

## 3. BEREAVEMENT CARE IS ESSENTIAL

Quality, respectful and supportive bereavement care – which spans antenatal, intrapartum and postnatal care – is essential for all bereaved parents and families everywhere. This chapter introduces and defines bereavement care and outlines principles of respectful bereavement care. It also provides links to available guidelines and lists additional considerations for bereavement care, as voiced by parents. More guidance on bereavement care is presented throughout the programme implementation chapter ([Chapter 5](#)), highlighted in orange boxes, as shown below.

For more information and guidance on bereavement care, see [Chapter 5](#).

### What is respectful and supportive bereavement care?

Stillbirth bereavement care encompasses holistic clinical, social and psychological care from the first signs of concern about a baby's well-being through diagnosis, labour and birth and the extended postnatal period. Bereavement care includes care of the woman, partner, baby and family members. Midwives, nurses, obstetricians, community health workers and general practitioners are instrumental in providing bereavement care, alongside support organizations and lay professionals, such as doulas specializing in bereavement.

#### Principles of respectful bereavement care

Eight globally applicable principles of bereavement care for women, babies and families have been developed, as follows (40):

1. Reduce stigma
2. Provide respectful care
3. Support shared, informed decision-making
4. Make every effort to investigate and provide an acceptable explanation for the death of the baby
5. Acknowledge the depth and variety of grief responses and offer support
6. Offer information and postnatal care to address physical, practical and psychological needs
7. Provide information about future pregnancy planning at appropriate time points
8. Enable high-quality care through workforce training and support (see [Chapter 5](#))



Adam and JC Unferdorfer hold their daughter Emmalee. She is their only child and was stillborn on September 30, 2017. Source: Stacey Fletcher

The International Stillbirth Alliance (ISA) Bereavement Working Group is currently working to build on these principles to ensure they fully incorporate the experience and voice of affected parents and health-care providers, especially those from low- and middle-income countries (LMICs).

## Guidelines for bereavement care following stillbirth

Bereavement care guidelines must support culturally appropriate care, recognizing the specific needs of minority and marginalized groups, while ensuring that all parents are given choices. While there are WHO guidelines for care at other stages along the continuum ([Chapter 2](#)), there are currently no global bereavement standards or guidelines. Some HICs have developed national guidelines, and several other guidelines provide relevant advice. Below is an annotated list of these resources in order of publication:

- [WHO: Managing Complications in Pregnancy and Childbirth: A Guided for Midwives and Doctors, 2nd Edition.](#) (2017) (**38**). This guide addresses care to be provided to a woman and her family at the time of and after stillbirth, with emphasis on emotional need, memory-making, naming, avoidance of sedation of the woman, and arranging a discussion with the woman and her partner about the stillbirth and possible preventive measures for subsequent pregnancies.
- [Sands Australian Principles of Bereavement Care](#) (Australia, 2018) (**41**). This guide describes 10 bereavement care principles following miscarriage, stillbirth and newborn death: individualized bereavement care; good communication; shared decision-making; recognition of parenthood; acknowledging a partner's and family's grief; acknowledging that grief is individual; awareness of burials, cremations and funerals; ongoing emotional and practical support; health-care professionals trained in bereavement care; health-care professionals with access to self-care.
- [Perinatal Society of Australia and New Zealand Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death](#) (2020) (**42**). This guideline includes a dedicated chapter on respectful and supportive care following stillbirth or newborn death. It describes 10 foundations for care and an organizing framework that sets out four overarching goals of care: good communication; shared decision-making; recognition of parenthood; and effective support, including in subsequent pregnancies.
- [Management of Stillbirth](#) (American College of Obstetricians and Gynecologists and the Society for Maternal-Fetal Medicine, 2020) (**43**). This guideline describes the recommended management of stillbirth, including bereavement care principles adapted from the Sands Australia principles of bereavement care.
- [National Bereavement Care Pathway \(NBCP\)](#) (UK, 2022). A parent-led bereavement care plan is recommended for women and their families to provide quality bereavement care following miscarriage, ectopic pregnancy, molar pregnancy, termination for fetal anomaly, stillbirth, neonatal death or sudden and unexpected death in infancy up to 12 months. The pathway also emphasizes bereavement care training for health-care providers. Read about the development and implementation of the NBCP in [Sharing what works](#) in [Chapter 4](#).
- [National Standards for Bereavement Care](#) (Ireland, 2022) (**44**). These national standards are built around four central themes related to pregnancy loss and perinatal death: bereavement; the hospital; the baby and parents; and the staff.
- [Parent Voices Initiative toolkits](#) (India/Kenya, 2022). The purpose of the Parent Voices Initiative (PVI) is to raise the voice and participation of parents bereaved by stillbirth to

strengthen advocacy for stillbirth prevention and bereavement support. See [Sharing what works](#).

