# Audit of Bereavement Care Provision in UK Neonatal Units

2018

Sands
Stillbirth & neonatal death charity

Bliss
for babies born premature or sick

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# Bereavement care in UK neonatal units: a snapshot

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Stillbirth & neonatal death charity

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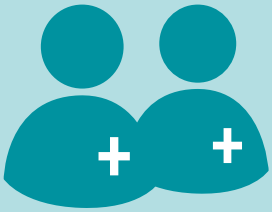
for babies born premature or sick

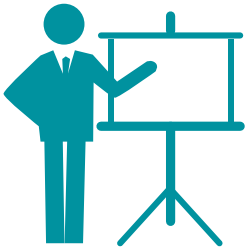
**Our survey of neonatal units across the UK illustrates the wide variation in policies, procedures and resources between hospitals, and that adherence to best practice bereavement care is not always followed.**



**83%**
of units have access to at least one specialist bereavement lead

However, only

**14%**
of leads have dedicated time in their work plan to provide support on the unit



Just
**12%**
of units have mandatory bereavement care training

**23%**
of unit's bereavement leads have not received bereavement care training in the death of a baby



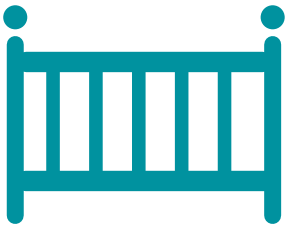
Only
**57%**
of bereavement rooms are away from the sound of other babies



Only
**15%**
are soundproofed where they may be able to hear other babies cries



**17%**
of units do not have access to a specific space for supporting bereaved families



**94%**
of units have access to at least one cuddle cot

**56%**
of units work closely with their local hospice

**Trusts and Health Boards need to ensure that units have the support and resources they need to maintain best practice and ensure all bereaved families receive the highest quality care.**

**Survey information:** Survey responses were obtained from 100 neonatal units across the UK between May-July 2018.

**sands.org.uk** **bliss.org.uk**

# 1. Executive summary

Each week in the UK, over 40 babies die in the neonatal period – from birth to 28 days old. The care that bereaved families receive before, during and following the death can have a critical impact upon their wellbeing, in the weeks, months and years ahead.

Sands have undertaken to conduct a series of audits on bereavement care provision in different healthcare settings. Over time, these will allow us to identify national trends in the provision of bereavement care – what works well, what is improving, and any areas of concern which require improvement.

The first of these, an analysis of bereavement care provision in UK maternity units, was published in 2017. This second report, undertaken jointly with Bliss, examines how bereavement care is provided in neonatal units across the country.

Between May-July 2018, survey responses were received from 100 neonatal units across the UK relating to the provision of bereavement care following the death of a baby. These focused on 5 key elements of the service: role of bereavement leads; bereavement care training; dedicated bereavement room and facilities; bereavement care literature and language translation; and post mortem consent.

While some of the findings are very welcome, such as the availability of cuddle and cold cots and provisions in place to take babies out of the hospital setting to die if this is what parents choose being in place, a number of the findings highlight inconsistencies in the service provided across the UK and the need for improved resource for bereavement care within neonatal settings.

Recommendations in this report are based on the National Bereavement Care Pathway standards (Appendix 1). The National Bereavement Care Pathway provides further information and resources for units looking to improve their bereavement care services. The pathway was rolled out nationally in October 2018 following a piloting process, so was not widely used at the time data was collected.

# Key findings

## Bereavement leads

- The majority (83.2%) of units have access to at least one specialist bereavement lead. The way in which they operate varies dramatically though, in terms of roles and dedicated work hours.
- Whilst many neonatal units reported having a bereavement lead, only 13.6% of units reported that the lead had dedicated time in their work plan to provide support on the neonatal unit. In level 3 units, this figure was only slightly higher (26.9%). Many reported that their bereavement lead would typically provide support on an ad-hoc basis, with some not having dedicated time to perform their bereavement role apart from fitting this around their other work.
- Of the minority of bereavement leads that have dedicated time on the neonatal unit in their work plan, two-thirds have less than 8 hours a week.
- Nearly one-quarter (23.1%) of bereavement leads for neonatal units have not received specialist training in bereavement care specific to the death of a baby.

# 1. Executive summary

## Staff training and support

- Bereavement care training was not available in one-fifth of neonatal units.
- Bereavement care training is mandatory in only 11.6% of units.
- Bereavement care training is not always readily accessible for staff – it is included in regular training sessions for just over one-third (38.5%) of neonatal units, and fewer than one-fifth (19.5%) of doctors.
- Over a quarter (26.5%) of units do not have measures in place to provide emotional support for neonatal nurses, and over one-third (37.5%) do not have similar measures in place for doctors.

## Bereavement room and facilities

- 17.3% of units do not have access to a specific space for supporting bereaved families. Nearly two-thirds (63%) have access to a bereavement suite that is shared with other departments. Just under one-third (29.4%) have access to a self-contained bereavement suite on the neonatal unit which includes washroom facilities.
- 57.3% of bereavement rooms are situated where parents cannot hear other babies. Only 14.9% are soundproofed, where they may be able to hear other babies.
- The vast majority (94%) of neonatal units have access to at least one cold or cuddle cot.
- Nearly all (94.1%) of neonatal units have provisions in place for bereaved parents to take their baby out of the hospital to die if they would like to and it is clinically appropriate

## Bereavement care literature and language translation services

- 94.9% of neonatal units provide support literature produced by specialist baby loss organisations.
- 77.7% of units usually or always use face-to-face interpreters when language translation services are required. However, many units make use of family members to perform this function, with only 10.8% never asking fathers or partners to do this. 11.2% routinely would ask other children of the mother to translate where necessary.
- Over two-thirds (72%) of interpreters are not given any support or mentoring from the healthcare team within the unit, and 87.7% of the interpreters have not received specific training on the issues surrounding the death of a baby.
- In fewer than one-fifth of units have most or all neonatal nurses and doctors received training in working with interpreters (16.7% and 18.1% respectively), or communicating with people who speak little or no English (19.2% and 19.5%).

## Post mortem consent

- Over four-fifths (81.6%) of neonatal units have an adapted post mortem consent form suitable for parents who experience a neonatal death.
- Consent is always requested by a senior member of staff who has had training in discussing post mortems and requesting consent from parents in the vast majority of units (92%).

