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Bereavement care in the UK: variability in resources and approaches

The care that bereaved parents receive in hospital following the death of their baby is crucial. For the rest of their lives, parents will remember these experiences. Good care cannot remove parents' grief but it can help them through this devastating time. Bad experiences of care, however, are likely to exacerbate feelings of pain and grief for bereaved parents. Research by Sands, the stillbirth and neonatal death charity, has found that bereavement care in maternity units in the UK continues to be under resourced, with considerable variation in approaches to care.

Small details can matter a great deal. Each contact professionals have with parents should be seen as a chance to get things right. It can be very complex for units to ensure that they are delivering appropriate and sensitive bereavement care; it requires a strong commitment throughout individual trusts and health boards to prioritise its development and delivery.

Recent years have seen a welcomed focus on the importance of ensuring these systems and procedures are in place. However, we know from parents who contact Sands that provisions for bereavement care can vary considerably across the country, across units within the same trust/health board and within the same hospital depending on access to individual staff members.

Bereavement support midwives	Staff should have access to a trained bereavement midwife who is responsible for training and support and for monitoring policies and procedures
Bereavement care training	Staff caring for parents whose baby has died should have training to enable them to give supportive, empathetic and sensitive care
Dedicated bereavement room and facilities	There should be at least one dedicated bereavement room or suite, away from celebrating families and the sound of live babies
Bereavement care literature and communication	Sands' support booklets for parents should be available
Post mortem consent	Parents should be offered the opportunity to discuss a post mortem examination with a senior doctor or midwife. Staff who seek consent should have had appropriate training.

TABLE 1 Sands' five recommendations for improving care for parents whose baby died before, during or shortly after birth (www.uk-sands.org/professionals/principles-of-bereavement-care).

The aim of Sands' recent audit of bereavement care in UK maternity units was to provide a snapshot of bereavement care provision, as it existed in 2016. The resources and processes we asked about were based around Sands' five ways to improve bereavement care, which the charity recommends as best practice for maternity units (**TABLE 1**).

Survey data were collected from 79 trusts and health boards across the UK in the summer of 2016. The trusts and health boards that responded to this survey covered at least 364,216 deliveries, 1,453 stillbirths and 543 neonatal deaths in 2015. In addition, a separate survey of Sands' local support groups obtained 34 responses from across the country, offering feedback about their understanding of bereavement care provision locally.

The findings from the report show that, while there are many examples of excellent care across the country, there are still very significant variations in approach that could compromise the overall quality of care in some areas. Some of the key recommendations and findings from the report include:

Every maternity unit across the UK should have access to a bereavement midwife

While the proportion of units that have an on-site specialist bereavement midwife has increased from 47% to 62% since 2010, over a third of units will not have regular access to a bereavement midwife. Bereavement support midwives play a significant role in providing and improving bereavement care and are a necessity to ensure that all parents can receive appropriate care following the death of a baby.

Bereavement midwives should be enabled to ensure that all maternity staff can confidently care for bereaved parents, not just to provide this care themselves

It is not possible for one or a small number of staff to deliver and be responsible for all bereavement care in isolation. As there is no nationally agreed job description for this role, the responsibilities of a bereavement support midwife in one trust or health board may be very different to that in another. It is crucial that although the particular details of the role may differ according to local needs, the focus on ensuring all members of the

team have the right skills and confidence to deliver care to bereaved parents should not be lost. Nearly three-quarters of the trusts and health boards surveyed reported that bereavement midwives are not present at the birth, illustrating the importance of ensuring that all members of maternity staff receive appropriate training and support to deliver sensitive, parent-led care.

Bereavement care training should be mandatory and sufficient time allocated to improve the skills and confidence of staff

Fewer than half of the trusts and health boards surveyed had mandatory bereavement care training. Of these, two-thirds provided annual mandatory training and 86% of these allocate one hour or less. This suggests that the vast majority of maternity unit staff either do not have mandatory bereavement care training or receive 60 minutes or less training per year. This is not appropriate given the importance and complexity of delivering high quality care to parents whose babies die. Trusts and health boards should be aware of the message this sends out regarding the relative importance of bereavement care.

Although many trusts and health boards reported that they facilitate training for staff, the demands of working on a busy maternity unit mean that unless this training is mandatory it is unlikely that everyone that needs to access it will be able to do so. It is a responsibility of trusts and health boards to ensure that their staff are adequately supported to deliver the highest level of care to bereaved parents and this is best facilitated by providing mandatory bereavement care training, with a reasonable amount of allocated time, to ensure improvement in the ability and confidence of staff.

Dedicated bereavement rooms should be available in each maternity unit and should be fit for purpose

Around one in 10 trusts and health boards surveyed did not have

a dedicated bereavement room in any of their maternity units. While it is recognised that it can be challenging to find an appropriate space for a dedicated bereavement room, their importance to delivering care for bereaved parents means that these facilities should be a priority. Care should also be taken to ensure that they provide the right environment for bereaved parents. It is important that the voice of bereaved parents is reflected in the design of facilities and services. One-quarter of trusts and health boards reported that their bereavement rooms had not been designed in consultation with bereaved parents. If bereaved parents are not consulted, there is a considerable risk that the facilities will not address the issues that those receiving care consider important.

Trusts and health boards should address shortages in the availability of interpreting services

Family members should not be used to interpret information apart from in the most exceptional circumstances. Nearly one-fifth of trusts and health boards do not always or usually use an interpreter when language assistance is required, with 16% always or usually using fathers or partners to translate, and 17% using children to translate out of hours and/or in emergencies. This is unacceptable and potentially puts mothers and their family members at risk.

The intention of this audit has not been to criticise the bereavement care provided in maternity units, which we know from feedback from bereaved parents is often excellent. Instead, it is hoped that this snapshot of provision across the country focuses attention on what is working well and what requires further action to ensure that all units have the resources and procedures they need to provide bereaved parents with the care they deserve.

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