from parents regarding their emotional state should guide the timing and delivery of information²⁷. 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^{21,29,35}. 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^{17,21}.

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 responses²⁷.

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 by the baby's condition (e.g., "24-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 wellbeing²⁷.

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^{11,29,41}.

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^{27,40}.

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^{41,42}. 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^{28,43}.

Parents want health care professionals to be transparent, even when the situation is uncertain, and to be assured that all possible is being done³⁸. 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^{11,27,41}.

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"⁴⁴.

Thoughtful communication is essential throughout the diagnostic process, using an approach such as the following⁴⁴: (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 suspected³⁸. Communicating detailed information and giving answers to parents' initial questions may increase parents' confidence in health care professionals³⁸. 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 details³⁸. When a diagnosis of stillbirth has been confirmed it is vital that parents feel supported and do not feel abandoned, or that their care has been de-prioritised^{10,22,28}.

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^{27,38}. When bad news is delivered, before leaving the room, it is important that health care professionals check with parents whether they would like them to stay for support or to answer questions, or if they would like to be left alone.

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^{27,39}.

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^{27,36}. 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 care²¹. 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^{10,11,27}. 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^{11,27}. 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 as their involvement may be an important part of the grief response for some parents.

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^{5,36,39}. 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^{10,11,27}. Continuity of staff and appropriate handover and documentation processes should be in place 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 death²⁶. 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 manner²⁶. Door signs and stickers should be used discreetly and with the mother's agreement as their use may distress some parents²⁷.

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^{10,14,33}. While some mothers may appreciate the cancellation 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 making³⁶. 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 conceiving⁴⁵. 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 care^{5,17,36,39}. 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 support³⁹. 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^{21,39}. Personal values, extended family, societal norms, religious beliefs, and legal issues are just some of the factors that will influence each parents' decision making³⁹. 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^{21,27}. 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 needs²¹: "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

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 created³⁹. Equally important is planning for the baby's death³⁶. 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^{17,27,36,39}.

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 explained. Unless clinically indicated, vaginal birth is the recommended mode of birth for most women to reduce risks related to morbidity and future pregnancy⁴⁶. 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^{22,28}. 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 procedure³⁹.

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^{11,17,27}. 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 support²⁷.

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^{10,22}. Adequate analgesia is critical, but mode and dosage must be titrated carefully and with discussion with the mother. Careful consideration needs to be given to sedation including the potential for regret about lost opportunities if the mother's ability to interact with her baby is compromised due to sedation.

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.^{22,28}

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^{28,47,48}. 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 deaths⁴⁹ 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^{22,49}. Parents usually want an explanation for why their baby died and also to help planning with future pregnancies^{27,50} but there are many influences on parents' decisions about consent for autopsy^{10,48,49,51}

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 overwhelmed⁴⁸. 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 made⁴⁸.

Where individual, religious and cultural beliefs make autopsy unacceptable to parents, these beliefs and the decision against autopsy should be respected²². Less invasive approaches may be

more acceptable to those who decline autopsy and these options should be discussed with parents⁴⁹.

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 decision⁴⁹. Sufficient time must be allocated to explain the options available, including less invasive and stepwise examinations, and to explore concerns and answer questions^{47,49}.

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^{10,49}. 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^{10,27}. Information provided verbally should be supported by parent-centred information in written or electronic formats⁴⁹.

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 stillbirth⁴⁹. It is important to convey to parents an understanding of the value of autopsy and that it is useful and respectful²⁸.

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.

Please also refer to: Section 4 – Perinatal Autopsy Including Placental Assessment for further details; Appendix M – Infant autopsy consent brochure and Appendix N – Information for health professionals seeking consent.

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.
 - 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^{17,26,27,34}.

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 baby²⁷. Health care professionals need to "ask the family what they want while realizing that they may not know"³⁶. 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^{11,27}.

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 parents³⁶. 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. Research on the consequences for parents of seeing and holding their stillborn baby has produced mixed findings and little clear guidance for parents or clinicians⁵². 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^{24,53}.

Above all, skilled and compassionate care that prepares, guides and supports parents is essential^{24,54}. 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 support²⁴. 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 made²⁷.

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 experience⁵². 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 baby²⁴; 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 professionals⁵⁴. Health professionals can also support parents to integrate siblings (or other family members) and help them "to be a family for a little while"²¹.

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^{22,26,27,39,54-56}. 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 care²⁴.

High quality photographs provide lasting and valuable memories for many parents^{57,58} 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 quality⁵⁷. 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 respected⁵⁷.

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^{11,27,57}.

Commemorative rituals

All parents should be supported in arranging bereavement rituals that meet their spiritual, religious and cultural needs³⁶. 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^{36,58}.

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^{10,36}. Information about financial support should also be offered to parents where available⁵⁸.

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** | Be knowledgeable and provide information about burial, cremation, and funeral options that are available for babies and support parents 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^{33,36}. It may also be helpful to prepare parents for interactions with others by: offering support to tell siblings and other family members²⁷; 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^{5,17,36}.

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^{33,36}.

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^{33,54}. Little evidence exists to indicate who is most likely to benefit from different types of psychological support^{22,59} and not all parents will require formal interventions³³. 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 times³³.

Parent support groups and the support of those who have had similar experiences will be helpful for many parents^{10,59}. 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^{33,34,59}.

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^{11,27}. All women should be offered lactation suppression in the absence of contraindications²², 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^{11,27,59}.

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 community³³. 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^{10,27,36}.

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^{10,28,33}.

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^{10,33,36}. 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^{10,22}.

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^{60,61}

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^{11,27}.

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

- 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^{10,11,27,36}.

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^{7-9,27,36}. 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^{9,36}. These include: ready access to debriefing and support; clinical supervision and mentoring with more experienced senior colleagues^{9,33}; and flexibility to enable rotation of health care professionals to avoid repeated exposure and to build confidence and experience across staff^{7,33}.

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^{62,63}.

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^{10,39}; the use of a universal symbol to indicate that a baby has died or has a life-limiting condition^{26,27}; the safe and reliable storage of images and mementoes for parents who may request these at a later time^{11,27,57}; 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^{33,54}.

Better collaborative care at the interface between hospital and community is essential to addressing the ongoing support needs of bereaved parents^{10,33}. Standard and consistent

approaches to managing the transition following hospital discharge and the continuity and transition across caregivers are required²⁸.

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^{14,33}.

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 services⁶⁴. 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 parents⁴³. 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 clinicians providing maternity and newborn care should attend the [IMproving Perinatal Mortality Review and Outcomes Via Education \(IMPROVE\) Workshops educational program](#)
 - All health care professionals in maternity settings should have training in bereavement care that addresses the emotional, physical and practical aspects of perinatal death and 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 Appendices

Appendix M – Infant autopsy consent brochure

Appendix N – Information for health professionals seeking consent

Appendix Z – Theoretical perspectives on perinatal bereavement

APPENDIX Z

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 attachment⁶⁵⁻⁶⁸ 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 dies⁶⁹.

The **Continuing Bonds** perspective⁷⁰ 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^{26,56,57}.

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^{71,72} 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 activities⁷¹. 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 grieving⁷³.

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^{74,75}. 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^{10,26}. 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.

Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death

Version 3.1, March 2018

Endorsed by



Produced by:

This clinical guideline was produced by the Perinatal Society of Australia and New Zealand (PSANZ) Care around the time of stillbirth and neonatal death guidelines group, under the auspices of the Stillbirth and Neonatal Death Alliance (SANDA) of PSANZ and in partnership with the Centre of Research Excellence in Stillbirth. Support for guideline development was received from PSANZ

Endorsed by:

The clinical guideline has been endorsed by: Australian College of Midwives (ACM); Australian and New Zealand Neonatal Network; Queensland Maternal and Perinatal Quality Council; Red Nose; Sands; Stillbirth Foundation Australia; South Australian Maternal and Perinatal Mortality Committee; Tasmanian Council of Obstetric and Paediatric Mortality and Morbidity; Women's Healthcare Australasia; Victorian Consultative Council on Obstetric and Paediatric Morbidity and Mortality.

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Disclaimer:

The main objective of the guideline is to assist clinicians in the investigation and audit of perinatal deaths, including communication with the parents, to enable a systematic approach to perinatal mortality audit in Australia and New Zealand. The overall aim is to reduce the risk of perinatal death and provide appropriate assistance to parents.

The guideline is not intended to be prescriptive, but is designed to provide reliable, up-to-date information enabling integration of best evidence, clinicians' judgement and individual choice in arriving at decisions about care. Clinical practice guidelines may be considered as generally recommended practice. Inevitably, given the nature and sensitivity of the subject and the lack of high quality studies, some contentious issues remain. The Working Party welcomes comments which will assist with further refinement of the Guideline in the future. Comments should be sent to Vicki Flenady, Email: stillbirthcre@mater.uq.edu.au with 'Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death' in the subject line.

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SECTION 1

OVERVIEW AND SUMMARY OF RECOMMENDATIONS

1.1 Introduction

The loss of a child who is either stillborn or dies in the neonatal period has enormous psychosocial impact on parents and their care providers¹, and wide-ranging economic impact on health systems and society at large². The care that parents receive is critically important to how they cope with this tragedy². However, care often does not meet parent's needs.

Stillbirths make up the majority of perinatal deaths where efforts to improve the quality of data on causes and contributing factors is critically important. Many stillbirths are not appropriately investigated or classified in terms of their cause, with around 50% at term classified as “unexplained”³. The lack of a diagnosis adds to parents' distress, as they struggle to understand “what went wrong” and “will it happen again” in a subsequent pregnancy. In 20-30% of stillbirths, deficiencies in the quality of care are implicated. National perinatal mortality audit programs can help to reduce these deaths^{4,5}.

This update of the guideline has been undertaken through a partnership between PSANZ and the NHMRC Stillbirth Centre of Research Excellence in Stillbirth.

For further assistance and clarification in this section of the PSANZ Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death, see *Appendices A – Y*.

1.2 Objective of the guideline

The overarching objective of the PSANZ Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death is to ensure best practice across Australia and New Zealand (ANZ) around the time of a perinatal death to improve maternity and newborn care for bereaved parents and families and to improve the quality of data on causes of stillbirth and neonatal deaths through appropriate investigation, audit and classification.

With effective implementation of this guideline the anticipated benefits are:

- Effective monitoring to reducing perinatal deaths;
- Increased understanding of causes to further reduce perinatal deaths; and
- Better care and outcomes in future pregnancies.
- Improved psychosocial outcome for parents and families;

1.3 Intended audience

The intended audience for the guideline is clinicians providing maternity and newborn care in hospitals in Australia and New Zealand.

1.4 Structure of the guidelines

This first section contains an overview of the guideline including a summary of key recommendations. The guideline is presented in 7 Sections as follows:

Section 1 - Overview and summary of recommendations;

Section 2 - Institutional perinatal mortality audit;

Section 3 - Psychological and social aspects of perinatal bereavement;

Section 4 - Perinatal autopsy examination;

Section 5 - Investigations for stillbirth;

Section 6 - Investigation of neonatal deaths; and

Section 7 - Perinatal mortality classifications.

Resources are provided to assist clinicians in implementation of the recommendations and to enhance the quality of information available for audit and research activities. To ensure the guideline remains relevant and useful, review, and revision as required, is planned as a minimum every two years. To ensure the most up-to-date version of the guideline is easily accessible, the guideline will not be produced as a bound document but rather each section will be made available in a downloadable format from the Stillbirth CRE (<https://www.stillbirthcre.org.au/>) and PSANZ website: <https://psanz.com.au/>

1.5 Definitions of stillbirth and neonatal death

Differences in definitions and reporting processes across regions within ANZ make comparisons of perinatal mortality rates difficult, and it is hoped that these differences will be addressed by the various reporting agencies.

In Australia, according to the Australian Institute of Health and Welfare (AIHW)⁶, perinatal deaths consist of stillbirths (the death of an unborn baby at 20 or more completed weeks gestation or at least 400 grams birthweight) and neonatal deaths (the death of a live born baby within 28 days of birth). However regional differences exist.

In New Zealand, perinatal death consists of fetal death (the death of a fetus of from 20 weeks gestation or weighing at least 400 grams if gestation is unknown⁷) and early neonatal death (the death of a liveborn baby that occurs before the 7th day of life⁵). Perinatal related mortality is fetal and neonatal deaths (up to 28 days) at 20 weeks or beyond, or weighing at least 400g if gestation is unknown. Fetal death includes stillbirth and termination of pregnancy⁸.

Please refer to *Appendix T – Australian and New Zealand definitions of perinatal mortality* for a summary of definitions across the jurisdictions.

1.6 Rates and causes of stillbirth and neonatal death

Australia and New Zealand have one of the lowest perinatal mortality rates in the world, however areas for further improvement are clear; notably the slow progress in reducing the rates of stillbirth - similar to many high income countries⁹. Stillbirths make up the majority of perinatal deaths and have been identified as an unaddressed global public health problem^{10,11}. In Australia and New Zealand, one in 165 women who reach 20 weeks gestation will have a stillbirth and for many, the loss occurs unexpectedly towards the end of pregnancy and a cause is never identified^{5,12-14}.

At the time of updating these guidelines, the most recent national data available in Australia was for the year 2014⁶ where there were 312,548 births, and 2986 perinatal deaths giving a perinatal mortality rate (PMR) of 9.6 per 1000 births including 2200 stillbirths (7.0 per 1000 births) and 786 neonatal deaths (2.5 per 1000 livebirths). The first comprehensive report on stillbirths was in Australia was in 2014¹⁵ and for perinatal deaths was released in 2016 covering the period 1993–2012¹⁶.

In New Zealand in 2014, there were 58,647 births and 656 perinatal deaths, giving a PMR of 11.2 per 1000 (8.1 and 3.1/1000 for fetal and neonatal death rates respectively)⁵.

For Indigenous and other disadvantaged women in both settings (similar to other high income settings), the risk of perinatal death is around double^{5,6,9,17}.

Using the PSANZ classification system the leading causes of stillbirth are congenital anomaly and spontaneous preterm. However in approximately 20-30% of stillbirths, a cause is never identified. Similarly, for neonatal mortality, the main cause of death using the PSANZ PDC is congenital anomaly and spontaneous preterm¹⁶.

Contributing factors relating to care (also called sub-optimal, avoidable or suspected preventable factors) have been reported in approximately 30-50% of perinatal deaths^{5,18-20}. Recent reports have reinforced that prevention is possible and that there is clear potential to reduce these deaths through improved quality of care driven by high quality perinatal mortality audit (e.g. the Bacchus Marsh enquiry into cases of substandard care in Victoria, the perinatal mortality report from Western Australia²¹, and the confidential enquiries from the UK²² and NZ⁸).

1.7 Changes in this update

In this update, revisions have been made to all sections. The changes are listed within each of the sections.

1.8 Summary of key recommendations

Section 2: Hospital Perinatal Mortality Audit

Section 2 Recommendations

- 1 All hospitals where births occur should implement a formal process for perinatal mortality audit of all perinatal deaths occurring in that hospitals. The process should be overseen by an interdisciplinary Perinatal Mortality Steering Committee.
- 2 Staff should be provided with appropriate training on best practice around the time of a perinatal death through the IMPROVE Program and access to support.
- 3 The review of perinatal deaths should occur as soon as possible after the death aiming to have results in time for the initial follow-up visit with parents. It may be necessary to re-review the death if test results are delayed.
- 4 A comprehensive clinical summary, including a detailed interview with the mother as soon as possible after the death, should be completed for every perinatal death to facilitate institutional audit using the recommended paper-based form or on-line tool (APMAT) which, following the completion of the audit, should be provided to the jurisdictional perinatal mortality council or respective body. Clinicians should ensure clear and accurately documentation in the medical record at the time of the event to facilitate this process.
- 5 The perinatal mortality audit meetings should have an experienced chairperson capable of ensuring a no-blame environment within an appropriate legal framework.

- 6** As part of the audit meeting, the PSANZ Classification system should be used to assign the cause of death and associated conditions for every perinatal death
 - 7** As part of the audit meeting, the presence of contributing factors relating to care should be assessed and documented for every perinatal death using the format recommended in this guideline.
 - 8** Recommendations emanating from the audit process should be carefully developed and accompanied by an implementation plan which should be completed within a nominated time frame e.g. following the PDSA and SMART cycles.
 - 9** Initiate discussions with parents as soon as possible after the perinatal death, using an open disclosure framework
 - 10** Senior clinicians should schedule follow-up meetings with the parents following perinatal death when relevant tests and reviews are complete, involving other specialists and additional investigations if indicated.
 - 11** Senior clinicians should notify the General Practitioner and other relevant care providers of the death as soon as possible and a comprehensive clinical summary sent to them promptly after the audit meeting.
 - 12** The Consultant responsible for care should complete or supervise completion of the Medical Certificate of Perinatal Death. The death certificate should be revised as required based on the outcome of the perinatal mortality audit meeting.
 - 13** To ensure consistency and comparability in perinatal death data across ANZ, the definitions recommended in this guideline are used including presenting data with and without the inclusion of perinatal deaths resulting from termination of pregnancy.
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Section 3: Respectful and supportive perinatal bereavement care

For foundations of care please refer to Section 3

Section 3 Recommendations

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 by the baby's condition (e.g., "24-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

- 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

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

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

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.

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

- 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 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.
- 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.

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 Be knowledgeable and provide information about burial, cremation, and funeral options that are available for babies and support parents in making an unhurried decision.

Effective support

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.

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 clinicians providing maternity and newborn care should attend the [IMproving Perinatal Mortality Review and Outcomes Via Education \(IMPROVE\) Workshops educational program](#)
- All health care professionals in maternity settings should have training in bereavement care that addresses the emotional, physical and practical aspects of perinatal death and 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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Section 4: Perinatal Postmortem Examination

Section 4 Recommendations

- 1 Clinicians should discuss the value of an autopsy with parents in all cases of perinatal death and offer them the option of the procedure.
- 2 To increase the rates of perinatal autopsy:
 - Clinicians should collaborate with pathologists and parent based organisations to raise public awareness of the value of perinatal autopsy and to advocate for high standards in perinatal autopsy at local and government level.
 - Clinical leaders should promote formal and informal educational opportunities for clinicians on: post-mortem examination procedures; the potential benefits of an autopsy; compassionate counselling and obtaining parental consent; and address specific local barriers to the conduct of perinatal autopsy.
All clinicians providing maternity and newborn care should attend the IMproving Perinatal Mortality Review and Outcomes Via Education (IMPROVE) Workshops educational program (<https://sanda.psanz.com.au/improve/>).
- 3 Seek advice from the coroner or an experienced coronial officer if any doubt exists as to whether a death should be referred to the coroner.
- 4 Clinicians need to be aware of costs associated with transferring an infant from non-metropolitan areas to tertiary centres for autopsies within their region and inform parents of any personal cost implications relevant to their decision-making.
- 5 The Guidelines on Autopsy Practice produced by the Royal College of Pathologists²³ should be used for guidance on minimum standards until guidelines for Australia and New Zealand are developed.
- 6 Specific protocols developed for post-mortem examination in the event of Sudden Unexpected Death in Infancy and death with suspected genetic metabolic disorders should be followed.
- 7 A perinatal/paediatric pathologist should perform or supervise all perinatal post-mortems. Clinicians should request autopsies from the service providing the highest quality.
- 8 Transport to a centre with appropriate expertise should be arranged to ensure that all perinatal post-mortem examinations are of sufficient quality. Transport should be arranged with a registered undertaker.
- 9 A comprehensive maternal history should accompany the baby for a post-mortem examination including:
 - Clinical/obstetric history including relevant previous obstetric history
 - Copies of all ultrasound reports
 - Copy of the death certificate if available
 - Copy of amniocentesis report if available.

- 10** Guidelines for post-mortem reports produced by the Royal College of Pathologists²⁴ should be used as a guide for reporting of perinatal post-mortem examinations.
- 11** Ideally, a preliminary post-mortem report should be forwarded to the referring clinician within three working days of the post-mortem. The final report should be forwarded to the referring clinician ideally within eight weeks of the autopsy.
- 12** The post-mortem report should be made available to the parents at a time when the primary care clinician is present to discuss the findings.
- 13** A Plain Language Report (PLR) should be available to parents on request.
- 14** A request for the General Practitioner (GP) to receive a copy of the report (including the PLR, if available) should be explicit on the request form, as they are the main care provider on discharge.
- 15** Where possible, a senior clinician who has established a rapport and understanding with the parents should discuss the value of an autopsy and offer the option of the procedure. Such clinicians should have high level communication skills and knowledge of all post-mortem examinations, and preferably witnessed several perinatal autopsies.
- 16** Any clinician approaching parents for autopsy consent should discuss:
 - Options for full, Less invasive autopsies (LIA), minimally invasive autopsies (MIA), Non-invasive autopsies (NIA) or stepwise post-mortem examinations
 - Issues related to retained tissues, organs and DNA for genetic and other tests
 - The value of autopsy
 - Possibility that cause of death may not be determined
 - Possibility that some potential causes of death could be excluded
 - Information gained may not directly benefit the family but may benefit others
 - Possible implications for future pregnancies
 - The care and respect that will be given to the baby
- 17** Discussion with parents should be supplemented by written information explaining autopsies to help in their decision on autopsy for their baby.
- 18** When consent is obtained for specific organ/s to be retained for further examination, parents should be offered the option of either delaying the funeral until the organs can be returned to the body or specifying their preferred method of organ disposal.
- 19** Consent for the autopsy which clearly outlines the extent of the investigation should be recorded on an approved consent form, relevant to the jurisdiction.
- 20** Where possible the pathologist should be available to discuss the autopsy with the parents before and/or after the procedure and, where feasible, the requesting clinician should attend the autopsy and provide the parents with a preliminary report immediately after the examination.

- 21** | Placentas should be sent for examination by the perinatal/paediatric pathologist regardless of whether consent for an autopsy has been gained following stillbirths, neonatal deaths in the delivery room or birth of high risk infants.
 - 22** | Consent should be sought from parents for less invasive testing if permission for an autopsy is not obtained, including: external examinations by skilled clinician; an MRI scan; babygram; ultrasound scan; post-mortem needle biopsy; laparoscopic autopsy and small incision access.
 - 23** | When an MRI scan is undertaken it should be undertaken as soon as possible after a stillbirth.
-

Section 5: Investigations for Stillbirth

Section 5 Recommendations

- 1** A non-selective approach according to the recommended core investigations should be adopted for all stillbirths (unless the cause of death has been unequivocally determined antenatally). These investigations are:
 - Comprehensive maternal (medical, social, family) and pregnancy history
 - Kleihauer-Betke test/Flow cytometry for fetal to maternal haemorrhage
 - External examination of the baby performed by the attending clinician
 - Clinical photographs of the baby
 - Autopsy
 - Detailed macroscopic examination of the placenta and cord
 - Placental histopathology
 - Cytogenetics (Chromosomal microarray (CMA) or karyotype if CMA is not available).
- 2** Further sequential and/or selective investigations should be undertaken according to the particular clinical scenario based on a comprehensive history, and information gained from core investigations.
- 3** An external examination of the baby should be performed at birth by the attending clinician using the recommended checklist (*Please refer to Appendix D – Clinical examination of baby checklist*) and clearly documented in the medical record. Where the family has consented to autopsy, all information gained from the initial external examination (along with comprehensive maternal (medical, social, family) and pregnancy history) should be forwarded to the pathology service to guide this procedure.
- 4** Following a stillbirth, the placenta, membranes and cord should be kept refrigerated and, where feasible, sent fresh and unfixed for macroscopic and histological examination by a perinatal pathologist. The pathology service should be informed if the parents have requested return of the placenta following examination.
- 5** Clinicians should discuss the value of a full autopsy with parents in all cases of perinatal death where the cause of death is not already known. If the parents decline a full autopsy, a limited/partial autopsy should be offered.

Section 6: Investigations of Neonatal Death

Section 6 Recommendations

- 1 Obstetric and neonatal care teams should collaborate closely to ensure that all relevant maternal (pregnancy and birth) and neonatal factors are considered in the investigation of the neonate. Comprehensive maternal medical, social and antenatal history including results of all investigations documented in the medical record by obstetric staff. A comprehensive neonatal history including death scene analysis is always required.
- 2 A detailed external examination of the baby must be performed by a perinatal pathologist, neonatologist or paediatrician where possible. *(Please see Appendix D – Clinical examination of baby checklist).*
- 3 Accurate anthropometric parameters of birth weight, length and head circumference plotted on appropriate gender specific birth growth charts.
- 4 A newborn screening blood sample should be taken for all neonatal deaths.
- 5 Clinicians should discuss the value of an autopsy with parents in all cases of a neonatal death and offer the option of the procedure.
(Please see Section 4; Perinatal postmortem examination).
- 6 Following consent from the parents, clinical photographs should be taken for later review, particularly in the circumstance of birth in non-tertiary hospital settings. These photos are additional to the bereavement photographs, and should be clearly labelled and filed in the medical record (not given to the parents) and be available for members of expert PNM committee to view. The use of digital imaging for this purpose is optimal, however issues regarding storage and patient confidentiality must be considered.
- 7 For neonates at high risk of death at the time of birth, or in birth suite, targeted investigations based on the presenting scenario should be undertaken.
 - Detailed external examination of the baby by a neonatologist or paediatrician (where possible) with clear documentation of findings in the medical record
 - Where possible, cord blood gas analysis that includes both arterial and venous samples
 - Newborn screening blood sample
 - Detailed macroscopic examination of the placenta and cord with findings documented in the medical record by obstetric staff
 - Histopathological examination of fresh and unfixed placenta, cord and membranes.
 - Autopsy.
- 8 Clinicians should initiate investigations specific to the circumstances of the birth (*see Section 6.7 for targeted investigations*).