# Recommendations for neonatal units, commissioners and NHS Trusts & Boards

## Bereavement leads

- A bereavement lead should be available in every neonatal unit.
- Commissioners and NHS Trusts and Boards should ensure that units have in place bereavement leads with adequate time and resources to be able to support staff in developing and delivering an effective bereavement care service.
- All bereavement leads should have received training to properly undertake this role.

## Staff training and support

- Health education and training bodies in each nation should ensure that bereavement care training is provided to all staff who come into contact with bereaved parents.
- All neonatal staff should be supported to be able to access this training.
- Hospitals should ensure policies are in place to ensure all staff can access emotional support when they need it.

## Bereavement room and facilities

- NHS Trusts and Boards should ensure that bereavement rooms are available and accessible for all neonatal units. The rooms should be situated away from where parents can hear other families and babies where possible, and soundproofed where necessary.

## Bereavement care literature and language translation services

- All units should have systems in place to be able to access translators when required, including in emergencies or out of hours.
- Family members should never routinely be asked to translate information, apart from in exceptional circumstances.

## Post mortem consent

- All units should ensure that they have an adapted consent form suitable for parents who experience a neonatal death.
- Consent should always be requested by a trained, senior member of staff.

# 2. Introduction

## 2.1. Background

Each week in the UK, over 40 babies die in the neonatal period – from birth to 28 days old. The care that bereaved families receive before, during and following the death can have a critical impact upon their wellbeing in the weeks, months and years ahead. No level of care can reduce the pain and suffering that the death of a child causes. High quality bereavement care can make a devastating experience more manageable though, whilst insensitive care can cause increased levels of suffering that can stay with families for a lifetime.

In order to deliver effective bereavement care, neonatal units require effective policies and resourcing which enables staff to respond to the particular needs of bereaved families in their care. It requires a system-level approach to prioritising bereavement care, and the support of management to ensure that staff are properly trained and supported to deliver this care to families.

In January 2017, Sands released *Audit of Bereavement Care in Maternity Units 2016*. These findings showed that there was significant variations in approach to the provision of bereavement care across the country, and that whilst there were many instances of excellent care, relatively minor changes could lead to significant improvements in bereavement care provision to ensure all parents have access to high quality care across the UK.

This report is intended to provide a similar snapshot of what bereavement care provision in neonatal units looks like at a national level. There is currently no comparable recent data that provides this information in neonatal settings. This report will help to identify both areas of bereavement care that are done well across the UK, and areas which may require further attention to ensure all parents receive the high level of care they deserve. Repeat surveys in future will allow us to monitor how bereavement care provision within hospitals is changing over time - both what is working well and whether there are particular areas which require further attention.

This year has also seen the launch of the National Bereavement Care Pathway in England, which has associated standards (Appendix 1) which can assist units in improving how services are organised and delivered locally. The pathway documents provide guidance for hospitals on how to put these standards into practice, and improve bereavement care provision.

***"I cannot fault the [bereavement service], they were beyond excellent and helped us through the worst time of our lives."***

**(Parent who experienced neonatal death in NBCP, 2018)**

# 2. Introduction

## 2.2. Aims

To provide an overview of bereavement care provision in neonatal units, a survey was developed looking at 5 key elements of the service:

- Role of bereavement leads
- Staff training and support
- Dedicated bereavement room and facilities
- Bereavement care literature and language translation
- Post mortem consent

These areas are similar in scope to those that were examined in the maternity audit report, with changes made to account for the different scenarios and care procedures on neonatal units.

## 2.3. Methodology

Surveys were distributed to neonatal units directly and via neonatal networks in May 2018. The data collection period ran from May to the end of July 2018.

Responses were received from 100 neonatal units across the country. In a small number of cases, multiple responses had been received from the same unit. In these cases, the response with the more complete set of data was used for analysis.

The previous maternity unit analysis had also asked Sands Groups a small number of questions about their impression of bereavement care locally. Sands and Bliss are both planning on undertaking more detailed work with bereaved parents about their experiences of bereavement care in future. This report focuses exclusively on the procedures and resources reported by neonatal units on how they organise bereavement care services. This will provide a benchmark to measure national changes against in the years ahead.

# 3. Bereavement leads

Bereavement support leads play a critical role in the organisation and delivery of bereavement care services in every setting where the death of a baby may occur. It is essential that all neonatal units that may provide care to bereaved parents have access to at least one of these specialist members of staff..

Whilst there is no nationally recognised role for bereavement leads or links, many local hospitals have specialist roles within the nursing team which carry out these functions. The remit and hours of these can vary significantly. It is generally agreed though that the role of a bereavement lead should include functions to support both bereaved families and the wider healthcare team:

- Quality assurance – development and implementation of bereavement care standards, guidelines and paperwork.
- Ensuring effective multidisciplinary working, through communication and liaison with relevant staff and departments.
- Staff support and training.
- Information and support for parents and families.

## 3.1. Bereavement leads in neonatal units

Taking the 'yes' and 'other' responses together, it is positive that over four-fifths of the units surveyed reported having at least one specialist bereavement lead in one form or another (Table 1).

Table 1: Neonatal units that have at least one specialist bereavement lead

| Does your neonatal unit have at least one specialist bereavement lead? | |
|---|---|
| | % |
| Yes | 56.2 |
| No | 16.9 |
| Other (please specify) | 27 |

**N = 89**

Whilst 56.2% of units reported having at least one specialist bereavement lead, just over a quarter (27%) provided details about the different ways in which they operate. The vast majority of these responses detailed how the unit shares or pools a bereavement lead role with other departments within the hospital, typically maternity:

*"There is a specialist bereavement midwife on maternity services and we have a practice improvement facilitator link nurse in the neonatal unit who is responsible for implementing end of life care pathway/ bereavement care within the neonatal unit."*

*"Maternity bereavement lead covers Neonatal unit and Maternity services."*

*"Shared with Maternity."*

# 3. Bereavement leads

Table 2: Bereavement leads that work across departments within a hospital

| Is the bereavement lead shared with other teams within the hospital, Trust or Health Board such as maternity, fetal medicine or paediatrics units? | |
|---|---|
| | % |
| Yes | 43.9 |
| No | 56.1 |

N = 82

This 'sharing' of specialist bereavement leads across departments within a hospital is widespread, with a significant minority of 43.9% of units stating that their leads operated in this way (Table 2).

