Audit of bereavement care provision in UK maternity units 2016

Sands
Stillbirth & neonatal death charity

"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. Staff in all relevant health settings need to be supported and encouraged to recognise and respond to their one chance to get it right, for the sake of all future parents who experience such a loss."

(Downe et al, 2013)

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1. Introduction

1.1. Background

Every week in the UK, over 100 babies die just before, during or shortly after birth. The care that parents receive at this time is of crucial importance for their physical and mental health, both in the short and long term. Whilst no level of care can remove the grief that many parents will feel, good care can make a devastating experience feel more manageable while poor quality or insensitively delivered care can compound and exacerbate pain.

> ***"It is the detail of events that matter so much"***
> (Mother in Sands, 2016a: 213)

High quality bereavement care is dependent on both the availability of resources and effective systems of care which can be tailored to the individual needs of bereaved parents. It is also important that there is a real commitment throughout the individual Trust or Health Board to prioritise the development and delivery of high quality bereavement care. This cannot be left to individuals to push forward.

Recent years have seen a welcome increased focus on the importance of ensuring that these resources and systems are available across the UK. 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 even within the same hospital depending on access to individual staff members.

Sands last examined this topic in the *Bereavement Care Report 2010*, using data obtained in May 2009. This report provided a much needed snapshot of bereavement care provision in the UK, using a survey of maternity units to examine the resources and systems which were available to provide care for bereaved parents. The report found that although good quality bereavement care was provided in the majority of units, around 20% reported significant deficits in resources and/or organisation which could compromise care (Sands, 2010: 4).

Bereavement care provision across the UK for parents when a baby dies has not been examined since this data was collected in 2009. There has therefore been a pressing need to obtain fresh data which takes account of changes which have been implemented since this time. This audit allows us to obtain a renewed understanding of current resources and provision for bereavement care across the country. This helps to both recognise areas where care has improved, whilst also identifying any areas where improvements are needed to ensure that all bereaved parents receive appropriate, individualised care.

1.2. Aims

The aim of this report is to provide a snapshot of current bereavement care provision. 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 **(http://www.uk-sands.org/professionals/principles-of-care/5-ways-to-improve-care)**. The findings of this report are therefore divided into the following five sections:

- Bereavement support midwives
- Bereavement care training
- Dedicated bereavement room and facilities
- Bereavement care literature and communication
- Post mortem consent

1. Introduction

1.3. Methodology

Surveys were distributed to Heads of Midwifery in Trusts and Health Boards in England, Wales, Scotland and Northern Ireland in June 2016. Following a relatively low response rate, the deadline for responses was extended from July to September 2016. The survey was also distributed more widely in July to bereavement support midwives, with a recommendation to speak with their Head of Midwifery about providing a response for the Trust or Health Board.

Responses were received from 79 Trusts and Health Boards across the UK. In a small number of cases, multiple responses had been received from the same Trust or Health Board. In these instances, the response with the most complete set of data was used.

Using data from the survey, the Trusts and Health Boards that responded to this survey covered at least 364,216 deliveries, 1453 stillbirths and 543 neonatal deaths in 2015[1].

Survey responses were also obtained from Sands Groups on their work with local hospitals, and their understanding of the provision of bereavement care in their area. Responses were received from 34 Sands Groups. As with the Trusts and Health Boards survey, this data was collected between June and September 2016. Where multiple responses were received from a Sands Group, the response with the most complete set of data was used.

[1] Some responses did not include this data, so the true figure for these is likely to be higher.

2. Bereavement support midwives

All maternity units should have access to at least one bereavement support midwife, who has specialist knowledge and training in working with parents whose baby has died. Whilst there is not a nationally recognised job description for bereavement support midwives, it is usually understood that their role can include (Sands, 2015):

- Being an information and support resource for staff, bereaved parents and their families;
- Being familiar with all the policies and protocols relevant to caring for parents whose baby dies before, during or shortly after birth;
- Ensuring that all protocols are regularly reviewed and up-to-date;
- Ensuring the relevant paperwork and equipment are always available and ensuring that staff are familiar with how to complete paperwork and use equipment;
- Supporting staff who come into contact with bereaved parents at any stage of their care in hospital;
- Organising and evaluating multidisciplinary training sessions;
- Helping to ensure high standards of bereavement care in each relevant department;
- Liaising with other staff such as chaplains, neonatal staff, fetal medicine, pathologists and mortuary staff;
- Promoting good communication between all relevant hospital departments and primary care staff;
- Building working relationships with external bodies such as the registrar of births and deaths, the coroner, local GP practices, funeral directors, crematorium and cemetery managers and local support groups such as Sands;
- Ensuring that parents are offered support literature such as the Sands booklets for parents;
- Monitoring contracts with funeral directors, the cemetery and the crematorium and the services they provide where hospitals offer to arrange and pay for funerals.

The role of a bereavement support midwife is therefore likely to be wide-ranging, and require detailed, specialist knowledge both of issues around bereavement and local resources and procedures for when a baby dies.

Whilst it is widely recognised that the role of bereavement support midwives can be key in improving bereavement care provision, there is currently little understanding of what this role looks like nationally. This audit of bereavement care provides an insight into the current operation of bereavement support midwives across the UK.

> ***"They [bereavement support midwives] are a vital part of the care of bereaved parents, we as a Group see the difference in parents that have access to a specialist bereavement midwife to those that do not."***
>
> (Comment from a Sands Group)

2. Bereavement support midwives

2.1. How many units have bereavement support midwives?

Sands' audit found that of the Trusts and Health Boards which responded, 62% of the maternity units they cover have at least one bereavement support midwife that is based there (Table 1).

