A pathway to improve bereavement care for parents in England after pregnancy or baby loss

national bereavement
care pathway
for pregnancy and baby loss

Neonatal Death

Full Guidance Document

Led by Sands

Sands

In partnership with:

ARC Antenatal Results & Choices
Bliss for babies born premature or sick
iHV Institute of Health Visiting Excellence in Practice
the lullaby trust
Miscarriage Association The knowledge to help
Neonatal Nurses Association
UCL EGA Institute for Women's Health
Royal College of Midwives
RCGP Royal College of General Practitioners
Royal College of Nursing
Royal College of Obstetricians & Gynaecologists
NHS England

NBCP for use in England from July 2022 onwards

Bereavement care standards

A Trust that meets these standards is considered to be providing good bereavement care. Trusts should audit provision against these standards and improve the bereavement care they offer where gaps are identified.

A self-assessment tool is available for all Trusts who sign up to the NBCP. more information can be found at nbcpathway.org.uk or by contacting the NBCP team at Sands.

Implementation of these standards via the pathway will help the Trust to meet the elements of the Care Quality Commission's Maternity Assessment Framework that cover these points **(www.bit.ly/2zNYZEd).**

In time we are hopeful that the CQC will also include these elements within their inspection frameworks for other departments.

- A parent-led bereavement care plan is in place for all families, providing continuity between settings and into any subsequent pregnancies.
- 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.
- All bereaved parents are informed about and, if requested, referred for emotional support and for specialist mental health support when needed.
- There is a bereavement lead in every healthcare setting where a pregnancy or baby loss may occur.
- Bereavement rooms (appropriately equipped and ideally soundproofed) are available and accessible in all hospitals.
- 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.
- All bereaved parents are offered opportunities to make memories.
- 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.
- Healthcare staff are provided with, and can access, support and resources to deliver high quality bereavement care.

The NBCP during the COVID-19 pandemic

The NBCP Core Group are aware of the restrictions the pandemic has had on good bereavement care practice. As the terminology page (overleaf) acknowledges, these are guidance notes rather than clinical necessities. As such, some best practice will not always be possible, for example providing face-to-face meetings, enabling partners to appointments, etc.

However, wherever practicably possible, healthcare professionals should aim to put the needs of the mother and partner as the highest level of priority.

Communication

All communication with parents experiencing a pregnancy loss or the death of a baby must be empathic, sensitive, non-judgemental and parent-led.

Differences between people's culture, ethnicity, age, socioeconomic status or other factors are likely to influence communication. Parents may have had different experiences of accessing medical care, of communicating with medical professionals. Some may find it less easy to ask questions, request clarification or express their wishes.

Use warm, open body language by sitting near parents, facing them, making eye contact and using touch if appropriate (being mindful of Covid restrictions). Be mindful of your tone and background noise if communicating over the telephone. Be honest with parents while being as sensitive as possible. It is okay to show emotion, but the parents should not feel they need to look after your feelings. Professionals should be their normal empathic self, avoiding being either 'cold and calculated' or 'touchy-feely'. In INSIGHT (Siassakos et al, BJOG 2017) parents asked for 'friendly contact'.

Parents may be shocked and/or very distressed, and may find it difficult to understand information or think clearly. Staff should speak clearly and use simple language and parents should be encouraged to ask questions. Be aware that cultural norms or personal circumstances may affect a parent's readiness to ask questions, request clarification or express their wishes.

It should be noted that multiples were 4.1 times more likely to experience neonatal death than singletons (MBRRACE 2019) and are much more likely to be born early, so practitioners should bear this in mind when communicating with parents of multiples (further sections of this pathway go into more detail).

Supporting parents when communication barriers are present

Staff should never assume that they can anticipate the needs of any individual with a sensory impairment, learning difficulties or who is experiencing a language barrier. Staff should ask parents if they need additional support and about their preferences. Staff should record this information in a prominent place in parents' medical notes (with their consent) (see Stillbirth Pathway, Appendix A10).

Staff should be patient and sensitive to individual needs. Where an interpreter is required, staff should have easy access to trained and experienced interpreters (ideally face-to-face) when supporting parents.

