

Best Practice

Evidence-based guidance for healthcare professionals

Caring for families experiencing stillbirth

Part 1 of 3: Diagnosis to birth

Evidence-based guidance for healthcare professionals providing care for parents from diagnosis to birth

Introduction

This document has been derived from a systematic review of the available evidence regarding the nature of meaningful and/or appropriate non-pharmacological, psychosocial supportive care for families to improve their psychological well-being following stillbirth.¹

This document provides evidence-based guidance for healthcare professionals providing care for parents around the time of diagnosis up until induction and birth. A number of factors centred around sensitivity, empathy, validation of parents' emotions, provision of clear, understandable information and consideration of the timing of information impact on parents' experience of being told that their baby has died or will be stillborn. There are also implications for practice regarding the importance of preparing parents for birth with clear and collaborative explanations, parents' preferences regarding the timing of birth and allowing parents enough time to process information.

Further information in this 3-part series about caring for families experiencing stillbirth can be found in 'Part 2: The birth' and 'Part 3: Care following birth'.

Implications for practice

The implications for practice listed below are based on the best available evidence. They are derived directly from the synthesised information contained in the systematic review of evidence as well as from expert and consumer representative advice. The implications for practice are intended as a guide to inform healthcare professionals' clinical decision-making in conjunction with their unique context, the preference of their patient and their own expert clinical judgement.

Diagnosis

Emotional impact upon parents

- Parents may have a potentially compromised ability to take in and process information due to the emotional impact of stillbirth.
- Cues from parents regarding their emotional state may be valuable for healthcare professionals when deciding how best to time the delivery of information.

Information provision and communication

- Prior to the confirmation of death, parents may appreciate honest and transparent news about their baby's status. Negating the parents' instincts that something is wrong can cause distress for the parents.
- Parents may experience potentially avoidable or unexplained delays in receiving information about the death of their baby in a negative way.
- Parents appreciate clear and understandable language and communication when learning that their baby has died. Medical terms and ambiguous descriptions may not be understood and can be distressing.
- After learning that their baby has died, parents may appreciate healthcare professionals asking them whether they would like them to stay to provide support and information, answer questions, or be left alone.
- Parents may appreciate being provided with verbal, electronic and written information, and may require information and details to be repeated. Having a supportive companion present can help.
- Parents may appreciate time to discuss their situation with healthcare professionals. Not allowing time for this, for instance, by leaving a room immediately after telling parents their baby has died or will be stillborn, may be distressing.

Continuity of care

- Where possible, parents may appreciate receiving care from the same healthcare professionals beyond the initial diagnosis of stillbirth.

Preparation for induction and birth

Informed preparation for birth

- Parents appreciate clear, step-by-step information of the induction and birthing process so as to know how to prepare themselves and what to expect.
- Verbal, electronic and written information may be appreciated by parents. Specific information around how to prepare for birth can be useful, such as informing parents that they can bring a camera and clothes for the baby back to the hospital if they wish if they are going home before the birth.

Emotional support

Both parents need emotional support. Parents prefer any communication and interaction with healthcare professionals to be conducted with sensitivity, compassion and empathy.

Respect for the situation, and the parents' emotions and reactions, is important. Parents appreciate it when healthcare professionals validate and affirm their feelings as natural and understandable, whatever they may be. It is important that parents feel that their identity as parents is understood by healthcare professionals.

It is also important to recognise that an entire family is affected by stillbirth. This can be especially true for older siblings and grandparents who also require emotional support and attention.

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- Parents may be distressed by medical terminology or language used by healthcare professionals, for example, 'product of conception' and 'termination'.
- The timing of particular hospital processes may distress parents and cues provided by the parents can be valuable for healthcare professionals in determining when it might be most appropriate to provide parents with paperwork.

Timing between diagnosis and birth

- Involving parents in collaborative discussion and informed decision making regarding the timing of the induction of birth may be appreciated by parents.
- Parents may have differing needs and individual preferences for the length of time between learning that their baby has died and induction of birth.
- Where possible, both parents may appreciate being included in information provision and discussion. Exclusion of a partner may cause feelings of ostracism and blame.

Communication

- Parents may feel neglected or blamed by healthcare professionals who seem insensitive or judgemental regarding their emotions or actions.