Table 1: Maternity units that have at least one specialist bereavement support midwife based there

How many of the units within your Trust or Health Board have at least one specialist bereavement support midwife based there?	
Units that have at least one specialist bereavement support midwife based there (%)	Units that do not have at least one specialist bereavement support midwife based there (%)
62	38

N = 106 maternity units across 66 Trusts and Health Boards

Sands recommends that each unit should have a specialist bereavement support midwife based there. Whilst this figure still falls short, it is encouraging that there has been a 15% increase in the proportion of units which have a bereavement support midwife based there since 2010.

Table 2: Maternity units that have at least one bereavement support midwife based there, 2010 and 2016

How many of the units within your Trust or Health Board have at least one specialist bereavement support midwife based there?	
Units that have at least one specialist bereavement support midwife based there - 2010 (%)	Units that have at least one specialist bereavement support midwife based there - 2016 (%)
47	62

N = 77 maternity units (2010); N = 106 maternity units (2016)

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

As illustrated in Table 2, the proportion of units that have at least one bereavement support midwife based there has risen from just under half in 2010 to a little under two-thirds in 2016. This suggests that whilst there is still significant room for improvement, there is increasing recognition amongst Trusts and Health Boards of the crucial role that specialist bereavement support midwives play in improving the quality of bereavement care that can be offered in maternity units, improving parent experience and support for staff.

2. Bereavement support midwives

2.2. Role of bereavement support midwives

It is encouraging to see that the vast majority of bereavement support midwives perform a wide range of roles relating to supporting staff and bereaved parents. Two points from Table 3 are worth further consideration though.

It was reported that in 83% of Trusts and Health Boards, bereavement support midwives ensure that the necessary paperwork is completed for all perinatal deaths on maternity units. Whilst this is important, care should be taken to ensure that it is not bereavement support midwives alone who are responsible for this. It is not possible for one individual to manage all issues relating to bereavement on a maternity unit, and the role of the bereavement support midwife should be to ensure that all members of staff are able to adequately care for bereaved parents. One of their key functions is to upskill their colleagues to develop a team which is competent and confident in delivering bereavement care, rather than deskilling others through taking on too much (Sands, 2016a: 393).

> ***"The hours and responsibilities of the role varies a lot between all the hospitals we cover"***
>
> (Comment from a Sands Group)

Table 3: Role of bereavement support midwives

Do the bereavement support midwives in the Trust or Health Board:

Role	Yes (%)
Are they present at the birth for parents when a baby dies?	27
Offer additional support to bereaved parents in any subsequent pregnancies?	75
Have regular formal input into the way services are provided?	79
Ensure that the necessary paperwork is completed for all perinatal deaths on maternity units across the Trust or Health Board?	83
Ensure all maternity staff are aware of and familiar with all paperwork and guidelines relating to perinatal death?	89
Deliver or organise bereavement care training for other maternity staff?	89
Offer ongoing support to parents after they have left hospital?	89
Have regular informal input into the way services are provided?	90
Provide emotional support for parents when a baby dies?	92
Support other staff?	94

N = 63 Trusts and Health Boards

2. Bereavement support midwives

Additionally, whilst the vast majority of Trusts and Health Boards report that bereavement support midwives have regular informal input into the way services are provided, one-fifth report that their bereavement support midwives do not have regular formal input into this. It is crucial that bereavement care is fully integrated into the practice of maternity units, and the bereavement support midwife should be involved in shaping service provision to ensure that the highest level of care can be offered to bereaved parents.

It is acknowledged that the actual responsibilities and roles of bereavement support midwives may vary from their formal job description, and that different Trusts and Health Boards may have based their answers on either of these.

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

2.3. When are parents referred to bereavement support midwives?

There is no compulsory point at which parents must be referred to bereavement support midwives, and responses to this survey indicate that there is a great deal of variation in this across the UK.

Table 4: Referrals to bereavement support midwives

From which week of gestation are bereaved parents referred to the bereavement midwife?	
Gestation	**%**
Any gestation	25
4-12 weeks	27
13-16 weeks	24
17-20 weeks	20
21-24 weeks	4

N = 55 Trusts and Health Boards

As Table 4 illustrates, the point at which parents may be referred to the bereavement support midwife varies greatly across Trusts and Health Boards. Whilst in over half of Trusts and Health Boards which have bereavement support midwives parents will be referred to them at any or early gestations, in nearly a quarter this referral will happen only beyond the 16th week of pregnancy. This means that at a national level, parents may experience a postcode lottery which will determine whether they receive care from a specialist bereavement support midwife. This is unacceptable. All bereaved parents must have access to specialist staff able to provide a good level of bereavement care at any gestation.

2. Bereavement support midwives

2.4. Training for bereavement support midwives

Bereavement support midwives perform a specialist role, and it is critical that they are appropriately trained to be able to support staff and bereaved families. There is not a nationally recognised resource or training scheme for bereavement support midwives, so the definition of 'training' in this area may differ between Trusts/Health Boards.

Table 5: Training for bereavement support midwives

Trusts and Health Boards with at least one bereavement support midwife that has not received specialist bereavement care training (%)	**13**
Trusts and Health Boards with at least one bereavement support midwife that has not received specialist training in bereavement care where one or more baby from a multiple birth dies (%)	**64**

N = 47 Trusts and Health Boards (specialist bereavement care training); N = 53 Trusts and Health Boards (specialist training where one or more baby from a multiple birth dies)

It is concerning that over one in 10 Trusts and Health Boards have at least one bereavement support midwife who has not received specialist bereavement care training. To provide the level of support required to staff and bereaved parents, specialist training in bereavement care is a prerequisite: this ensures that they have the skills, knowledge and understanding to be able to do a difficult job well. Training is also important in reducing stress and supporting bereavement support midwives to be confident and competent in their role.