- 9** Clinicians should investigate possible thrombophilic disorders in mothers with preeclampsia or with a personal/family history of thrombosis, or following the birth of an infant with severe growth restriction.
- 10** Selective screening in addition to placental examination for thrombophilic disorders should be undertaken following the birth of high risk neonate or a neonatal death:
- Anticardiolipin, lupus anticoagulant, anti-B2 glycoprotein-1 antibodies
 - Microarray/karyotype
 - Autopsy
- 11** Investigation for maternal diabetes, if not previously undertaken, should include:
- Maternal HbA_{1c} level (as soon as possible after delivery); and
 - If the HbA_{1c} level is raised, a fasting blood glucose should be undertaken and, if abnormal, a glucose tolerance test performed 6-8 weeks postnatally.
- 12** Other causes of macrosomia, such as Beckwith Wiedemann syndrome, should be investigated if there is no maternal or paternal diabetic history.
- 13** In the case of a suspected genetic metabolic disorder, Clinicians should discuss individual cases with their State Laboratory to identify the optimum tests to request and consult a clinical metabolic specialist if more expert guidance required.
- 14** All tissue samples should be stored and transported to a Specialist Metabolic Laboratory for investigation.
- 15** When a lethal genetic metabolic disorder is suspected prior to birth, clinicians should:
- Seek consent from the parents for a metabolic autopsy
 - Consult a metabolic physician or a histopathologist before collecting the following samples:
 - Blood sample (0.8ml) in lithium heparin tube (refrigerate)
 - Urine sample (5-10ml)
 - Knee cartilage and/or skin biopsy (3 x 2 mm punch biopsies) (sent to cytogenetics with request for fibroblast culture and store)
 - Liver and muscle biopsies (for electron microscopy, histopathology and enzymology).
- 16** Investigation of any sudden unexpected neonatal death should include:
- Coroner notification
 - Thorough maternal and infant medical histories
 - Full autopsy examination by a forensic pathologist skilled in perinatal autopsy or a forensic pathologist in conjunction with a perinatal pathologist
 - Investigation of the various scenes where incidents leading to the death might have occurred including the infants sleeping environment.
- 17** Investigations for genetic metabolic disorders should be undertaken for all sudden unexpected neonatal deaths.

Section 7: Perinatal Mortality Classification

Section 7 Recommendations

- 1** All stillbirths and neonatal deaths should be classified according to the PSANZ SB&ND classification system to identify a single underlying cause of death for both stillbirths and neonatal deaths.
- 2** Following classification of a single underlying cause, up to two associated factors which contributed to the death (i.e. not considered as the underlying cause) should be classified using the PSANZ SB&ND associated conditions list.
- 3** The classification of stillbirths and neonatal deaths should be based on the best available information from a comprehensive history and appropriate investigation (as recommended in Sections 4 and 5 of this guideline) and should form part of a formal institutional clinical audit process as outlined in Section 2 of this guideline.
- 4** The classification should be included in the routine perinatal data collections across jurisdictions for every perinatal death to enable comprehensive reporting regionally and nationally including disaggregation and identification of timing of the death (i.e. antepartum, intrapartum, early and late neonatal deaths).
- 5** Following application of the PSANZ SB&ND system, mapping to ICD-PM categories should be undertaken to enable high quality global reporting.

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1.10 Appendices

Appendix A – Stillbirth investigations algorithm

Appendix B – Estimation of severity of feto-maternal haemorrhage

Appendix C – Placental examination; Accoucheur flow chart

Appendix D – Clinical examination of baby checklist

Appendix E – Australian perinatal mortality audit tool

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Appendix W – Methods

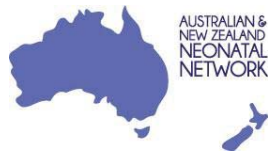
Appendix X – Glossary of terms and abbreviations

Appendix Y – Contact details and regional coordinators 2018

Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death

Version 3.1, March 2018

Endorsed by



SECTION 2

INSTITUTIONAL PERINATAL MORTALITY AUDIT

2.1 Introduction

This section of the PSANZ Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death presents recommendations on perinatal mortality audit in maternity hospitals, including classification of causes, associated conditions and contributing factors. Perinatal mortality audit is:

“a process to document the medical causes of each death and contributing systemic failures in order to identify solutions and take action. It is not a solution in itself. It is a systematic way of improving quality of care through collecting and analysing data, linking solutions and ensuring accountability for changes in care”¹.

The critical analysis of each death in a no-blame, interdisciplinary setting has the potential to “tell a story about what could have been done differently to unlock the solutions that should have been available for each woman and baby to prevent perinatal deaths”¹. Audit, when combined with feedback to care providers, can change practice and improve health outcomes, particularly when combined with an action plan and clear measurable targets².

The 2016 Lancet series on stillbirth highlighted the importance of high quality audit in reducing stillbirths³. In New Zealand, stillbirth rates at term have declined over the seven years since national perinatal audit began⁴. Perinatal mortality audits in the Netherlands⁵, the UK⁶, and New Zealand⁴ show substandard care factors are present in a high proportion of cases (20-30%, and up to 60% for intrapartum stillbirths). In Australia, while a national perinatal audit program is yet to be implemented, state committees produce regular reports on rates and causes of perinatal mortality⁷⁻¹⁴ and in Victoria¹⁰ and Western Australia⁷ health departments routinely undertake perinatal mortality audits.

In this section of the PSANZ Guideline for Care Around Stillbirth and Neonatal Death, practice recommendations are supplemented by audit tools checklists to assist clinicians to implement the guideline recommendations (See *Appendices E - G, J, K and T*).

This update of the guideline has been undertaken through a partnership between PSANZ and the NHMRC Stillbirth Centre of Research Excellence in Stillbirth.

2.2 Objective of this section

The main objective of Section 2 of the PSANZ Guideline for Care Around Stillbirth and Neonatal Death is to improve the quality of data collected on causes and contributing factors relating to care for stillbirths and neonatal deaths for the purposes of:

- Helping parents to understand why the death occurred and to assist in future pregnancy planning;
- Improving the quality of care parents receive after their child is either stillborn or dies in the neonatal period;
- Assisting in implementing audit as a tool for quality improvement in general; and

- Reducing stillbirths and neonatal deaths by improving clinical practice and informing appropriate research through enhancing the conduct of appropriate research, epidemiology and health surveillance and regional/international comparisons

2.3 What has changed in this update?

In this update, changes have been made to align the guideline with the recently developed WHO guideline “The WHO Stillbirth and Neonatal Death Review Tool”¹. While key recommendations are unchanged from the previous version, additional advice and justification is provided to enhance the conduct of high quality perinatal mortality audit at the facility level. Further, the recommended tool for systematic review of contributing factors has been revised to align with that used by the New Zealand Perinatal and Maternal Mortality Review Committee (PMMRC)⁴. As with other sections of this guideline, we have revised the formatting and reduced duplication across the different sections to enhance readability.

2.4 Research gaps

While perinatal mortality audit is accepted as an essential component of care and case studies across countries highlight the yield in terms of identifying substandard care factors, further high quality studies are needed to determine its value in improving practice and health outcomes¹⁵. Research to identify the optimal approaches to classification of perinatal deaths is also needed¹⁶. Additionally, outcomes associated with involving parents in perinatal mortality audit¹⁷ and methods to improve autopsy counselling and consent requires further research¹⁸.

2.5 Establishing a hospital based perinatal mortality audit program

Hospital leadership and support

Successful perinatal audit programs are those that are thoughtfully planned and where strong leadership is provided by committed health professionals. Poorly planned programs in which no action is taken following the review, result in disinterest and demoralised staff^{1,19}.

The perinatal mortality audit program should be linked with local standards in clinical quality and safety activities including the findings of root cause analysis (RCA)^{20,21} where undertaken, and the implementation of the perinatal audit review recommendations to improve practice and to avoid the same clinical errors occurring in future.

The audit program should have established systems for clear reporting of de-identified audit findings to the health service board’s quality (clinical governance) committee or lead. Further, systems for authorisation, implementation and evaluation of those recommendations and a process of escalation and reporting processes where serious system failures or misconduct are identified.

Hospital-based perinatal mortality audit programs should be overseen by an interdisciplinary perinatal mortality audit steering committee. The hospital administration needs to provide the committee with adequate support and governance to:

- Ensure an appropriate legal and ethical framework is in place;
- Encourage staff to actively support and participate in the audit program, enabling relevant clinical staff to attend the audit meetings;
- Ensure appropriate scheduling of meetings so the maximum number of key staff can attend, and cases are reviewed within an acceptable time frame;

- Ensure adequate staffing and resources are available for administration of meetings, and for data collection, analysis and report preparation, and organisation of meetings.

Membership and Roles of the Perinatal Mortality Audit Steering Committee, Audit and Educational meetings

The Perinatal Mortality Steering Committee should include an interdisciplinary team of key stakeholders with responsibility and authority to ensure recommendations are translated into actions.

Membership Perinatal Mortality Steering Committee may include representatives from: administration, neonatology/paediatrics, obstetrics, midwifery/nursing, pathology, clinical genetics, pharmacy, epidemiology/ statistics, social worker, general practice, but the committee should not be too large. The involvement of parents and/ or community representatives is gaining increasing interest and requires further exploration of potential benefits¹⁶.

The Perinatal Mortality Steering Committee members attend and oversee each *Perinatal Mortality Audit meeting* where individual perinatal deaths are reviewed in detail. Other members of staff may be invited to attend depending on the cases being reviewed.

The Perinatal Mortality Audit meetings are distinct from other *perinatal mortality educational meetings* which may be undertaken to present aggregate data on rates and trends in perinatal deaths and to assist in dissemination of recommendations and practice change and are open to all interested parties, including students. With appropriate mentorship, the Perinatal Mortality Audit meetings may also be helpful as an educational activity for students.

Smaller regional facilities and regional groups of facilities with smaller numbers of staff and infrequent perinatal deaths may combine the functions of the Perinatal Mortality Audit Steering Committee and the Perinatal Mortality Audit meetings.

Role of the Perinatal Mortality Steering Committee

- Establish and oversee the audit process including assigning responsibility and providing training and oversight of tasks such as data collection;
- Arrange a schedule of perinatal mortality audit meetings, setting the ground rules for and identifying an appropriate chairperson, and inviting relevant participants;
- Oversee the development and facilitate the dissemination and implementation of practice recommendations emanating from the audit;
- Oversee the production of reports on the outcome of the audit program including those required to relevant health department agencies;
- Oversee the implementation of the PSANZ Clinical Practice Guidelines for Care Around Stillbirth and Neonatal Death using the IMPROVE educational program²²;
- Oversee the revision and resubmission of the perinatal death certificate if required based on findings of the audit meeting; and
- Ensure that all staff members have access to adequate support following a perinatal death.

Section 2 Recommendations

- 1 All hospitals where births occur should implement a formal process for perinatal mortality audit of all perinatal deaths occurring in that hospitals. The process should be overseen by an interdisciplinary Perinatal Mortality Steering Committee.
- 2 Staff should be provided with appropriate training on best practice around the time of a perinatal death through the IMPROVE Program and access to support.

2.6 Regional and national considerations

Aggregated high quality audit can reveal common modifiable factors and potential solutions^{e1}. Consistent data systems and approaches provide a powerful tool for practice change to reduce perinatal deaths. Hospital-based perinatal mortality audit programs should be supported by, and feed into, regional and national audit programs overseen by key stakeholder committees. This process has been established in New Zealand (since 1994) with clear benefits⁴ and is currently being considered for Australia. In Australia production of an annual perinatal mortality report for Australia by the Australian Institute of Health and Welfare (AIHW) and establishment of a national advisory committee, and piloting of an on-line perinatal audit database through a NHMRC grant²³ are in progress. Establishing perinatal mortality audit at the national level will require support from national bodies, including ministries of health and professional colleges³.

2.7 The perinatal mortality audit cycle steps

We propose a seven-step cycle based on the cycle developed by the WHO¹; an additional step is included on feedback to parents. The seven steps are as follows: (1) identifying and scheduling the review of all perinatal deaths; (2) collecting and managing the information; (3) analysing information; (4) recommending solutions; (5) feedback and communication with parents; (6) implementing solutions; and (7) evaluating both the process and the outcomes and refining as indicated (Figure 1).

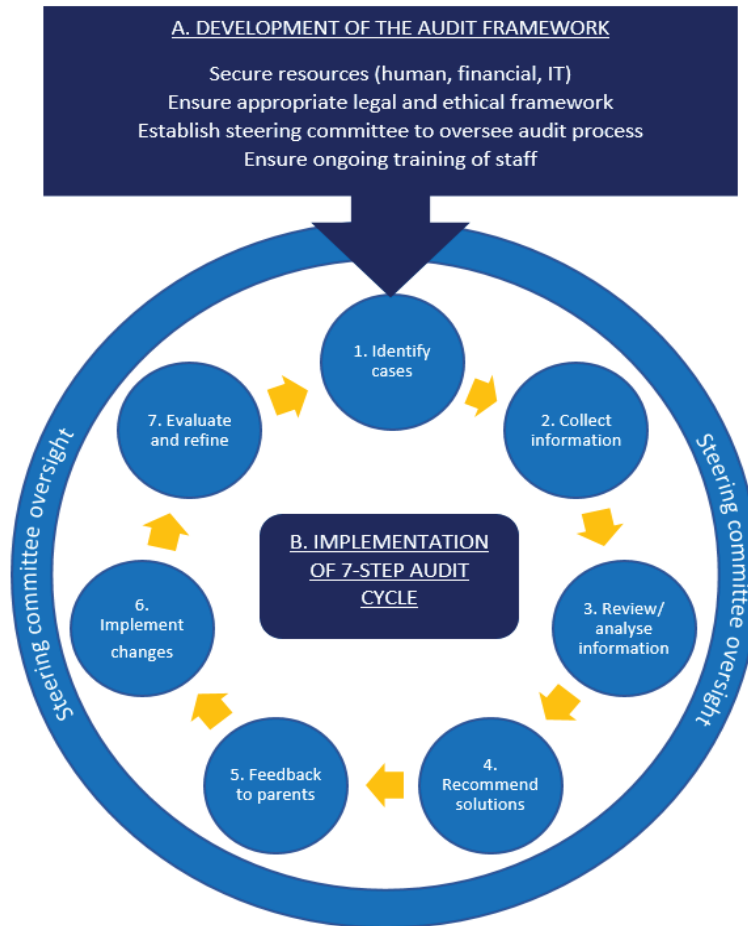


Figure 1 Steps in the perinatal mortality audit cycle

Step 1: Identify cases and schedule the review

- Establish a system to quickly identify all cases of perinatal deaths.
- Flag priority cases for rapid review (e.g. unexpected deaths in late gestation and intrapartum deaths).

The review of a perinatal death should be undertaken in a timely manner so that it occurs within recent memory of those involved and enables information from the review to be incorporated into discussion with the parents at their follow-up visit. A review should take place as soon as results are available from initial investigations. A further review of the death by the Mortality Committee, once the results of all investigations are available, may be necessary to finalise the cause of death and to ensure further follow-up is arranged as required. Timely review of the death may also facilitate appropriate counselling and support for staff.

Section 2 Recommendations

- 3** | The review of perinatal deaths should occur as soon as possible after the death aiming to have results in time for the initial follow-up visit with parents. It may be necessary to re-review the death if test results are delayed.

Step 2: Collect and manage the information

- Complete a comprehensive clinical summary for every perinatal death

Consultation with the woman (and her partner) about the course of events leading to the death should be undertaken as soon as possible and findings included in the case summary.

- Identify and train staff in data collection for perinatal mortality audit

This should include collecting a thorough history from the mother as soon as possible.

The Australian Perinatal Mortality Audit Tool (APMAT) (see *Appendix E – Australian perinatal mortality audit tool*) and New Zealand Rapid Reporting Form for a Perinatal Death (see *Appendix F (baby)* and *Appendix G (mother)*) have been designed to capture a standardised data set that should be collected for all perinatal deaths. This form is designed to fulfil requirements of health departments to ensure high quality data on causes of perinatal death nationally. To facilitate the data collection process clinicians should ensure that all relevant clinical details are documented clearly and accurately in the medical record at the time of the event and that all relevant documentation is completed according to local policy.

Data on each case should be:

- Recorded electronically;
- Include rates, causes, and contributing factors
- Link with other routinely collected data to minimise additional workload from the audit process

Section 2 Recommendations

- 4 | A comprehensive clinical summary, including a detailed interview with the mother as soon as possible after the death, should be completed for every perinatal death to facilitate institutional audit using the recommended paper-based form or on-line tool (APMAT, NZ Rapid reporting forms for a perinatal death) which, following the completion of the audit, should be provided to the jurisdictional perinatal mortality council or respective body. Clinicians should ensure clear and accurately documentation in the medical record at the time of the event to facilitate this process.

Step 3 Review and analyse the information

Generally, proceedings of the hospital Perinatal Mortality Audit meetings should include review of all perinatal deaths occurring in that hospital. Maternity services (particularly smaller hospitals) may choose to combine the audit meetings with another hospital committee or a regional mortality review committee.

- Develop a format for review of perinatal deaths, taking into account principles of confidentiality and impartiality, and any specific policy or legislative requirements relevant to the jurisdiction.

The aim of a perinatal mortality audit meeting is to provide an atmosphere of confidentiality and security that will encourage health care providers and managers to communicate openly and honestly with their colleagues. To achieve this, assurance should be sought by the administration of the institution that any information and discussion arising from the formal review will not be used in legal proceedings. As mechanisms for establishing perinatal mortality committees with the appropriate protection differ across Australia and New Zealand (ANZ), committees should seek advice from their respective health departments. It is the responsibility of each hospital's management to ensure that committee members and their deliberations are appropriately indemnified if required while undertaking this kind of audit on their behalf. Having case presentations which are completely anonymous may be helpful. However, within a single hospital, it is difficult to achieve a truly anonymous review.

Section 2 Recommendations

- 5 | The perinatal mortality audit meetings should have an experienced chairperson capable of ensuring a no-blame environment within an appropriate legal framework.

Chair and “rules of the meeting”

Review by a multidisciplinary team has been shown to increase the yield of information about the cause of deaths from mortality review²⁴. Multidisciplinary involvement provides an opportunity for all members of the team providing care to participate in a comprehensive assessment of the standards of care and to consider strategies for care improvement where necessary. Perinatal mortality audit meetings should be multidisciplinary, involve those health care professionals familiar with the circumstances of the perinatal death, and be conducted with a “no-blame” approach. The chairperson should be skilled in chairing meetings of a highly sensitive nature and accepted by peers to appropriately guide the discussion. While a senior medical practitioner usually fulfils the role of the chairperson, it is also important to involve nurses and midwives in this role¹. Having participants agree to a code of practice for review meetings and ensuring confidentiality as much as possible can contribute to an environment where audit is more likely to be successful²⁵ (see *Appendix K – WHO mortality audit meeting code of practice declaration*).

Assigning the cause of death

Every perinatal death occurring in the facility should be reviewed at the audit meeting and classified as to the causes of death according to the Perinatal Society of Australia and New Zealand (PSANZ)-Perinatal Death Classification (PDC) and Neonatal Death Classification (NDC). (Please refer to *Appendix E – Australian perinatal mortality audit tool*; *Appendix J – Perinatal mortality classifications: Quick reference sheet*). After review and classification of the cause of death, the death certificate may need to be revised and resubmitted (see item 6 below). For global comparisons, WHO recommends use of the ICD for perinatal mortality (ICD PM) which draws on the cause of death assigned on the death certificate. To ensure accuracy in cause of death data for perinatal deaths, the ICD PM²⁶ should be assigned after the audit meeting based on a revised death certificate where required. The purposes of the ICD and PSANZ system differ somewhat and these are discussed in more detail in Section 7 of the guideline.

Section 2 Recommendations

- 6 | As part of the audit meeting, the PSANZ Classification system should be used to assign the cause of death and associated conditions for every perinatal death

Systems Review - Determining the presence of contributing factors relating to care

The circumstances surrounding perinatal deaths should be considered to identify areas for practice improvement using the PSANZ Contributing Factors Relating to Care tool (included in *Appendix E – Australian perinatal mortality audit tool* to classify the type of factors present and also their relation to the death. Recommendations for practice improvement emanating from this review need to be carefully formulated (see below). This review should take into account recommendations of facility-based RCA if one was conducted. Determining whether contributory factors are present is an essential element of the review process that requires a systematic approach. PSANZ has adopted the tool used in New Zealand by the PMMRC²⁷ with a minor modification to include grades of certainty in the final decision of avoidability of the death. This has now been recommended for use by the AIHW for all Australian perinatal mortality committees.

Contributory factors are defined as modifiable components of the health system and issues of quality of care that cover a broad spectrum of organisation and/or management, personnel and access and/or engagement with care factors. The presence of these factors does not imply that a death could have been prevented if they were not present but rather that the risk of death may have been reduced. A death is considered potentially avoidable if the absence of the contributory factors may have prevented the death²⁷. Contributory factors may be highly specific to the death or generalised to the system(s). Identifying contributory factors that occur, and are inherent in, the system is an important part of the review. These factors are sub-classified into organisational and management, personnel and those relating to barriers to access and/or engagement in care. When assessing the presence of contributing factors relating to clinical care, best practice standards should be used as a benchmark, including hospital protocols and relevant national and international guidelines. Consideration of aspects of care provided after the death that may be improved in the future should also be undertaken and recommendations made to address these e.g. communication, counselling and bereavement support and investigations performed. It is important that the classification and coding of the contributing factors – and the preventability assessment – is performed consistently. This will allow reliable analysis and comparison of data relating to contributing factors.

Section 2 Recommendations

- 7 | As part of the audit meeting, the presence of contributing factors relating to care should be assessed and documented for every perinatal death using the format recommended in this guideline.

Step 4 Recommend solutions

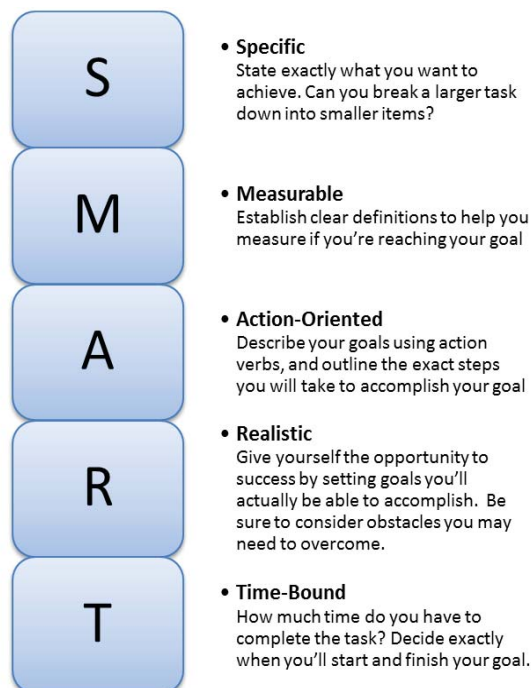


Figure 2 SMART criteria

The Perinatal Mortality Steering Committee should oversee the development of recommendations for action/solutions to problems identified. The SMART (specific, measurable, appropriate, relevant, and timely)²⁸ criteria (Figure 2) can help to ensure the proposed actions are achievable.

Section 2 Recommendations

- 8 Recommendations emanating from the audit process should be carefully developed and accompanied by an implementation plan which should be completed within a nominated time frame e.g. following the PDSA and SMART cycles.

Step 5 Communication and feedback to parents

Discussions between the parents and the main responsible health care provider about the death should be initiated as soon as possible after every perinatal death, using an open disclosure framework²⁹,

Meetings should preferably be led by the senior clinician responsible for care and include explanation and information appropriate to the parents' needs as well as an agreed plan for follow up meetings. It is important for the clinicians to acknowledge at this early meeting that there may be little information about the cause of death but that more information will be provided as results of investigations are available. Early feedback to the General Practitioner and

other relevant clinicians is important. Other key considerations in communication with parents are as follows:

- Follow-up meetings with parents to outline and explain the circumstances of the case should be scheduled with the senior clinicians who provided care present (obstetric, midwifery and paediatric)
- Where possible, someone with specific expertise in interpreting the results of perinatal death investigations and providing feedback on the outcome of the audit review should also attend
- Schedule these meetings after all relevant test results are available and following Perinatal Mortality Audit meeting review. Additional visits may need to be arranged if final results are delayed.
- Inform parents if the results of key investigations (such as autopsy) will not be available at the time of the scheduled meeting and offer them an additional or alternate time to receive those results

In cases of a congenital abnormality it may be appropriate to discuss the need for genetic counselling with a geneticist prior to the follow-up appointment with the senior clinician who provided care. The geneticist can then either attend the follow-up consultation or a further appointment can be offered at the time. Depending on the results of the initial investigation, it may also be necessary to arrange further tests.

Section 2 Recommendations

- 9** Initiate discussions with parents as soon as possible after the perinatal death, using an open disclosure framework
- 10** Senior clinicians should schedule follow-up meetings with the parents following perinatal death when relevant tests and reviews are complete, involving other specialists and additional investigations if indicated.
- 11** Senior clinicians should notify the General Practitioner and other relevant care providers of the death as soon as possible and a comprehensive clinical summary sent to them promptly after the audit meeting.

Step 6 Implement changes

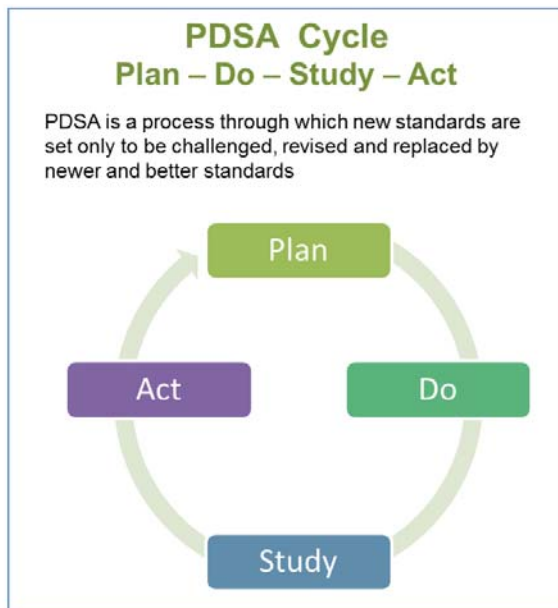


Figure 3 PDSA CYCLE

A process of feedback to clinicians needs to be in place so that individual practice and hospital policy can be improved as a result of the review process. Educational meetings, in addition to the perinatal mortality audit meetings, which engage a wider group of clinicians across the hospital may be helpful in translating findings from the audit into practice. The PDSA cycle is one method to assist in this process (Figure 3).

Step 7 Evaluate and refine the process

The final step in the audit cycle involves examining how successful each step of the process has been and in particular how effective it has been in changing practices and policies when required. An electronic data system is necessary to enable easy access to aggregate data to assess time trends in rates and causes of perinatal deaths and contributing factors. WHO has suggested a list of questions to help users assess and reflect on progress (Box 1)³⁰.