Whilst a bereavement lead that works across departments can be well placed to ensure that bereavement care services across settings where the death of a baby may occur are aligned, it is important that they receive support from the hospital to ensure that they are not overstretched.

Table 3: How the bereavement lead operates on the neonatal unit

| How does the bereavement lead(s) operate on the neonatal unit? | | |
|---|---|---|
| | All units | Level 3 units only |
| | % | % |
| They have dedicated time in their work-plan to be providing support on the neonatal unit | 13.6 | 26.9 |
| The neonatal unit can access the support of the bereavement lead by making a referral | 34.6 | 23.1 |
| Other (please explain) | 51.9 | 50 |

N = 81 (all units); N = 26 (level 3 units only)

However, only 13.6% of units reported that the bereavement lead has dedicated time in their work plan to provide support on the neonatal unit (Table 3), and just over one-third of units were able to access support from the bereavement lead through making a referral. Even in level 3 units, which could expect to care for the majority of babies who will die or are expected to die, only around one-quarter of bereavement leads have dedicated time in their work-plan to provide support on the neonatal unit.

# 3. Bereavement leads

Half of units provided details about the different ways that their bereavement lead operates, with a key theme being that they perform this role on an 'ad-hoc' basis, either when required or when they can fit this into their working hours. These responses from level 3 units are typical:

*"Ad-hoc time given when needed."*

*"They have no dedicated time except when they are on shift."*

*"Given office time throughout the month to support the development of the service."*

Table 4: Dedicated hours for bereavement care leads in neonatal units

| If the bereavement care lead has dedicated time on the neonatal unit in their work plan, how many hours per week do they have allocated to this role? | |
|---|---|
| | % |
| 0-8 hours | 66.7 |
| 9-16 hours | 13.3 |
| 17-24 hours | 13.3 |
| 25-32 hours | 0 |
| 33-40 hours | 6.67 |

**N = 15**

The minority which do have dedicated time are very limited in the time they have available, with two-thirds having less than 8 hours in their work plan dedicated to this role (Table 4).

It is important for hospitals to facilitate bereavement leads' role through time and support to enable them to perform the appropriate variety of functions that the position entails. The lack of units with a bereavement lead that has dedicated time to provide support within the unit is an area of concern, particularly in level 3 units.

## 3.2. Training for bereavement leads

Bereavement leads perform a role requiring particular skills and knowledge, and those taking up these positions should be provided with specialist training.

Table 5 shows however that nearly a quarter (23.1%) of bereavement leads in neonatal units have not received specialist training in bereavement care specific to the death of a baby. It is integral to the role of the bereavement lead to deliver high quality bereavement care directly to families and to support their colleagues to be able to do so too. Every bereavement lead should therefore have specialist training for their role.

Table 5: Training for bereavement leads

| Has the bereavement lead received specialist training in bereavement care specific to the death of a baby? | |
|---|---|
| | % |
| Yes | 76.9 |
| No | 23.1 |

N = 78

Table 6: Training for leads in bereavement care where one or more babies from a multiple birth dies

| Has the bereavement lead received specialist training in bereavement care where one or more babies from a multiple birth die? | |
|---|---|
| | % |
| Yes | 54 |
| No | 46.1 |

N = 76

Furthermore, nearly half (46.1%) of bereavement leads have not received specialist training in bereavement care where one or more babies from a multiple birth dies. Bereavements involving multiple births on a neonatal unit include a range of factors and considerations which can make the provision of care very complex (Sands, 2016a: 193-4). It is therefore vital that the bereavement lead has this knowledge to be able to support colleagues in providing appropriate care in these situations.

## 3.3. Role of bereavement leads

Table 7: Role of the bereavement lead

| Does the bereavement lead: | | | |
|---|---|---|---|
| | No (%) | Yes (%) | N |
| Support other staff? | 17.3 | 82.7 | 75 |
| Deliver or organise bereavement care training for other neonatal unit staff, including consultants? | 48.7 | 51.3 | 78 |
| Ensure that the necessary paperwork is completed for all neonatal deaths on the unit? | 35.4 | 64.6 | 79 |
| Ensure all neonatal unit staff are aware of and familiar with all paperwork and guidelines relating to neonatal death? | 22.8 | 77.2 | 79 |
| Have regular formal input into the way services are provided? | 61 | 39 | 77 |
| Have regular informal input into the way services are provided? | 27.3 | 72.7 | 77 |
| Provide emotional support for parents when a baby is expected to die? | 24.7 | 75.3 | 77 |
| Provide emotional support for parents when a baby dies? | 19 | 81 | 79 |
| Offer advice on funeral planning to parents? | 37.7 | 62.3 | 77 |
| Offer advice on sources of financial support to parents? | 39.5 | 60.5 | 76 |
| Offer ongoing support to parents after they have left hospital? | 41.6 | 58.4 | 77 |
| Offer additional support to bereaved parents in any subsequent pregnancies? | 58.4 | 41.6 | 77 |

# 3. Bereavement leads

Bereavement leads perform a wide range of roles which involve supporting both bereaved families and the healthcare staff caring for them. There is considerable variation in the functions undertaken by different bereavement leads, as we would expect from the difference in the time allocations and the nature of the units and departments covered.

Unfortunately, around one-fifth of bereavement leads do not support other staff as part of their role, and just under a quarter do not ensure all neonatal staff are aware of and familiar with all paperwork and guidelines relating to neonatal death (Table 7). A key function of a bereavement lead must be to support and upskill colleagues to ensure that all staff can provide appropriate care following the death of a baby, reducing variability in the provision of care within a unit.

It is also a concern that the majority of bereavement leads in neonatal units do not have regular formal input into the way services are provided. Bereavement leads are in a unique position to provide insight and direction to ensure bereavement care services suit the needs of bereaved families, both within units and across departments within a hospital. Their input is vital to ensuring that bereavement care services are fit for purpose, and more hospitals need to ensure that these staff are involved in establishing and delivering bereavement care processes. The resource and time constraints already identified in this report inevitably have a significant impact upon the functions that bereavement leads are able to undertake. Future work should investigate the impact of limits on allocated time and the roles that bereavement leads undertake on neonatal units, and whether these have a negative impact on the quality of service that can be provided.