The hospital environment

- Parents may be distressed when the birthing suite or delivery ward is not set up or equipped to support parents during a stillbirth.
- In the time between learning that their baby has died and birth, exposure to the cries of newborn babies and other parents can be highly distressing to parents.
- Ideally, a designated private area away from newborn babies and parents within the delivery ward and access to staff who are prepared to support parents of stillborn babies may better support parents.

Implications for practice relevant throughout the stillbirth experience

The implications for practice listed below relate to each phase of the stillbirth experience, including from the time of diagnosis up until birth.

Sensitive, genuine and empathetic care

- Parents who experience stillbirth are often emotionally fragile and appreciate healthcare professionals' empathy and support from the time when they suspect that something is wrong with their pregnancy to thenceforth, even for many years after the immediate experience.
- If possible, parents may appreciate when healthcare professionals give them the option to have friends or family members present to provide support.
- Parents may appreciate it when healthcare professionals engage with them genuinely and provide individualised and personal care.
- Parents may appreciate it when healthcare professionals show emotion and empathy towards their experience.

Information provision

Parents are rarely prepared for the experience of stillbirth and information provision is critical.

Any information – verbal, electronic and written – is appreciated when provided in clear, understandable language and in a step-by-step manner so that parents can prepare and take in the information.

Healthcare professionals can take cues from parents, their families and companions to help identify the most appropriate times to provide honest and sensitive information and guidance.

Referrals to where parents and families can access additional information of support can also be very helpful.

It is important for parents that they are both provided with information. Failure to provide information to partners can lead to feelings of ostracism, blame and isolation.

Parents appreciate it when they are consulted by healthcare professionals to establish their preferences and desires. Involvement and collaboration in decision making and having time to ask questions are also important for parents.

Upon discharge from hospital, it is important to ensure that parents are provided with information to take home.

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- Parents experience stillbirth as the death of their baby rather than as a medical event. Over-medicalisation of the event by healthcare professionals may cause unnecessary distress.
- Parents appreciate it when healthcare professionals respect and validate their emotional experience and reactions of being parents of a baby that has died shortly before or during birth.

Information provision and communication

- Parents may be distressed by healthcare professionals who appear disengaged or do not take time to provide information, support and empathetic care.
- Parents should be provided with honest, forthcoming and step-by-step information in advance of each event and procedure.
- Dismissive, blunt, cold or inconsiderately worded communication will distress parents.
- Even small comforting gestures and simple words of sympathy and reassurance can help parents feel supported.
- Parents may wish to understand the cause of their baby's death. Verbal, electronic and written information may be helpful for parents to help them decide whether they would like investigations performed or post-mortem examinations conducted.

Support and training for healthcare professionals

- Healthcare professionals who attend to parents of stillborn babies may be better able to provide meaningful and appropriate care if they are provided with training and support to develop their knowledge and skills to perform their role as well as to cope with their own emotional reactions.

Culturally appropriate care

These implications for practice around culturally appropriate care were derived from the perspectives of a limited number of cultural groups only. With consultation with the expert advisory group, † these implications however may be appropriate and relevant for people from diverse cultural backgrounds as well as Aboriginal and Torres Strait Islander people. Healthcare professionals must be aware that there is no 'one size fits all' approach to providing culturally appropriate care.

- Parents appreciate healthcare professionals who acknowledge, are aware and inclusive of spiritual, religious and cultural beliefs that may be different from their own. For example, parents may have particular needs such as speaking to their baby in their own language or performing important cultural, spiritual or religious rituals while in the healthcare setting.
- Some cultural groups have particular beliefs and practices around death which may impact on their preferences for care. Parents appreciate healthcare professionals being aware of and considering these when providing care.
- Parents may have individual preferences for care that do not necessarily match more general preferences of their cultural, spiritual or religious group. Healthcare professionals must ensure that parents' individual preferences are heard and acknowledged rather than assuming they will want the same care as other parents with a similar background.

Environment

Parents may have different preferences for where they would like to be located within the hospital.

Some parents may be distressed by being located in the proximity of other parents and their babies, and may desire a private room if one is available. Parents may not wish to be located outside the maternity ward which can be isolating and distressing if staff are unaware of their situation.

Communication between staff on the parents' situation before parents are moved to other areas is likely to be appreciated, avoiding the necessity for parents to repeat their story multiple times to different hospital staff which is often distressing.

Healthcare professionals should be aware that it is important to respect parents' privacy when talking about their situation with other healthcare professionals in public areas of the hospital.

This can be especially important in hospitals in small communities.