Box 1. Questions for reflection on the implementation and maintenance of the audit system

- How can review meetings be improved and used more effectively?
- How often and to whom is feedback given?
- What are the gaps in our feedback procedures?
- How can the feedback to service providers and senior management in the facility be improved?
- How can engagement in the audit process, the use of the findings and the application of recommendations be improved?
- How can feedback outside the facility be improved, e.g. district or provincial levels, and community?
- How can involvement from each of these levels be improved?
- Who is responsible for keeping the audit system together, e.g. one person, a team, formally or informally designated?
- Who is leading the audit? Who takes responsibility when the leader(s) is/are not there? What kind of succession plan do we have?
- How do staffing issues such as rotations and turnovers influence the audit activities?
- If lacking, how can staff stability be improved?
- What is our facility's responsibility in reaching out to another facility or facilities to introduce and establish an audit programme?

Source:³⁰

2.8 Completion of perinatal death certificates

The Royal College of Pathologists Australasia (RCPA) recommends that death certificates be issued or supervised by the senior clinician responsible for care³¹. As Perinatal Death Certificates are often issued prior to the results of investigations (particularly autopsy and placental pathology), this may result in significant error in cause of death data³²⁻³⁴. Review by a multidisciplinary clinical group has been shown to increase the value of post-mortem examinations in determining an accurate cause of death. Therefore it is essential that the audit meeting includes reviewing the details on death certificates for all perinatal deaths²⁴ and revisions made as required. The process of revising death certificates varies across regions. It is recommended that the Perinatal Mortality Committee become familiar with the process within their region and implement a process that ensures that a revised death certificate is submitted when required and to advise parents and their General Practitioners.

Section 2 Recommendations

- 12** | The Consultant responsible for care should complete or supervise completion of the Medical Certificate of Perinatal Death. The death certificate should be revised as required based on the outcome of the perinatal mortality audit meeting.

2.9 Definitions for registration and reporting of births and perinatal deaths

The definitions below are those from the AIHW³⁵ and New Zealand³⁶. Please note that definitions vary across jurisdictions in ANZ, please refer to *Appendix T – Australian and New Zealand definitions of perinatal mortality* for regional definitions.

Registration

The following definitions and examples are provided for clarification of the requirements for registration of births and perinatal deaths. While these terms are required for legal purposes care should be taken to use language appropriate for the intended audience, particularly in communication with parents, when relevant.

Livebirth

A livebirth is the complete expulsion or extraction from its mother of a product of conception, irrespective of the duration of the pregnancy, which after such separation, breathes or shows any other evidence of life, such as beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles, whether or not the umbilical cord has been cut or the placenta is attached; each product of such a birth is considered liveborn³⁷.

Neonatal death

Neonatal death is defined as liveborn infant dying within 28 completed days of life regardless of gestation³⁸. Early neonatal death is death of a live born baby within 7 days of birth. Late neonatal death is death of a live born baby after 7 is completed days and before 28 completed days.

The Medical Certificate of Cause of Perinatal Death (MCCPD) for stillbirths neonatal death³⁹ is required by the ABS for all neonatal deaths according to the above definition. This definition applies regardless of the birthweight or gestational age and also for resuscitated stillbirths.

Example 1: Resuscitated stillbirth

Where an infant is stillborn and, following active resuscitation, a heartbeat is detected, the birth is required to be registered as a livebirth. If the infant subsequently dies up to 28 days of age registration as a neonatal death is necessary.

Fetal death (stillbirth)

In Australia:

Death, before the complete expulsion or extraction from its mother, of a product of conception of 20 or more completed weeks of gestation or of 400 grams or more birthweight. Death is indicated by the fact that, after such separation, the fetus does not breathe or show any other evidence of life, such as beating of the heart, pulsation of the umbilical cord, or definite movement of voluntary muscles⁴⁰.

The MCCPD is required by the Australian Bureau of Statistics (ABS) for all stillbirths according to the above definition. This definition applies regardless of the known or presumed timing of the death in utero. Examples are provided here of circumstances which may require clarification. There are some variations in approaches across regions e.g. in QLD the Registrar of Births Deaths and marriages does not require a death certificate for stillbirths where the death is known to occur prior to 20 weeks gestation regardless of the timing of birth. However, the QLD Health Department's Perinatal Data Collection still requires these deaths to be registered if the stillbirth is birthed is 20 weeks or greater, or weighs 400 grams or more.

In New Zealand:

A stillbirth is 'a dead fetus that'

(a) weighed 400 grams or more when it issued from its mother, or

(b) issued from its mother after the 20th week of pregnancy. (Births, Deaths and Marriages Registration Act 1995)

And, Stillbirths must be registered according to the legal requirements of this Act. They require a birth registration (stillbirth), but not a death registration³⁶.

Example 1: Fetus papyraceous

In the case of a birth after 20 weeks gestation where the birth weight is less than 400g and where a fetal death may have occurred at some time before the birth, the birth is considered a stillbirth. However, in the case of fetus papyraceous where the fetus is not readily recognisable, the requirement for registration varies across jurisdictions.

Example 2: Multiple pregnancy

2A: In the case of a twin pregnancy with a fetal death of Twin 1 at 19 weeks and spontaneous onset of labour and delivery at 23 weeks gestation where Twin 2 is live born weighing 550g and Twin 1 weighs 200g, Twin 1 is registered as a stillbirth and Twin 2 as a livebirth.

2B: In the case of a twin pregnancy with a fetal death and spontaneous delivery of Twin 1 at 19 weeks weighing 200g and subsequent fetal death and delivery of Twin 2 at 21 weeks weighing 300g, Twin 1 is not required to be registered, however Twin 2 must be registered as a stillbirth.

Reporting to enhance comparability across ANZ

Variation due to different definitions used for reporting of perinatal deaths makes comparisons across ANZ problematic (*Appendix T – Australian and New Zealand definitions of perinatal mortality*). To ensure consistency and comparability, it is recommended that reporting of stillbirths and neonatal deaths adhere to the above recommended definitions. Further, aggregate data on rates and causes should identify perinatal deaths resulting from a termination of pregnancy (TOP), presenting data with and without the inclusion of terminations. The PSANZ classification enables identification of TOP for each condition in this system (please refer to Section 7).

Section 2 Recommendations

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To ensure consistency and comparability in perinatal death data across ANZ, the definitions recommended in this guideline are used including presenting data with and without the inclusion of perinatal deaths resulting from termination of pregnancy.

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2.12 Acknowledgements

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2.13 Appendices

Appendix E – Australian perinatal mortality audit tool

Appendix F – New Zealand rapid reporting form for a perinatal death - baby

Appendix G – New Zealand rapid reporting form for a perinatal death - mother

Appendix J – Perinatal mortality classifications: Quick reference sheet

Appendix K – WHO mortality audit meeting code of practice declaration

Appendix T – Australian and New Zealand definitions of perinatal mortality

Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death

Section 3

Respectful and Supportive Perinatal Bereavement Care

Version 3.2, August 2018

Endorsed by

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 parent 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 Bereavement Care Global Expert Consensus Group, now called RESPECT: *Research of Evidence based Stillbirth care Principles to Establish global Consensus on respectful Treatment*

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 associated with stigma and misperceptions^{1,4,17}. 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^{1,5,18}. Lack of acknowledgement of their baby, the extent of their loss, and their identity as bereaved parents can lead to disenfranchised grief¹⁹ where

parents feel their grief is not legitimate or socially acceptable. Validating perinatal loss is an essential part of improving support and reducing the stigma and sense of isolation that is commonly described by parents^{1,11,20}.

No single approach will meet the needs of all parents and perinatal bereavement care cannot be reduced to a checklist of activities²¹. Respectful and supportive care is personalised and takes account of the needs, preferences, circumstances and cultural context of each bereaved parent^{10,22}. 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^{5,17,23}.

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.

(Appendix Z provides a short overview of current theoretical perspectives that are relevant to perinatal bereavement care.)

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^{10,24}.

Health care professionals have a major role in helping parents to make decisions that minimise regret and avoid missed opportunities^{11,24}. 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 expectations²⁵.

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^{5,10,17,22,26-28}, 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 is essential to supporting parents and reducing the stigma and sense of isolation often experienced by 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^{10,11,29}. 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”³⁰. A systematic review found decisional conflict, limited information, and less involvement in decision making predicted patient regret about medical decisions³¹. In the context of perinatal loss, the value parents place on supported and informed decision making is well-documented^{10,32}.

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^{17,26,27}. 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^{10,33}.

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^{10,11,17,27,34}.

Information about a baby’s diagnosis and prognosis is often complex and uncertain¹⁷. Parents want health care professionals to communicate with honesty and compassion³⁵ and to show emotion, empathy and human reactions²⁷.

Where appropriate it is important to involve both parents in communication and decision making. Including fathers in communication and information-giving is essential to ensuring their loss is recognised^{27,29}. Responses to grief differ and fathers may have a strong need to protect and support their partner. It is important to assist them to find ways to do this and to express their own needs^{5,10,36}. The death of a baby affects families and the needs of siblings, grandparents and other family members should be considered^{27,36}.

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 loss³⁷.

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 the baby’s condition (e.g., “23-weeker”)²¹. 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^{11,21,38,39}.

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^{27,29}. Extreme emotional distress combined with sudden exposure to complex and unfamiliar medical information can leave parents overwhelmed and with limited capacity to processing and make sense of information⁴⁰.

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^{17,27,38}. 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 others⁴⁰. 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 language⁴⁰.

Parents want to be kept informed and to be given as much information as possible⁴⁰, 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 needs³⁵.

Cues from parents regarding their emotional state should guide the timing and delivery of information²⁷. 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^{21,29,35}. 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^{17,21}.

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 responses²⁷.

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 by the baby's condition (e.g., "24-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 wellbeing²⁷.

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^{11,29,41}.

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^{27,40}.

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^{41,42}. 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^{28,43}.

Parents want health care professionals to be transparent, even when the situation is uncertain, and to be assured that all possible is being done³⁸. 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^{11,27,41}.

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"⁴⁴.

Thoughtful communication is essential throughout the diagnostic process, using an approach such as the following⁴⁴: (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 suspected³⁸. Communicating detailed information and giving answers to parents' initial questions may increase parents' confidence in health care professionals³⁸. 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 details³⁸. When a diagnosis of stillbirth has been confirmed it is vital that parents feel supported and do not feel abandoned, or that their care has been de-prioritised^{10,22,28}.

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^{27,38}. When bad news is delivered, before leaving the room, it is important that health care professionals check with parents whether they would like them to stay for support or to answer questions, or if they would like to be left alone.

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^{27,39}.

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^{27,36}. 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 care²¹. 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^{10,11,27}. 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^{11,27}. 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 as their involvement may be an important part of the grief response for some parents.

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^{5,36,39}. 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^{10,11,27}. Continuity of staff and appropriate handover and documentation processes should be in place 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 death²⁶. 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 manner²⁶. Door signs and stickers should be used discreetly and with the mother's agreement as their use may distress some parents²⁷.

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^{10,14,33}. While some mothers may appreciate the cancellation 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 making³⁶. 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 conceiving⁴⁵. 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 care^{5,17,36,39}. 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 support³⁹. 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^{21,39}. Personal values, extended family, societal norms, religious beliefs, and legal issues are just some of the factors that will influence each parents' decision making³⁹. 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^{21,27}. 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 needs²¹: "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

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 created³⁹. Equally important is planning for the baby's death³⁶. 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^{17,27,36,39}.

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 explained. Unless clinically indicated, vaginal birth is the recommended mode of birth for most women to reduce risks related to morbidity and future pregnancy⁴⁶. 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^{22,28}. 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 procedure³⁹.

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^{11,17,27}. 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 support²⁷.

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^{10,22}. Adequate analgesia is critical, but mode and dosage must be titrated carefully and with discussion with the mother. Careful consideration needs to be given to sedation including the potential for regret about lost opportunities if the mother's ability to interact with her baby is compromised due to sedation.

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.^{22,28}

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^{28,47,48}. 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 deaths⁴⁹ 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^{22,49}. Parents usually want an explanation for why their baby died and also to help planning with future pregnancies^{27,50} but there are many influences on parents' decisions about consent for autopsy^{10,48,49,51}

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 overwhelmed⁴⁸. 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 made⁴⁸.

Where individual, religious and cultural beliefs make autopsy unacceptable to parents, these beliefs and the decision against autopsy should be respected²². Less invasive approaches may be

more acceptable to those who decline autopsy and these options should be discussed with parents⁴⁹.

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 decision⁴⁹. Sufficient time must be allocated to explain the options available, including less invasive and stepwise examinations, and to explore concerns and answer questions^{47,49}.

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^{10,49}. 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^{10,27}. Information provided verbally should be supported by parent-centred information in written or electronic formats⁴⁹.

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 stillbirth⁴⁹. It is important to convey to parents an understanding of the value of autopsy and that it is useful and respectful²⁸.

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.

Please also refer to: Section 4 – Perinatal Autopsy Including Placental Assessment for further details; Appendix M – Infant autopsy consent brochure and Appendix N – Information for health professionals seeking consent.

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.
- 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.

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^{17,26,27,34}.

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 baby²⁷. Health care professionals need to "ask the family what they want while realizing that they may not know"³⁶. 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^{11,27}.

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 parents³⁶. 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. Research on the consequences for parents of seeing and holding their stillborn baby has produced mixed findings and little clear guidance for parents or clinicians⁵². 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^{24,53}.

Above all, skilled and compassionate care that prepares, guides and supports parents is essential^{24,54}. 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 support²⁴. 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 made²⁷.

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 experience⁵². 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 baby²⁴; 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 professionals⁵⁴. Health professionals can also support parents to integrate siblings (or other family members) and help them "to be a family for a little while"²¹.

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^{22,26,27,39,54-56}. 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 care²⁴.

High quality photographs provide lasting and valuable memories for many parents^{57,58} 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 quality⁵⁷. 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 respected⁵⁷.

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^{11,27,57}.

Commemorative rituals

All parents should be supported in arranging bereavement rituals that meet their spiritual, religious and cultural needs³⁶. 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^{36,58}.

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^{10,36}. Information about financial support should also be offered to parents where available⁵⁸.

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** | Be knowledgeable and provide information about burial, cremation, and funeral options that are available for babies and support parents 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^{33,36}. It may also be helpful to prepare parents for interactions with others by: offering support to tell siblings and other family members²⁷; 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^{5,17,36}.

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^{33,36}.

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^{33,54}. Little evidence exists to indicate who is most likely to benefit from different types of psychological support^{22,59} and not all parents will require formal interventions³³. 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 times³³.

Parent support groups and the support of those who have had similar experiences will be helpful for many parents^{10,59}. 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^{33,34,59}.

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^{11,27}. All women should be offered lactation suppression in the absence of contraindications²², 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^{11,27,59}.

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 community³³. 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^{10,27,36}.

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^{10,28,33}.

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^{10,33,36}. 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^{10,22}.

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^{60,61}

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^{11,27}.

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

- 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^{10,11,27,36}.

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^{7-9,27,36}. 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^{9,36}. These include: ready access to debriefing and support; clinical supervision and mentoring with more experienced senior colleagues^{9,33}; and flexibility to enable rotation of health care professionals to avoid repeated exposure and to build confidence and experience across staff^{7,33}.

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^{62,63}.

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^{10,39}; the use of a universal symbol to indicate that a baby has died or has a life-limiting condition^{26,27}; the safe and reliable storage of images and mementoes for parents who may request these at a later time^{11,27,57}; 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^{33,54}.

Better collaborative care at the interface between hospital and community is essential to addressing the ongoing support needs of bereaved parents^{10,33}. Standard and consistent

approaches to managing the transition following hospital discharge and the continuity and transition across caregivers are required²⁸.

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^{14,33}.

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 services⁶⁴. 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 parents⁴³. 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 clinicians providing maternity and newborn care should attend the [IMproving Perinatal Mortality Review and Outcomes Via Education \(IMPROVE\) Workshops educational program](#)
 - All health care professionals in maternity settings should have training in bereavement care that addresses the emotional, physical and practical aspects of perinatal death and 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.

3.13 References

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3.16 Appendices

Appendix M – Infant autopsy consent brochure

Appendix N – Information for health professionals seeking consent

Appendix Z – Theoretical perspectives on perinatal bereavement

APPENDIX Z

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 attachment⁶⁵⁻⁶⁸ 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 dies⁶⁹.

The **Continuing Bonds** perspective⁷⁰ 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^{26,56,57}.

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^{71,72} 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 activities⁷¹. 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 grieving⁷³.

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^{74,75}. 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^{10,26}. 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.

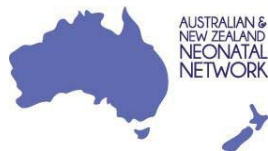
Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death

Section 4

Perinatal Autopsy Including Placental Assessment

Version 3.1, March 2018

Endorsed by



SECTION 4

PERINATAL AUTOPSY INCLUDING PLACENTAL ASSESSMENT

4.1 Introduction

The perinatal autopsy remains the gold standard in diagnostic evaluation of the causes of perinatal death¹⁻³. Information gained from an autopsy can assist in the understanding of events surrounding the death and enable consideration of potential risk recurrence and appropriate management strategies in future pregnancy planning. Despite the value that perinatal autopsies offer, two challenges persist; low autopsy rates and the quality of post-mortem examinations.

This section of the update of the guideline has been undertaken through a partnership between PSANZ and the NHMRC Stillbirth Centre of Research Excellence in Stillbirth.

To view further information on the described guidelines in this section of the PSANZ Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death see *Appendices G-Q*.

4.2 Objective of this section

The main objective of section 4 of the PSANZ Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death is to assist clinicians to improve standards for perinatal autopsy examination. This includes communication with parents, which directly affect autopsy rates.

For further information regarding communication with parents after a perinatal death please refer to Chapter 3 - Psychological and social aspects of perinatal bereavement.

4.3 What has changed in this update?

In this update, based on the findings of an updated literature review, the recommendations have remained unchanged. We have revised the formatting and reduced duplication across the different sections of the guidelines to enhance readability.

4.4 Purpose of perinatal autopsy

The purpose of any autopsy examination extends beyond diagnosis of the cause of death⁴⁻⁹.

The main purposes of an autopsy are to:

- Identify an accurate cause of death^{4,5,7,9}
- Exclude some potential causes of death¹⁰
- Identify disorders that have implications for counselling and monitoring in future pregnancies¹⁰⁻¹⁶
- Provide other information related to the death, including excluding possibilities that may alleviate feelings of guilt^{1,8,9,11,16}
- Obtain tissues for genetic tests (see *Appendix S – Components of the genetic autopsy for investigations of metabolic disorders*)
- Assist grieving by helping parents' understanding of the events surrounding the death^{1,11,16,17}
- Contribute to research, for example, by the recognition of new disease entities and expansion of knowledge on known diseases^{14,15,18-24}

- Inform clinical audit of perinatal deaths, including deaths due to iatrogenic conditions²⁰ and to confirm antenatal diagnoses or suspected fetal pathology^{21,22}
- Teach pathologists and medical students^{10,11,25}
- Avoid inaccuracies in data on causes of death for audit activities and subsequent public health policy²⁶⁻²⁹.
- Inform medico-legal processes, for example, provide information in coronial investigations or cases of litigation^{10,16}.

Value of an autopsy including placental examination

The autopsy examination remains the gold standard for identifying cause of perinatal death^{1,2}. The value of a perinatal autopsy has been demonstrated in several studies where the information obtained changed diagnoses or provided important additional findings^{17,21,30-38}. A review of 27 studies found that perinatal autopsy revealed a change in diagnosis or additional findings in 22% to 76% of cases³⁰. Another review of 53 studies, across a broad range of health care settings, on diagnostic errors detected at autopsy demonstrated a median error rate of 23.5% for major errors (clinically missed diagnoses involving a principal underlying disease or primary cause of death) and 9% for Class 1 errors (major error that, had they been detected during life, “would”, “could”, “possibly” or “might” have affected patient prognosis or outcome). This study also showed some decrease in error rate over time however the rate remained sufficiently high, supporting the ongoing use of autopsy³⁹. Value from an adequate numbers of perinatal autopsies to ensure standards in perinatal pathology has also been suggested⁴⁰.

A systematic review concluded that pathology of the placenta, cord, or membranes is attributed as a cause or contributory to stillbirth in 11% to 65%⁴¹. Placental histopathology can be causal and associated with factors associated with causing neonatal morbidity and mortality including: fetal growth restriction; pre-eclampsia; infection; conditions as a result of hypoxia such as necrotising enterocolitis and cerebral palsy; and infants who fail to respond to resuscitation^{23,37}

Pathways to an autopsy

An autopsy results from one of two major pathways: with parent consent or mandated by the coroner. Informed parental consent is essential for any post-mortem examinations that are not coroner-mandated (see Section 3).

Coroner-mandated autopsy

The purpose of a coroner's autopsy is to determine the cause of death, and specifically whether it was natural or unnatural. Each jurisdiction has reasons for notification and so it is important to reference the Coroner's act for your state or territory. Some examples are:

- Babies dead on arrival at hospital
- Unattended stillbirths
- Deaths after an operation, anaesthetic or invasive procedure
- Deaths as a result of accident
- Unnatural, criminal or suspicious deaths, e.g. neglect, abuse, poisoning
- Deaths caused by drugs, prescribed or otherwise
- Deaths as a result of medical mishap
- Deaths in which the doctor is uncertain of the cause of death and unable to confidently complete the death certificate
- Unexpected death on the ward¹⁰.

If there is any doubt as to whether a death should be referred to the coroner, discussion with an experienced coronial officer or with the coroner is advised.

Coroners should ideally arrange for paediatric pathologists to perform the autopsy⁴, and provide results to relevant clinicians rather than use general or forensic pathologists.

The Coroner’s act for each state and territory can accessed via the relevant links listed:

State/Territory	Web site address/URL
Victoria	http://www.coronerscourt.vic.gov.au/find/legislation/
South Australia	https://www.legislation.sa.gov.au/LZ/C/A/CORONERS%20ACT%202003.aspx
Queensland	https://www.legislation.qld.gov.au/LEGISLTN/CURRENT/C/CoronersA03.pdf
New South Wales	http://www.legislation.nsw.gov.au/#/view/act/2009/41/whole
Western Australia	https://www.slp.wa.gov.au/legislation/statutes.nsf/main_mrtitle_201_homepage.html
Tasmania	http://www.thelaw.tas.gov.au/tocview/index.w3p;cond=;doc_id=73%2B%2B1995%2BAT%40EN%2B20160707000000;histon=;pdfauthverid=;prompt=;rec=;rtfauthverid=;term=;webauthverid=
Northern Territory	http://www.austlii.edu.au/au/legis/nt/consol_act/ca120/
Australian Capital Territory	http://www.legislation.act.gov.au/a/1997-57/
New Zealand	http://www.legislation.govt.nz/act/public/2006/0038/latest/whole.html

4.5 Different types of autopsy

Autopsies are generally defined in terms of their extent. The “gold standard” is the ‘classical’ conventional or full autopsy, which involves the combination of review of the clinical notes and maternal investigations, placental examination and examination of the baby. In a full autopsy examination of the baby includes external examination (including measurements and clinical photographs), radiological investigations, evisceration, dissection and organ examination including detailed histological evaluation. Other special tests like microbiology, molecular karyotyping/cytogenetics and molecular studies may also need to be performed. All other forms of autopsy are compared to the full autopsy in terms of the level of examination and degree of invasiveness³.

Less invasive autopsies (LIA) include all post-mortem examinations that take an approach other than a full autopsy. LIA include limited and minimally invasive or non-invasive autopsies. Limited

autopsies take an organ-specific approach and usually require some form of surgical incision. For example, the examination involves an incision to look at the heart or brain only. Minimally invasive autopsies (MIA) do not make a large surgical incision but use a laparoscopic or keyhole approach to obtain organ samples with radiological guidance. Non-invasive autopsies (NIA) use no internal examination, but instead rely on the detailed external, placental and umbilical cord examinations and external measurements, skin/needle blood sampling, clinical photography, and radiological investigations that are performed. Radiology may also include conventional radiographs, computed tomography, or magnetic resonance imaging^{42,43} (see 4.13 below). Stepwise post-mortem may include sampling tissue immediately after death (for example for metabolic reasons) then performing the full autopsy.

4.6 Autopsy rates

While data to establish an optimal perinatal autopsy rate is lacking, the Working Party of the Royal College of Pathologists⁵ recommended a rate of 75%. However, perinatal autopsy rates have steadily declined over recent years to rates much lower than this recommendation in many regions. A 2.8% per year decline over the decade 1990-1999 was reported by one tertiary setting in the UK¹⁷. Reports of perinatal autopsy rates more than a decade ago ranged from 33% to 67%^{17,23,24,44}. An analysis of perinatal deaths in Australia from 2011-2012 showed an overall perinatal autopsy rate of 38.7% (42.3% stillbirth and 28.2% neonatal deaths). Over half (57.5%) of all perinatal deaths were recorded as not having an autopsy performed⁴⁵.

Why the decline in autopsy rates?

Consent is the major limiting factor to achieving adequate autopsy rates^{16,46}. Consent for autopsy is difficult for both clinicians and parents. Parents are confronted by a proposed process that appears intrusive, and that requires them to understand detailed consent procedures when they are in a state of grief¹⁰ while clinicians are reluctant to place further burden on parents⁴⁷.

Adverse publicity generated from inquiries into autopsy practices in the United Kingdom over retained organs⁴⁸⁻⁵⁰ and the inquiry at the NSW Institute of Forensic Pathology⁵¹ are believed to have adversely influenced clinicians' willingness to seek consent and parents' acceptance of the procedure^{52,53}. Practice improvements resulted from the NSW inquiry but complexity in the consent process also increased, which may have created an additional deterrent for clinicians⁸. However, clinician reluctance to seek consent because of the added burden placed on families may be misplaced. A survey of UK parents found significantly more parents who did not have an autopsy were dissatisfied with their decision (OR=2.43, 95% CI 1.53-3.87)⁵⁴. The low autopsy rate may also indicate that clinicians are ambivalent about the value of an autopsy^{10,55,56} or may be reluctant to discuss difficult issues with families where no pre-existing relationship exists

Other factors identified as possibly affecting clinicians' willingness to approach parents for consent for autopsy include: lower gestational age at death^{17,57}; clinician discipline and seniority^{16,57}; and workforce shortages⁸.