It is also worth noting that although the deaths of one or more babies from a multiple birth form a significant minority of stillbirths and neonatal deaths, around two-thirds of bereavement support midwives have not received specialist training in providing care for parents in these complex situations. Deaths from multiple births can include a range of factors and considerations that are specific to these cases, such as where one or more babies has died but the other/s are in a critical condition (Sands, 2016a: 42-45). If the bereavement support midwife has not received specific training in these situations, it is unlikely that other staff within the Trust or Health Board will be able to access the knowledge and support they need to provide high quality bereavement care to these parents.

Specialist bereavement care training should be a prerequisite for specialist bereavement support midwives.

2. Bereavement support midwives

2.5. The work of Sands Groups with bereavement support midwives

Table 6: Sands Groups' contact with local bereavement support midwives

Is the Group in regular contact with the local bereavement support midwife/midwives?	%
Yes, at each of the hospitals we work with	56
Yes, at most of the hospitals we work with	16
Yes, at some of the hospitals we work with	13
No	16

N = 33 Groups

Across the country, Sands Groups work closely with hospitals. They can provide a wide range of bereavement support materials to hospitals, as well as offer ongoing peer support to bereaved parents locally. Many local hospitals benefit from these relationships, and it is encouraging to see from the survey of Sands Groups that the majority work with specialist bereavement support midwives at their local hospitals to help improve bereavement care in the area.

2.6. Other staff who work with bereaved parents

Table 7: Other staff who work with bereaved parents

Are there other (non-midwife) staff with a special remit to work with bereaved parents?	
Yes (%)	No (%)
55	45

N = 70 Trusts and Health Boards

Over half of the Trusts and Health Boards that responded to the above question reported that they had other staff who had a special remit to work with bereaved parents, in addition to midwifery staff. Predominantly, these additional staff were in the chaplaincy, with others broadly falling within the category of bereavement or counselling services.

Whilst it is positive that there are other staff who have a remit to work with bereaved parents, these should be seen as complimentary to the role of bereavement support midwives, rather than as an alternative to them. A bereavement support midwife is uniquely placed to provide information and support all areas of care, and it is important that there is at least one staff member who can provide overall oversight of bereavement care provision and training across the unit.

3. Bereavement care training

Bereaved parents and healthcare professionals have both identified that bereavement care training for staff is crucial (Downe et al, 2013; NHS Improving Quality, 2014; Redshaw et al, 2014). Parents' experiences of care can stay with them for a lifetime, and it is important that staff have support and training in order to deliver appropriate standards of care. Improving skills and knowledge also increases the confidence of professionals in working with bereaved parents, reducing stress and enabling them to operate more effectively (Kenworthy and Kirkham, 2011).

3.1. Availability and duration of staff training

Table 8: Is bereavement care training available for maternity unit staff, and is it mandatory?

Thinking about the training of your team:		
	Yes (%)	No (%)
Is bereavement care training available?	90	10
Is bereavement care training mandatory?	46	54

N = 70 Trusts and Health Boards

The vast majority of Trusts and Health Boards in the UK who responded to the survey reported that bereavement care training is available for staff. Whilst this is positive, there can be a great deal of variation in whether it is practical for busy frontline staff to access this training if they are not properly supported to do so by management. The fact that bereavement care training is mandatory in less than half of Trusts and Health Boards (46%) suggests that the perceived importance of bereavement care training differs across Trusts and Health Boards in the UK.

> *"Irregular informal bereavement care training [is] provided by specialist bereavement midwife"*
>
> (Comment from Trust / Health Board)

3.2. Mandatory bereavement care training

Within Trusts and Health Boards that do have mandatory bereavement care training, there is significant variation in the regularity of this provision.

Table 9: Regularity of mandatory bereavement care training

If bereavement care training is mandatory, how often is this provided?	%
Monthly	13
Quarterly	9
Bi-annually	9
Less often than bi-annually	3
Annually	66

N = 32 Trusts and Health Boards

3. Bereavement care training

> *"Training for midwives was mandatory until last year but it has been taken off the training agenda because of too many other mandatory requirements."*
>
> (Comment from Trust / Health Board)

Table 10: Duration of mandatory bereavement care training

If bereavement care training is mandatory, how long is allocated for this training?	%
30 minutes	31
60 minutes	44
90 minutes	6
120 minutes	6
Half day	10
Full day	3

N = 32 Trusts and Health Boards

Only one-third of the Trusts that have mandatory bereavement care training have this more regularly than annually, and 75% of training sessions allocate an hour or less. Amongst those that have annual mandatory training, 86% of those allocate one hour or less. Of the Trusts and Health Boards that have mandatory bereavement care training, over half (56%) dedicate one hour or less a year to this. This is unacceptable, providing insufficient time for anything more than a cursory look at bereavement care, and not enough to improve the skills or confidence of maternity unit staff in this area.

3.3. Are staff supported to access training?

It is important that all maternity staff are supported by management so that they can be released for bereavement care training (NICE 2015).

Table 11: Is bereavement care training facilitated?

Do all units within the Trust/ Health Board facilitate training (i.e. by allowing staff time for training purposes) for:		
	Yes (%)	No (%)
Midwives	87	13
Doctors	66	34

N = 67 Trusts and Health Boards for midwives; 64 for doctors

Whilst the Trusts and Health Boards that responded to the questions in Table 11 reported that a large majority (87%) facilitate training for midwives, only two-thirds facilitate bereavement care training for doctors.
As doctors are integral to care for women experiencing the death of a baby, this creates a barrier to ensuring that all staff they may come into contact with have received appropriate training to deliver empathic, parent-led care.