Parents appreciate being consulted regarding their preferences around where they are located. It is also necessary to consider the mother's clinical presentation when making decisions regarding the parents' location within the hospital and when discussing hospital discharge arrangements.

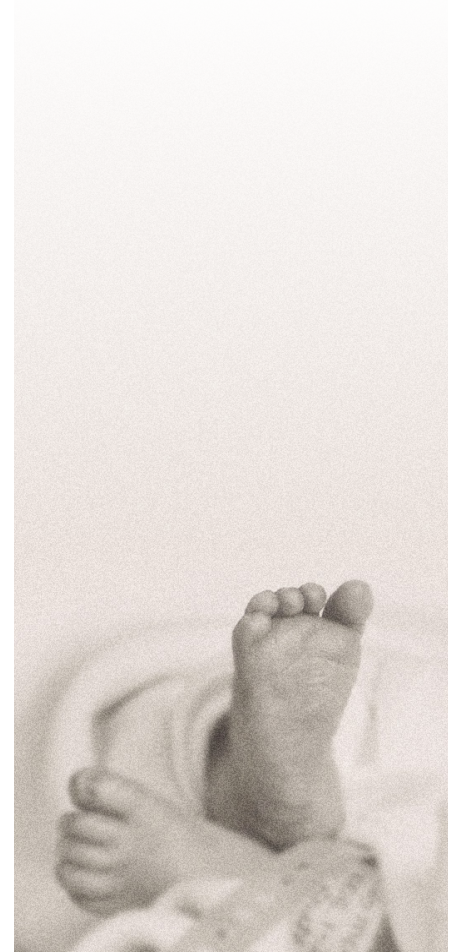
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- Parents appreciate healthcare professionals' assistance to contact their preferred spiritual, religious and/or cultural support and services while in hospital.
- Lack of respect and acknowledgement of parents' cultural heritage and beliefs can result in parents losing trust in the healthcare service.
- Healthcare professionals attending to parents of stillborn babies may be better able to provide culturally appropriate care if they are provided with training and support to develop their knowledge and skills to acknowledge and understand different cultural groups' needs and preferences for care.
- Aboriginal and Torres Strait Islander people may wish to have family members, elders and/or community leaders there to support them through their experience.
- Healthcare professionals may be able to contact specialist services such as Aboriginal healthcare workers and Aboriginal and Maternal Infant Care (AMIC) workers from outside their local healthcare service and area for information and advice when caring for Aboriginal and Torres Strait Islander people.
- Healthcare professionals attending to Aboriginal and Torres Strait Islander people should be aware of and acknowledge that kinship and family structure is of particular cultural significance. Parents may want family members and/or elders to be there for them to provide support.
- For many Aboriginal and Torres Strait Islander people, mothers assign the 'birth order' to their children. Understanding that a stillborn baby may have a particular place in this birth order and for example may be the mothers' 'firstborn' is important.

Background

Parents experiencing stillbirth require supportive and sensitive care during the period prior to confirmation of the diagnosis and during the birth. Parents are often unprepared for the experience of stillbirth and may benefit from information provided about stillbirth in the antenatal period. Parents who experience stillbirth are at risk of detrimental psychosocial effects including grief, depression and self-blame. Parents may also experience culture-related impact following stillbirth, for example in relation to their system of kinship and how they relate to their immediate family.

These negative effects may be mitigated and relieved by healthcare professionals who are trained and prepared to help parents cope with this tragic experience. Conversely, these negative feelings may be compounded or in some cases inadvertently caused by healthcare professionals with whom parents may interact prior to birth. In some cases, healthcare professionals who provide care for these parents may not be adequately prepared or trained to provide the appropriate supportive and sensitive care required. Furthermore, healthcare professionals may themselves be emotionally affected by stillbirth and this can influence their interaction with parents.