Khong *et al* found that obstetricians and neonatologists were less averse to seeking consent for perinatal autopsies than midwives and neonatal nurses who were more influenced by those factors unfavourable to consent-seeking¹⁶. Obstetricians and neonatologists surveyed considered nurses and midwives influential in parents' decision-making about autopsy¹⁶.

Provision of educational opportunities for all members of clinical teams, both formal (during undergraduate and post graduate training) and informal (through day-to-day positive reinforcement from clinical leaders) is crucial to increasing the rates of perinatal autopsy.

Section 4 Recommendations

- 1 Clinicians should discuss the value of an autopsy with parents in all cases of perinatal death and offer them the option of the procedure.
- 2 To increase the rates of perinatal autopsy:
 - Clinicians should collaborate with pathologists and parent based organisations to raise public awareness of the value of perinatal autopsy and to advocate for high standards in perinatal autopsy at local and government level.
 - Clinical leaders should promote formal and informal educational opportunities for clinicians on: post-mortem examination procedures; the potential benefits of an autopsy; compassionate counselling and obtaining parental consent; and address specific local barriers to the conduct of perinatal autopsy.All clinicians providing maternity and newborn care should attend the IMproving Perinatal Mortality Review and Outcomes Via Education (IMPROVE) Workshops educational program (<https://sanda.psanz.com.au/improve/>).
- 3 Seek advice from the coroner or an experienced coronial officer if any doubt exists as to whether a death should be referred to the coroner.

4.7 Costs of a post-mortem examination and transport

Diverse arrangements exist across Australia regarding payment for autopsy⁸. The cost of autopsy are estimated to be around \$1500⁵⁸ – \$2600⁵⁹. Currently the post-mortem examination of a stillborn baby is not adequately covered under Medicare and consequently the costs for the post-mortem examination need to be covered either by the institution state health departments or their designated authorities.

Recommendation

- 4 Clinicians need to be aware of costs associated with transferring an infant from non-metropolitan areas to tertiary centres for autopsies within their region and inform parents of any personal cost implications relevant to their decision-making.

4.8 Quality of perinatal autopsies and minimum standards

Research on the quality of perinatal autopsies is limited however the available data suggests that approximately half may not reach minimum standards^{23,55,60}. Approaching parents for consent when a quality post-mortem service is not available raises important ethical questions² that demand attention to the requirements of minimum standards.

The post-mortem examination of an infant is very different to that performed on an adult^{5,61-63}, and ideally should be performed by a paediatric pathologist. Pathologists with paediatric training find a higher incidence of causes of death in infants⁶⁴, provide a much higher proportion of adequate reports^{65,66}, and the causes of death based on perinatal/paediatric pathologists reports are infrequently revised by the Confidential Enquiry into Stillbirths and Deaths in Infancy (CESDI) review panel⁶⁷. There are currently no guidelines for Australia and New Zealand on quality and minimum standards for perinatal autopsies. Until the availability of such guidelines, the Guidelines on Autopsy Practice produced by the Royal College of Pathologists should be used for guidance⁴.

Appropriate clinical information is an essential part of a good quality post mortem. The history of the pregnancy, results of antenatal investigations and circumstances of perinatal loss are vital in determining the relevant questions to be addressed by the post mortem and enable judicious use of investigations (please refer to *Appendix I – Autopsy clinical summary form*). Transportation of the baby to a centre with appropriate perinatal pathology expertise should be offered to parents where this expertise does not exist in the birth facility. Transport should be arranged with a registered undertaker.

There is growing use of new molecular techniques in the assessment of perinatal deaths. Chromosomal microarray is fast becoming standard practice as it detects a significant number of pathological changes not seen with standard karyotyping, although balanced chromosomal translocations and triploidy may not be detected⁶⁸. However, this is a developing technology and the range of normal and pathological variants are yet to be established. Interpretation can be time consuming. Next generation sequencing is already used diagnostically with large studies funded in the US and under discussion in the UK and Australia for more routine⁶⁹. Material like cartilage or skin can be used for these techniques. This needs to be retained and should be included in the consent process.

Following recent reviews the use of microarray is becoming standard⁶⁸. Identification of previously undiagnosed genetic disorders always was part of the post mortem process making a full informed consent difficult. However the parents should be informed that material for DNA and genetic tests is likely to be retained, and should be if there are features suggesting a genetic cause. Consent for further genetic testing may be sought by the genetics team after the autopsy using material retained at autopsy.

Specific autopsy protocols have been developed for examinations when genetic metabolic disorders are suspected⁷⁰ and in the event of a Sudden Unexpected Deaths in Infancy⁷¹. Please refer to these protocols for full details.

(Please see Appendix Q – Suspected genetic metabolic disorders)

(Please see:

- *Appendix O – RCPATH guidelines for autopsy investigation of fetal and perinatal death*
- *Appendix Q – Suspected genetic metabolic disorders*
- *Appendix I – Autopsy clinical summary form*

Recommendations

- 5 The Guidelines on Autopsy Practice produced by the Royal College of Pathologists⁵ should be used for guidance on minimum standards until guidelines for Australia and New Zealand are developed.
- 6 Specific protocols developed for post-mortem examination in the event of Sudden Unexpected Death in Infancy and death with suspected genetic metabolic disorders should be followed.
- 7 A perinatal/paediatric pathologist should perform or supervise all perinatal post-mortems. Clinicians should request autopsies from the service providing the highest quality.
- 8 Transport to a centre with appropriate expertise should be arranged to ensure that all perinatal post-mortem examinations are of sufficient quality. Transport should be arranged with a registered undertaker.
- 9 A comprehensive maternal history should accompany the baby for a post-mortem examination including:
 - Clinical/obstetric history including relevant previous obstetric history
 - Copies of all ultrasound reports⁹
 - Copy of the death certificate if available
 - Copy of amniocentesis report if available.

4.9 Post-mortem reporting

A preliminary report is usually available within three days of the examination, and should include a summary of the clinical history, samples taken and further tests requested, and macroscopic findings. The final report may take up different times in different jurisdictions; up to eight weeks in most cases although more complex genetic or metabolic workups can take six to 12 months. The post-mortem report includes demographic details, a clinical summary, and findings of the external and internal examination including: organ weights; microscopic findings; results of ancillary examinations such as cytogenetics; microbiology; radiology a summary of findings; a commentary to suggest the most likely pathophysiological pathway; and a cause of death if appropriate. Other details ideally recorded are mode of identification, a list of samples taken, a record of X-rays and photographs taken, and details of the consent and any limitations imposed¹⁰.

Delays with and poor communication of results can be a source of much distress to parents^{72,73}. Establishing clear processes and timelines for informing parents of results may help to alleviate such distress.

A plain language report (PLR) may be helpful to parents⁸. A copy of the PLR, if available, and full autopsy report should also be sent to the GP. Autopsy reports should not be sent directly to the parents but provision should be made to discuss the findings with the parents, even if the results are inconclusive⁷⁴. Parents should be advised in instances where, based on the findings of investigations, a revised death certificate may be submitted. Such discussions should take

place at a suitable venue (e.g., away from antenatal clinics). Parents should be advised in instances where, based on the findings of investigations, a revised death certificate will be submitted.

Recommendations

- 10** Guidelines for post-mortem reports produced by the Royal College of Pathologists⁴ should be used as a guide for reporting of perinatal post-mortem examinations.
- 11** Ideally, a preliminary post-mortem report should be forwarded to the referring clinician within three working days of the post-mortem. The final report should be forwarded to the referring clinician ideally within eight weeks of the autopsy.
- 12** The post-mortem report should be made available to the parents at a time when the primary care clinician is present to discuss the findings.
- 13** A Plain Language Report (PLR) should be available to parents on request.
- 14** A request for the General Practitioner (GP) to receive a copy of the report (including the PLR, if available) should be explicit on the request form, as they are the main care provider on discharge.

4.10 Communication and consent

All hospital perinatal autopsy examinations require written consent from parent(s) following informed discussion⁴⁷, although little is known on the best ways to inform parents making decisions about autopsy or other post-mortem examinations and we rely on the knowledge and experience of those involved at the time⁷⁵. Such knowledge and experience can be highly variable among health professionals⁵⁴.

The influences on parents' decision-making regarding autopsy are complex and diverse^{72,73,76}. Assumptions need to be avoided as barriers perceived by clinicians are often different from those reported by parents⁷². Parents are often overwhelmed and need clear, easily understandable and structured information presented verbally and in written form⁷². Parents should be given written information explaining autopsies to assist in their decision about an autopsy examination for their baby (please refer to *Appendix M – Infant autopsy consent brochure*). The extent of the examination including retention of organs and DNA needs to be clearly explained and documented in the consent form. Options for a full, limited or stepwise autopsy should be explained. Parents need to be counselled that limited autopsy may result in the loss of important information. Written consent from parents is also required for peri-mortem investigations such as clinical photographs, tissue and blood sampling by cardiac puncture. Written consent is not required for histopathological examination of the placenta, however parents should be informed that this is a part of the routine investigation that may provide valuable information⁷⁷.

Parents want to know why their baby died and a desire for information is a strong motivating factor for consent to autopsy; concerns about the invasiveness of the procedure and a desire to

protect the baby from unnecessary harm are major barriers to consent (Lewis et al., 2017). A UK survey that included 460 parents, found professional advice influenced the decisions about autopsy for more than one in five parents (22%). The majority of parents were satisfied with their decision related to autopsy, although those who did not have an autopsy were more likely to be dissatisfied⁵⁴. Regret is more common among parents who have not had an autopsy even when a cause of death is not found, although sample sizes are commonly small or skewed^{54,78,79}. Informed discussion with the parents should include the possibility that a cause of death may not be found, but that the information obtained may benefit other babies in the future. Clinicians need to be aware of religious and cultural beliefs and values which may influence parents' decisions^{8,11}. It is important and appropriate to ask parents what is important to them.

Where possible, consent from parents should be sought by an experienced clinician who has rapport with them. Responsibility for obtaining informed consent lies with the primary attending physician^{2,10} and in most cases the consultant clinician should approach the parents, although this may be delegated to another attending clinician (e.g. midwife, nurse)⁸⁰. Clinicians seeking consent should be prepared to answer in a sensitive manner questions about what actually happens to the baby during the procedure and how the baby may look after the examination⁸⁰. Therefore, all clinicians seeking consent should have in-depth knowledge of post-mortem procedures and, preferably, have witnessed several autopsy examinations. Discussion with parents about consent for all post-mortem examination needs to take into account the importance of partnerships in decision making⁸¹. Parents are likely to need practical information about the process and the implications of their decision, such as advice on how long the baby can remain in the hospital or be taken home without adversely affecting post-mortem results, whether they will be able to see the baby again, and if any costs might be involved.

(Please refer to Appendix N – Information for health professionals seeking consent.)

Recommendations

- 15** | Where possible, a senior clinician who has established a rapport and understanding with the parents should discuss the value of an autopsy and offer the option of the procedure. Such clinicians should have high level communication skills and knowledge of all post-mortem examinations, and preferably witnessed several perinatal autopsies.
- 16** | Any clinician approaching parents for autopsy consent should discuss:
 - Options for full, Less invasive autopsies (LIA), minimally invasive autopsies (MIA), Non-invasive autopsies (NIA) or stepwise post-mortem examinations
 - Issues related to retained tissues, organs and DNA for genetic and other tests
 - The value of autopsy
 - Possibility that cause of death may not be determined
 - Possibility that some potential causes of death could be excluded
 - Information gained may not directly benefit the family but may benefit others
 - Possible implications for future pregnancies
 - The care and respect that will be given to the baby

- 17 Discussion with parents should be supplemented by written information explaining autopsies to help in their decision on autopsy for their baby.
- 18 When consent is obtained for specific organ/s to be retained for further examination, parents should be offered the option of either delaying the funeral until the organs can be returned to the body or specifying their preferred method of organ disposal.
- 19 Consent for the autopsy which clearly outlines the extent of the investigation should be recorded on an approved consent form, relevant to the jurisdiction.
- 20 Where possible the pathologist should be available to discuss the autopsy with the parents before and/or after the procedure and, where feasible, the requesting clinician should attend the autopsy and provide the parents with a preliminary report immediately after the examination.

4.11 Placenta, membranes and cord histopathology

Examination of the placenta, membranes and cord should occur after all births. The placenta is also an integral part of the post-mortem examination and, ideally, all placentas should be retained for a few days after birth to allow for subsequent retrieval should an infant deteriorate. This may happen with sepsis or metabolic disorder¹⁰. The placenta, membrane and cord should be sent to the pathologist fresh and unfixed for histopathological examination once samples have been collected for cytogenetics and microbiology. A perinatal/paediatric pathologist should undertake the examination²³. A standardised reporting form for placental histopathology is provided to enable high quality reporting (Please see *Appendix P – Placental histopathology reporting form*).

Placental examination by a perinatal/paediatric pathologist should be performed for specific maternal, placental, fetal and neonatal indications⁸².

Maternal indications include:

- Systemic disorders such as an active autoimmune disease, uncontrolled diabetes, or other significant maternal disease that has affected the pregnancy
- Moderate or severe pre-eclampsia
- Intrapartum fever or infection
- Suspected chorioamnionitis
- Unexplained bleeding in the third trimester
- Excessive bleeding (more than 500ml)
- Placental abruption
- Severe maternal trauma
- Amniotic Fluid Index (AFI) abnormalities.

Fetal and neonatal indications include:

- Admission to neonatal intensive care
- Failure to respond to resuscitation
- Spontaneous or iatrogenic preterm birth
- Fetal compromise including growth restriction
- Severe cardiorespiratory depression at birth

- Signs consistent with congenital infection
- Severe growth restriction
- Diagnosis of hydrops fetalis
- Suspected severe anaemia
- Suspected or known major congenital abnormalities
- Death.

Placental indications include:

- Physical abnormality
- Abnormal placental size or weight for gestational age (small or large)
- Suspected vasa praevia
- Umbilical cord lesions
- Abnormal cord length.

Recommendation

- 21** | Placentas should be sent for examination by the perinatal/paediatric pathologist regardless of whether consent for an autopsy has been gained following stillbirths, neonatal deaths in the delivery room or birth of high risk infants.

4.12 Alternative investigations: When permission for autopsy is not obtained

If permission for an autopsy is not obtained, other less invasive testing may assist to establish whether any important abnormalities have been missed. These options should be offered to parents as these alternatives permit detailed investigation of the baby while respecting the wishes of parents⁸³. However, a Working Group of the Royal College of Paediatrics and Child Health found little evidence for valid alternatives to the paediatric post-mortem⁶¹. Parents should be informed at the time of consent about the possibility of missing an important finding when a full post-mortem investigation is not undertaken. All alternative investigations are subject to the same requirements of informed consent as autopsy examinations.

External examination

Examination by an experienced clinician (by a perinatal/paediatric pathologist, clinical geneticists or paediatrician) is of particular importance when an autopsy examination is declined⁸⁴. Clinicians should discuss the importance of this examination with the parents and arrange for an appropriately skilled clinician to perform it.

Please refer to Chapter 5 - Investigation of stillbirths and Chapter 6 - Investigation of neonatal deaths for further details

Babygram

Parents who decline an autopsy should be provided with further information about and asked to consent to the use of a full body X-ray (babygram) as an alternative non-invasive investigation. A babygram may detect abnormalities (mainly skeletal) which may not be detected on an

external examination. The Wisconsin Stillbirth Service Program has estimated that approximately 20% of unselected stillborn babies will have abnormalities which are detectable on X-ray⁸⁴.

Please refer to Chapter 5 - Investigation of stillbirths for further details.

Ultrasound scan

A detailed ultrasound examination of the infant at the time of confirmation of an intrauterine death or after the birth may identify fetal abnormalities not identified by an external examination⁸⁵.

Please refer to Chapter 5 - Investigation of stillbirths for further details.

Magnetic Resonance Imaging (MRI)

Magnetic Resonance Imaging (if available) may be offered to parents who decline an autopsy investigation. The investigation should be undertaken as soon as possible after a stillbirth. Clinicians should explain to the parents that a full autopsy remains the gold standard as the MRI does not supply tissue samples and therefore important information may be missed.

A comprehensive overview presented the advantages and disadvantages of the post-mortem MRI¹. The major advantages of post-mortem MRI included the non-invasive nature of the examination and the detection of pathologies and malformations of the central nervous system. The disadvantages included the lack of tissue sampling; limitations in detection of complex cardiac malformations, and other abnormalities (e.g. tracheo-oesophageal fistula, bowel perforations) which are undetectable by post-mortem MRI; and lack of experience in perinatal post-mortem MRI. The authors concluded that a full autopsy remains the gold standard; however, MRI may play an important role when an autopsy is declined¹.

More recent literature comparing MRI with autopsy in accurately identifying cause of death or most clinically significant abnormality in stillborn fetuses found that sensitivity for MRI was 69%, and specificity was 95%⁸⁶. Following on from these results, one large study showed that concordance for detection of major pathological abnormalities between full autopsy and MRI is near 43% for stillbirth ≤ 24 weeks' gestation, and 63% for stillbirths > 24 weeks' gestation⁸⁷. However the discordance between MRI and full autopsy is relatively high, 23% for stillbirth ≤ 24 weeks' gestation, and 33% for stillbirths > 24 weeks' gestation⁸⁷, suggesting that MRI only may not be an optimal substitution for full autopsy. Current ongoing studies are exploring yield of techniques combining computed tomography (CT) scans with MRI to guide biopsy sampling, so-called virtual autopsy⁸⁸. It is possible that MRI in combination with additional techniques may provide an option for cause of death investigations when full or partial autopsy is declined

Clinical photographs

Following consent from parents, clinical photographs should be taken for later review, particularly for births that occur in non-tertiary hospital settings. These photos are additional to the bereavement photographs and should not be given to the parents. They should be clearly labelled and filed in the medical record. The use of digital imaging for this purpose is optimal, however issues regarding storage and patient confidentiality should be considered.

Please refer to Chapter 5 - Investigation of stillbirths and Chapter 6 - Investigation of neonatal deaths for further details.

Other alternatives to a full post-mortem examination

Post-mortem needle biopsy; laparoscopic autopsy and small incision access are other alternatives to a full post-mortem for focussed investigation of suspected abnormalities. Recent studies suggest that minimally invasive post-mortem examinations may be a valuable investigation to determine cause of death in stillbirth if a full post-mortem is declined⁸⁷.

Section 4 Recommendation

- 22** | Consent should be sought from parents for less invasive testing if permission for an autopsy is not obtained, including: external examinations by skilled clinician; an MRI scan; babygram; ultrasound scan; post-mortem needle biopsy; laparoscopic autopsy and small incision access.
- 23** | When an MRI scan is undertaken it should be undertaken as soon as possible after a stillbirth.

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4.14 Section authors

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4.16 Appendices

Appendix I – Autopsy clinical summary form

Appendix M – Infant autopsy consent brochure

Appendix N – Information for health professionals seeking consent

Appendix O – RCPATH guidelines for autopsy investigation of fetal and perinatal death

Appendix P – Placental histopathology reporting form

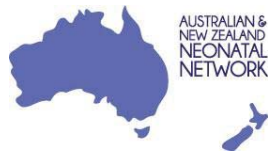
Appendix Q – Suspected genetic metabolic disorders

Appendix S – Components of the genetic autopsy for investigations of metabolic disorders

Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death

Version 3.1, March 2018

Endorsed by



SECTION 5

INVESTIGATIONS FOR STILLBIRTH

5.1 Introduction

This section of the PSANZ Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death presents recommended investigations to be undertaken following fetal death/stillbirth. Accurate identification of the cause of stillbirth is the cornerstone to prevention and is critically important to parents to help them to understand why their baby has died and to plan future pregnancies. The high proportion of unexplained stillbirths reported globally is an impediment to these goals¹. Wide variation in reported causes of stillbirth internationally has been attributed to different approaches to investigation. However, the classification system used also plays a role². Please refer to Section 7 of the PSANZ Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death for further details on classification of stillbirths and neonatal deaths.

This update of the guideline has been undertaken through a partnership between PSANZ and the NHMRC Stillbirth Centre of Research Excellence in Stillbirth.

In this section of the PSANZ Guideline for Care Around Stillbirth and Neonatal Death, for practice recommendations to assist clinicians to implement the guideline recommendations see *Appendices A - T*.

5.2 Objective of this section

The objective of this section is to provide guidance on the investigations to perform following a stillbirth to identify an accurate cause of death. Detailed objectives are:

- To provide quality information for parents to help understand why the death occurred;
- To inform future pregnancy planning;
- To inform care in future pregnancies; and
- To inform strategies for prevention at the population-level, and future research.

5.3 What has changed in this update?

The findings of a recent literature review have informed changes in this update. Readability has also been enhanced and reduced duplication across the different sections of the guidelines.

Several investigations previously recommended as core investigations following all stillbirths are now recommended as selective investigations only. These investigations (e.g. thrombophilia studies, tests for infectious diseases, Haemoglobin A1c (HbA1c), liver function and bile acid tests) should be undertaken on the basis of the results of core investigations. Maternal ultrasound scan, full blood count, renal and thyroid function testing are no longer recommended investigations for determining the causes of stillbirth. Amniocentesis for cytogenetic analyses and microbiological studies are no longer recommended.

5.4 Research gaps

Due to the lack of high-quality studies on appropriate diagnostic testing following stillbirth, contentious issues remain and, consequently, components of stillbirth investigation protocols internationally vary^{3,4}. While there are limited data on costs of stillbirth investigations, one study from the US by Michalski et al in 2002 suggest that a specific comprehensive investigation

protocol was of sufficient economic value to be incorporated into routine antenatal care⁵. Others report that a selective⁶ or sequential approach to testing may be appropriate^{7,8}. The findings of the National Health and Medical Research Council (NHMRC)-funded study on the yield and costs and benefits of stillbirth investigations across maternity settings in Australia and a Cochrane systematic review of the evidence for test protocols⁴ are expected in 2017 and 2018.

5.5 Approach to investigation of stillbirth

The recommended investigations following stillbirth include those that should be routine for the majority of stillbirths (core investigations) and those that should be carried out based on information revealed from core investigations, or in the presence of specific clinical scenarios (sequential or selective investigations) (see Figure 1).

Situations will exist where the cause of a fetal death is already known (e.g. unequivocal diagnosis from prenatal testing), however, as selective investigative approaches may result in important diagnoses being missed⁹, a non-selective approach using the core investigations should be the standard in the absence of unequivocal diagnosis from prenatal testing. The relative merits of not following this approach should be considered on an individual-case basis and involve consultation with the family. Depending on the particular circumstances of a perinatal death (e.g. family wishes, access to services), it may not be feasible for some stillbirth investigations to be carried out.

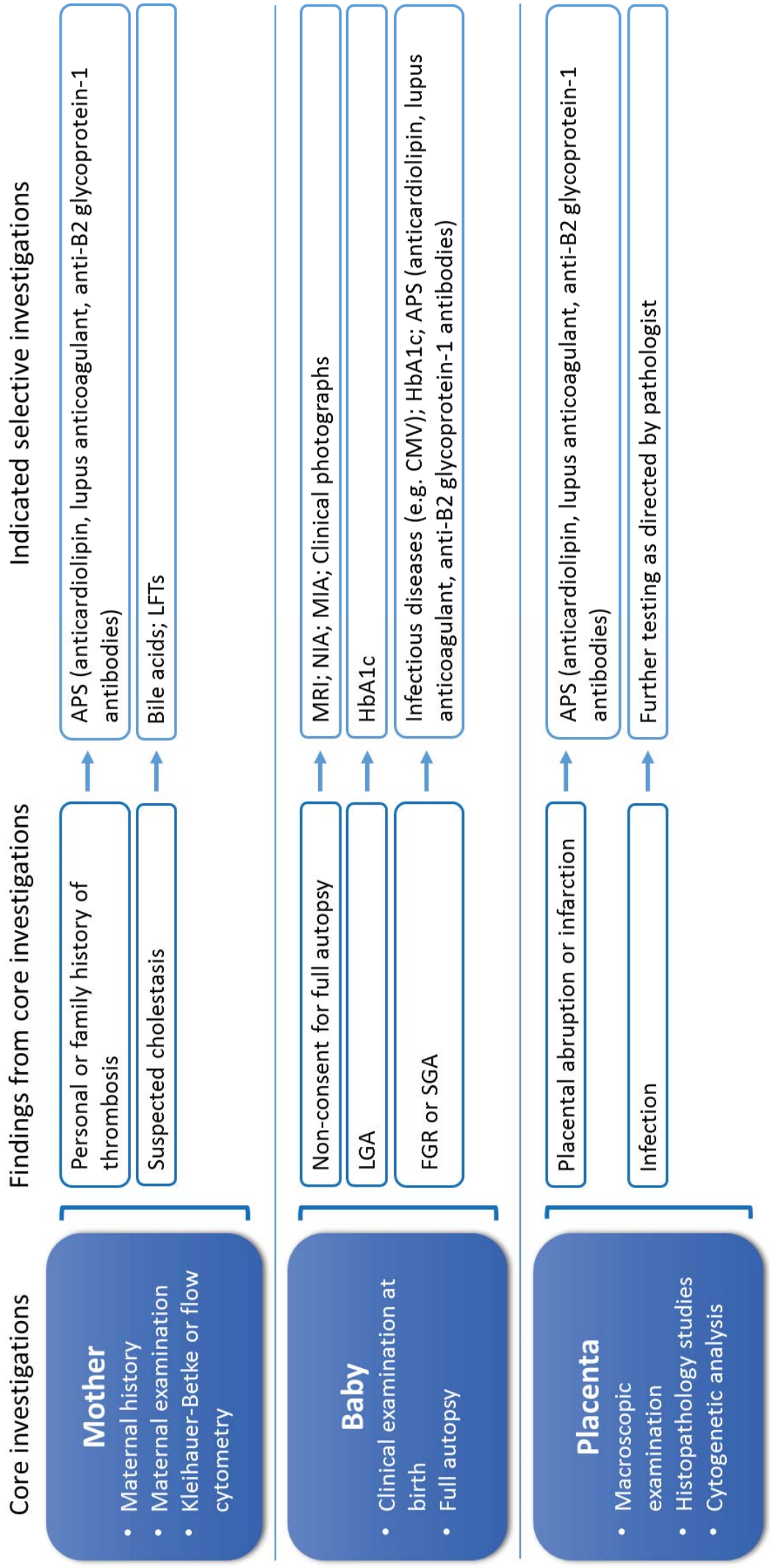
This Guideline provides checklists and data collection forms (*see Appendix A – T*) to assist clinicians with uniform investigation and reporting of stillbirths.