Table 12: Bereavement care training for doctors

Is bereavement care training included in regular training sessions for all doctors?	
Yes (%)	No (%)
28	72

N = 65 Trusts and Health Boards

Table 12 further illustrates that more work can be done on ensuring doctors have access to bereavement care training. For the majority of doctors in maternity units, bereavement care training will be neither mandatory nor covered in other regular training sessions.

A significant proportion of doctors will also not receive support from the Trust or Health Board to facilitate training. There is considerable room for improvement to ensure that non-midwifery staff in maternity units are trained in delivering good bereavement care.

3. Bereavement care training

3.4. Emotional support for staff

Table 13: Emotional support for staff

Are measures in place to provide emotional support for these professionals working with bereaved families?		
	Yes (%)	No (%)
Midwives	80	20
Doctors	61	39

N = 65 Trusts and Health Boards for midwives; 64 for doctors

It is critical that midwives and doctors who work with bereaved families have appropriate emotional support themselves (Sands, 2016a: 385-387). Support during these often very distressing situations can help avoid undue pressure building on staff, and help them to continue delivering high quality care. Table 13 suggests that midwives in one-fifth of Trusts and Health Boards do not receive this support, as well as one-third of doctors. Given the importance of ensuring those working with bereaved parents have access to appropriate support, this is an area which many Trusts and Health Boards need to reassess to determine whether they are doing all they can to ensure maternity unit staff are supported in their work.

3.5. Resources for staff

Table 14: Resources for staff

	Yes (%)	No (%)
Is a copy of Sands' *Pregnancy Loss and the Death of a Baby: Guidelines for Professionals* publication available for staff to access?	92	8
Has the unit used Sands' Audit Tool to evaluate the care that is offered to bereaved parents?	67	33

N = 66 Trusts and Health Boards for Guidelines; 67 for Audit Tool

Sands produces a range of resources for professionals to ensure they have access to reliable information that can assist them in providing empathic, parent-led bereavement care. *Pregnancy Loss and the Death of a Baby: Guidelines for Professionals* is Sands' benchmark publication on bereavement care. It is encouraging that 92% of the Trusts and Health Boards which responded reported that a copy was available for staff to access. Trusts and Health Boards should ensure that maternity unit staff have time to consult and learn from the Guidelines, and that they are supported to implement recommendations to improve bereavement care. Two-thirds of Trusts and Health Boards have also used the Sands Audit Tool, a tool for those who commission and provide services to assess current levels of bereavement care, and identify areas for improvements (Sands, 2011).

3. Bereavement care training

3.6. Sands Groups and improving bereavement care training

Table 15: Take-up of Sands' Improving Bereavement Care Training

Have midwives at the hospitals you work with received Sands' Improving Bereavement Care Training?	%
Yes, within the past 2 years	50
Yes, more than 2 years ago	30
No	20

N = 30 Groups

Table 16: Sands Groups' funding of bereavement care training

Has your Group offered to fund bereavement care training for the hospitals that you work with?	%
Yes, and the offer was accepted	83
Yes, but the offer was rejected	7
No	10

N = 29 Groups

The survey of Sands Groups illustrated the level of support that is provided by Groups to local hospitals. Half of the Groups which responded reported that the midwives had received Sands' Improving Bereavement Care Training within the past two years, a skills-based training course accredited by the Royal College of Midwives.

Nine out of ten had also offered to fund bereavement care training for the hospitals that they work with. Sands Groups clearly play a pivotal role in many areas of the country to ensure that bereavement care training is available and accessible to midwives locally.

4. Dedicated bereavement room and facilities

The experiences of parents whilst in hospital may stay with them for a lifetime, with even small details often meaning a great deal to those being cared for. The environment in which they are looked after, and the facilities which are available on maternity units following the death of a baby, are therefore of paramount importance.

4.1. Bereavement rooms

Every hospital with a maternity unit should have a dedicated bereavement room. This should be located away from other expectant/ new mothers, and/or be soundproofed; equipped with suitable facilities for the mother and family, including a double bed, en-suite bathroom and small kitchen area where possible; have a cooling facility situated in the bereavement room, so parents can spend time with their baby if they wish; and be comfortably and sensitively decorated (Sands, 2016b).

> ***"I wasn't happy about staying in a postnatal ward. It was painful to watch other mothers with their babies, it was unbearable to hear the cries of other babies."***
>
> (Mother in Redshaw et al, 2014: 34)

Forget-Me-Not bereavement suite, Royal Surrey County Hospital

Table 17: Provision of bereavement rooms across UK Trusts and Health Boards

	Trust and Health Boards (%)
Has a bereavement room in each maternity unit in the Trust / Health Board	63
Has a bereavement room in at least one maternity unit, but not all within the Trust / Health Board	26
Has no dedicated bereavement room in the Trust / Health Board	11

N = 62 Trusts and Health Boards

4. Dedicated bereavement room and facilities

Table 17 shows that there is variable coverage of bereavement rooms across Trusts and Health Boards. Just under two-thirds have a bereavement room in each maternity unit that they cover, which is positive. It is concerning however that in just over one in 10 Trusts and Health Boards, there are no dedicated bereavement rooms available. This means that significant numbers of women in the UK are unlikely to have access to a local bereavement room in a maternity unit if they experience the death of a baby. It is unacceptable that in these Trusts and Health Boards there is no dedicated area where bereaved parents can receive care, and provision of these facilities should be an urgent priority.

Table 18: Features of bereavement rooms across the UK

Of those that have at least one unit with a bereavement room, what proportion of Trusts and Health Boards **do not** have access to a bereavement room with the following features:	(%)
Are situated where parents cannot hear other babies?	41
Are large enough to accommodate other family members?	2
Were designed in consultation with bereaved parents?	25

N = 62 Trusts and Health Boards

Looking in more detail at the bereavement rooms covered by Trusts and Health Boards in this survey, there is a mixed picture regarding the facilities provided. Whilst nearly all Trusts and Health Boards report that they have at least one bereavement room large enough to accommodate other family members, a quarter do not have rooms which were designed in consultation with bereaved parents. Trusts and Health Boards must ensure that when developing a bereavement room, the experiences and feedback of parents is incorporated into the design to ensure that it meets the needs of parents. Sands Groups will often be able to facilitate this (see Table 19).