***"I could spend as much time with my baby as I wanted, and the bereavement midwife brought us lunch, so we could spend longer with our baby and have them special memories."***

**(Parent who experienced neonatal death in NBCP, 2018)**

## 3.4. Other bereavement care staff

Table 8: Other staff with a special remit to work with bereaved parents

| Are there other staff on or available to the neonatal unit with a special remit to work with bereaved parents? | |
|---|---|
| | % |
| Yes | 58.6 |
| No | 41.4 |

N = 87

Over half ( 58.6%) of units reported that in addition to the bereavement lead, they had other staff who also had a special remit to work with bereaved parents (Table 8). These staff represented a variety of roles and specialisms, including bereavement teams, chaplaincy services, nurses with specialisms or a special interest in bereavement, link nurses, consultants, counsellors and psychologists, amongst others. This would seem to reflect the considerable variation in how bereavement services are set up and delivered across different units and hospitals. It is positive that many units have multiple staff members with a special remit to work with bereaved parents, rather than responsibility resting with an individual.

Table 9: Roles performed by other staff with a special remit to work with bereaved parents

| Thinking about the staff you identified in the previous question, what roles do they perform? | |
|---|---|
| | % |
| Support other staff | 65.6 |
| Ensure all neonatal staff are familiar with necessary paperwork and guidelines | 34.4 |
| Deliver or organise training for other staff | 57.4 |
| Input into the ways that bereavement services are provided | 54.1 |
| Ensure that necessary paperwork is completed | 55.7 |
| Support bereaved families | 82 |
| Other (please specify) | 13.1 |

N = 61

These staff, similar to the bereavement leads, perform a variety of different roles. They have an important role in supporting the organisation and delivery of bereavement care, and provide support for both bereaved families and other staff. The precise nature of these roles appears to vary considerably between units.

# 4. Staff training and support

Training in bereavement care focuses on the unique impact of grief from the death of a baby. It ensures staff learn how to communicate sensitively with bereaved families, how to support them in making informed decisions about care for themselves and their baby, and provides information about how to deliver individualised care, such as through memory making activities, (for example photographs and hand/foot prints.)

Bereavement care training specific to the death of a baby can help healthcare professionals to ensure that parents receive the highest standard of care. By improving bereavement care skills and knowledge the confidence of staff working in this area is also increased, which can help to reduce stress and assist staff and units in providing high quality care consistently.

## 4.1. Bereavement care training availability

Table 10: Bereavement care training availability

| Is bereavement care training available? | | | |
|---|---|---|---|
| | No | Yes | N |
| All units | 20.9 | 79.1 | 86 |
| Level 3 units | 11.1 | 88.9 | 27 |
| Level 2 units | 22 | 78 | 41 |
| Level 1 units | 37.5 | 62.5 | 16 |
| **Is bereavement care training mandatory?** | | | |
| | No | Yes | N |
| All units | 88.4 | 11.6 | 86 |
| Level 3 units | 81.5 | 18.5 | 27 |
| Level 2 units | 90.2 | 9.8 | 41 |
| Level 1 units | 93.8 | 6.3 | 16 |
| **Is bereavement care training tailored to the specific needs of families on a neonatal unit?** | | | |
| | No | Yes | N |
| All units | 41.7 | 58.3 | 84 |
| Level 3 units | 26.9 | 73.1 | 26 |
| Level 2 units | 42.5 | 57.5 | 40 |
| Level 1 units | 68.8 | 31.3 | 16 |

# 4. Staff training and support

Around four-fifths (79.1%) of units reported that bereavement care training is available for staff (Table 10). Looking at this by unit level, 88.9% of level 3 units reported that bereavement care training was available, falling to a little under two-thirds of level 1 units. It is particularly concerning that more than 1 in 10 level 3 units do not have bereavement care training available, as these units are most likely to regularly care for babies that will die or are expected to die. Those units that do not have training available for their staff should address this as a matter of urgency. All neonatal units however should ensure bereavement care training is available, as neonatal deaths can occur suddenly and unexpectedly.

The impact of bereavement care training is also dependent on both the content and the access that all staff have to the training.

Fewer than 60% of units have training which is tailored to the specific needs of families on a neonatal unit. This ranged from around three quarters of level 3 units to fewer than one-third of level 1 units. With the particular complexities of providing bereavement care in neonatal settings, such as critical care decisions, parallel planning and palliative care, this training needs to focus on the challenges that face bereaved families in these situations in order to have the most affect.

Bereavement care training was only mandatory in 11.6% of units. Even in level 3 units, where the majority of babies who die or are expected to die will be cared for, under 20% provide mandatory training. With the continual pressure on staff time, if training in a particular area is not mandatory, it may be very difficult for all staff to be able to access it. Placing staff who are untrained or unprepared to provide sensitive bereavement care at a critical point of time risks causing additional pain and stress to bereaved families, in addition to increasing stress for staff placed in difficult situations without support.

***"Although we hand on heart found everyone to be great, there was one person who from the moment we found out there was a problem was very negative and to be honest needs to go on a course on how to handle emotional parents… We appreciate that she's not allowed to sit there and say that everything would be okay, but her way was inappropriate, hurtful and she was also very rude."***

**(Parent who experienced neonatal death in NBCP, 2018)**

# 4. Staff training and support

The data gathered on training for different groups of professionals, and how they are supported to access this training, shows that each face barriers in accessing bereavement care training.

Table 11: Bereavement care training for different groups of professionals

| Is bereavement care training included in regular training sessions for: | | | |
|---|---|---|---|
| | No | Yes | N |
| Neonatal nurses | 61.5 | 38.5 | 78 |
| Doctors | 80.5 | 19.5 | 77 |
| Allied healthcare professionals | 6.8 | 3.2 | 6 |

Table 11 shows that bereavement care training is not included in regular training sessions for the majority of neonatal nurses, doctors or allied healthcare professionals. This is particularly acute for doctors and allied healthcare professionals, where bereavement care training is not included regularly in over 80% of units. Doctors have a significant role in critical care decisions and communication with parents regarding these. The particularly sensitive nature of these conversations is just one of the reasons why bereavement care training for doctors should be a priority, and Trusts and Health Boards should ensure that doctors are provided with this training.