Section 5 Recommendations for stillbirth investigations

- 1** A non-selective approach according to the recommended core investigations should be adopted for all stillbirths (unless the cause of death has been unequivocally determined antenatally). These investigations are:
 - Comprehensive maternal (medical, social, family) and pregnancy history
 - Kleihauer-Betke test/Flow cytometry for fetal to maternal haemorrhage
 - External examination of the baby performed by the attending clinician
 - Clinical photographs of the baby
 - Autopsy
 - Detailed macroscopic examination of the placenta and cord
 - Placental histopathology
 - Cytogenetics (Chromosomal microarray (CMA) or karyotype if CMA is not available).
- 2** Further sequential and/or selective investigations should be undertaken according to the particular clinical scenario based on a comprehensive history, and information gained from core investigations.
- 3** An external examination of the baby should be performed at birth by the attending clinician using the recommended checklist (*Please refer to Appendix D – Clinical examination of baby checklist*) and clearly documented in the medical record. Where the family has consented to autopsy, all information gained from the initial external

examination (along with comprehensive maternal (medical, social, family) and pregnancy history) should be forwarded to the pathology service to guide this procedure.

- 4** Following a stillbirth, the placenta, membranes and cord should be kept refrigerated and, where feasible, sent fresh and unfixed for macroscopic and histological examination by a perinatal pathologist. The pathology service should be informed if the parents have requested return of the placenta following examination.
 - 5** Clinicians should discuss the value of a full autopsy with parents in all cases of perinatal death where the cause of death is not already known. If the parents decline a full autopsy, a limited/partial autopsy should be offered.
-



APS: Antiphospholipid syndrome; CMA: Chromosomal microarray; CMV: Cytomegalovirus; FGR: Fetal growth restriction; LFTs: Liver Function Tests; LGA: Large-for gestational-age; HbA1c: Haemoglobin A1c; MIA: Minimally-invasive autopsy; MRI: Magnetic Resonance Imaging; NIA: Non-invasive autopsy; SGA: Small for gestational age.

Figure 1: Stillbirth investigations algorithm

5.6 Core investigations for all stillbirths

After the diagnosis of stillbirth, and at an appropriate time, the responsible clinician should explain to the parents the value of performing the recommended core investigations as outlined below.

Maternal history

A comprehensive maternal (medical, social, family) and pregnancy history should be taken following all perinatal deaths.

Please refer to *Appendix E – Australian perinatal mortality audit tool*; and *Appendix G – New Zealand Rapid reporting form for a perinatal death - mother*

Fetal-maternal haemorrhage (FMH)

In a large study from Ireland over 25 years, fetal-maternal haemorrhage (FMH) accounted for 4.1% of antepartum stillbirths, mostly at term gestations (74%), with multiple gestations being up to six times as likely to be affected as singleton pregnancies¹⁰. Another case controlled study also noted that women with FMH were more likely to work outside the home during pregnancy than women without evidence of FMH¹¹. By general consensus, >50ml is considered a significant fetal haemorrhage, although various studies use limits ranging from 30 to 150ml^{12,13}. However, as the impact of a haemorrhage of a given volume is dependent on gestational age, fetal size and total blood volume, individual assessments need to be calculated¹⁴.

A Kleihauer-Betke test or flow cytometry to detect FMH should be performed following the diagnosis of any fetal death, preferably prior to birth^{7,15-18}. Limited evidence suggests that this may also be useful postpartum^{18,19}.

Please refer to Appendix B – Estimation of severity of feto-maternal haemorrhage.

Autopsy

Please refer to *Section 4 Perinatal autopsy examination for further details on the post-mortem examination* and *Section 3 Psychological and social aspects of perinatal bereavement, Appendix M – Infant autopsy consent brochure* and *Appendix N – Information for health professionals seeking consent* for information brochures for parents and professionals about post-mortem examinations.

The following should accompany the infant for autopsy examination:

- Autopsy consent form
- Placenta (fresh and unfixed)
- Comprehensive maternal (medical, social, family) and pregnancy history
- Copies of the death certificate
- Copies of all antenatal ultrasound reports (including post-mortem ultrasound if undertaken)
- Copy of prenatal karyotyping results if available
- Findings from initial external examination performed at birth by attending clinician using the checklist provided (*Please refer to Appendix D – Clinical examination of baby checklist*).

External examination of the baby

A comprehensive external examination of the baby is an essential component of the investigation of a stillbirth^{15,20-28}. A report on a large case series from the Wisconsin Stillbirth Service Program (WiSSP) suggested that approximately 25% of stillborn infants were found, on clinical examination, to have demonstrable abnormalities and also indicated that lack of external examination would have resulted in approximately 4% of diagnoses being missed²⁹.

A detailed external examination of the baby is a component of a full autopsy. As the perinatal pathologist is the most appropriate person to carry out the external examination, parents who have declined a full autopsy should be asked for their consent for the baby to have a detailed external examination by a perinatal pathologist. This should not replace the initial external examination performed at birth by the attending clinician, which may provide important information to guide the full autopsy. In the circumstance where it is not possible for a pathologist to perform the examination, then a neonatologist or paediatrician or clinical geneticist should conduct the examination. A proforma is provided to assist the midwife/doctor in carrying out the procedure.

Please refer to Appendix D – Clinical examination of baby checklist.

Clinical photographs

Clinical photographs should be taken for every stillborn baby for later review. The clinical photographs are additional to the bereavement photographs, and should be clearly labelled and filed in the medical record. The WiSSP case series indicates that 28% of all stillborn babies had observable abnormalities identifiable on photographs and photographs were critical in establishing a diagnosis in approximately 5% of cases²⁹. Consent from the parents for clinical photographs should be documented in the medical record.

Please refer to Appendix H – Instructions on taking clinical photographs

Placental and cord investigations by clinician

At time of birth, the clinician should undertake:

- A detailed macroscopic examination of the placenta and cord and document the normal and abnormal findings;
- Sampling of cord and placental tissue for chromosomal analysis (only if the placenta is not being sent to the pathology service). If a prenatal karyotype has already been performed, these samples should still be taken for DNA extraction and storage;
- Following a stillbirth, the placenta, membranes and cord should be sent fresh and unfixed for macroscopic and histological examination. If removal of an entangled cord from the baby is necessary, then clinical photographs should be taken first.

Please refer to Appendix C – Placental examination; Accoucheur flow chart.

Placenta, membranes and cord histopathology

Examination of the placenta, membranes and cord should occur for all stillbirths. The placenta, membrane and cord should be sent to the pathologist fresh and unfixed for histopathological examination once samples have been collected for cytogenetics and microbiology. A perinatal/paediatric pathologist should undertake the examination³⁰. For further details, please

refer to Section 4. A standardised reporting form for placental histopathology is provided to enable high quality reporting (See *Appendix P – Placental histopathology reporting form*).

Cytogenetic investigations

Chromosome microarray (CMA), in contrast to conventional culture karyotyping, uses DNA and does not require viable cells, which means that chromosomal abnormalities can be detected in macerated stillbirth samples³¹⁻³³. Microarray is also superior to karyotype as it can detect additional genetic abnormalities, including microdeletions and microduplications³². Targeted genetic testing using fetal and/or placental DNA (e.g. for monogenic disorders) will always have a place where a specific phenotype is suspected or when the family history is informative.

Advances in molecular genetic testing using DNA have facilitated a greater depth of testing of both the fetal and placental genome. New technologies currently under evaluation include exome and whole genome sequencing³⁴. Such advances have highlighted the importance of storing fetal and placental DNA for later evaluation where a cause for fetal death remains unknown.

Specific advice around extended genetic investigation cannot be prescribed at this time as data are limited, and access is variable and costs are generally high. It is therefore recommended that each service explore genetic testing options available to them both locally and further afield through transportation of tissue or DNA samples.

5.7 Selective investigations based on findings of core investigations

Congenital infections

Routine testing of all stillbirths for infection is no longer recommended^{7,18}. Targeted investigation should be undertaken if infection is suspected on the basis of maternal history, autopsy and/or placental findings¹⁸ and/or a small for gestational age (SGA) baby. To assign infection as the cause of death, positive serology should be supported by autopsy and/or placental findings consistent with infection^{17,18}. Detailed information about specific infections is outlined below.

Cytomegalovirus (CMV)

Cytomegalovirus is the most frequent infectious cause of newborn developmental abnormalities in the developed world³⁵. A prospective study of more than 10,000 women found an increase in fetal loss associated with infection in early pregnancy³⁶. CMV DNA can be detected in a high proportion of fetal or placental tissue samples and a strong association between CMV infection in pregnancy and stillbirth is suggested³⁷. CMV can also infect the placenta and is associated with villitis³⁸. Congenital CMV may also be discovered in cases where there are no obvious macroscopic sequelae³⁹. Maternal CMV serology CMV should be considered where placental histopathology shows evidence of CMV infection and/or when the baby is SGA.

Toxoplasmosis

Congenital toxoplasmosis can cause miscarriage, stillbirth, neurological disability and visual impairment but the majority of fetuses infected will not have sequelae. As toxoplasmosis is not

a common cause of stillbirth⁴⁰, routine testing in the absence of other indications is not recommended.

Parvovirus (B19)

Parvovirus (B19) can cause severe fetal anaemia, nonimmune hydrops and fetal death^{40,41}. One study found parvovirus to be the cause of death in 10% of all non-malformed fetal deaths that occurred between 10 and 24 weeks of gestation and referred for pathological examination⁴². A small proportion of susceptible pregnant women (1%-3%) will develop serologic evidence of parvovirus infection in pregnancy, of which the transmission rate to the fetus is between 17% and 33%⁴³⁻⁴⁵. The spontaneous loss rate of fetuses affected by Parvovirus B19 after 20 weeks gestation is 2.3%^{44,46,47}. However, where parvovirus has caused stillbirth, signs of the disease will be evident following examination of the baby and/or placenta. Routine testing following stillbirth in the absence of other indications is therefore not recommended. Testing for parvovirus should be recommended where severe anaemia and/or non-immune hydrops is found^{7,18}.

Rubella

Rubella is associated with a wide variety of fetal abnormalities including stillbirth^{48,49}. However with universal vaccination, congenital rubella infection in developed countries is rare⁵⁰. Most pregnant women are immune and, if they have not been tested during the initial routine antenatal blood testing, testing for rubella should be done only if indicated on the basis of core investigations.

Syphilis

Congenital syphilis may result in fetal loss/neonatal death, prematurity and major long term sequelae in surviving children. In a South American study, even after controlling for congenital anomalies, gestational age, maternal age, and previous stillbirth, gestational syphilis was significantly associated with stillbirth (odds ratio 1.88, 95% confidence interval 1.25-2.83; P=0.002)⁵¹. This increase in mortality with congenital syphilis has also been confirmed in a systematic review on this topic⁵². Antenatal screening for syphilis for all women is currently recommended to facilitate treatment early in pregnancy. Syphilis remains an uncommon cause of stillbirth in developed settings¹⁸ and routine testing following stillbirth in the absence of other indications is not currently recommended.

Other investigations

Blood group and antibody screen

A maternal blood group and antibody screen is recommended as a routine antenatal test at booking and again in the 3rd trimester of pregnancy. If a blood group and antibody screen has not been performed antenatally, it should be performed selectively to exclude haemolytic disease of the fetus due to maternal sensitisation to red cell antigens⁵³ where the baby is anaemic, jaundiced and/or hydropic.

Thrombophilia testing

Inherited thrombophilia⁵⁴ has been associated with a number of adverse pregnancy outcomes including stillbirth, but the relationship remains controversial and the role of testing is still debated. The role of treatment for women with inherited thrombophilia and adverse pregnancy outcomes also remains controversial⁵⁵⁻⁵⁷.

The most common acquired thrombophilia is the antiphospholipid syndrome (APS). The diagnosis of APS includes venous or arterial thrombosis and/or fetal loss in the presence of antiphospholipid antibodies (anticardiolipin, lupus anticoagulant, anti-B2 glycoprotein-1). Confirmation of the presence of antiphospholipid antibodies is required at a minimum of 12 weeks apart, after an initial positive test. APS is associated with both early and late fetal loss, pre-eclampsia and placental insufficiency. The prevalence of antiphospholipid antibodies is estimated to be 5% while the syndrome affects 0.5%⁵⁸. In a systematic review, the presence of antiphospholipid antibodies was significantly associated with late fetal loss⁵⁹.

The presence of thrombophilia may be most significant where placental pathology is apparent¹⁸. In a small prospective cohort study, 64% of women who had a stillbirth of placental cause had at least one thrombophilia⁶⁰. This proportion was increased to 70% when looking specifically at preterm stillbirths of placental cause. A population based study in Finland found an almost four-fold increased risk of Factor V Leiden mutation among women with unexplained stillbirth⁶¹. The prevalence of this mutation was over ten-fold among women with an unexplained stillbirth in the presence of placental lesions. More recently, a population-based case-control study within the Stillbirth Collaborative Research Network found the only heritable thrombophilia associated with stillbirth was Factor V Leiden mutation, and the association was statistically weak⁵⁵.

Given the evidence, routine testing for thrombophilic disorders following stillbirth without other indications is not currently justified. Testing for APS (anticardiolipin, lupus anticoagulant, and anti-B2 glycoprotein-1 antibodies)^{60,62} is recommended selectively where stillbirth occurs in the presence of one or more of the following: (1) family history of thrombosis; (2) personal history of venous thrombosis; (3) fetal growth restriction; (4) placental abruption or (5) placental infarction^{8,54}. Other thrombophilia studies, such as Prothrombin G20210A mutation^{60,63-65} and Factor V Leiden mutation^{55,61,65}, should be carried out as indicated and in accordance with individual jurisdiction guidance.

Haemoglobin A1c (HbA1c)

Increased risk of fetal morbidity and mortality for women with pre-existing diabetes is well known. A stillbirth rate of 35 per 1000 births for Type 2 diabetic mothers has been reported⁶⁶, and a systematic review has shown that women with pre-existing diabetes have an almost three-fold increased risk of stillbirth⁶⁷. There is some evidence to indicate that gestational diabetes mellitus (GDM) is also associated with increased perinatal mortality⁶⁸, and poor detection and management of the condition has been documented in association with term antepartum stillbirth⁶⁹. It is recognised that some women with GDM have unrecognised type 2 diabetes, with unfavourable pregnancy outcomes⁷⁰. HbA1c provides information about maternal glycaemia over the previous 3 months by reflecting the average glucose concentration over the life of the red cells⁷¹. Therefore, it may provide information regarding the contribution of maternal diabetes to a fetal death. One study suggested that pregnant women with an HbA1c of $\geq 5.4\%$

(36 mmol/mol) may have gestational diabetes⁷². Another study also noted that although HbA1c cannot replace Oral Glucose Tolerance Test (OGTT) in the diagnosis of GDM, it can be used as a screening test if a cut-off of 5.3% is used⁷³. In such women an OGTT should be performed postnatally. Nonetheless, diabetes has not been shown to be a common cause of stillbirth⁷. Routine HbA1c following stillbirth without other indication is not currently justified^{7,18}. It is recommended that HbA1c be carried out where SGA, FGR or SGA is detected. Please refer to the Australian Diabetes in Pregnancy Society Guidelines or the New Zealand Screening, Diagnosis and Management of GDM Guideline for further information^{68,74,75}.

Thyroid function test

Overt hyper and hypothyroidism are both associated with stillbirth⁷⁶. However the effect on stillbirth of subclinical hypothyroidism or a positive thyroid antibody test in pregnancy is not clear^{77,78}. Due to this very low risk of stillbirth, routine screening of thyroid function in a clinically euthyroid woman after stillbirth is of limited value⁷⁹.

Liver function tests and bile acids

Abnormalities in liver function tests are markers for viral hepatitis, acute fatty liver of pregnancy, HELLP syndrome and obstetric cholestasis (OC)^{80,81}. Obstetric cholestasis (OC) is a pregnancy-specific liver disease, characterised by maternal pruritus and raised serum bile acids. Risk factors for OC include ethnicity, history of previous liver and/or gallbladder disease including hepatitis B and C, prior OC and multiple pregnancy. A large prospective study of has confirmed the association between severe OC and adverse perinatal outcomes including⁸². The association was maintained despite bile acid testing being non-fasting. Liver function and (non-fasting) bile acid testing is therefore recommended following the diagnosis of fetal death if there is a maternal history of pruritus.

Drug screen

Illicit drug use including amphetamine, methamphetamine, cocaine, pethidine, meperidine, hydrocodone, and tetrahydrocannabinolic acid may contribute to a range of adverse pregnancy outcomes, and use of these substances has been associated with a 2-3 fold increased risk of stillbirth⁸³. While screening for illicit substance use is not recommended as a routine investigation following stillbirth, testing should be considered where indicated on the basis of maternal history.

5.8 Alternative investigations: When permission for full autopsy is not obtained

Parents should be informed about the possibility of missing an important finding when a full autopsy is not undertaken. If permission for a full autopsy is not obtained, an external examination, X-ray (babygram) and clinical photos (as described above) are important investigations to perform^{6,84}.

Where available, Magnetic Resonance Imaging (MRI) should be offered to parents who decline an autopsy⁸⁵. MRI may be diagnostic in some cases (e.g. where intracranial abnormalities are detected)⁸⁵⁻⁸⁷. Clinicians should however explain to parents that a full autopsy remains the gold standard, as MRI does not supply tissue samples and therefore important information may be

missed. Other alternatives to a full post-mortem examination including post-mortem needle biopsy; laparoscopic autopsy, and small incision access for focussed investigation of suspected abnormalities.

Please refer to Section 4 Autopsy examination for further details on alternate investigations to autopsy.

5.9 Storage of plasma and amniotic fluid

Unexplained fetal death is currently the subject of extensive research. Storage of placental and fetal DNA, blood and amniotic fluid allows for future testing for other potential factors that are currently not identified. Even if it is not initially possible to provide an explanation as to the cause of death, parents and siblings may benefit from future research findings if material is stored appropriately. Any storage of human samples requires informed consent to be obtained.

The Stillbirth Centre of Research Excellence in Stillbirth is developing a national collaboration in placental sample storage for research purposes.

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5.13 Appendices

Appendix A – Stillbirth investigations algorithm

Appendix B – Estimation of severity of feto-maternal haemorrhage

Appendix C – Placental examination; Accoucheur flow chart

Appendix D – Clinical examination of baby checklist

Appendix E – Australian perinatal mortality audit tool

Appendix F – New Zealand Rapid reporting form for a perinatal death - baby

Appendix G – New Zealand Rapid reporting form for a perinatal death - mother

Appendix H – Instructions on taking clinical photographs

Appendix I – Autopsy clinical summary form

Appendix J – Perinatal mortality classifications: Quick reference sheet

Appendix K – WHO mortality audit meeting code of practice declaration

Appendix L – Birthweight percentiles

Appendix M – Infant autopsy consent brochure

Appendix N – Information for health professionals seeking consent

Appendix O – RCPATH Guidelines for Autopsy Investigation of Fetal and Perinatal Death

Appendix P – Placental histopathology reporting form

Appendix Q – Suspected genetic metabolic disorders

Appendix R – Screening for genetic metabolic disorders

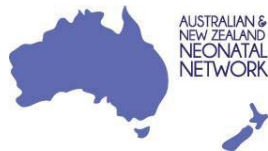
Appendix S – Components of the genetic autopsy for investigations of metabolic disorders

Appendix T – Australian and New Zealand definitions of perinatal mortality

Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death

Version 3.1, March 2018

Endorsed by



SECTION 6

INVESTIGATION OF NEONATAL DEATHS

6.1 Introduction

In Australia, neonatal death is defined as the death of a live born baby within 28 days of birth. Neonatal death can be further categorised as early (within 7 days of birth) or late (after 7 completed days and before 28 completed days of birth). Post neonatal death is the death of an infant occurring after day 28 and up to one year of age¹.

Neonatal deaths can result from disorders of the neonate, placenta or mother. The majority of neonatal deaths are due to major congenital anomalies and complications of preterm birth. Due to the presence of a wide range of aetiological, clinical and geographic circumstances across the spectrum of neonatal deaths, the nature of investigations undertaken following death may vary widely. For example, the investigation of the sudden collapse and death of a newborn receiving standard hospital postnatal care will require a very different investigative approach to that of an infant born at 24 weeks gestation who eventually succumbs to the complications of prematurity after a lengthy course of neonatal intensive care.

Therefore, it is not feasible or appropriate to develop a comprehensive standardised protocol for investigation of neonatal deaths that accommodates all scenarios. Decisions regarding appropriate investigations should be made by the clinical team providing care based on the individual circumstances and accessing additional specialist expertise as required. This could include a neonatologist (even if the death occurs outside a tertiary centre), a clinical geneticist and/or a metabolic physician.

However, the importance of a high quality autopsy to accurately determine the cause of a neonatal death must be stressed. Neonatal care providers are encouraged to discuss the value of an autopsy with the parents for all neonatal deaths.

For further discussion on post-mortem examination and placental pathology please refer to Section 4; Perinatal post-mortem examination and/or Section 5; Investigation of stillbirths.

This section of the update of the guideline has been undertaken through a partnership between PSANZ and the NHMRC Stillbirth Centre of Research Excellence in Stillbirth.

To view further information on the described guidelines in this section of the PSANZ PSANZ Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death see *Appendices A-Q*.

6.2 Objective of this section

This section of the guideline provides a list of core investigations, based on the consensus of the Working Party, which should be undertaken at the birth of high risk newborns. Investigation of at risk neonates who subsequently die will commence shortly after birth. Investigations that may be considered in certain clinical scenarios are also provided.

For further information regarding communication with parents after a perinatal death please refer to Chapter 3 Psychological and social aspects of perinatal bereavement.

6.3 What has changed in this update?

In this update, based on the findings of an updated literature review, the recommendations have remained unchanged. We have revised the formatting and reduced duplication across the different sections of the guidelines to enhance readability.

6.4 Newborns at high risk of mortality and place of death

Newborns at high risk of mortality include those where there is:

- Extreme prematurity, either pre-viable or in grey zone of viability (≤ 24 weeks)
- Severe cardiorespiratory depression at birth, including overwhelming sepsis
- Signs consistent with congenital infection
- Severe growth restriction
- Hydrops fetalis and severe anaemia
- Lethal congenital anomalies.

A large proportion of neonatal deaths occur outside of the neonatal nurseries². Neonatal Deaths occur in a variety of settings including:

- Birth suite - predominantly in the subcategories of congenital anomaly and extreme prematurity and others with severe cardiorespiratory depression
- Babies admitted to the neonatal intensive care unit
- Postnatal ward
 - Palliative care involving parental wishes
 - Sudden unexpected death in first 48 hours
- At home - deaths after hospital discharge may be planned (palliative care) or unexpected.

Section 6 Recommendations

- 1 | Obstetric and neonatal care teams should collaborate closely to ensure that all relevant maternal (pregnancy and birth) and neonatal factors are considered in the investigation of the neonate. Comprehensive maternal medical, social and antenatal history including results of all investigations documented in the medical record by obstetric staff. A comprehensive neonatal history including death scene analysis is always required.
- 2 | A detailed external examination of the baby must be performed by a perinatal pathologist, neonatologist or paediatrician where possible.
(Please see Appendix D – Clinical examination of baby checklist).
- 3 | Accurate anthropometric parameters of birth weight, length and head circumference plotted on appropriate gender specific birth growth charts.
- 4 | A newborn screening blood sample should be taken for all neonatal deaths.
- 5 | Clinicians should discuss the value of an autopsy with parents in all cases of a neonatal death and offer the option of the procedure.
(Please see Section 4; Perinatal postmortem examination).
- 6 |

Following consent from the parents, clinical photographs should be taken for later review, particularly in the circumstance of birth in non-tertiary hospital settings. These photos are additional to the bereavement photographs, and should be clearly labelled and filed in the medical record (not given to the parents) and be available for members of expert PNM committee to view. The use of digital imaging for this purpose is optimal, however issues regarding storage and patient confidentiality must be considered.

- 7 For neonates at high risk of death at the time of birth, or in birth suite, targeted investigations based on the presenting scenario should be undertaken.
 - Detailed external examination of the baby by a neonatologist or paediatrician (where possible) with clear documentation of findings in the medical record
 - Where possible, cord blood gas analysis that includes both arterial and venous samples
 - Newborn screening blood sample
 - Detailed macroscopic examination of the placenta and cord with findings documented in the medical record by obstetric staff
 - Histopathological examination of fresh and unfixed placenta, cord and membranes.
 - Autopsy.
- 8 Clinicians should initiate investigations specific to the circumstances of the birth (*see Section 6.7 for targeted investigations*).

6.5 Further investigations for high risk newborns at the time of birth

Further investigations at the time of birth may provide valuable information in specific situations, which are detailed below, particularly in the event of neonatal death, where consent for autopsy is not obtained.

Suspected congenital infection including birth after clinical chorioamnionitis and spontaneous preterm labour and delivery and severe cardiorespiratory depression at birth

- Maternal low vaginal/anorectal culture for Group B streptococcus (GBS) and vaginal culture for other common bacterial pathogens associated with perinatal death (e.g. E coli, Klebsiella);
- Maternal blood cultures
- Infant blood samples for haematological assessment (full blood count with nucleated red cell count), CRP, and antibody screen and;
- Baby blood taken with aseptic technique for microbiological culture (cord blood not recommended)
- Placental swab taken between amnion and chorion using aseptic technique for aerobic and anaerobic bacterial and fungal culture (ideally taken by pathologist with macroscopic placental examination)

- Placental macroscopic and histological examination (*see Appendix P – Placental histopathology reporting form*) specifically for maternal and fetal inflammatory responses; and
- If viral infection is suspected a placental biopsy should be sent for appropriate PCR or viral culture
- Maternal serology for Cytomegalovirus, Toxoplasma, Parvovirus B19, Rubella, Syphilis and Zika (if not already undertaken in this pregnancy);
- If infection suspected before birth consider amniotic fluid for multiplex PCR.