41% of Trusts and Health Boards do not have at least one bereavement room within the maternity units they cover which is situated where parents cannot hear other babies. The *Listening to Parents* report highlighted that being cared for in a location where they are able to hear other parents and babies can cause a great deal of distress for bereaved parents (Redshaw et al, 2014). It is therefore concerning that for many parents, they will be cared for in a setting which could add to their distress, rather than mitigate it. It is not enough to simply have a room where bereaved parents are cared for; they must also be fit for purpose, providing an appropriate environment for bereavement care. The Sands position statement *Bereavement care rooms and bereavement suites* looks in detail at what should be included in the design of bereavement rooms (Sands, 2016b).

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

4. Dedicated bereavement room and facilities

Table 19: Sands Groups' funding of bereavement rooms

Has your Sands Group helped to fund the establishment of, or improvements to, dedicated bereavement rooms in the hospitals you work with?	%
Yes, within the past 2 years	61
Yes, more than 2 years ago	18
No	21

N = 28 Groups

Many Sands Groups play a vital role in funding improvements to bereavement care locally, and this is reflected in funding they have provided for bereavement rooms. 79% of the Sands Groups which responded had funded the establishment of or improvements to bereavement rooms in their local hospitals, 61% of those within the past two years. These facilities can make a tremendous difference to the experience of care for bereaved parents, and the work of Sands Groups to help Trusts and Health Boards provide and improve these facilities is vital.

4.2. Cooling facilities

Table 20: Mortuary fridges on maternity units

Is there a mortuary fridge in the maternity unit of each hospital where babies' bodies can stay, so that parents can have easy access whenever they want?	
Yes (%)	42
No (%)	58

N = 69 Trusts and Health Boards

Considerably less than half (42%) of Trusts and Health Boards have a mortuary fridge on the maternity unit of each hospital they cover. This may limit the amount of time many parents are able to spend with their baby on the maternity unit. Without access to a fridge on the unit, it is likely parents would need to go to the mortuary to see their baby or wait for an available porter. It was not possible with this data to look further into the provision of mortuary fridges across individual units, but it would appear that there is considerable scope for improvement in this area.

4.3. Cold cots and cuddle cots

It is positive that there appears to be widespread access to cold cots and cuddle cots across the UK. 91% Of Trusts and Health Boards reported that each of the maternity units they cover have access to at least one of these (Table 21).

Table 21: Provision of cold cots and cuddle cots

Does each maternity unit within the Trust or Health Board have access to a cold cot or cuddle cot?	
Yes (%)	91
No (%)	9

N = 69 Trusts and Health Boards

4. Dedicated bereavement room and facilities

> *"The bereavement midwife organised for [baby's name] to stay with us in a cold cot so I could be a proud mum for a few hours – very precious memories. I got to hold her, kiss her, put a nappy on and show her to interested midwives/ doctors and also to my family who came to visit their granddaughter/ niece."*
>
> (Mother in Redshaw et al, 2014: 33)

It is also encouraging to see that where cold or cuddle cots are available, 77% of Trusts and Health Boards report that more than one is available. This is important, in cases where a unit may experience more than one death at a given time, to ensure that all families have access to this facility should they need it. It is not possible from this data to determine whether access to these is shared across Trusts or Health Boards or apply to each unit. However, it does suggest that fundraising efforts by baby loss charities in recent years that have focused on cold and cuddle cots have helped to improve access to these facilities. Cold cots and cuddle cots enable parents to spend more time with their babies and to take them outside of the hospital if they so wish, and their increasing provision ensures that all parents can be offered this choice.

Table 22: Number of cold cots and cuddle cots available to units within Trusts and Health Boards

Where a cold cot or cuddle cot is on a unit, how many are available on average?	%
1	23
2	39
3	25
More than 3	13

N = 64 Trusts and Health Boards

Table 23: Sands Groups' funding of cold and cuddle cots

Has the local Sands Group helped to fund a cold or cuddle cot for the hospitals you work with?	%
Yes, within the past 2 years	61
Yes, more than 2 years ago	18
No	21

N = 27 Groups

Sands Groups have helped to raise funds for cold and cuddle cots across the country. 79% of the Groups which responded to this question had raised funds for a cold or cuddle cot for the hospitals they work with, a little under two-thirds (61%) of those within the past two years.

4. Dedicated bereavement room and facilities

4.4. Provisions for taking the baby out of hospital

Some parents may find it comforting to take the baby's body away from a clinical setting, either home or to another place which is meaningful to them (Sands, 2016a: 247). Whilst not all parents will choose to do this, it is important that provisions are in place to support parents in doing this if they wish to, and that this offer is made to them.

There is no legal reason to prevent parents from taking the body out of hospital unless the death has been referred to a coroner or procurator fiscal. Sensitive and efficient procedures should be in place to support parents, including timings in relation to post mortems (if one has been or will be carried out), provision of information on keeping the body cool, information on transporting the body, and the provision of documentation from the hospital (though not a legal requirement, this can be useful to avoid potential difficulties) (Sands, 2016a: 248).