***"There was a doctor who was really, really helpful with me… It was never too much trouble for her, and I needed that… She's a doctor, she's a very busy woman, but she always made time to speak to me."***

**(Parent who experienced neonatal death in NBCP, 2018)**

# 4. Staff training and support

Table 12: Accessibility of bereavement care training for different groups of professionals

| Is training facilitated for these professionals on the unit, eg. by giving staff time for training purposes? | | | |
|---|---|---|---|
| | No | Yes | N |
| Neonatal nurses | 42.5 | 57.5 | 73 |
| Doctors | 63.9 | 36.1 | 72 |
| Allied healthcare professionals | 3.3 | 6.7 | 2 |

There are systemic barriers which can prevent professionals from accessing training. It is particularly concerning that training is not facilitated for nearly half of neonatal nurses (Table 12), who can expect to spend significant amounts of time with families before and after a bereavement on the neonatal unit. All professionals who work with bereaved families have an important role to play in the delivery of bereavement care, and it is vital that all of these professionals are supported by their hospitals to access the training they need.

## 4.2. Multidisciplinary training

Table 13: Multidisciplinary training

| How much of the bereavement care training provided is multidisciplinary (ie. for doctors, neonatal nurses and other health professionals together)? | |
|---|---|
| | % |
| None | 47.3 |
| Some training | 41.9 |
| Most training | 4.1 |
| All training | 6.8 |

**N = 74**

Multidisciplinary training is an important aspect of improving care, helping different groups of professionals to better understand each other's roles and assisting with communication across teams to improve care delivery.

Table 13 illustrates that this is another area which could be improved in neonatal settings. 10.9% of units have all or most of their bereavement care training as multidisciplinary sessions. Where possible, units should ensure that bereavement care training for staff takes a multidisciplinary approach.

## 4.3. Emotional support for staff

It is important that measures and processes are in place to provide emotional support for healthcare professionals who deliver bereavement care, which can be very distressing (Sands, 2016a: 385-287). Ensuring staff receive the support they need can lead to improved morale, and also help to lessen staff turnover from specialist roles.

Table 14: Emotional support for staff

| Are measures in place to provide emotional support forneonatal nurses working with bereaved families? | | | |
|---|---|---|---|
| | No | Yes | N |
| Neonatal nurses | 26.5 | 73.5 | 83 |
| Doctors | 37.5 | 62.5 | 80 |

Over a quarter of units do not have measures in place to provide emotional support for neonatal nurses, and over one-third do not have similar measures in place for doctors. The type of support available was similar for both nurses and doctors, and across units included a mix of formal and informal support:

*"Debrief and psychological support from Trust."*

*"Clinical supervision."*

*"There is always a debrief when a baby has died between maternity and the neonatal unit."*

*"Trust bereavement team."*

*"Support offered is not good – but debrief sessions are given to staff and offered to staff."*

The provision of effective, ongoing support for staff who work with bereaved families is critical to ensuring their long-term wellbeing, and maintaining high levels of care within the unit. Hospitals should ensure that these measures are in place in every setting where staff may care for parents who have experienced the death of a baby.

# 5. Bereavement rooms and facilities

The room and surroundings where parents are cared for and spend time with their baby after they have died is a critical aspect of bereavement care. This is because these experiences are likely to be remembered by bereaved parents for the rest of their lives, and seemingly small details can make a great deal of difference.

## 5.1. Availability of bereavement rooms

Table 15: Bereavement room facilities

| Does the unit have any of the following spaces available to care for bereaved parents and their baby? | | | |
|---|---|---|---|
| | No (%) | Yes (%) | N |
| A self-contained bereavement suite on the neonatal unit (including washroom facilities) | 70.6 | 29.4 | 85 |
| A bereavement suite (without washroom facilities) | 88.1 | 11.8 | 76 |
| A bereavement suite which is shared with other departments (eg. maternity) | 37 | 63 | 81 |
| A parent bedroom which is also used for overnight accommodation | 3.6 | 96.4 | 83 |
| A side room or consultation room | 13.4 | 86.6 | 82 |
| We have no specific space for supporting bereaved families | 82.7 | 17.3 | 52 |

It is alarming that 17.3%[1] of units do not have access to any specific space for supporting bereaved parents (Table 15). Any unit can experience a neonatal death, and it is incumbent on all hospitals with a neonatal unit to ensure that parents will be cared for in an appropriate space, should a bereavement occur.

1. There was a smaller response rate to this part of the question than the others featured in this table. However, had the response rate been more in line with other parts of this question, and the remainder had all answered no, this would still represent a significant minority of neonatal units with no specific space for supporting bereaved parents. The analysis or recommendation would not change.

# 5. Bereavement rooms and facilities

Two thirds of the units responding to the survey share a bereavement suite with another department, which is an effective way to pool resources and link up bereavement care services. Table 16 also suggests that there are relatively few units that have issues in ensuring bereaved parents are able to access these facilities.

Table 16: Availability of bereavement room facilities

| What is the availability of the space that you have described above? | |
|---|---|
| | % |
| This is a dedicated space, neonatal parents are always able to access it | 45.2 |
| This is not a dedicated space, but neonatal parents who are bereaved are always able to access it | 42.9 |
| This is not a dedicated space and neonatal parents are not always able to access it | 6 |
| Other (please specify) | 6 |

N = 84

## 5.2. Features of bereavement rooms

Every hospital with a neonatal unit should have access to a dedicated bereavement room. It is very important that these facilities are designed to meet the needs of parent in this situation. They should be: located away from other new mothers, and/or be soundproofed equipped with suitable facilities for the mother and family, including 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 be comfortably and sensitively decorated.

42.7% of the units surveyed had bereavement rooms situated where parents can hear other babies, and only around 14.9% have soundproofing if they are in this type of location (Table 17. This can be incredibly distressing for bereaved parents, and hospitals should take all steps that they can to ensure this is avoided. Fewer than half of units reported that their bereavement rooms had been designed in consultation with bereaved parents. It is vital that facilities are designed in consultation to ensure that they meet the needs of bereaved families. Local support groups can often assist hospitals in this process.

