



Ross Jones

Improving Bereavement Care
Coordinator, Sands
info@uk-sands.org



Pregnancy loss and the death of a baby: guidelines for professionals

Sands' *Guidelines for Professionals* is a unique collaboration between bereaved families and healthcare professionals that has driven forward significant improvements in bereavement care since it was first published in 1991. The fourth edition was launched on 14 September 2016 (FIGURE 1) and provides very comprehensive guidance and best practice on caring for parents whose baby has died.

As a national charity working to support thousands of bereaved parents and their families across the country, Sands is uniquely placed to ensure that the voices of bereaved parents are heard and reflected in how parents are cared for following the death of a baby. The guidelines – Sands' benchmark publication on standards of bereavement care – are used to support health professionals in providing care that is tailored to the needs of bereaved parents.

Guidelines for Professionals provides bereavement care standards for the death of a baby through early and late miscarriage, termination for fetal anomaly, stillbirth and neonatal death. It provides a single reference point for anyone working with families who experience the death of a baby in an area where many professionals understandably feel concerned about how to best provide the care that bereaved

parents need. Sands' decades of work supporting families affected by the death of a baby is combined in the fourth edition with the advice and feedback of over 60 experts from a wide range of healthcare specialties, to ensure that the evidence-based guidance distils the latest best practice in supporting bereaved families. The guidelines have been endorsed by 21 Royal Colleges and charities working with bereaved families (TABLE 1).

The guidelines do not just provide a description of what good care looks like, but also offer practical guidance on how to meet the needs of parents in a variety of situations. As the evidence base for what constitutes high quality bereavement care has grown in the nine years since the previous edition was published, so too has the level of detail offered by the Sands guidelines. One thing remains the same, however; the principles underpinning good bereavement care that inform all of Sands' work in this area. These are as follows:

1. Care should be individualised so that it is parent-led and caters for personal, cultural or religious needs. Parents should always be treated with respect and dignity. Sensitive, empathetic care is crucial and may involve spending time with parents. This should be recognised by managers and staff.
2. Clear communication with parents is key and it should be sensitive, honest and tailored to meet the individual needs of parents. Childbearing losses can involve periods of uncertainty and staff should avoid giving assurances that may turn out to be false. Trained interpreters and signers should be available for parents who need them.
3. In any situation where there is a choice to be made, parents should be listened to and given the information and support they need to make their own decisions about what happens to them and their baby.
4. No assumptions should be made about the intensity and duration of grief that a parent will experience. It is important that staff accept and acknowledge the feelings that individual parents may experience.
5. Women and their partners should always be looked after by staff that are specifically trained in bereavement care and in an environment that the parents feel is appropriate to their circumstances. In addition to good emotional



FIGURE 1 The launch of the Sands guidelines in September 2016 at the Royal Institution, London. The event included a parent's perspective on why good care is important and a panel discussion on how to implement the guidelines in a range of healthcare settings.

support, women should receive excellent physical care during and after a loss.

6. A partner's grief can be as profound as that of the mother; their need for support should be recognised and met.
7. All staff that care for bereaved parents before, during or after the death of a baby should have opportunities to develop and update their knowledge and skills. In addition, they should have access to good support for themselves.
8. All parents should be offered opportunities to create memories following the death of their baby. Their individual wishes and needs should be respected.
9. The bodies of babies and fetal remains should be treated with respect at all times. Options around sensitive disposal should be discussed and respectful funerals should be offered.
10. Good communication between staff and healthcare teams is crucial in ensuring that staff are aware of parents' preferences and decisions; parents do not need to repeatedly explain their situation. This includes the handover of care from hospital to primary care staff, which should ensure that support and care for parents is seamless. Ongoing support is an essential part of care and should be available to all those who want it and should continue to be made available to all women and their partners during a subsequent pregnancy and after the birth of another baby.

The new edition of the guidelines has seen updates to content throughout the publication, with four new chapters on specific aspects of care:

1. Termination of pregnancy for fetal anomaly or maternal medical conditions
2. Labour and birth when a baby has died
3. Mental health
4. Receiving and responding to feedback: parent experiences.

Guidelines for Professionals incorporates new guidance from a range of organisations, including NICE and the Royal Colleges, to ensure professionals have access to the most relevant and up-to-date information about working with bereaved parents.

Neonatal staff will find a wealth of information to support their work. There are dedicated chapters on care in neonatal units and care following a loss. These cover specific scenarios, such as how to approach conversations with parents about whether to withhold or withdraw life-sustaining treatment, as well as topics such as seeing and holding the baby, registration of the death, funerals and memory making, which can influence parents' memories of the care they received for a lifetime.

- ARC (Antenatal Results and Choices)
- British Association of Perinatal Medicine
- Bliss
- The British Maternal and Fetal Medicine Society
- The British Pregnancy Advisory Service
- The Lullaby Trust
- Cruse
- The Ectopic Pregnancy Trust
- Child Bereavement UK
- The Miscarriage Association
- The Multiple Births Foundation
- NHS Wales
- Neonatal Nurses Association
- Perinatal Institute
- The Royal College of Pathologists
- The Royal College of General Practitioners
- Royal College of Midwives
- Royal College of Nursing
- Royal College of Obstetricians and Gynaecologists
- The Twins And Multiple Births Association
- Tommy's

TABLE 1 The organisations that have endorsed *Sands' Guidelines for Professionals*.

No level of care can take away the pain or shock of the death of a baby. Poor or insensitive care can exacerbate these feelings. However, small steps or changes in the provision of care can make a big difference to the quality of care. By focusing on the needs of bereaved parents throughout the caregiving process, professionals can ensure that they are providing appropriate care in these situations. Good communication is essential for high quality bereavement care. Providing parents with the information and support they need to exercise informed choice throughout their care is crucial, as is ensuring that all parents receive individualised care appropriate to their particular needs.

By focussing on putting these key elements of care into practice, Sands' guidelines enable healthcare professionals to improve their skills and confidence in working with bereaved parents to ensure that parents receive personalised, empathic care at the time they need it most.

Pregnancy Loss and the Death of a Baby: Guidelines for Professionals (fourth edition) is available to purchase in hard copy and e-publication formats via the Sands shop (<http://portal.uk-sands.org/public/shop/default.aspx> and www.sandsguidelines.co.uk).

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