Table 24: Provisions for taking the baby out of hospital

Are there provisions in place for bereaved parents to take their baby out of the hospital, if they would like to?	
Yes (%)	93
No (%)	7

N = 68 Trusts and Health Boards

Table 24 shows that the vast majority of Trusts and Health Boards have provisions in place for parents to take their baby's body out of the hospital. Whilst this is positive, it is important that all parents are informed that this is an option, and that these provisions are not just referred to if a parent requests to take the body away from the hospital. It is important that all maternity unit staff are aware of local policies to facilitate parents taking their baby out of hospital, and that they have received suitable training to be able to confidently suggest this option to parents in a non-directive manner.

4.5. Relationship with other support services

It is important that bereaved families have access to support following the death of a baby, both in the immediate period following a loss and in the longer term. It is not possible for maternity units to provide all of this potential support in isolation. Hospitals should therefore have strong links with specialist support organisations, to ensure that they can provide appropriate information and signpost to specialist services where necessary.

4. Dedicated bereavement room and facilities

Table 25: Relationships with other support services

Do units within the Trust or Health Board work with any of the following organisations to enable parents to access support?			
	Work closely with this organisation (%)	Units signpost to this organisation, but do not work closely on an ongoing basis (%)	No (%)
Sands Groups	59	41	0
Bereavement counselling services	42	49	9
Other national support organisations	25	66	9
Other local baby loss organisations	35	48	17

N = 69 Trusts and Health Boards (Sands Groups); 67 (bereavement counselling services); 67 (other national support organisations); 66 (other local baby loss organisations)

It is encouraging that more than 80% of Trusts and Health Boards reported either working closely with or signposting to each of the above forms of support organisations. The figure for Sands Groups is particularly high, though it is reasonable to assume that the Trusts and Health Boards which provided responses to this survey are likely to be weighted towards those that already have a relationship with the charity. It is positive to see that the vast majority of Trusts and Health Boards work with a range of organisations to ensure that bereaved families have access to the most appropriate support services.

5. Bereavement care literature & communication

Communication is one of the most important components of delivering effective care (Sands, 2016a: 47). It is crucial that information is communicated to parents effectively and sensitively, enabling them to make informed decisions about care for themselves and their baby.

In this report, we focused on two key areas of communication relating to bereavement care; the provision of bereavement care literature, and the availability of training and services to assist staff in communicating with parents who speak little or no English.

5.1. Bereavement care literature

Table 26: Bereavement care literature – features

How many of the leaflets, certificates etc. provided to parents are:				
	All (%)	Most (%)	Some (%)	None (%)
Easy to understand?	79	16	3	2
Free of religious symbols?	89	4	5	2
Attractively produced?	70	18	9	3

N = 58 Trusts and Health Boards (Easy to understand?); 56 (Free of religious symbols?); 56 (Attractively produced?)

Written information for bereaved parents is an important facet of the support provided by maternity units. It can be very difficult to retain or understand information when in shock or distressed, and written information is a resource which bereaved parents can refer back to in their own time, if they wish. Successful written materials need to be clear and easy to understand, non-directive, and should be developed in consultation with bereaved parents to ensure that it contains appropriate information (Sands, 2016a: 60).

The vast majority of Trusts and Health Boards which responded to the survey (95%) reported that all or most of the literature provided to parents was easy to understand, and a similar proportion (88%) reported that it was attractively produced. A very high proportion (89%) were also entirely free of religious symbols.

Of greater concern is that one-third of Trusts and Health Boards reported that the literature provided following the death of a baby had not been developed in consultation with bereaved parents (Table 27).

Table 27: Bereavement care literature – consultation with parents

Was this literature produced in consultation with bereaved parents?	
Yes (%)	67
No (%)	33

N = 54 Trusts and Health Boards

It is only possible to develop resources which address the issues and concerns relevant to bereaved parents if they have been involved in the development process. There are a wide range of national and local organisations, including MSLCs, which represent bereaved parents who are happy to engage with units to develop these resources, and it is important to ensure that the experiences of bereaved parents are reflected in these materials.

5.2. Translation services

Communication difficulties can be a significant barrier to bereaved parents accessing appropriate care. There is a legal requirement on those providing services to ensure that they are accessible, and that specific equipment, auxiliary aids and services are in place to meet the communication needs of service users.

For the purposes of this audit, questions on translation services focused on those who speak little or no English, and not on parents who may have sensory impairments. This decision reflects the MBRRACE-UK report highlighting that those who speak little or no English are a high risk group in terms of stillbirth and neonatal death (Draper et al, 2015).

Table 28: Interpretation services across Trusts and Health Boards

When parents need interpreters, do units within the Trust/ Health Board use:					
	Always (%)	Usually (%)	Only out of hours and in emergencies (%)	Only in emergencies (%)	Never (%)
Trained advocates	6	9	4	13	68
Trained interpreters	42	41	0	8	9
Telephone interpreters	33	30	15	19	3
Fathers or partners	2	14	17	59	8
Children	0	0	4	13	83
Other relatives	0	10	21	51	18

N = 53 Trusts and Health Boards (Trained advocates); 64 (Trained interpreters); 64 (Telephone interpreters); 63 (Fathers or partners); 60 (Children); 61 (Other relatives)

It is clear from Table 28 that there is considerable variation in how Trusts and Health Boards provide interpreting services. Although relatively few use trained advocates, 83% always or usually use trained interpreters. Conversely, this means that 17% never use trained interpreters, or only in emergencies. Telephone interpreters are quite commonly used, which may reflect areas where there are relatively few people who speak little or no English and restricted budgets to pay interpreters (telephone services are cheaper).

> *"We can sometimes get interpreters in an emergency but it will depend on language, but not out of hours"*
>
> (Comment from Trust / Health Board)

Of greater concern is that 16% of Trusts and Health Boards always or usually use fathers or partners to translate, and 17% use children to translate out of hours and/or in emergencies. Staff should always avoid using family members to interpret as it can increase the likelihood of errors in interpretation, as they will likely be experiencing pain or distress themselves, and the mother may be uncomfortable sharing personal information with them (Sands, 2016a: 73-74). Using family members may also result in all choices not being communicated in full depending on the family members' own preferences, and the nature of their relationship.