# 5. Bereavement rooms and facilities

Table 17: Features of bereavement rooms

| Is this bereavement room: | | | |
|---|---|---|---|
| All units | | | |
| | No (%) | Yes (%) | N |
| Situated where parents cannot hear other babies? | 42.7 | 57.3 | 82 |
| Soundproofed, if they are situated where parents may be able to hear other babies? | 85.1 | 14.9 | 74 |
| Designed in consultation with bereaved parents? | 55.7 | 44.3 | 79 |
| Large enough to accommodate other family members? | 22.8 | 77.2 | 79 |
| Level 3 units only | | | |
| Situated where parents cannot hear other babies? | 42.3 | 57.7 | 26 |
| Soundproofed, if they are situated where parents may be able to hear other babies? | 95.7 | 4.4 | 23 |
| Designed in consultation with bereaved parents? | 65.4 | 34.6 | 26 |
| Large enough to accommodate other family members? | 34.6 | 65.4 | 26 |

## 5.3. Cuddle cots

Cuddle cots are a brand of cold cot, equipment which has a cooling system within a cot that allows bereaved families to spend more time with their baby following the death, should they wish to. The terms cold cots and cuddle cots are often used interchangeably, so the questions on this equipment used both terms to avoid confusion.

It is very positive that nearly all units have access to a cold or cuddle cot (Table 18), and over half of these units had more than 1 of these available (Table 20).

Table 18: Access to cold or cuddle cots

| Does the neonatal unit have access to a cold or cuddle cot? | |
|---|---|
| | % |
| Yes | 94 |
| No | 6 |

N = 83

Table 19: Number of cold or cuddle cots available in units

| How many cold or cuddle cots are available? | |
|---|---|
| | % |
| 1 | 44.3 |
| 2 | 31.7 |
| 3 | 16.5 |
| More than 3 | 7.6 |

N = 79

Cold cots or cuddle cots both allow parents to spend more time with their baby, either within the hospital or to take them out of the hospital for longer periods than would otherwise be possible should they wish to. This enables greater choice for bereaved parents about what they would like to do with their baby following the death, and the provision of these across UK neonatal units is very positive.

***"I liked that we could go and visit (our baby) whenever we liked while she was still at the hospital and the room where we went was so nice and made it a little easier."***

**(Parent who experienced neonatal death in NBCP, 2018)**

## 5.4. Provisions for parents to take their baby out of the hospital

Some parents find it comforting to take their baby out of the hospital to die. Whilst not all families will want to do this it is important that they are given the choice to do so, and that hospitals have provisions in place to enable this wherever possible and clinically appropriate.

Table 20: Provisions for taking a baby out of hospital to die

| Are there provisions in place for bereaved parents to take their baby out of the hospital to die, if they would like to and if it is clinically appropriate? | |
|---|---|
| | % |
| No | 5.9 |
| Yes, to a local hospice | 81.2 |
| Yes, to home | 78.8 |
| Other (please explain) | 11.8 |

**N = 85**

Only 5.9% of units have no provisions in place for bereaved parents to take their baby out of hospital to die, with around 80% of units able to facilitate this to either a local hospice or to the parents' home (Table 20). A small number of units also offered examples of other places they have been able to facilitate transport to. An example of this included:

*"We have taken babies to hospices, home and to local places of beauty that are meaningful to the parents for their baby to die. These include picturesque gardens and the beach."*

Many units do all they can to meet parents' wishes for where their baby will be cared for when they die, and this holistic approach to care can make a great deal of difference to bereaved families.

## 5.5. Other support services

Table 21: Relationship with other support services

| Does the unit work with any of the following organisations to enable bereaved parents to access support? | | | | |
|---|---|---|---|---|
| | No (%) | Units signpost parents to this organisation, but do not work closely on an ongoing basis (%) | Work closely with this organisation (%) | N |
| Sands groups | 4.8 | 75.9 | 19.3 | 83 |
| Bereavement counselling services | 10.1 | 69.6 | 20.3 | 79 |
| Other national support organisations | 17.1 | 72.4 | 10.5 | 76 |
| Other local baby loss support groups | 26.0 | 61.0 | 13.0 | 77 |
| Local hospices | 7.3 | 36.6 | 56.1 | 82 |

The majority of units signpost to a variety of organisations, including Sands groups, bereavement counselling services, other national support organisations and other local baby loss support groups (Table 21). Over half of units also reported working closely with local hospices, with just 7.3% having no direct relationship with them.

It is important for neonatal units to have strong links with support organisations, to ensure that bereaved families can be signposted to specialist services and can provide parents with further information where necessary.

# 6. Literature and language translation services

One of the most critical components of sensitive, individualised bereavement care is effective communication (Sands, 2016a: 47). It can be very difficult for bereaved parents to take in the range of information that is provided at a deeply distressing time. Providing this sensitively in a manner which can be readily understood is vital to ensuring parents are able to make informed decisions about care for them and their baby.

Many neonatal units provide services to diverse communities in which a number of languages are spoken, and all units can expect to care for parents who speak little or no English at some stage. Communicating across language barriers can create significant challenges to ensuring that parents receive the information and support they need to be able to make informed choices about their care. All units therefore need to ensure that they have measures in place to ensure that they can communicate well with families that speak little or no English, as this is central to providing effective bereavement care.

It should be noted that there are a wide range of reasons why parents may require assistance with communication beyond language barriers, including sensory impairments and parents with learning difficulties. Whilst this report focuses on communication across language barriers in particular, there is a clear need for future work to look further into bereavement care provision for parents with communication difficulties, potentially vulnerable parents and those with complex needs in greater detail.

## 6.1. Bereavement care literature

Written information is an important source of support for bereaved families, offering a recap of what has been discussed which parents can refer back to in their own time.

Table 22: Provision of support literature

| | No (%) | Yes (%) | N |
|---|---|---|---|
| Does the unit produce their own support leaflets or literature to give to bereaved parents? | 69.1 | 30.9 | 81 |
| Does the unit provide support literature produced by specialist baby loss organisations? | 5.1 | 94.9 | 79 |

The vast majority of units provide support literature produced by specialist baby loss organisations, and around one-third also produce their own support leaflets (Table 22).