Information source

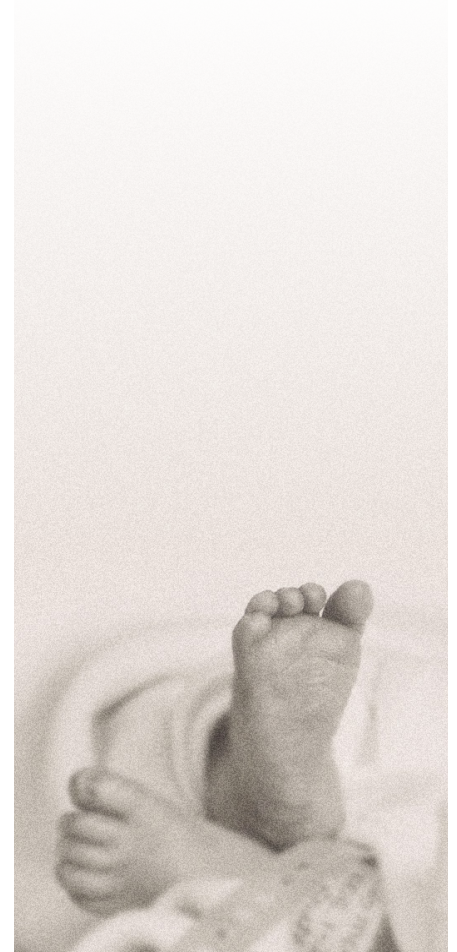
For the purposes of the review stillbirth was defined as the death of a baby *in utero* at any time from 20 weeks until immediately before birth. Studies that considered neonatal death, perinatal death (before or after birth), miscarriage, termination of pregnancy for non-medical reasons or pregnancy loss prior to 20 weeks were excluded. It is important to note that any medical definition of stillbirth is unlikely to be meaningful to parents'. As such, parents whose loss of a baby before birth does not align specifically with this period should be treated with the same sensitivity and care.

Twenty-two qualitative studies included in the systematic review examined descriptions of the experiences and accounts of parents with the care they received aimed at improving their psychological well-being following stillbirth.¹ This phenomenon was investigated from the time of diagnosis and forwards until many years after the tragic event. The majority of included studies reported on both experiences of care from healthcare professionals who were felt to be positive and supportive and those perceived to be negative and distressing.

Development of evidence-based guidance

A series of three documents has been developed to assist healthcare professionals to provide supportive and meaningful care for the parents of stillborn babies. The first document pertains to the time preceding birth, i.e. from just prior to diagnosis until induction. The second document relates to the period immediately following birth and the third document contains implications for practice relating to ongoing care and follow-up beyond the immediate experience of stillbirth.

The implications for practice contained within these documents have been developed from the evidence presented in the systematic review and directly based on its synthesised findings (Level 1 evidence – Meaningfulness,[‡] as well as the input of an expert advisory group.[†] The review protocol and systematic review report have been subjected to a rigorous internal and external review process. Where limited or no evidence was identified in the systematic review, the authors and the expert advisory group developed consensus statements to inform practice.



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Disclaimer

"The procedures described in this document must only be used by people who have appropriate expertise in the field to which the procedure relates. The applicability of any information must be established before relying on it. While care has been taken to ensure that this document summarises available research and expert consensus, any loss, damage, cost, expense or liability suffered or incurred as a result of reliance on these procedures (whether arising in contract, negligence or otherwise) is, to the extent permitted by law, excluded."

± Joanna Briggs Levels of Evidence - Meaningfulness

Level 1	Qualitative or mixed-methods systematic review
Level 2	Qualitative or mixed-methods synthesis
Level 3	Single qualitative study
Level 4	Systematic review of expert opinion
Level 5	Expert opinion

These levels are intended to be used alongside the supporting document outlining their use.² Using Levels of Evidence does not preclude the need for careful reading, critical appraisal and clinical reasoning when applying evidence.

References

- 1 Peters M, Riitano D, Lisy K, Jordan Z, Aromataris E. Providing care for families who have experienced stillbirth: a comprehensive systematic review. The Stillbirth Foundation Australia [Internet]. 2014. Available from: <http://www.stillbirthfoundation.org.au/provision-of-effective-and-appropriate-care-for-families-who-have-experienced-stillbirth/>
- 2 The Joanna Briggs Institute Levels of Evidence and Grades of Recommendation Working Party*. Supporting Document for the Joanna Briggs Institute Levels of Evidence and Grades of Recommendation. The Joanna Briggs Institute [Internet]. 2014. Available from: www.joannabriggs.org
- 3 Pearson A, Wiechula R, Court A, Lockwood C. The JBI Model of evidence-based healthcare. Int J of Evid Based Healthc 2005; 3(8):207-215.

† The expert advisory group was assembled to provide guidance and input for the development of these implications for best practice and to ensure that the information meets the specific needs of parents and families who have experienced stillbirth. For the full details of the expert advisory group please refer to the systematic review.¹

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