It is never acceptable for children under the age of 16 to be used as informal interpreters, apart from in the most pressing of emergencies where no other alternative is available (Sands, 2016a: 74).

5.3. Trained advocates and trained interpreters

Table 29: Availability of trained advocates and trained interpreters

Can trained advocates and/or trained interpreters be contacted in emergencies/ out of hours?	
Yes (%)	79
No (%)	21

N = 57 Trusts and Health Boards

Table 30: Training for advocates and interpreters

If units within the Trust or Health Board use trained advocates and/or trained interpreters, have the advocates and/or interpreters had specific training on the issues surrounding childbearing loss?	
Yes (%)	37
No (%)	63

N = 48 Trusts and Health Boards

Table 29 suggests that in one-fifth of Trusts and Health Boards, trained advocates/interpreters can only be contacted in advance or during regular hours. In a maternity unit where situations can deteriorate suddenly and at any time, this is problematic if those Trusts and Health Boards are to ensure that they can deliver appropriate care to parents who require translation services.

Training should be available for interpreters working with bereaved parents, to ensure they have received the same sort of training on how to provide services sensitively and empathically for bereaved parents as other healthcare staff (Sands, 2016a: 69). Only a little over one-third of the Trusts and Health Boards which use trained advocates/interpreters reported that they had received such training.

Trusts and Health Boards should address shortages in the availability of interpreting services. Arrangements should be in place to access phone interpretation services in emergencies and/or out of hours. Family members should not be used to interpret information, apart from in the most exceptional circumstances.

5.4. Staff training on working with interpreters and across language barriers

Table 31: Staff training in working with interpreters

Have these staff had training in how to work with interpreters:				
	All (%)	Most (%)	Some (%)	None (%)
Midwives?	6	14	28	52
Doctors?	8	10	32	50

N = 65 Trusts and Health Boards for Midwives; 60 for Doctors

5. Bereavement care literature & communication

There are specific skills involved in working with an interpreter for maternity staff. This is to ensure that staff retain control of the situation, the interpreter fully understands the information and purpose of the discussion, and that parents are able to make fully informed decisions about their care (Sands, 2016a: 70-72).

Perhaps surprisingly though, few midwives or doctors on maternity units have received training in working with interpreters. Half of the Trusts and Health Boards which responded to these questions reported that none of their midwives and doctors had received this training.

Table 32: Staff training in communicating with people who speak little or no English

Have these staff had training in communicating with people who speak little or no English:				
	All (%)	Most (%)	Some (%)	None (%)
Midwives?	6	12	39	43
Doctors?	7	11	38	44

N = 66 Trusts and Health Boards for Midwives; 61 for Doctors

All staff should also have training in how to communicate across language barriers (Sands, 2016a: 73). This is because it may not always be possible to use an interpreter in an emergency, or parents may refuse the offer of an interpreter.

It is worrying that a little under half of both doctors and midwives in Trusts and Health Boards have received no specific training in communicating with people who speak little or no English. In only under one-fifth of Trusts and Health Boards have all or most doctors and midwives received training in communicating across language barriers. This potentially places parents who speak little or no English at greater risk, and could complicate the process of obtaining consent for treatment or decisions on care.

6. Post mortem consent

Deciding on whether to have a post mortem investigation conducted can be one of the most difficult decisions bereaved parents face in the period immediately after their baby dies. It is critical that all parents are given the facts they need, sensitively but clearly, regarding the post mortem process. It is a legal requirement that consent from parents should be obtained and recorded before any post mortem examination takes place (unless the death has been referred to the coroner or procurator fiscal).

To ensure that consent is appropriately sought and recorded, maternity units should have clear resources and procedures in place. Consent should always be requested by a senior member of staff trained in discussing post mortems and obtaining consent; the unit should have an adapted post mortem consent form suitable for perinatal loss; and all parents should receive appropriate written information, suitable for their experience (Sands, 2016a: 257-260).

6.1. Obtaining consent

Do all units within the Trust or Health Board have an adapted post mortem consent form that is suitable for parents who experience a perinatal loss?	
Yes (%)	97
No (%)	3

N = 64 Trusts and Health Boards

Nearly all of the Trusts and Health Boards which responded to questions regarding the consent process reported that consent is obtained by a trained, senior member of staff, an adapted, suitable consent form is used, and parents are given appropriate written information about post mortem investigations. This is very positive, and it is to be hoped that it is a practice which is followed across other UK Trusts and Health Boards.

Table 34: Post mortem – written information for parents

Are all parents given written information about post mortems that is suitable for a perinatal loss?	
Yes (%)	100
No (%)	0

N = 65 Trusts and Health Boards

Table 35: Who obtains consent

Is consent always requested by a senior member of staff who has had training in discussing post mortems and requesting consent from parents?	
Yes (%)	97
No (%)	3

N = 65 Trusts and Health Boards

Table 36: Sands Groups' experience of written information about post mortems

In your Group's experience, are all parents given written information about post mortems that is suitable for a stillbirth or neonatal death?	
Yes (%)	75
No (%)	25

N = 20 Groups

Comparing tables 34 and 36 though, it is interesting to note that a quarter of Groups which responded did not consider the information provided about post mortems was suitable, whereas all Trusts and Health Boards considered that it was. This highlights the importance of ensuring bereaved parents are consulted in the development of resources, to ensure that they fully meet their needs.

All Trusts and Health Boards should provide post mortem information and support that is deemed to be appropriate by both staff and parents.