Severe fetal growth restriction

Studies to identify possible thrombophilic disorders should be considered in mothers with preeclampsia or with a personal/family history of thrombosis, or following the birth of an infant with severe growth restriction^{3,4}. These should include initial testing followed by further testing at 8-12 weeks postpartum as required (see section 5 Selective screening for thrombophilic disorders following birth of a high risk neonate or a neonatal death may be helpful in assisting parents and clinicians to understand the cause of death, plan future pregnancies and give consideration to the risks and benefits of antithrombotic therapy⁵).

Screening

Please see Section 5; Stillbirth investigations algorithm for further details of screening Section 5; Investigation of stillbirth for further discussion on Thrombophilia.

Section 6 Recommendations

- 9 Clinicians should investigate possible thrombophilic disorders in mothers with preeclampsia or with a personal/family history of thrombosis, or following the birth of an infant with severe growth restriction.
- 10 Selective screening in addition to placental examination for thrombophilic disorders should be undertaken following the birth of high risk neonate or a neonatal death:
 - Anticardiolipin, lupus anticoagulant, anti-B2 glycoprotein-1 antibodies
 - Microarray/karyotype
 - Autopsy

Suspected major congenital anomalies

With the advances in Maternal Fetal Medicine the majority will have been investigated and diagnosed antenatally.

- Maternal serology for Cytomegalovirus, Toxoplasma, Parvovirus B19, Rubella and Syphilis (if not already undertaken in this pregnancy);
- Viral placental culture and placental biopsy for viral PCR if viral infection suspected
- Infant blood samples for haematological assessment (full blood count with nucleated red cell count), blood group, DCT and antibody screen and microbiological culture and CRP;

- Infant cord or peripheral blood sample for chromosomal analysis; microarray /karyotype
- placental histopathology to determine possible causes for growth restriction
- routine and specific clinical photographs to display dysmorphic features
- for hydropic infants blood test for Transferrin Isoforms for Carbohydrate deficient glycoprotein disorders (CDG), chromosomes, comparative genomic hybridization array
- Glycosylated Hb (HbA1C) may be indicated
- Consultation with geneticist and access to syndrome identification digital technology
- Consider investigation for genetic metabolic disorder.

Severe cardiorespiratory depression

- Maternal low vaginal/anorectal culture for GBS and vaginal culture for other common bacterial pathogens associated with perinatal death (e.g. E-coli, Klebsiella)(2);
- Maternal serology for Cytomegalovirus, Toxoplasma, Parvovirus B19, Rubella and Syphilis if not undertaken in this pregnancy;
- Infant blood samples for haematological assessment (full blood count with nucleated red cell count); CRP, blood group, DCT and antibody screen and microbiological culture;
- Placental swabs between the amnion and chorion using aseptic technique for aerobic and anaerobic bacterial and fungal cultures. (*See Appendix C – Placental examination; Accoucheur flow chart*); and
- Consider investigation for genetic metabolic disorder and blood sample for chromosomal analysis.

Birth trauma

While this has declined in high income countries over recent decades, deaths still occur particularly associated with instrumental and assisted deliveries. Acquired prepartum lesions rarely cause the infant to have a low Apgar score. The exception is severe damage to the brainstem and basal ganglia. Traumatic injury to the brain is most commonly subdural haemorrhage.

Careful autopsy, particularly of the neck and paravertebral tissues, spinal cord, brainstem and nerve roots is important when trauma is suspected.

These NNDs usually necessitate escalated enquiry such as Root Cause Analysis and/or Coronal investigation.

Macrosomic infant

The increased risk of perinatal morbidity and mortality with maternal diabetes is well known^{6,7}. As universal screening for diabetes is not currently implemented throughout Australia and New Zealand it is essential that the possibility of undiagnosed maternal diabetes is excluded; HbA1C monitors glycaemia over the previous 3 months by reflecting the average glucose concentration over the life of the red cells.

If there is no clear maternal diabetic history, other causes of macrosomia such as Beckwith Wiedemann syndrome with close examination for syndromic features and placental changes should be considered.

Section 6 Recommendations

- 11** Investigation for maternal diabetes, if not previously undertaken, should include:
 - Maternal HbA_{1c} level (as soon as possible after delivery); and
 - If the HbA_{1c} level is raised, a fasting blood glucose should be undertaken and, if abnormal, a glucose tolerance test performed 6-8 weeks postnatally.
- 12** Other causes of macrosomia, such as Beckwith Wiedemann syndrome, should be investigated if there is no maternal or paternal diabetic history.

Suspected genetic metabolic disorders

To ensure a precise diagnosis, peri mortem evaluation of infants suspected of genetic metabolic disorders is required. Parental consent needed for post-mortem examinations and for any tissue and blood samples taken prior to death. Clinicians need to counsel parents sensitively about the importance of an accurate diagnosis for future genetic risks in this very distressing time. Metabolic disease may cause a baby to be both weak and floppy and respiratory failure at birth or shortly afterwards and should be investigated for peroxisomal disorders, non-ketotic hyperglycinaemia, lipid and storage disorders and mitochondrial disease

Due to the complexity and number of different possible diseases, it is strongly recommended that clinicians discuss each individual case with the State Laboratory to identify the optimum tests to request. Should more expert guidance be required a clinical metabolic specialist should be consulted.

Peri-mortem investigation by the clinician should include the following:

Christodoulou and Wilcken⁸ highlight the need for an increased index of suspicion for genetic metabolic disorders (inborn errors of metabolism) in neonatal cases. The authors describe predominant clinical or biochemical presentations of genetic metabolic disorders in the neonatal period and recommend a protocol for screening for these disorders and also for a genetic autopsy.

Please see Appendix S – Components of the genetic autopsy for investigations of metabolic disorders.

The predominant clinical or biochemical presentations of genetic metabolic disorders are as follows: acute encephalopathy: hypoglycaemia, hyperammonaemia, ketosis, disorders of acid-base balance, seizures as an early predominant feature; acute hepatocellular disease; sudden death; severe hypotonia; non-immune hydrops fetalis; facial dysmorphism, with or without congenital malformations⁸.

Please see Appendix C – Placental examination; Accoucheur flow chart and Appendix H – Instructions on taking clinical photographs.

Section 6 Recommendations

- 13** In the case of a suspected genetic metabolic disorder, Clinicians should discuss individual cases with their State Laboratory to identify the optimum tests to request and consult a clinical metabolic specialist if more expert guidance required.
- 14** All tissue samples should be stored and transported to a Specialist Metabolic Laboratory for investigation.
- 15** When a lethal genetic metabolic disorder is suspected prior to birth, clinicians should:
- Seek consent from the parents for a metabolic autopsy
 - Consult a metabolic physician or a histopathologist before collecting the following samples:
 - Blood sample (0.8ml) in lithium heparin tube (refrigerate)
 - Urine sample (5-10ml)
 - Knee cartilage and/or skin biopsy (3 x 2 mm punch biopsies) (sent to cytogenetics with request for fibroblast culture and store)
 - Liver and muscle biopsies (for electron microscopy, histopathology and enzymology).

6.5.1 Sudden unexpected neonatal collapse in the first weeks of life

The sudden unexpected death of a neonate requires comprehensive investigation as to the cause of the death. Although, Sudden Infant Death Syndrome (SIDS) is rare in the neonatal period since implementation of Back to Sleep campaigns, there has been a proportionate increase in the number of cases occurring at less than one month of age^{8,9}. It is important that all unexpected deaths are investigated fully prior to designation to the category of SIDS and the role of infection/inflammation examined¹⁰. Based on epidemiological and population characteristics classification of these deaths is incorporated into the PSANZ classification systems^{11,12}. The classification includes a category for unclassified sudden death where no cause for the death was identified and where inadequate investigation was undertaken. Classification of deaths into this category will hopefully decrease in number with appropriate investigations ensuring that a diagnosis is found in most cases.

The Royal College of Pathologists and The Royal College of Paediatrics and Child Health have published a comprehensive protocol for care and investigation for sudden unexpected deaths in infancy. Please refer to this document for further details¹³.

For further details on the classification of SIDS, please refer to Section 7 Perinatal death classifications.

Section 6 Recommendations

- 16** Investigation of any sudden unexpected neonatal death should include:
- Coroner notification
 - Thorough maternal and infant medical histories

- Full autopsy examination by a forensic pathologist skilled in perinatal autopsy or a forensic pathologist in conjunction with a perinatal pathologist
 - Investigation of the various scenes where incidents leading to the death might have occurred including the infants sleeping environment.
- 17** Investigations for genetic metabolic disorders should be undertaken for all sudden unexpected neonatal deaths.

6.6 Alternative investigations: When permission for autopsy not obtained

If permission for an autopsy is not obtained, an external examination, detailed ultrasound of the infant, babygram, and clinical photos (as described above) are important tests to perform. Other alternatives to a full post-mortem examination including Post-mortem needle biopsy; laparoscopic autopsy and small incision access are other alternatives to a full post-mortem for focussed investigation of suspected anomalies.

Magnetic Resonance Imaging (if available) may be offered to parents who decline an autopsy investigation. Clinicians should however explain to the parents that a full autopsy remains the gold standard as the MRI does not supply tissue samples and therefore important information may be missed MRI should only be offered when available and if radiologists experienced in reporting post mortem MRIs. Parents should be informed about the possibility of missing an important finding when an autopsy is not undertaken.

Please refer to Section 4; Perinatal postmortem examination for further details on alternate investigations to autopsy

6.7 References

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6.9 Acknowledgements

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6.10 Appendices

Appendix A – Stillbirth investigations algorithm

Appendix C – Placental examination; Accoucheur flow chart

Appendix D – Clinical examination of baby checklist

Appendix H – Instructions on taking clinical photographs

Appendix P – Placental histopathology reporting form

Appendix R – Screening for genetic metabolic disorders

Appendix S – Components of the genetic autopsy for investigations of metabolic disorders

Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death

Section 7

The PSANZ Classification System for Stillbirths and Neonatal Deaths

Version 3.1, March 2018

Endorsed by



SECTION 7

THE PSANZ CLASSIFICATION SYSTEM FOR STILLBIRTHS AND NEONATAL DEATHS

7.1 Introduction

This section of the Perinatal Society of Australia and New Zealand (PSANZ) Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death presents the third revision of the PSANZ Classification System for causes of stillbirths and neonatal deaths. The system was first released in May 2003.

Accurate classification of the causes of the stillbirths and neonatal deaths is the cornerstone of prevention and the ability to compare causes of death across and within countries is key to this effort. The main driver for the PSANZ system is the limitations of the International Classification of Disease (ICD) for classifying perinatal deaths¹⁻³. This has also been the case globally, with over 80 disparate systems recently identified, none of which appear optimal³. The new adaptation of ICD 10 by WHO – ICD for perinatal mortality (ICD-PM)⁴, which is recommended for use as part of perinatal mortality audit, holds promise for consistent global reporting of causes of perinatal deaths. Initial piloting of ICD-PM has highlighted important areas for improvement when ICD is next updated⁵. The ICD-PM uses ICD rules based only on death certificate data⁴ and classifies the underlying cause of perinatal death. In Australia, death certificate reporting of causes of perinatal deaths (particularly stillbirths) is often inaccurate and overestimates the proportion of unexplained up to 50%⁶. This inaccuracy is partly a systems issue in that the mandated timing of completion of the death certificate precedes results of investigations, including autopsy, becoming available and also the lack of supervision and training in completion.

Until further enhancements are made to the ICD system, the PSANZ Classification System for Stillbirths and Neonatal deaths is recommended as the primary system for causes of perinatal deaths in Australian and New Zealand (ANZ). However, in order to facilitate global comparisons and to inform future improvements to ICD-PM, simultaneous application of ICD-PM and the PSANZ system or later mapping from PSANZ to ICD-PM is optimal. The ICD-PM (as for the PSANZ system) should be based on the findings of adequate investigation into the causes of death including committee review of the death (see Section 2 of the PSANZ Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death).

The PSANZ system has been shown to perform well against other systems^{3,7}. In a recent evaluation of global classification systems for perinatal deaths against expert consensus of a quality system, some limitations were identified including the need for better definitions and rules. In this update, an attempt has been made to address these limitations. Accurate classification of stillbirths and neonatal deaths is only possible following adequate investigation and review of the clinical circumstances of the death and is an integral part of high quality perinatal mortality audit.

The standardised perinatal mortality data collection forms for New Zealand (*see Appendix F – New Zealand rapid reporting form for a perinatal death – baby* and *Appendix G – New Zealand rapid reporting form for a perinatal death – mother*) and for Australia (The Australian Perinatal Mortality Audit Tool (*see Appendix E – Australian perinatal mortality audit tool*)) should be completed by the hospital perinatal committees to enhance the quality of classification of death.

For a history on the development of the PSANZ PDC and a summary of the changes made to the system since its inception please refer to *Appendix V – Development of PSANZ Perinatal Death Classification and PSANZ Neonatal Death Classification*.

This update of the guideline has been undertaken through a partnership between the PSANZ Stillbirth and Neonatal Death Alliance and the NHMRC Stillbirth Centre of Research Excellence in Stillbirth.

7.2 Principles, structure and performance indicators

Principles

The key principles of the PSANZ system are:

- To identify an underlying cause of death for stillbirths and neonatal deaths
- To identify up to two associated conditions for stillbirths and neonatal deaths
- To enable reporting by ICD-PM through identifying timing of death and mapping of categories to ICD-PM.

Including the assigned PSANZ system category codes as part of routinely collected individual birth record data across ANZ jurisdictions will enable reporting by timing of death (ante partum, intrapartum, early and late neonatal deaths or timing of death unknown) and also allows more detailed analyses by demographic and clinical factors to aid identify where attention is most needed.

Structure

The PSANZ System for stillbirths and neonatal deaths consists of two main sets of conditions (categories) and one set of associated conditions (contributory).

The two main category grouping are: 1) The Perinatal Death Classification (PDC) which includes maternal/fetal causes of stillbirths and neonatal deaths; and 2) The Neonatal Death Classification (NDC) including neonatal causes of death.

The PSANZ Associated Conditions list includes both the PDC and NDC categories plus other associated factors e.g. maternal risk factors and placental pathologies.

Performance indicators

Evaluation of the PSANZ system is being planned including the following measures of success:

- 10% or less deaths classified as *Other unspecified*
- 20% or less stillbirths classified as *Unexplained* with full investigation
- Ease of use by clinicians
- Valued by end-users
- Good to excellent agreement between classifiers assigned within the major categories
- Good alignment with ICD-PM

7.3 Objective of this section

The main objective of section 7 of the PSANZ Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death is to present the PSANZ system for stillbirths and neonatal deaths and to provide detailed instructions for use to ensure consistent and comprehensive data on the underlying causes and associated conditions of stillbirths and neonatal deaths across Australia and New Zealand.

7.4 What has changed in this update?

In this update, changes have been made to categories based on new knowledge around the causes of perinatal death and to address deficiencies identified in a recent evaluation⁸.

The PSANZ system no longer uses a hierarchical approach between categories but rather employs rules around common scenarios when multiple factors are involved. This is to ensure consistency with the ICD principles of identifying an underlying cause of death.

Improvements in classification of placental pathology have been made although limitations remain and further research and consistency with reporting are needed to better define placental categories⁹. The 'Unexplained Antepartum Stillbirth' category now excludes stillbirths as a result of placental insufficiency and identifies those which were inadequately investigated. Placental pathology is now identified in more detail as Category 9 Placental dysfunction, replacing the previous category of 'Fetal Growth Restriction' (FGR). If present, FGR is now classified as an associated condition. The list of associated conditions has been expanded to include placental pathology thought to be contributory but not causal. Congenital anomalies have been updated to include more detail on chromosome and genetic conditions in line with advances in prenatal testing, and to align categories with *ICD-10 version 2016 Chapter XVII Congenital malformations, deformations and chromosomal abnormalities* (<http://apps.who.int/classifications/icd10/browse/2016/en#/XVII>).

The subcategories on the duration of membrane rupture (MR) in Category 10 Spontaneous preterm have been removed and a subcategory to identify cervical shortening preceding MR has been added. The Congenital anomaly category (Category 1) has been revised to acknowledge developments in genetic testing. Lastly, a new category (Category 6) to capture complications of multiple pregnancy.

The PSANZ Associated Conditions list includes both the PDC and NDC categories plus other associated factors e.g. maternal risk factors and placental pathologies.

As with other sections of this guideline, the formatting has been revised to enhance readability and reduce duplication across the different sections of the guideline. Please refer to *Appendix U – Changes on this version of the classifications system* to see a full list of changes in this revision.

Section 7 Recommendations for all perinatal deaths

- 1 All stillbirths and neonatal deaths should be classified according to the PSANZ classification system to identify a single underlying cause of death for both stillbirths and neonatal deaths and up to two associated factors which contributed to the death.
- 2 The classification of stillbirths and neonatal deaths should be based on the best available information from a comprehensive history and appropriate investigation (as recommended in Sections 4 and 5 of this guideline) and should form part of a formal institutional clinical audit process as outlined in Section 2 of this guideline.
- 3 The classification should be included in the routine perinatal data collections across jurisdictions for every perinatal death to enable comprehensive reporting regionally and nationally including disaggregation and identification of timing of the death (i.e. antepartum, intrapartum, early and late neonatal deaths)
- 4 Following application of the PSANZ system, mapping to ICD-PM categories should be undertaken to enable high quality global reporting. This will often require alteration to the cause of death on the perinatal death certificate.

7.5 Purpose of the PSANZ System

The purpose of the PSANZ Perinatal Death Classification System is to ensure comprehensive and consistent data on causes and associated conditions for stillbirths and neonatal deaths across Australia and New Zealand to enable benchmarking and monitoring of causes of death to inform policy, practice and research, to help parents understand why the death occurred and to assist in future pregnancy planning.

7.6 General rules for applying the PSANZ PDC System

Classification of underlying cause and associated conditions

In accordance with ICD-PM, the PSANZ Classification System identifies a single underlying cause of death for stillbirths and neonatal deaths as well as the presence of associated conditions. For all stillbirths and neonatal deaths a maternal/fetal condition according to the PDC is assigned and, in addition for neonatal deaths, the underlying neonatal condition which caused the death is assigned according to the NDC. Therefore, for neonatal deaths the PSANZ system at least two conditions are assigned; the neonatal condition which resulted in the death and a maternal/fetal condition (according to the PDC). If no maternal/fetal condition is identified the classification category of “no obstetric antecedent” is applied.

Definitions

Underlying cause of death: According to ICD

“the disease or injury which initiated the train of morbid events leading directly to a person's death or the circumstances of the accident or violence which produced the fatal injury, as represented by a code¹⁰”

Associated conditions are defined as conditions which were considered to have contributed to the death but are not considered to be the main underlying cause. Conditions which were present but not considered to be contributory are not classified as associated conditions.

Please refer to the PSANZ Associated Conditions list (see page 35).

Classification of terminations of pregnancy

All terminations of pregnancy are identified by the inclusion of an “009” for two-digit codes and a “09” for the three digit codes and “9” for four digit codes i.e. 1.1 becomes 1.1009; 1.83 becomes 1.8309; 6.111 becomes 6.1119. This includes induction of labour without expectation of fetal survival e.g. in the case of severe pre-eclampsia at pre-viable gestations, or prolonged premature rupture of membranes with severe infection.

Classification numbering approach

As far as possible, the subcategory .8 has been used for ‘Other conditions’ and .9 for ‘Unspecified conditions’ within its category, as has been the case in the ICD classification.

If data are entered with a decimal point, a subcategory such as ‘Structural anomaly’ (Category 1, *Congenital Anomaly*) would be 1.1, but as a 4 digit numeric would be 0110. Similarly subcategory ‘Group B Streptococcus’ (Category 2, *Perinatal Infection*) would be 2.11 or 0211.

Inclusion in routine perinatal data collections at the individual case record level

It is recommended that PSANZ classification codes are included within routine perinatal data collections in each region for every perinatal death to enable disaggregation to better identify areas to focus prevention e.g. by Indigenous and socioeconomic status and other risk factors, and timing of death. The ability to analyse causes of perinatal deaths by timing of death (i.e. antepartum, intrapartum, neonatal, or unknown) is consistent with ICD-PM rules.

Reporting according to ICD-PM

Reporting by ICD-PM system enables international comparisons and should be based on the causes of perinatal deaths following thorough investigation and perinatal mortality committee review. Following application of the PSANZ classification system to stillbirths and neonatal deaths, mapping of the categories to ICD-PM should be undertaken for global reporting requirements. Jurisdictions may wish to classify according to ICD-PM simultaneously with the PSANZ system to assist in global reporting and to inform future improvements in classification.

7.7 PSANZ-PDC Classification including rules and definitions

1 Congenital anomaly

- 1.1 Structural anomaly
 - 1.11 Nervous system
 - 1.12 Cardiovascular system
 - 1.13 Genitourinary system
 - 1.14 Gastrointestinal system
 - 1.15 Musculoskeletal
 - 1.151 Congenital diaphragmatic hernia
 - 1.152 Gastroschisis/omphalocele
 - 1.16 Respiratory system (include congenital pulmonary airway malformation (CPAM))
 - 1.17 Haematological
 - 1.18 Multiple Congenital anomaly (no chromosomal/genetic cause or not tested)
 - 1.19 Other congenital abnormality
 - 1.192 Idiopathic hydrops fetalis
 - 1.193 Fetal tumour (include sacro-coccygeal teratoma)
 - 1.198 Other specified
 - 1.199 Congenital anomaly, unspecified
- 1.2 Chromosomal anomaly
 - 1.21 Down syndrome (trisomy 21)
 - 1.22 Edward syndrome and Patau syndrome (trisomy 18, trisomy 13)
 - 1.23 Other trisomies and partial trisomies of the autosomes, not elsewhere classified (includes pathogenic duplications, unbalanced translocations and insertions)
 - 1.24 Monosomies and deletions from the autosomes, not elsewhere classified (includes pathogenic deletions e.g. 22q11.2 deletion syndrome (diGeorge syndrome), Wolff-Hirschorn syndrome, Cri-du-chat syndrome)
 - 1.25 Turner syndrome (monosomy X)
 - 1.26 Other sex chromosome abnormalities (e.g. Klinefelter syndrome)
 - 1.28 Other chromosomal abnormalities, not elsewhere specified (includes Fragile X syndrome, imprinting syndromes, triploidy)
 - 1.29 Unspecified
- 1.3 Genetic anomaly
 - 1.31 Genetic condition, specified (includes inborn errors of metabolism e.g. Tay-Sachs disease;)
 - 1.32 Syndrome/association with demonstrated chromosomal/gene anomaly
 - 1.39 Genetic condition, unspecified

Definitions and Rules:

This category includes deaths in which a major congenital anomaly, whether structural or chromosomal, is considered to have been the reason for the death. All categories correspond to the ICD10 numbering in Chapter XVII Congenital malformations, deformations and chromosomal abnormalities (Q00-Q99) as presented in ICD-PM¹¹

If termination of pregnancy was undertaken as a result of the anomaly include the digit “09” at the end the numerical classification e.g. Termination of Trisomy 21 (Down Syndrome) 1.2109. All terminations of pregnancy for congenital anomalies regardless of the causal link to perinatal death are also classified here. With mapping to ICD coding, non-lethal abnormalities may be identified.

Chromosomal and genetic testing are categorised separately, in recognition of advances in prenatal screening and testing. The scope of genetic testing is widening to include some conditions that may not manifest with structural anomalies in the prenatal period (e.g. Fragile X syndrome). If there is both a chromosomal/genetic and structural abnormality, code for the chromosome or genetic condition with the structural condition as an associated condition. Results of genetic testing of unknown significance are captured under associated conditions.

The chromosomal abnormality category excludes deaths where molecular karyotyping identifies an anomaly which is not thought to be causal. Findings of genetic testing of unknown significance (variations of uncertain or unknown significance, VUS) are classified as associated conditions. Where there is both a chromosomal and a structural abnormality, classify according to the chromosome abnormality with the structural abnormality as an associated condition.

Specific examples:

Down syndrome (Trisomy 21) is classified as a Chromosome abnormality (Down syndrome 1.21). If a cardiac anomaly is also present, this would be an associated condition (1.12 cardiovascular system).

Vater and *Vacterl* are 1.18 Congenital malformations affecting multiple systems, specified. For syndromes where DNA testing is available and has been confirmed for VATER or CHARGE association classify as genetic condition 1.31, specified.

Hydrops Fetalis: Antibody related hydrops (Immune Hydrops) e.g. Rhesus or Kell incompatibility and Bart’s haemoglobinopathy (alpha thalassemia) is coded under as 1.17.

Non immune hydrops if due to chromosomal/genetic anomalies, classify under 1.2 and appropriate sub-classification, e.g. 1.25 Turner syndrome.

Idiopathic hydrops fetalis as 1.192 Other specific congenital anomaly, hydrops fetalis, idiopathic.

If the hydrops is secondary to underlying structural pathology e.g. congenital heart abnormality, neuromuscular disorders, skeletal dysplasia (achondrogenesis) or infection—classify in appropriate systems.

Hydrops associated with monochorionic twins classify under 6.1 category.

Multiple anomalies: Where the multiple anomalies are a part of a chromosomal anomaly found in the decedent, e.g. cleft lip and palate with heart defect as in velocardiofacial syndrome associated with 22q11 deletion, they should be classified under Category 1.2 but only if chromosome testing confirms deletion.

Anterior wall defects: Omphalocele (exomphalos), gastroschisis, and congenital diaphragmatic hernia are now classified under musculoskeletal anomalies (Category 1.15), in line with ICD10-PM.

If omphalocele is an isolated anomaly classify 1.15; if associated with multiple structural anomalies classify as 1.18; if associated with aneuploidy e.g. trisomy 18, classify as 1.22.

Acquired CNS anomalies: Infection-related abnormalities should be classified under Category 2, e.g. microcephaly/hydrocephaly secondary to CMV or toxoplasma infections should be classified as Category 2.21 and 2.3 respectively.

Congenital intracranial haemorrhage/injury may be classified as Category 7.5 *Fetal antenatal intracranial injury*.

Disruptions due to amniotic band disruption sequence may cause extensive asymmetric injury to the cranium and brain. It may also present as anencephaly or encephalocele. Classify under Category 7.5 *Fetal antenatal intracranial injury* but if due to alloimmune thrombocytopenia Code as 1.17 Haematological.