- **NEST360 UNICEF newborn kit** (Kenya, Malawi, India, 2022). Family-centred bereavement care is advocated by NEST360. Family-centred care revolves around a mutual relationship between the family and health-care providers, in the care of a well, sick or dying child.

Across all these documents is a consistent message: the need for effective communication and respectful bereavement care for every woman and family.



### REFLECTION

*The evidence base for best practice bereavement care in LMICs is very limited. Given this fact, what can you do in the short and medium term to improve bereavement care in your setting?*

## Additional considerations

In the absence of global guidelines for bereavement care, action can still be taken to help ensure that women and families receive respectful care after stillbirth. Along with the resources listed in this chapter, recommendations and considerations from affected parents are invaluable. Some of these recommendations and considerations are evidence-based, while others are informal, reflecting insufficient research into bereavement care. All could be incorporated into caregiver training, health facility policy or stillbirth advocacy initiatives. These include:

- **What to say to parents** when they are told their baby has died. See [Box 3.1](#) for a list of suggested phrases, and what not to say.
- The value of parental closure in **seeing, holding and photographing** their baby. Many parents find that creating memories and keepsakes helps in the grieving process.

- The power of **peer-to-peer support** and finding other families who have experienced similar losses. The [ISA Global Registry of Stillbirth Support Organizations and Individuals](#) is a registry of organizations that provide support to those affected by stillbirth. Many local and national support organizations sponsor support meetings at community level. These services could reach even more affected parents with increased awareness and integration into postnatal bereavement care at the facility level.
- The importance of **follow-up care**. Families often experience shock while in the health facility after learning of their baby's death, and they require follow-up care weeks, months or even years later. Referrals and following through with additional resources such as psychiatric care is essential and can be life-saving. Health-care providers need to understand that parents do not quickly “get over” grief, and that women and their partners often require additional emotional and physical support during subsequent pregnancies (see [Box 3.2](#)).
- **Burial, cremation and memorial rituals**. While not universal practices, burial, cremation and memorial rituals are common in some settings and are often of great comfort to families.

Ruthie Mae Unkovic was stillborn on September 16, 2020. Her mother is Rachel Unkovic. Source: Stacey Fletcher



**BOX 3.1: COMMUNICATING WITH PARENTS**

## What you can say to parents:

- ✔ "I cannot find your baby's heartbeat. Your baby is not alive. I am sad to say that your baby has died. I am sorry for your loss."
- ✔ "I am saddened by the loss you have to bear. We will do some investigations to try to find out the reasons for your baby's death."
- ✔ "Have you thought of a name for the baby? (if yes) Would you allow me to use that name to talk about your baby?"
- ✔ "Many women have found it helpful to see and hold their stillborn baby after she or he is born. Would you like to do this?"

## What you should never say to parents:

- ✘ "Do not worry, it was only a girl child."
- ✘ "This happened because you came late for delivery."
- ✘ "At least you know you can get pregnant again."
- ✘ "This baby was sick. It is good that the baby died."
- ✘ "It was your fault: you were late for your check-up."
- ✘ "There might have been something wrong with it."
- ✘ "It's for the best."

Adapted from the Raising Parent Voices Advocacy Toolkit – India Providers' Version

**BOX 3.2: CARE IN SUBSEQUENT PREGNANCIES**

Most women conceive again after having a stillborn baby, often within the following 12 months (45). These women face an increased risk of stillbirth, as well as heightened anxiety, fear and stress during subsequent pregnancies. There is a lack of evidence on how best to provide care to these women and families (46), but consensus on 12 key recommendations has been reached. These recommendations highlight the importance of meeting psychosocial needs and the value of peer support.

Access the consensus statement: [No. 369-Management of Pregnancy Subsequent to Stillbirth \(47\)](#).