***"When somebody is saying something to you, it's so overwhelming you don't take it in. But if somebody actually gives you something in writing to take away, you can look back at that, you can read that as many times as you want."***

**(Parent who experienced neonatal death in NBCP, 2018)**

## 6.2. Language translation services

Table 23: Provision of language translation services

| When parents need interpreters, does the unit use: | | | | | | |
|---|---|---|---|---|---|---|
| | Never (%) | Only out of hours and in emergencies (%) | Only in emergencies (%) | Usually (%) | Always (%) | N |
| Face-to-face interpreters | 7.9 | 6.6 | 7.9 | 46.1 | 31.6 | 76 |
| Telephone interpreters | 1.3 | 19.5 | 22.1 | 23.4 | 33.8 | 77 |
| Fathers or partners | 10.8 | 9.5 | 33.8 | 32.4 | 13.5 | 74 |
| Children | 59 | 7 | 22.5 | 5.6 | 5.6 | 71 |
| Other relatives | 19.2 | 16.4 | 48 | 9.6 | 6.9 | 73 |

There is considerable diversity between units in how language interpreting services are provided. Face-to-face and telephone interpreters are usually or always used in 77.7% and 57.2% of units respectively (Table 23). However, a significant proportion of units routinely make use of fathers, partners or other relatives to translate. Staff should always avoid using family members to interpret wherever possible because 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' understanding, and the nature of their relationship.

A smaller proportion of units also ask the parents' other children to translate. 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).

Table 24: Use of interpreters

| If the unit uses interpreters: | | | |
|---|---|---|---|
| | No (%) | Yes (%) | N |
| Can they be called in emergencies and out of hours? | 15.4 | 84.6 | 78 |
| Are the interpreters given any support and/or mentoring from the healthcare team within the unit? | 72 | 28 | 75 |
| Have the interpreters had specific training on the issues surrounding baby loss? | 87.7 | 12.3 | 65 |

Where units use interpreters, the majority (84.6%) can make use of them in emergencies and out of hours. As situations in neonatal units can change rapidly and with little warning, it is important that all hospitals have procedures in place to enable them to access interpreting services should they be required at short notice.

Less than a third of interpreters have been given support from the healthcare team within the unit, and just 12.3% of interpreters have received specific training on issues surrounding baby loss. It is important that interpreters receive training on how to provide services sensitively and emphatically for bereaved parents, as they are integral to the provision of bereavement care in those situations (Sands, 2016a: 69). Sands provides training for interpreters that looks at these issues in greater detail (information available here).

## 6.3. Staff training in working with interpreters across language barriers

Working with an interpreter to deliver bereavement care, or trying to communicate where an interpreter is not available, requires particular skills and approaches to ensure effective communication (Sands, 2018). However, only a small proportion of neonatal staff have received training in this area (Table 25). In fewer than 20% of units have most or all neonatal nurses and doctors received training in working with interpreters, or communicating with people who speak little or no English. In a little under two-thirds of units none of the neonatal nurses have had training in how to work with interpreters, and in over half of units none have had training in communicating with people who speak little or no English. Similarly, in nearly half of units doctors have not received this form of training.

# 6. Literature and language translation services

Table 25: Staff training in working with interpreters and across language barriers

| Thinking of staff in your unit: | | | | | |
|---|---|---|---|---|---|
| | None of them | Some of them | Most of them | All of them | N |
| Have neonatal nurses had training in how to work with interpreters? | 61.5 | 21.8 | 15.4 | 1.3 | 78 |
| Have neonatal nurses had training in communicating with people who speak little or no English? | 53.9 | 26.9 | 14.1 | 5.1 | 78 |
| Have doctors had training in how to work with interpreters? | 45.8 | 36.1 | 15.3 | 2.8 | 72 |
| Have doctors had training in communicating with people who speak little or no English? | 43.1 | 37.5 | 13.9 | 5.6 | 72 |

All staff should 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. If staff have not received training for these situations it can further complicate the process of parents making informed decisions about their care, and potentially place them at greater risk. Sands have produced an information sheet to assist healthcare staff in working with interpreters to deliver bereavement care (available here).

# 7. Post mortem consent

The decision whether to have a post mortem investigation undertaken can be one of the most distressing that bereaved parents need to make following the death of their baby. With the decision needing to be made very soon following the death, at a time of deep distress and alongside other decisions that need to be made regarding care, it is critical that the information is provided and presented in a suitable way to assist parents throughout the 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).

## 7.1. Obtaining consent

To ensure that consent is appropriately sought and recorded, neonatal 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).

Table 26: Post mortem consent forms

| Does the unit have an adapted post mortem consent form that is suitable for parents who experience a neonatal death? | |
|---|---|
| | % |
| Yes | 81.6 |
| No | 18.4 |

**N = 76**

Whilst some units will have a very low expected rate of neonatal deaths there is always the possibility that a death will occur unexpectedly, and suitable consent forms for local adaption are readily available (such as those included in the Sands Post Mortem Consent Package). Table 26 suggests that a little under one-fifth of neonatal units do not have an adapted post mortem consent form that is suitable for parents who experience a neonatal death.

# 7. Post mortem consent

Table 27: Who requests 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 | 92.0 |
| No | 8.0 |

N = 75

In the majority of units, consent is always requested by a senior member of staff who has had training in discussing post mortems and requesting consent from parents (Table 27).

Over 92% of units provide written information about post mortems that is suitable for a neonatal death. This information provides an important summary of information that is introduced and discussed initially with the consent taker, enabling families to consider their options and refer back to information they would not necessarily recall from an initial discussion. Post mortem consent is an ongoing process, not a single conversation or completed form. The provision of written information is an important component of this process, and all units should have written information available when it is needed.