Neuromuscular disorders: Classify under 1.11. These are a complex group that may include primary muscle anomalies, CNS anomalies – both acquired and primary - and metabolic abnormalities. Some are syndromic with recognised recurrence risk. Associated anomalies may include pulmonary hypoplasia, hydrops and cleft palate. The cause of death may have been respiratory failure but the death should be classified as the underlying abnormality.

If the underlying aetiology is known classify accordingly – e.g. *Fetal antenatal intracranial injury* Category 7.5.

Unspecified Congenital Abnormalities: Category 1.19 *Congenital anomaly, unspecified* covers those cases where an abnormality was stated as the cause but where insufficient information was available to classify under other categories.

2 Perinatal infection

- 2.1 Bacterial
 - 2.11 Group B Streptococcus
 - 2.12 E coli
 - 2.13 Listeria monocytogenes
 - 2.14 Spirochaetal e.g. Syphilis
 - 2.18 Other bacterial
 - 2.19 Unspecified bacterial
- 2.2 Viral
 - 2.21 Cytomegalovirus
 - 2.22 Parvovirus
 - 2.23 Herpes simplex virus
 - 2.24 Rubella virus
 - 2.25 Zika virus
 - 2.28 Other viral
 - 2.29 Unspecified viral
- 2.3 Protozoal e.g. Toxoplasma
- 2.5 Fungal
- 2.8 Other specified organism
- 2.9 Other unspecified organism

Definitions and Rules

In order to qualify for this category, there must be evidence of fetal or neonatal infection as in Table 1. Determination of perinatal infection.

This category aims to identify all perinatal deaths due to infection as the primary cause including perinatal deaths with infection following spontaneous preterm labour or rupture of the membranes. Deaths in preterm infants following spontaneous rupture of the membranes or labour not fulfilling the definition of infection should be classified under Category 10 *Spontaneous Preterm*.

Category 2.8 *Other specified organism* includes deaths due to other identified organisms other than those in Categories 2.1 to 2.5. Category 2.9 *Other unspecified organism* includes cases where there is an obvious infection however the organism was either not identified or not specified.

Examples:

Classify here: Prelabour rupture of the membranes at term, with birth following 24 hours of membrane rupture, neonatal pneumonia identified within 48 hours of birth, subsequent neonatal death, group B Streptococcus identified on vaginal and placental cultures. Classify as subcategory 2.11 Group B Streptococcus and PSANZ-NDC subcategory 4.13.

Classify here: Spontaneous rupture of membranes preterm followed by spontaneous labour at 26 weeks and stillbirth. Membranes were ruptured for 12 hours prior to birth. Fetal pneumonia was detected at autopsy and growth of E Coli from the lungs. Placental pathology showed chorioamnionitis and funisitis. Classify 2.12 with an associated condition as Category 10.11 *Spontaneous preterm, with chorioamnionitis on placental histopathology*.

Classify here: Spontaneous rupture of the membranes at 24 weeks gestation. Clinical chorioamnionitis ensued after 6 days of membrane rupture. Induction of labour was undertaken resulting in birth of a liveborn infant. Birthweight was 650gms. Active resuscitation was unsuccessful. No autopsy or placental pathology was undertaken. Classify as Category 2.11 with an associated category of Spontaneous preterm Category 10.13 and PSANZ-NDC unspecified congenital infection 4.19 with an associated classification of NDC 2.2 *Extreme prematurity – Unsuccessful resuscitation*.

Classify here: Spontaneous rupture of membranes at 14 weeks, with severe chorioamnionitis at 22 weeks. Labour was induced (with a live baby) and the baby was born without signs of life, the birthweight was 350gms. Autopsy findings of *E.coli* growth from lung fluid. Placental histopathology showed chorioamnionitis and funisitis. Classify as Category 2.1209.

Do not classify here: Spontaneous rupture of membranes at 21 weeks, with spontaneous onset of labour and birth at 22 weeks gestation. Baby was born without signs of life with a birthweight was 450gms No autopsy was undertaken. Placental histopathology showed chorioamnionitis (no funisitis), no organism was grown. Classify as Category 10.11

Do not classify here: Neonatal death from late onset (≥ 48 hrs of age) Group B Streptococcal disease in a term infant. Classify under Category 12. *Neonatal death with no obstetric antecedent factor* and PSANZ-NDC as 4.4. The organism involved (GBS) may be classified as an associated condition under NDC associated factors using Category 2 sub classifications as a pragmatic way of collecting organisms in acquired infection. Alternately (and more appropriately), the organism should be included in a minimum dataset for all perinatal deaths

Death type	Criteria for Perinatal and Acquired Infection category
Fetal	1. Histological confirmation of inflammation in cord (funisitis) or fetus (pneumonitis or pneumonia) with or without microbiological evidence of infection or 2a. Convincing clinical evidence of primary maternal infection and 2b. Positive culture of a pathogen from mother or placenta (specimen taken aseptically between amnion and chorion)
Neonatal	<p>A. Congenital Early onset infection (within 48 hours of birth), defined as:</p> <ol style="list-style-type: none"> 1. Clinical signs in neonate consistent with sepsis and 2. Haematological changes consistent with sepsis and one or more of the following: <ol style="list-style-type: none"> 3a. Positive culture of a pathogen (bacterial or viral) from the neonate or 3b. Pathological evidence at autopsy or 3c. Positive serology or 3d. Positive culture of a pathogen from the mother or the placenta or 3e. Pneumonia without specified bacterial or viral pathogens <p>NB: Some congenital viral infections may have onset later than 48 hours after birth</p> <p>B. Acquired Onset of infection at 48 hours or later, with criteria as above, but excluding 3d</p>

Table 1. Determination of perinatal infection

3 Hypertension

- 3.1 Chronic hypertension: essential
- 3.2 Chronic hypertension: secondary, e.g. renal disease
- 3.3 Chronic hypertension: unspecified
- 3.4 Gestational hypertension
- 3.5 Pre-eclampsia
- 3.6 Pre-eclampsia superimposed on chronic hypertension
- 3.9 Unspecified hypertension

Definitions

The classification of *Hypertension* follows that of the Society of Obstetric Medicine of Australia and New Zealand¹² with the exceptions that unspecified subcategories have been included. The definitions are as follows:

Hypertension is diagnosed when the systolic blood pressure is ≥ 140 mm Hg and /or diastolic blood pressure (Korotkoff V) is ≥ 90 mm Hg. These blood pressures should be confirmed by repeated readings over several hours in a clinic or day assessment unit or after rest in hospital.

Gestational hypertension is defined as hypertension arising in pregnancy after 20 weeks gestation without any other feature of the multisystem disorder pre-eclampsia and which resolves within 3 months postpartum.

Pre-eclampsia may be defined as hypertension arising after 20 weeks gestation and the onset after 20 weeks gestation of one or more of: proteinuria, renal insufficiency, liver disease, neurological problems, haematological disturbances, fetal growth restriction. The hypertension will have returned to normal within 3 months postpartum.

Rules

This category includes deaths where the hypertensive disorder is considered the factor initiating the chain of events leading to the death. If placental abruption complicates a hypertensive disorder, the death is classified here, as the abruption is attributed to the hypertensive disorder. Specific placental pathology can be coded as associated conditions (see PSANZ-SB&ND Associated conditions list page 34)

This category excludes the circumstance when the hypertension is secondary to an underlying systemic disorder, e.g. Diabetes, where this is severe and uncontrolled (in which case, classify as subcategory 5.2 *Diabetes*, under *Maternal Conditions*). However, if the systemic disorder such as diabetes or gestational diabetes is mild or well controlled, and the death appeared to be due to hypertension or its complications, classify in this category. This category also includes hypertension secondary to renal disease as this often presents first with hypertension.

4 Antepartum haemorrhage (APH)

- 4.1 Placental abruption
- 4.2 Placenta praevia
- 4.3 Vasa praevia
- 4.9 APH of undetermined origin

Definitions

Placental abruption: The diagnosis of placental abruption is made clinically. Confirmation by evaluation of the placenta after delivery is not essential for assigning the death to abruption. Clinically features are classically with vaginal bleeding (although the bleeding may be concealed), abdominal pain, uterine contractions and tenderness¹³.

Placenta praevia: Placenta praevia is defined as a placenta that lies wholly or partly within the lower uterine segment diagnosed on ultrasound¹³. With improved diagnosis and management stillbirth as a result of bleeding for placenta praevia is now rare.

Vasa praevia: Vasa praevia is the presence of unsupported fetal vessels below the fetal presenting part, where the cord insertion is velamentous¹³. Classically, vaginal bleeding following amniotomy with subsequent fetal bradycardia suggests vasa praevia. The diagnosis of vasa praevia can be confirmed by Doppler and endovaginal ultrasound studies if aberrant vessels over the internal cervical os are suspected¹³.

APH of undetermined origin: This category is used where insufficient information is available on the reason for the bleeding. However, there is convincing clinical evidence that the stillbirth was as a result of the bleeding¹³.

Rules

This category includes all perinatal deaths where the primary factor leading to the death was an APH.

Convincing clinical signs of abruption alone is sufficient to assign the category of 4.1 Abruption. If abruption occurs as a complication of a hypertensive disorder, the death is attributed to the hypertensive disorder (Category 3) with Category 4.1 Placental abruption as an associated condition. Other placental pathology thought to be contributory may also be classified under associated conditions Category 9.

Examples:

Classify here: A woman presents at 38 weeks' gestation with abdominal pain, tense abdomen and uterine contractions and a fetal death diagnosed. Placental macroscopic examination showed a large adhesive clot however placental histopathology was inconclusive. Classify as 4.1 Placental abruption.

5 Maternal Conditions

- 5.1 Termination of pregnancy for maternal psychosocial indications
- 5.2 Diabetes
 - 5.21 Gestational diabetes
 - 5.22 Pre-existing diabetes
- 5.3 Maternal injury
 - 5.31 Accidental
 - 5.32 Non-accidental
- 5.4 Maternal sepsis
- 5.5 Antiphospholipid syndrome
- 5.6 Obstetric cholestasis
- 5.8 Other specified maternal conditions
 - 5.81 Maternal suicide
 - 5.88 Other specified maternal medical or surgical conditions

Definitions and Rules

Category 5 includes perinatal deaths attributed to any medical or surgical condition in the mother, or to its complications or treatment, excluding conditions elsewhere classified i.e. APH, hypertension. The subcategory 5.1 excludes terminations of pregnancy undertaken for medical indication including congenital and other complications (e.g. prolonged preterm rupture of membranes (PPROM) with severe infection) where a pregnancy is terminated and the fetus is not expected to survive. In this scenario the death is classified under the specific condition including termination of pregnancy due to a congenital anomaly (classified under Congenital Anomaly, Category 1) and other conditions such as severe chorioamnionitis following preterm rupture of the membranes at 20 weeks (classify 10.1 Spontaneous preterm); adding the coding number “9” to identify termination as described under “General rules for applying the PSANZ PDC System” on page 4.

Renal disease is not included as a separate subcategory here, but under Hypertension, subcategory 3.2, as it usually presents first as hypertension. Maternal conditions should only be attributed here if there is a high probability that they were the cause of death, e.g. a well-documented history of lupus obstetric syndrome with a previous stillbirth. Maternal substance use or smoking may be classified as an associated condition if there is a significant history (including alcohol, cocaine, and marijuana) and where it is reasonable to assume that the fetal or neonatal death may be linked.

Examples:

Classify here: Fetal death as a result of severe uncontrolled Type I Diabetes with mild pre-eclampsia classify as subcategory 5.22 with an associated condition of Hypertension, Category 3.5.

6 Complications of multiple pregnancy

- 6.1 Monochorionic twins
 - 6.11 Twin to twin transfusion syndrome (TTTS)
 - 6.12 Selective fetal growth restriction (FGR) (i.e. affecting only one twin)
 - 6.13 Monoamniotic twins (including cord entanglement)
 - 6.18 Other
 - 6.19 Unknown or unspecified
- 6.2 Dichorionic twins
 - 6.21 Early fetal death in a multiple pregnancy (<20 weeks gestation)
 - 6.22 Selective fetal growth restriction (FGR)
 - 6.28 Other
 - 6.29 Unknown or unspecified
- 6.3 Complications of higher order multiples (3 or more fetuses)
 - 6.31 Twin to twin transfusion syndrome (TTTS)
 - 6.32 Selective fetal growth restriction (FGR)
 - 6.33 Monoamniotic multiples (including cord entanglement)
 - 6.34 Early fetal death in a multiple pregnancy (<20 weeks gestation)
 - 6.38 Other
 - 6.39 Unknown or unspecified
- 6.4 Complications where chorionicity is unknown
- 6.8 Other
- 6.9 Unspecified

Rules

For 6.12, 6.22 and 6.32 read Explanatory Notes under Associated Condition, Section 15, Fetal Growth Restriction.

Where one of the twins (or multiples) is growth restricted as a result of twin to twin transfusion syndrome, classify as 6.11, 6.31 and not 6.12 or 6.32 respectively. Where one or more of the twins (or multiples) is growth restricted from a known underlying cause, classify elsewhere as appropriate, e.g. classify under Category 9 if there is placental disease in one of dichorionic twins.

7 Specific perinatal conditions

- 7.1 Fetomaternal haemorrhage
- 7.2 Antepartum cord or fetal vessel complications (excludes monochorionic twins or higher order multiples)
 - 7.21 Cord vessel haemorrhage
 - 7.22 Cord occlusion (True knot with evidence of occlusion or other)
 - 7.28 Other cord complications
 - 7.29 Unspecified cord complications
- 7.3 Uterine abnormalities
 - 7.31 Developmental anatomical abnormalities (e.g. bicornuate uterus)
 - 7.38 Other
 - 7.39 Unspecified
- 7.4 Alloimmune disease
 - 7.41 Rhesus isoimmunisation
 - 7.42 Other red cell antibody
 - 7.43 Alloimmune thrombocytopenia
 - 7.48 Other
 - 7.49 Unspecified
- 7.5 Fetal antenatal intracranial injury
 - 7.51 Subdural haematoma
 - 7.52 Fetal antenatal ischaemic brain injury
 - 7.53 Fetal antenatal haemorrhagic brain injury
- 7.6 Other specific perinatal conditions
 - 7.61 Complications of antenatal, diagnostic or therapeutic procedures:
 - 7.611 Complications of prenatal diagnostic procedures (e.g. amniocentesis, chorionic villus sampling,) (e.g. rupture of membranes after amniocentesis)
 - 7.612 Complications of fetal ultrasound guided needle interventions (e.g. FBS/fetal transfusion, thoracocentesis, vesicocentesis, fetal cardiac valvoplasty, division of amniotic bands, fetal skin biopsy, unipolar/bipolar diathermy, RFA procedures)
 - 7.613 Complications of fetal shunt interventions (e.g. pleuroamniotic shunt, vesicoamniotic shunt)
 - 7.614 Complications of minimally invasive fetoscopic interventions (e.g. fetoscopic laser surgery for TTTS, FETO for CDH, laser ablation of posterior urethral valves)
 - 7.615 Complications of open maternal fetal surgery (e.g. open maternal fetal surgery for spina bifida)
 - 7.618 Other
 - 7.62 Termination of pregnancy for suspected but unconfirmed congenital anomaly
 - 7.63 Amniotic band
 - 7.68 Other
- 7.9 Unspecified

Definitions

Category 7.22 Cord occlusion: A cord knot is where the cord becomes tangled with itself (or another cord in a multiple pregnancy) such that the vessels of the cord may be compromised. To be considered significant there should be evidence of congestion or haemorrhage in the cord, and/or changes in the placenta such as fetal vessel thrombosis or villous oedema to suggest vascular compromise. A knot could cause death without these changes but not every knot causes fetal compromise and therefore should not be accepted as a cause of death without further evidence as above, or strong clinical suspicion by the delivering clinician based on CTG or other changes during delivery. Cord accidents usually only account for a few percent of perinatal deaths.

Other cord compression: For stillbirths, and also neonatal deaths as a result of hypoxic ischaemic encephalopathy (HIE), where the cord is found to be tightly around neck or body with skin blanching (indicating significant cord compression) classify as 7.28.

Category 7.21 includes cord haemorrhage following cordocentesis, umbilical cord ulceration leading to cord haemorrhage, and torn velamentous vessels.

Rules

This category includes deaths in which the specific perinatal condition present was thought to be the cause of death. The category excludes perinatal deaths with a major congenital anomaly. Cord complications during labour and other complications of twins e.g. head entrapment in labour should be categorised under *Hypoxic Peripartum Death*, subcategory 8.18.

Examples:

Do not classify here: Spontaneous prelabour rupture of membranes (ROM) at 33 weeks, with immediate cord prolapse and fetal death. Categorise as Spontaneous Preterm Category 10 as the cord complication occurred as a result of the preterm ROM. Cord prolapse is classified as an associated condition.

8 Hypoxic peripartum death

- 8.1 With intrapartum complications (sentinel events)
 - 8.11 Uterine rupture
 - 8.12 Cord prolapse
 - 8.13 Shoulder dystocia
 - 8.14 Complications of breech presentation
 - 8.15 Birth trauma
 - 8.16 Intrapartum haemorrhage
 - 8.18 Other
- 8.2 Evidence of significant fetal compromise (excluding other complications)
- 8.3 No intrapartum complications and no evidence of significant fetal compromise identified
- 8.9 Unspecified hypoxic peripartum death

Definitions and rules

This category includes both intrapartum fetal deaths and neonatal deaths as a result of acute or chronic hypoxia in babies without major congenital anomalies or other major conditions such as antepartum haemorrhage at a gestation in which survival in the context of the birth would be expected (typically of >28 weeks gestation or >1000g birthweight). If placental pathology is identified which resulted in fetal compromise and death then classify under the relevant category i.e. Category 9 Placental pathology or Category 4 Antepartum haemorrhage.

Where intrapartum fetal death or neonatal death occurs following preterm spontaneous onset of labour or rupture of membranes which fulfils the definition of Infection then classify under Category 2. If not fulfilling the criteria for infection and less than 24 weeks then classify under Category 10 *Spontaneous preterm*.

Neonatal deaths as a result of hypoxic ischaemic encephalopathy and otherwise unexplained severe cardiorespiratory depression at birth are included here. Where possible, evidence for intrapartum hypoxia should include fetal, umbilical artery or early neonatal (within one hour) blood gases showing evidence of a severe metabolic acidosis. Otherwise peripartum death might also be due to non-hypoxic causes, e.g. infection or chronic ischaemia but wrongly assumed to be due to acute hypoxia.

There may have been intrapartum complications (subcategory 8.1), or no intrapartum complications but with evidence of non-reassuring fetal status (subcategory 8.2), or no intrapartum complications or evidence of non-reassuring fetal status (subcategory 8.3). A specific major intrapartum complication, such as uterine rupture, cord prolapse or shoulder dystocia, is required for inclusion as subcategory 8.1. However, if there were no apparent intrapartum complications (as defined in category 8.1) but there was evidence of placental insufficiency antenatally, then the death should be attributed to Category 9. In this case Category 8 is captured as an associated condition.

If there is insufficient information about fetal wellbeing or intrapartum complications, classify as subcategory 8.9 *Unspecified hypoxic peripartum death*.

Evidence of non-reassuring fetal status is defined as abnormal fetal heart rate, fetal scalp pH/lactate, fetal pulse oximetry without intrapartum complications.

The term 'non-reassuring fetal status' has been used in preference to the term 'fetal distress' as 'clinical signs often poorly predict a compromised fetus and continued use of this latter term may encourage wrong assumptions or inappropriate management'^{14,15}.

Examples:

Classify here: No known problems prior to labour at gestation 38 weeks. Severe fetal heart rate decelerations in second stage of labour, without other major complication. Baby is born with no signs of life with a birthweight of 3500gm, placental histopathology did not identify any significant pathology and no autopsy was performed. Classify as subcategory 8.2.

Classify here: No known problems prior to labour at 36 weeks. No evidence of intrapartum fetal distress. At birth, the baby shows signs of severe respiratory depression and hypoxia. Subsequently develops encephalopathy and multiorgan failure and dies on Day 10 of life. Placental histopathology did not identify any significant pathology and no autopsy was performed. Classify as subcategory 8.3 and PSANZ NDC as 5.1.

Do not classify here: Spontaneous membrane rupture at 22 weeks' gestation, severe oligo hydramnios with positional deformities shown on ultrasound at 26 weeks. Labour and birth at 26 weeks gestation of a baby boy weighing 700gms and was not able to be resuscitated. Placental pathology showed chorioamnionitis but no organisms identified on placental culture or baby blood cultures. Classify as 10.11 *Spontaneous preterm* and PSANZ NDC as Category 2.2 *Not resuscitated*.

Do not classify here: No complications during pregnancy. Spontaneous preterm labour and birth at 38 weeks gestation. Intrapartum fetal distress in second stage and delivered by forceps. Baby boy weighing 2200gms, Apgars 1 and 4, mechanically ventilated and admitted to NICU. Seizures commenced at 2 hrs and active management ceased at 24 hrs due to poor prognosis. Placental pathology showed fetal vascular malperfusion and mild chorioamnionitis however no organisms were identified on culture of the placental or baby. Classify as 9.2 *Placental dysfunction* and PSANZ NDC 5.1 *Hypoxic ischaemic encephalopathy/Perinatal asphyxia*

9 Placental dysfunction or causative placental pathology

- 9.1 Maternal vascular malperfusion
- 9.2 Fetal vascular malperfusion
- 9.3 High grade villitis of unknown etiology (VUE)
- 9.4 Massive perivillous fibrin deposition/maternal floor infarction
- 9.5 Severe chronic intervillitis (Histiocytic intervillitis)
- 9.6 Placental hypoplasia (small-for gestation placenta)
- 9.7 No causal placental pathology demonstrated, with antenatal evidence of poor placental function identified (such as abnormal fetal umbilical artery Doppler)
- 9.8 Placental pathological examination was not performed, with antenatal evidence of poor placental function was identified (such as abnormal fetal umbilical artery Doppler)
- 9.9 Other placental pathology (e.g. multiple pathologies with evidence of loss of placental function leading to death)

Definitions

This category is based on the Amsterdam Placental Workshop Group Consensus Statement⁹.

Category 9.1 *Maternal vascular malperfusion (MVM)*. Placental features considered to be indicative of MVM include both gross and microscopic findings. Gross findings include placental hypoplasia, infarction, and retroplacental haemorrhage.

Any infarction seen in a preterm placenta and, at term, anything more than 5% of non-peripheral infarction should be classified as a cause. Although marginal infarcts in a term placenta may have less meaning than in a preterm placenta, they should be classified as an associated condition. *Microscopic findings* include abnormalities of villous development, which can be separated into distal villous hypoplasia, and accelerated villous maturation (vide infra), and infarcts. It should be recognized that many of these histologic findings will coexist in some placentas.

Category 9.6 Placental hypoplasia is reflected by a placental weight that is low for the stated gestational age and context (weight <10th centile) and/or a thin cord (<10th centile or <8-mm diameter at term).

Category 9.7 and 9.8 includes stillbirths or neonatal deaths where clinical evidence of poor placental function sufficient to explain the death was identified however significant causal pathology of the placental was not demonstrated or placental histopathology was not performed. Clinical evidence of poor placental function is defined as evidence of placental disease either on antenatal ultrasound studies or biochemistry. This former can include evidence of reduced maternal (uterine artery) or fetal (umbilical artery, ductus venosus, middle cerebral artery Doppler) vascular perfusion on Doppler studies. The latter can include angiogenesis-related factors such as s-Flt-1/PlGF; further clinical evaluations may clarify which biochemical markers robustly identify placental dysfunction.

Category 9.9 includes multiple pathologies with evidence of loss of placental function leading to death. It excludes pathologies listed in 9.1 to 9.8. Where one or more pathologies listed under 9.1-9.8 are identified, a single pathology must be classified as the primary cause of death with the additional pathologies classified as associated conditions (see Category 16 page 34).

Rules

This category includes perinatal deaths where placental dysfunction is considered the underlying cause of the death. It excludes perinatal deaths as a result of an identified maternal or fetal condition where the death is classified according to the condition (e.g. Pre-Eclampsia, Pre-existing hypertension). It should exclude pathology which is not thought to be causal, and also amniotic fluid infection/acute chorioamnionitis. Placental pathology which is thought to be contributory rather than causal should be classified as an associated condition (See Associated conditions page 34).

It is acknowledged that multiple pathologies may exist. In these circumstances a dominant pathology needs to be identified and classified as the main cause and others as associated conditions. This category overrides deaths following intrapartum related events as defined in Category 8 Hypoxic peripartum deaths.

Examples:

Classify here: Normal pregnancy. Spontaneous preterm labour and birth at 40 weeks gestation. Non-reassuring fetal status in second stage ensued and birth was by emergency caesarean section. Baby boy weighing 2600gms, Apgars 2 and 4, mechanically ventilated and admitted to NICU with subsequent diagnoses of meconium aspiration and persistent pulmonary hypertension of the newborn. Despite intensive care the baby died at 12 hrs of age. Placental pathology showed massive perivillous fibrin deposition/maternal floor infarction and mild chorioamnionitis, no organisms were identified on placental culture or baby blood cultures. Classify as 9.4 *Massive perivillous fibrin deposition/maternal floor infarction* and PSANZ NDC 3.3 *Primary persistent pulmonary hypertension*, with an Associated condition of *Fetal growth restriction*.

Do not classify here: Normal pregnancy until maternal presentation at 40 weeks' gestation with decreased fetal movements and abdominal pain. Antepartum fetal death was diagnosed and spontaneous labour ensued shortly after. A baby girl was born, mildly macerated, weighing 3400gms. Placental pathology showed massive abruption. Maternal investigations were normal. No organisms were identified on placental culture or baby blood cultures. Classify as *APH Abruption 4.1*.

10 Spontaneous preterm labour or rupture of membranes (<37 weeks gestation)

- 10.1 Spontaneous preterm
 - 10.11 With histological chorioamnionitis
 - 10.12 Without histological chorioamnionitis
 - 10.13 With clinical evidence of chorioamnionitis, no examination of placenta
 - 10.17 No clinical signs of chorioamnionitis, no examination of placenta
 - 10.19 Unspecified or not known whether placenta examined
- 10.2 Spontaneous preterm preceded by premature cervical shortening

Definitions

Clinical evidence of chorioamnionitis is defined as maternal fever ($\geq 38^{\circ}\text{C}$) associated with one or more of the following symptoms or signs: maternal or fetal tachycardia, uterine tenderness, malodorous amniotic fluid, and maternal leukocytosis or raised C-reactive protein¹⁶⁻¹⁸.