6.2. Sands Post Mortem Consent Package

Sands provides a post mortem consent package that units can use to assist staff in obtaining consent. It contains guidance for consent takers, guidance for parents, and adaptable consent forms which can be used by units. The package is approved by the Human Tissue Authority. Whilst most of the content is applicable across the UK, the forms can currently only be used in England; in Scotland, Wales and Northern Ireland, the standard consent or authorisation form must be used.

Table 37: Past use of the Sands Post Mortem Consent Package

Have units within the Trust / Health Board used the Sands Post Mortem Consent Package in the past?	
Yes (%)	63
No (%)	37

N = 62 Trusts and Health Boards

Table 38: Current use of the Sands Post Mortem Consent Package

Do units within the Trust or Health Board currently use the Sands Post Mortem Consent Package?	
Yes (%)	52
No (%)	48

N = 63 Trusts and Health Boards

Table 39: Impact of using the Sands Post Mortem Consent Package

If units within the Trust or Health Board have used the Sands Post Mortem Consent Package, did it improve confidence amongst staff?	
Yes (%)	85
No (%)	15

N = 41 Trusts and Health Boards

Tables 37-39 show that just under two-thirds of the Trusts and Health Boards have used the Sands post mortem consent package in the past, and around half currently use it. In Trusts and Health Boards which have used the package, 85% reported that it had improved confidence amongst staff. Trusts and Health Boards which are looking to improve their documentation or procedures around post mortem consent can therefore be confident that using the Sands package would help to support their staff in this process.

7. Recommendations

This audit of bereavement care provision in maternity units has focused on five key areas for improving bereavement care: bereavement support midwives; bereavement care training; dedicated bereavement rooms and facilities; bereavement care literature and communication; and post mortem consent.

It is acknowledged that this survey does not cover every Trust and Health Board which provides maternity services, and that the full national picture may vary. There is enough data however to provide a snapshot of current bereavement care provision, and it is clear that whilst there are areas of good practice, there are also aspects which require improvement to ensure bereaved parents receive suitable care.

In this summary, recommendations are listed by topic for Trusts and Health Boards to improve bereavement care in maternity units, along with key findings from this audit.

Bereavement support midwives

Every maternity unit across the UK should have access to a bereavement support midwife. Whilst the proportion of units which have a specialist bereavement support midwife based there has increased from 47% to 62% since 2010, this means that over a third of units will not have regular access to a bereavement support midwife. It is clear that bereavement support midwives play a significant role in both providing and improving bereavement care within maternity units, and are a necessity to ensure that all women can receive appropriate care following the death of a baby.

Bereavement support midwives should be enabled to ensure that all 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 this audit has suggested, the remit of bereavement support midwives can vary significantly. 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 support midwives are not present at the birth, illustrating the importance of ensuring that all members of staff receive appropriate training and support to deliver sensitive, parent-led care.

Specialist bereavement care training should be a prerequisite for specialist bereavement support midwives, and Trusts and Health Boards should ensure that appropriate, skills-based training is available to them.

Bereavement care training

Bereavement care training should be mandatory, and allocated sufficient time 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 on

this per year. This is not appropriate, given the importance and complexities of delivering high quality care to parents whose babies die in a maternity setting. 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 means that unless this training is mandatory, it is unlikely that everyone that needs to access this training will be able to. 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 time allocated to ensure the ability and confidence of staff is improved.

Bereavement rooms and facilities

Dedicated bereavement rooms should be available in each maternity unit, and should be fit for purpose. Whilst it is recognised that it can be challenging to find an appropriate space for a dedicated bereavement room in each maternity unit, their importance to delivering care for bereaved parents means that these facilities should be a priority. It is not enough however that these rooms are available; care should 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 which those receiving care consider to be important.

Bereavement care literature and communication

Trusts and Health Boards should address shortages in the availability of interpreting services. Arrangements should be in place to access phone interpretation services in emergencies and/or out of hours. Family members should not be used to interpret information, apart from in the most exceptional circumstances.

Post mortem consent

All Trusts and Health Boards should provide post mortem information and support that is deemed to be appropriate by both staff and parents. Whilst it is positive that the vast majority of Trusts and Health Boards have measures in place to ensure parents receive information and support to be able to make a decision about whether to have a post mortem, there is a discrepancy between Trusts/Health Boards and bereaved parents on whether this information is always appropriate. This illustrates again the importance of listening to bereaved parents, and ensuring that they have input into the design of resources and services.

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About Sands

Sands, the stillbirth and neonatal death charity, was founded in 1978 by a small group of bereaved parents.

Since that time, we have supported many thousands of families whose babies have died, offering emotional support and information. Today Sands operates throughout the UK and focuses on three key areas:

We support anyone affected by the death of a baby

Bereavement support is at the core of everything we do. Some of the services that we offer include:

- Helpline for parents, families, carers and health professionals
- UK-wide network of support groups run by trained befrienders
- Online forum and message boards enabling bereaved families to connect with others
- Website and a wide range of books, leaflets and other resources

We work in partnership with professionals to try to ensure that bereaved parents and families receive the best possible care

We produce a wide range of online and printed resources to support professionals to provide sensitive, empathic bereavement care, focused upon the needs of parents. We also deliver high quality, evidence-based, accredited training workshops in bereavement care to professionals across the country, providing the latest information and support in working with bereaved parents.

We promote and fund research that could help to reduce the loss of babies' lives

We believe many babies' deaths could be prevented with better care and information. We raise vital funds for research and work with clinicians and experts to understand why babies die and how to save lives. We also provide policy expertise at government level and campaign to make addressing the tragedy of too many baby deaths a policy priority nationally and locally.

We depend on the extraordinary energies of our supporters to raise the vital funds that we need to deliver the wide range of services that we offer.

If you would like any further information or support please contact us or visit our website.

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