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One chance to get it right

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Amanda Hunter talks about providing bereavement care after stillbirth or the death of a baby

The Listening to Parents report examined parents' experiences of bereavement care when their baby is stillborn or dies after birth.1 Many of the 720 women who participated in the research felt that they had been treated with kindness, respect and sensitivity around the time when their baby died1 It is important to recognise, however, that 30% of these women 'did not feel listened to or felt listened to only "to some extent" at this point, that their concerns were not always taken seriously or did not feel wholly informed about what was happening.'1

That 30% of women were not fully satisfied with their bereavement care is significant as several pieces of research looking at bereaved parents' experiences of stillbirth highlight the importance of the communication between healthcare staff and parents following perinatal death2'3'4'5 These studies have found that the support received by bereaved parents from healthcare professionals has potential long-term implications for parents' emotional and mental health.2'3'4'5 For example, one study showed that parents' perceptions of the support they receive from professionals have been associated with the parents' risk of developing post traumatic stress disorder (PTSD) or depression after the stillbirth of their baby.3

The impact of parents' experiences of bereavement care is also seen in quotes from parents commenting on their care during the stillbirth of their baby.

*'I was so worried about having to walk in there [delivery area] and say who I was. I didn't have to. I walked through the door and she [her midwife] looked at me and she knew it was me... She was so friendly and so honest. She holds a special place in our lives.'*2

*'The delivery was just awful from beginning to end. They almost treated me like "The Woman With The Dead Baby"[mother's emphasis]. There was no sympathy. When I asked to see a doctor, this particular doctor came in and said "we're very busy." And his exact words, I'll never forget them "Well, with all due respect, your baby's dead already." Which was just the most awful thing you could say.'*2

Furthermore, Downe et al. highlight that: 'Professionals in hospitals and in the community have only one chance to provide care that fosters the clinical, emotional, practical and psychosocial well-being of parents who have experienced stillbirth. By ensuring that parents receive care that is clinically skilled, emotionally intelligent, consistent and authentically caring, there is the best chance that, even in the midst of a difficult situation, they will have the healthiest experience possible, as well as the best chance

of achieving optimum well-being in the longer term.'2

To ensure that bereaved parents receive the best care possible, it is important that measures intended to improve bereavement care such as training, skill-sharing and support are available for healthcare staff2 The recently completed InSight study investigated bereavement care practices and found that many staff wanted more maternity bereavement care training while highlighting the significant emotional effects of providing stillbirth care on staff and their need for support.6 Support for staff is important as personal and professional grief and loss may be experienced or triggered when providing bereavement care following a stillbirth.7

Sands (Stillbirth and neonatal death charity) offers support to professionals including bereavement care training and other resources. Sands' bereavement care training provides healthcare professionals with the insight, understanding and skills needed to deliver supportive, empathetic and sensitive care for parents after the death of their baby. The Sands helpline is available to support anyone who is affected by the death of a baby, including healthcare professionals.

Ideally, all maternity unit staff should have access to support from a specially trained bereavement midwife.8 A bereavement midwife would also have the responsibilities of organising staff training and monitoring policies and procedures to ensure that bereaved parents receive good quality care. Despite this recommendation, any member of staff could organise or attend bereavement care training or assess their practice using a tool such as Sands' Audit Tool for Maternity Services. Parents should also have access to a dedicated bereavement room where they can be cared for during and after labour when their baby has died.8 This room would ideally be away from other expectant parents and the sounds of crying babies. When it is not possible for parents to access a dedicated bereavement room, staff can prepare parents for what they might see or hear while in the room or on their way to the room that is available. For example, it may be helpful for staff to acknowledge that parents may find it distressing if they pass expectant parents or hearthe sounds of babies crying.

Bereavement care best practice points:

- Communicate with bereaved parents sensitively and empathetically.
- Support bereaved parents to make informed choices.
- Care for bereaved parents in a dedicated bereavement room or suite.
- Provide written information and support literature for bereaved parents (including a list of local resources).
- Ensure staff have access to a bereavement midwife, adequate support and training in bereavement care.
- Bereavement care literature such as Sands' Support booklets should also be available for parents and healthcare professionals.8

Written support information for parents and a copy of Sands' Pregnancy Loss and the Death of a Baby: Guidelines for professionals should be available on every maternity unit. In addition to receiving written

information, all parents should be offered the opportunity to discuss a post mortem examination[8] This discussion should take place with a senior doctor or midwife who is properly trained in taking consent for a post mortem. Consent for a post mortem should also be taken using a form that is based on Sands' post mortem consent form. This form has been designed to support the needs of bereaved parents

While Sands promotes best practice in bereavement care following the death of a baby, we recognise that these recommended resources are not always available to healthcare professionals. Despite this, good care needs to be available to parents in any setting and many healthcare professionals provide good bereavement care to parents in conditions that are not optimal.[9] Even when resources are limited, healthcare professionals are able to provide parents with empathy and respect. Parents must also be supported to make informed choices about their care following the death of their baby. Healthcare professionals can support bereaved parents to make informed choices by providing them with information about their options and sufficient time to make a decision about their care or options for creating memories with their baby.[9] Additionally, it is important that midwives are able to listen actively and attentively to bereaved parents' stories in order to support parents as they narrate their experiences.[7]

It is good practice for staff to compile a list of local resources that are available to bereaved parents. This list should be kept on every maternity unit and a designated member of staff should be responsible for updating this list regularly (at least every six months). This list should also include information about local post mortem and mortuary practices and how parents obtain certificates and register their baby's stillbirth, birth and/or death. Every parent should be offered this list.

In order to provide good bereavement care, healthcare professionals and their employers have a responsibility to ensure that they are as prepared as possible to support the needs of bereaved parents and staff. This may be difficult given the time and resource constraints faced by healthcare services. However, the significance of the quality of bereavement care for parents' well-being should not be underestimated and many of our suggestions can be implemented without great pressure being placed on local budgets and staff time.

It is important to rememberthat there is only one chance to get it right.

Improving Bereavement Care Co-ordinator Sands, the Stillbirth and neonatal death charity Training is available at:
www.uk-sands.org/professional-training. For support, Sands can be contacted on 0207 436 5881 or helpline@uk-sands.org

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