Table 28: Written information for parents about post mortem investigations

| Are all parents given written information about post mortems that is suitable for a neonatal death? | |
|---|---|
| | % |
| Yes | 92.1 |
| No | 7.9 |

N = 76

## 7.2. Sands post mortem consent package

Sands produces a post mortem consent package which can be used in units to assist with the consent process. It contains information for both the consent takers and bereaved families, as well as template forms. 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 29: Use of the Sands post mortem consent package in neonatal units

| Has the unit used the Sands post mortem consent package in the past? | |
|---|---|
| | % |
| Yes | 44.6 |
| No | 55.4 |

N = 74

Table 30: Effect of using the Sands Post Mortem Consent Package

| If the unit has used the Sands post mortem consent package, did it improve confidence amongst staff? | |
|---|---|
| | % |
| Yes | 77.1 |
| No | 22.9 |

N = 35

The Sands post mortem consent package has been used in 55.4% of the units surveyed (Table 29). Table 30 shows that where the package has been used, it has helped to improve the confidence of staff in over three-quarters of units (Table 30). Any units that have experienced issues with the consent process can adapt elements of the post mortem consent package to improve care, and the majority of units which have used the package have benefited from it.

# 8. Recommendations

This audit of bereavement care in neonatal units has found that whilst there are many examples of good practice across the country, there is much work to do to ensure that all bereaved parents receive consistently high levels of care following the death of a baby.

There are steps that all NHS Trusts and Boards, commissioners and neonatal units themselves can take to ensure that they have the processes and procedures in place to deliver an effective bereavement care service.

Where appropriate, recommendations in this report have been linked back to the National Bereavement Care Pathway Standards, more details of which can be found in Appendix 1.

**Bereavement leads**

- A bereavement lead should be available in every neonatal unit.
- Commissioners and NHS Trusts and Boards should ensure that units have in place bereavement leads with adequate time and resources to be able to support staff in developing and delivering an effective bereavement care service . This role may be split between departments or across a hospital, but should include dedicated time to provide support on the unit. Whilst the exact remit and hours of this role may vary depending on the size of the unit, they should all have dedicated time on the neonatal unit to ensure that this important function is properly supported, and staff do not have to fit this in on an 'ad-hoc' basis.
- All bereavement leads should have received training to properly undertake this role.

**Staff training and support**

- Health education and training bodies in each nation should ensure that bereavement care training is provided to all staff who come into contact with bereaved parents.
- Staff should be supported in able to access this training . Where possible, training should have a multidisciplinary focus to ensure that all staff are aware of both their own role and how the service enables all staff to contribute to and deliver high quality care following the death of a baby.
- Hospitals should ensure policies are in place to ensure all staff can access emotional support when they need it.

# 8. Recommendations

**Bereavement rooms and facilities**

- NHS Trusts and Boards should ensure that bereavement rooms are available and accessible for all neonatal units, and they should be fit for purpose. This includes being situated away from where they would be able to hear the cries of other babies, or being soundproofed where this is not possible. Improvements to the care environment can make a significant difference to how a bereavement is experienced and remembered.

**Bereavement care literature and language translation services**

- All units should have systems in place to be able to access translators when required, including in emergencies / out of hours. This could be in person or by phone. Clear communication is vital to ensure that all parents are able to make informed choices about their care, and it is incumbent on hospitals to ensure that they can communicate with families appropriately.
- Family members should never routinely be asked to translate information apart from in exceptional circumstances.

**Post mortem consent**

- All units should ensure that they have an adapted consent form suitable for parents who experience a neonatal death.
- Consent should always be requested by a trained, senior member of staff.

# 9. Appendix 1: National Bereavement Care Pathway standards

The National Bereavement Care Pathway (NBCP) project funded by the Department of Health and Social Care has established nine standards which a Trust in England must meet in order to provide high quality bereavement care. These standards were developed and agreed by the collaborative project team, including: Sands; NHS England; RCOG; RCM; RCN; ARC; Bliss; The Lullaby Trust; Miscarriage Association; RCGP; Institute of Health Visiting; Neonatal Nurses Association. They have also been endorsed by the All Party Parliamentary Group (APPG) on Baby Loss. A National Bereavement Care Pathway is also currently being developed in Scotland.

Neonatal units looking to improve their bereavement care service can use the standards as the basis for this. The specific neonatal pathway available on the NBCP website provides guidance on how to put these standards into practice.

Hospitals should audit provision against these standards and improve the bereavement care they offer if gaps are identified.

1. A parent-led bereavement care plan is in place for all families, providing continuity between settings and into any subsequent pregnancies.
2. Bereavement care training is provided to all staff who come into contact with bereaved parents, and staff are supported by their Trust to access this training.
3. All bereaved parents are informed about and, if requested, referred for emotional support and for specialist mental health support when needed.
4. There is a bereavement lead in every healthcare setting where a pregnancy or baby loss may occur.
5. Bereavement rooms are available and accessible in all hospitals.
6. The preferences of all bereaved families are sought and all bereaved parents are offered informed choices about decisions relating to their care and the care of their babies.
7. All bereaved parents are offered opportunities to make memories.
8. A system is in place to clearly signal to all healthcare professionals and staff that a parent has experienced a bereavement to enable continuity of care.
9. Healthcare staff are provided with, and can access, support and resources to deliver high-quality bereavement care.

# 10. References and resources

**NBCP (2018)** *Evaluation of the National Bereavement Care Pathway (NBCP) Wave 1 Final Report*, available at nbcpathway.org.uk/file/nbcp_wave_one_evaluation_report_final_0.pdf

**Sands (2016a)** *Pregnancy Loss and the Death of a Baby: Guidelines for Professionals, 4th edition*, London: Sands

**Sands (2017)** *Audit of Bereavement Care Provision in UK Maternity Units 2016* sands.org.uk/sites/default/files/Bereavement%20Care%20Audit%20Report%202016%20DIGITAL%20-%2010.01.17.pdf

**Sands (2018)** *"Working with interpreters when a baby dies: Best practice for health professionals",* available at sands.org.uk/sites/default/files/Working%20interpreters%20when%20a%20baby%20dies_Best%20Practice_LR_WEB_150418_1.pdf

# Additional Resources

Bliss Baby Charter

National Bereavement Care Pathway

Sands bereavement care training courses

Sands Perinatal Post Mortem Consent Package

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Sands
Stillbirth & neonatal death charity

**t:** 020 7436 7940
**e:** info@sands.org.uk
**w:** sands.org.uk



Bliss
for babies born premature or sick

**t:** 020 7378 1122
**e:** hello@bliss.org.uk
**w:** bliss.org.uk