The diagnosis of histological chorioamnionitis should only be made when there is histological evidence of inflammation or microbiological evidence of infection of the placenta and membranes.

The subcategory of premature cervical shortening is reserved for those circumstances where the primary event appears to be cervical change based on clinical or ultrasound findings. This may occur as consequence of pre-existing damage to the cervix from a surgical procedure, due to a congenital structural cervical anomaly (with or without uterine anomaly) or clinically determined from previous obstetric history and/or clinical factors in the current pregnancy.

Rules

Deaths of normally formed, appropriately grown preterm babies following spontaneous onset of preterm labour or spontaneous rupture of membranes, irrespective of induction of labour or mode of delivery (e.g. elective caesarean section). There should be no evidence of fetal or neonatal infection (see Table 1 Determination of perinatal infection), otherwise classify under Category 2 *Perinatal Infection*. Careful examination of the placenta macroscopically and microscopically is recommended.

In cases where there is histological evidence of chorioamnionitis with or without evidence of clinical chorioamnionitis, classify as subcategory 10.11. In cases of clinical chorioamnionitis where placental pathological examination was not performed or it is not known whether the placenta was examined, classify as subcategory 10.13.

Where cervical incompetence is followed by spontaneous preterm labour or ROM classify as 10.2 as opposed to 10.1. There may be some bleeding at the time of onset of labour, or earlier in pregnancy, but not in amounts to warrant the antecedent cause being attributed to *Antepartum Haemorrhage* Category 4. Early bleeding, which is often associated with preterm premature rupture of the membranes may be classified as an associated condition (see page 34).

Examples:

Classify here: Spontaneous labour at 26 weeks, no apparent explanation, and membranes intact. Vaginal delivery after 6 hours of membrane rupture, no evidence of intrapartum hypoxia or chorioamnionitis; subsequent early neonatal death from respiratory distress syndrome. Classify here as subcategory 10.12 *Spontaneous preterm with intact membranes, or membrane rupture, without chorioamnionitis on placental histopathology* and NDC: Category 3.1

Do not classify here: Spontaneous onset of labour at 28 weeks with intact membranes. No cause identified for preterm labour. Delivery following 24 hours of membrane rupture. Maternal intrapartum pyrexia. Chorioamnionitis and funisitis on placental histology, no organism identified. Classify as Category 2.9 *Perinatal Infection; other unspecified organism*

Do not classify here: Alive at the onset of spontaneous labour at 31 weeks, no apparent explanation, and membranes intact. After 12 hrs, continuous intrapartum fetal monitoring showed deep decelerations and emergency caesarean section undertaken. Baby girl weighing 1700g was stillborn and could not be resuscitated. Placental pathology showed chorioamnionitis (no funisitis) no organisms were identified, and no other pathology was demonstrated. No autopsy was performed. Macroscopic examination of the baby was normal, no maceration. Classify as Category 8.2 *Hypoxic peripartum death; Evidence of significant fetal compromise (excluding other complications)*.

11 Unexplained antepartum fetal death

- 11.1 Unexplained antepartum fetal death despite full investigation
- 11.2 Unclassifiable antepartum fetal death with incomplete investigation
- 11.3 Unclassifiable antepartum fetal death due to unknown level of investigation

Rules

This category applies to fetal death prior to the onset of labour where no cause for the death was identified. Antepartum fetal death with associated placental pathology (i.e. not thought to be causative) are coded as associated conditions.

Category 11.1 Unknown antepartum fetal death despite full investigation.

An antepartum fetal death where no cause of death was identified following (as a minimum): comprehensive maternal and pregnancy history; histopathology of the placenta and cord; full autopsy; karyotype/cytogenetics; and testing for Feto-Maternal Haemorrhage (Kleihauer or flow cytometry).

Category 11.2 is used where none or some of the above investigations were performed and Category 11.3 is used where it is unknown/unclear if these investigations were performed or the results were unavailable.

Whether or not each of the above tests were performed should be recorded to identify areas of practice improvements and future research. The minimum dataset for perinatal deaths as defined in the Australian Perinatal Mortality Audit Tool APMAT (see Appendix E – Australian Perinatal Mortality Audit Tool) and the New Zealand PMMRC audit form¹⁹ (Appendix F – Rapid reporting form for a perinatal death – baby and Appendix G – Rapid reporting form for a perinatal death - mother) includes these data fields.

Examples:

Classify here: Intrauterine Fetal Death (IUFD) at 37 weeks, with no maternal conditions, no antepartum haemorrhage, with membranes intact, before onset of labour, where no cause of death was identified following full investigation (*comprehensive maternal and pregnancy history; histopathology of the placenta and cord; full autopsy; karyotype/cytogenetics; and Kleihauer*) Classify as Unexplained Antepartum Fetal Death, subcategory 11.1.

Intrauterine Fetal Death (IUFD) at 40 weeks, with no maternal conditions, no antepartum haemorrhage, with membranes intact, before onset of labour, where no cause of death was identified and perinatal death investigations were incomplete (e.g. *No karyotype/cytogenetics*) Classify as Unexplained Antepartum Fetal Death, subcategory 11.2.

Do not classify here: Spontaneous ROM at 27 weeks, no significant maternal conditions present, subsequent IUFD prior to onset of labour. No chorioamnionitis on examination of the placenta. Classify as subcategory 10.12 *Spontaneous preterm labour or ROM (<37 weeks gestation); without histological chorioamnionitis.*

12 Neonatal death without obstetric antecedent

- 12.1 Neonatal death with no obstetric antecedent factors despite full investigation
- 12.2 Neonatal death unclassifiable as to obstetric antecedent with incomplete investigation
- 12.3 Neonatal death unclassifiable as to obstetric antecedent due to unknown level of investigation

Rules

This category includes neonates where no obstetric antecedent factors (according to the PDC list) were identified as contributing to the death.

Category 12.1 applies to a neonatal death where not obstetric antecedent factor was identified following negative findings for the following (as a minimum): comprehensive maternal and pregnancy history and full autopsy.

Category 12.2 is used where the full autopsy was not performed and Category 11.3 where it is unknown if they were performed or the results were unavailable.

NB: Whether a PDC code is assigned or not, all neonates require a neonatal cause of death according to the PSANZ NDC to be assigned. The NDC provides information on the causes and associated conditions present in the neonatal period.

Examples:

Classify here: Baby boy born at term weighing 3.5kg was discharged home well on Day 2 of life. On day 27, the baby was found dead in his cot by the parents and following full investigation was classified as SIDS. Please refer to the NDC to classify the neonatal cause of death.

Classify here: Baby boy born at 38 weeks weighing 3kg was discharged home well. On day 10, the baby became unwell and died. Blood cultures and CSF were positive for Group B Streptococcus. Please refer to the NDC to classify the neonatal cause of death and classify as 4.1.

Do not classify here: Neonatal death on Day 7 of a 29 week baby girl with severe fetal growth restriction and reverse end diastolic flow delivered by emergency caesarean section who developed fulminating necrotising enterocolitis. Placental pathology showed high grade villitis of unknown etiology (VUE). Classify as Category 9.3 with the PSANZ Associated condition of *Fetal growth restriction* and NDC Category 6.1 *Necrotising enterocolitis*.

2 PSANZ-NDC Classification including rules and definitions

The Neonatal Death Classification has been developed for use in conjunction with the PSANZ Perinatal Death Classification in order to identify the underlying and associated neonatal conditions as well as the underlying and associated maternal conditions for neonatal deaths. For example, a mother who has an antepartum haemorrhage at 32 weeks gestation delivers a 1500g infant who thrives in the neonatal nursery but subsequently acquires a lethal nosocomial infection: the obstetric antecedent is antepartum haemorrhage, but neonatal death classification is subcategory 4.4 *Acquired Bacteria*. Both APH and neonatal nosocomial infection are important conditions on which to focus prevention strategies.

1 Congenital anomaly (please refer to PDC)

2 Perivable infants (typically <24 weeks)

- 2.1 Not resuscitated (including infants where there is an antenatal plan for no resuscitation at birth)
- 2.2 Unsuccessful resuscitation
- 2.9 Unspecified or not known whether resuscitation attempted

This group includes infants deemed too immature or too small for resuscitation or continued life support beyond the delivery room. Resuscitation in this context means the use of positive pressure ventilation.

3 Cardio-respiratory disorders

- 3.1 Hyaline membrane disease / Respiratory distress syndrome (RDS)
- 3.2 Meconium aspiration syndrome
- 3.3 Primary persistent pulmonary hypertension
- 3.4 Pulmonary hypoplasia
- 3.5 Pulmonary haemorrhage
- 3.6 Air leak syndromes
 - 3.61 Pneumothorax
 - 3.62 Pulmonary interstitial emphysema
 - 3.68 Other
- 3.7 Patent ductus arteriosus
- 3.8 Chronic neonatal lung disease (typically, bronchopulmonary dysplasia)
- 3.9 Other
 - 3.91 Neonatal anaemia/hypovolaemia

Definitions and Rules

Subcategory 3.1 *Hyaline membrane disease / Respiratory Distress Syndrome (RDS)* is used for deaths of infants who were receiving mechanical ventilation for acute RDS at the time of death or at the time of the complication such as pulmonary haemorrhage, sepsis, pneumothorax or necrotizing enterocolitis.

Neonates with resolving RDS, i.e. who are past the acute phase of the disease and are stable or improving, but who are still on low rate ventilation for immature lungs, extreme prematurity or apnoea, or who no longer require mechanical ventilation, and who developed a complication which led to the death should be classified according to that particular complication.

3.4 Pulmonary hypoplasia; this category includes pulmonary hypoplasia secondary to preterm prolonged rupture of the membranes. Congenital pulmonary airway malformation (CPAM), formerly known as congenital cystic adenomatoid malformation of the lung (CCAM) would be classified as 1.16. Congenital diaphragmatic hernia is classified as 1.151

Categorisation as chronic neonatal lung disease (subcategory 3.5) should be reserved for infants with deteriorating lung function and major chest X-ray changes consistent with bronchopulmonary dysplasia.

Examples:

Classify here: A 26-week gestation infant with RDS receives mechanical ventilation (SIPPV R50, P20/5, FiO2 0.4), develops complications of pneumothorax requiring drainage, followed by a patent ductus arteriosus and dies on day 2 of life is classified as Category 3.1 with associated conditions classified as 3.61 *Pneumothorax* and 3.7 *Patent ductus arteriosus*.

Do not classify here: A 26 week gestation infant with RDS weaning off mechanical ventilator has a Grade IV Intraventricular Haemorrhage (IVH) with ventricular dilation on ultrasound on Day 5. She is successfully weaned to CPAP on Day 7 but requires re-ventilation for sepsis on Day 10 and on Day 21 has developing BPD and post hemorrhagic hydrocephalus (PHH) following which ventilation is withdrawn. Classification is dependent on the major reason for withdrawal of support. In this case 5.3 *Post haemorrhagic hydrocephalus* with an associated classification of 3.8 *Chronic neonatal lung disease* and 4.49 *Sepsis*.

4 Neonatal infection

- 4.1 Congenital/Perinatal bacterial infection (early onset<48 hrs)
 - 4.11 Blood stream infection/septicaemia
 - 4.111 Positive culture of a pathogen
 - 4.112 Clinical signs of sepsis + ancillary evidence but culture negative
 - 4.12 Bacterial meningitis
 - 4.13 Bacterial pneumonia
 - 4.15 Multiple site bacterial infection
 - 4.18 Other congenital bacterial infection e.g. gastroenteritis, osteomyelitis, cerebral abscess
 - 4.19 Unspecified congenital infection
- 4.2 Congenital/Perinatal viral infection
- 4.3 Congenital fungal, protozoan, parasitic infection
- 4.4 Acquired bacterial infection (late onset>48hrs)
 - 4.41 Blood stream infection/septicaemia
 - 4.411 Positive culture of a pathogen
 - 4.412 Clinical signs of sepsis + ancillary evidence but culture negative
 - 4.42 Bacterial meningitis
 - 4.43 Bacterial pneumonia
 - 4.48 Other acquired bacterial infection e.g. gastroenteritis, osteomyelitis
 - 4.49 Unspecified acquired infection
- 4.5 Acquired viral infection
- 4.6 Acquired fungal, protozoan, parasitic infection

Rules

This category is intended to be used in conjunction with the PDC Category 2 *Perinatal Infection* to identify the organism causing the infection resulting in the death (including for an acquired infection). To take a pragmatic approach to storage of these data within the current system structure, in the case of a neonatal death from infection, the relevant NDC code can be stored as the primary neonatal condition and the PDC Category 2 code as an associated condition.

Determination of congenital and acquired neonatal infection

A. Congenital

Early onset infection (within 48 hours of birth), defined as:

1. Clinical signs in neonate consistent with sepsis

and

2. Haematological changes consistent with sepsis

and one or more of the following:

3a. Positive culture of a pathogen (bacterial or viral) from the neonate

or

3b. Pathological evidence at autopsy

or

3c. Positive serology

or

3d. Positive culture of a pathogen from the mother or the placenta. Swap taken aseptically between amnion and chorion.

or

3e. Pneumonia without specified bacterial or viral pathogens

NB: Some congenital viral infections may have onset later than 48 hours after birth.

B. Acquired/nosocomial

Onset of infection at 48 hours or later, with criteria as above, but excluding 3d.

Table 4. Determination of infection

5 Neurological

- 5.1 Hypoxic ischaemic encephalopathy/Perinatal asphyxia
- 5.2 Cranial haemorrhage
 - 5.21 Intraventricular haemorrhage
 - 5.22 Subgaleal haemorrhage
 - 5.23 Subarachnoid haemorrhage
 - 5.24 Subdural haemorrhage
 - 5.28 Other intracranial haemorrhage
- 5.3 Post haemorrhagic hydrocephalus
- 5.4 Periventricular leukomalacia
- 5.8 Other

Definitions and Rules:

Hypoxic ischaemic encephalopathy/Perinatal asphyxia:

Inclusion as hypoxic ischaemic encephalopathy or perinatal asphyxia usually requires a defining asphyxial event +/- evidence of severe non-reassuring fetal status and encephalopathy.

Examples of defining asphyxial events:

Massive antepartum haemorrhage from abruption (4.1), placenta praevia (4.2) or ruptured vasa praevia (4.3), breech presentation (8.14) or delivery with complications, e.g. cervical constriction ring or difficult delivery, feto-maternal haemorrhage (7.1), twin-twin transfusion (6.11).

Where possible, evidence for perinatal asphyxia should include fetal, umbilical artery or early neonatal blood gases (within one hour) showing evidence of a severe metabolic acidosis. Otherwise peripartum death might also be due to non-hypoxic causes, e.g. infection or chronic ischaemia but wrongly assumed to be due to acute hypoxia. In the absence of a defining asphyxial event every effort must be undertaken to exclude alternative diagnosis.

6 Gastrointestinal

- 6.1 Necrotising enterocolitis (NEC)
- 6.2 Short gut syndrome
- 6.3 Gastric or intestinal perforation (excluding NEC)
- 6.4 Gastrointestinal haemorrhage
- 6.8 Other

Definitions and Rules

When Short gut syndrome is a consequence of NEC or gastroschisis (1.152) then classify as Category 6.2 Short gut syndrome for the cause and other conditions as associated. Short gut syndrome Category 6.2 includes major intestinal infarction (such as midgut volvulus (1.14)).

7 Other

- 7.1 Sudden unexpected death in infancy (SUDI)
 - 7.11 Sudden Infant Death Syndrome (SIDS)
 - 7.112 SIDS Category IA: Classic features of SIDS present and completely documented
 - 7.113 SIDS Category IB: Classic features of SIDS present but incompletely documented
 - 7.114 SIDS Category II: Infant deaths that meet category I except for one or more features
 - 7.12 Unclassified Sudden Infant Death in the neonatal period
 - 7.121 Bed sharing/unsafe sleep
 - 7.122 Not bed sharing
 - 7.19 Unknown/Undetermined
- 7.2 Multisystem failure
 - 7.21 Secondary to intrauterine growth restriction
 - 7.28 Other specified
 - 7.29 Unspecified/undetermined primary cause or trigger event
- 7.3 Trauma
 - 7.31 Accidental
 - 7.32 Non accidental
 - 7.39 Unspecified
- 7.4 Treatment complications
 - 7.41 Surgical
 - 7.42 Medical
- 7.5 Unsuccessful resuscitation in infants of 28 weeks gestation or more without an obvious sentinel event
- 7.8 Other specified

Definitions

7.1 *SIDS* and 7.91 *Unclassified Sudden Infant Death* are defined according to the new SIDS classification system by Krous et al²⁰.

General Definition of SIDS

SIDS is defined as the sudden unexpected death of an infant <1 year of age, with onset of the fatal episode apparently occurring during sleep, that remains unexplained after a thorough investigation, including performance of a complete autopsy and review of the circumstances of death and the clinical history.

Category IA SIDS: Classic Features of SIDS Present and Completely Documented

Category IA includes infant deaths that meet the requirements of the general definition and also all of the following requirements.

Clinical:

- More than 21 days and <9 months of age;
- Normal clinical history, including term pregnancy(gestational age of ≥ 37 weeks);
- Normal growth and development.

- No similar deaths among siblings, close genetic relatives (uncles, aunts or first-degree cousins), or other infants in the custody of the same caregiver.

Circumstances of Death:

- Investigation of the various scenes where incidents leading to death might have occurred and it is determined that they do not provide an explanation for the death.
- Found in a safe sleeping environment, with no evidence of accidental death.

Autopsy:

- There is an absence of potentially fatal pathologic findings. Minor respiratory system inflammatory infiltrates are acceptable; intrathoracic petechial haemorrhage is a supportive but not obligatory or diagnostic finding.
- There is no evidence of unexplained trauma, abuse, neglect, or unintentional injury.
- There is no evidence of substantial thymic stress effect (thymic weight of <15g and/or moderate/severe cortical lymphocyte depletion). Occasional “starry sky” macrophages or minor cortical depletion is acceptable.
- Results of toxicologic, microbiologic, radiologic, vitreous chemistry, and metabolic screening studies are negative.

Category IB SIDS: Classic Features of SIDS Present but Incompletely Documented

Category IB includes infant deaths that meet the requirements of the general definition and also meet all of the criteria for category IA except that investigation of the various scenes where incidents leading to death might have occurred was not performed and or ≥ 1 of the following analyses was not performed: toxicologic, microbiologic, radiologic, vitreous chemistry, or metabolic screening studies.

Category II SIDS

Category II includes infant deaths that meet category I criteria except for ≥ 1 of the following.

Clinical:

- Age range outside that of category 1A or 1B (i.e., 0-21 days or 270 days [9 months] through first birthday);
- Similar deaths among siblings, close relatives, or other infants in the custody of the same caregiver that are not considered suspect for infanticide or recognised genetic disorders;
- Neonatal or perinatal conditions (for example, those resulting from preterm birth) that have resolved by the time of death.

Circumstances of Death:

- Mechanical asphyxia or suffocation caused by overlaying not determined with certainty.

Autopsy:

- Abnormal growth and development not thought to have contributed to death;
- Marked inflammatory changes or abnormalities not sufficient to be unequivocal causes of death.

Unclassified Sudden Infant Death

The unclassified category includes deaths that do not meet the criteria for category I or II SIDS but for which alternative diagnoses of natural or unnatural conditions are equivocal, including cases for which autopsies were not performed.

Post-resuscitation cases

Infants found in extremis who are resuscitated and later die (“temporarily interrupted SIDS”) may be included in the aforementioned categories, depending on the fulfilment of relevant criteria.

Rules

Subcategory 7.92 *Other Unknown/Undetermined* has been included to identify unknown causes of death which do not fulfil the criteria of Category 7.91. Subcategory 7.4 *Other accident, poisoning or violence (postnatal)* excludes cases of antepartum deaths which should be classified in Category 5 *Maternal Conditions* under subcategory 5.3 *Maternal injury*. Subcategory 7.8 *Other specified* is used to classify other identified conditions which are not included in subcategories 7.1 to 7.4.

7.8 PSANZ Associated Conditions

Following classification of the underlying cause of death according to the PSANZ-PDC for stillbirths and neonatal deaths, and in addition a PSANZ NDC for neonatal deaths, associated conditions thought to be contributory (but not causal) to the death should be classified. The associated conditions list includes the PSANZ-PDC categories and, in addition for neonatal deaths, the PSANZ-NDC categories and other conditions which may be contributory to stillbirth as listed below in Categories 13-16.

Associated conditions for both stillbirths and neonatal deaths

Categories 1 -11 PSANZ PDC Plus the following additional categories:

13 Genetic testing results not diagnostic

- 13.1 Copy number variant of unknown or uncertain significance
- 13.2 No mutation identified matching phenotype
- 13.3 Tested for genetic mutations but failed
- 13.4 Not tested or not known if tested for genetic mutations

Explanatory/clarifying notes:

Where a pathogenic or a likely pathogenic mutation has been identified, this would have been classified under Category 1.2 Chromosomal anomaly as stated in the Definitions and Rules section of Category 1 Congenital anomaly. 1.31 and 1.34 are self-explanatory. 13.3 tested for genetic mutations but failed, refer to those tests that may have failed due to culture failure (with conventional cytogenetics) or poor DNA (with molecular techniques)

14 Associated placental pathology

- 14.1 Delayed villous maturation
- 14.2 Large chorioangioma
- 14.3 Early bleeding often leading to preterm prelabour ROM
- 14.8 Other associated placental pathology

Explanatory/clarifying notes:

Early bleeding is defined as bleeding in the second trimester (often on one or more occasions) which does not immediately lead to spontaneous birth or rupture of membranes.

15 Associated cord pathology

- 15.1 True knot (excluding histological evidence of causation)
- 15.2 Hypercoiled cord
- 15.3 Tethered cord
- 15.4 Velamentous insertion
- 15.8 Other associated cord pathology

16 Fetal Growth Restriction (FGR)

- 16.1 Autopsy evidence (brain:liver ratio equal to or greater than 4:1)
- 16.2 Antenatal ultrasound evidence of FGR
- 16.3 Clinical examination of the baby (by paediatrician, pathologist)
- 16.4 Birthweight (less than 10th centile for gestational age)
 - 16.41 Customised centiles²¹
 - 16.42 Population centiles^{22,23}

Explanatory/clarifying notes:

Fetal growth restriction is defined as:

1. A brain:liver ratio equal to or greater than 4:1 at autopsy
AND/OR
1. Where antenatal ultrasound assessment has shown evidence of FGR (e.g. reduced growth velocity on serial biometry and/or abnormal utero-placental blood flow on Doppler ultrasound and reduced amniotic fluid volume)
AND/OR
2. Clinical examination of the baby (by paediatrician, pathologist)
AND/OR
3. Birthweight <10th centile for gestational age for livebirths or non-macerated stillbirths

Classifying FGR in stillbirths

It is also recommended that for fetal deaths, where possible, the gestational age on the date of death and not date of birth be used to define the presence of FGR.

For macerated stillbirths, in the absence of prior ultrasound evidence of FGR and where no autopsy has been performed or the brain:liver ratio is less than 4:1, the death should be classified as Unexplained Antepartum Death (Category 11), as the weight discrepancy may be a post mortem effect.

Customised or non-customised centiles

Either customised or non-customised centiles charts can be used to classify FGR as an associated condition under 16.2.1 or 16.2.2 respectively. Customised birthweight (CBW) centiles are being increasingly used to determine the presence of FGR²¹. However controversy around the use of customised centiles continues^{24,25} including concerns that customisation may mask pathology^{24,26}. It is recommended that the variables required for calculation of CBW (maternal age, ethnicity, height, weight, and fetal gestation and gender) be routinely collected to enable evaluation of birthweight according to CBW centiles. The recommended Australia population standards are those published by Dobbins et al²² and for preterm birth by Fenton et al²³.

17 Maternal risk factors (optional category)

- 17.1 Smoking
- 17.2 Substance use
- 17.3 High BMI
- 17.4 Maternal mental health disorder
- 17.5 Socioeconomic deprivation
- 17.6 Refugee or asylum seeker

Ideally risk factors would be included as part of a minimum dataset for all livebirths and stillbirths to enable ongoing assessment of the contribution of these factors to perinatal deaths. Further, inclusion of the PSANZ classification in this dataset for each perinatal death will provide a rich source of information for understanding causal pathways for maternal risk factors.

Associated conditions for neonatal deaths only

NDC Categories 1- 6

In addition to the above for associated maternal/fetal conditions the NDC Categories 1- 6 can be used to assign associated neonatal conditions

7.9 References

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7.12 Appendices

Appendix A – Stillbirth investigations algorithm

Appendix B – Estimation of severity of feto-maternal haemorrhage

Appendix C – Placental examination; Accoucheur flow chart

Appendix D – Clinical examination of baby checklist

Appendix E – Australian perinatal mortality audit tool

Appendix F – New Zealand Rapid reporting form for a perinatal death - baby

Appendix G – New Zealand Rapid reporting form for a perinatal death - mother

Appendix H – Instructions on taking clinical photographs

Appendix I – Autopsy clinical summary form

Appendix J – Perinatal mortality classifications: Quick reference sheet

Appendix K – WHO mortality audit meeting code of practice declaration

Appendix L – Birthweight percentiles

Appendix M – Infant autopsy consent brochure

Appendix N – Information for health professionals seeking consent

Appendix O – RCPATH Guidelines for Autopsy Investigation of Fetal and Perinatal Death

Appendix P – Placental histopathology reporting form

Appendix Q – Suspected genetic metabolic disorders

Appendix R – Screening for genetic metabolic disorders

Appendix S – Components of the genetic autopsy for investigations of metabolic disorders

Appendix T – Australian and New Zealand definitions of perinatal mortality

Appendix U – Changes on this version of the classifications

Appendix V – Development of PSANZ Perinatal Death Classification and PSANZ Neonatal Death Classification

Appendix W – Methods

Appendix X – Glossary of terms and abbreviations

Appendix Y – Contact details and regional coordinators 2017