Communicating if there is no interpreter

- Using family and friends to interpret is strongly discouraged.
- Parents may not want the informal interpreter to know everything about them and may not feel able to discuss things fully or truthfully.
- An informal interpreter who is a family member or friend may themselves be deeply affected by the situation and their ability to interpret may also be affected if they become distressed.
- It is never acceptable to use a child or a young person under the age of 16 years to interpret for parents who are experiencing the death of a baby unless immediate emergency care is required and no other options are available. This can put the child in an extremely difficult situation and can cause serious emotional trauma.
- Some parents may be accustomed to their children interpreting for them. They may have a cultural expectation that their children will interpret for them. However, staff should inform parents that it is the hospital or clinic's policy to not allow children to interpret in order to avoid possible misunderstandings.

Multiple births

In the case of a multiple birth, parents may feel torn between their babies and feel even more pressure if they have other children. Parents should be encouraged to spend time with healthy babies and with babies that are sick or unlikely to live.

Many hospitals will also try to keep babies together. If parents have two or more babies in the unit, they should be placed near to each other if possible. The babies' incubators should be visually distinguishable from each other and individual care plans should be devised for the babies.

For many parents it is very important to see, hold and/ or photograph all their babies together and with the family. This may be their only chance to do so if one of the babies is critically ill and this opportunity should be offered to parents. Some parents may also want to place a photo of the baby or babies who dies with or near the surviving baby or babies.

If one baby has already died, it is important that the staff caring for the surviving baby or babies in the neonatal unit recognise the importance of all the babies to the parents and listen when the parents want to talk about the baby who has died. Support from staff will be crucial for parents' well-being. If multiple agencies / departments are involved in caring for a family, one member of staff should be allocated as the main contact for the family so as not to overwhelm them. Many parents appreciate it if staff bring up the subject of the baby who has died, as this gives them an opportunity to express their feelings. Parents should be offered specialist bereavement support if one baby has died and another baby is still being cared for on the neonatal ward. However, some parents may find that they are not ready to access this support, particularly if they are putting their feelings on hold while focusing on the surviving baby or babies. Parents should be told about the support that Twins Trust bereavement group can offer them at any point after the death of one or more of their twins, triplets or higher order multiples.

Staff should also be aware of the position of the cot or incubator of the surviving baby or babies. It may be distressing for some parents if surviving babies are located near other multiples on the unit. It can be particularly difficult after one baby has died to see a new baby in the same incubator/ cot so staff should be sensitive to this.

Parents should be offered a purple butterfly cot card which can be placed in the surviving twin or triplets incubators or cots, and the name of the baby that has died can be written on the card. https://twinstrust.org/bereavement/support/purple-butterfly-cot-card.html. A training session also provides further information: www.futurelearn.com/courses/loss-of-a-baby-from-a-multiple-pregnancy-the-butterfly-project.

Some parents may feel pressured to make funeral arrangements in haste for the baby or babies who have died, particularly if they feel that they need to focus on the surviving baby or babies. Staff should offer parents informed choices about their options for a funeral. Parents may also choose to delay the funeral for the baby who has died while any other siblings remain in the hospital.

> **"We know we are luckier than some, at least we had three bitter-sweet days with our baby. But losing her just broke my heart."** Mother

Memory making

Providing care for their baby who is not expected to survive may help parents feel like they are parents and help create some precious memories.

Many parents will welcome suggestions and ideas from experienced staff such as touching and talking to their baby, having skin-to-skin contact, changing their baby's nappy or feeding their baby. Mothers may wish to put the baby to the breast for comfort rather than only for feeding.

Parents should be supported but not pressured. Staff could also suggest that the parents might want to create keepsakes or take photographs or videos of their baby in the unit. Some neonatal units provide journey boxes or parents may wish to make one where they can store keepsakes from their baby's time spent on theneonatal unit. Older siblings can be supported to take part in memory making activities.

Some parents may want to put a toy, family photograph, drawings or letters from siblings in the incu bator. Others may want to bring in religious items.

If necessary, parents should be asked to check with staff before they bring anything in so as to reduce the risk of infection. Religious and other valued items should not be disturbed or removed without prior discussion with the parents.

Parents should also be offered information about transferring their baby's care to a local children's hospice when this option is available. The environment in a children's hospice is less clinical and parents will be supported to spend as much time as they would like with their baby and their family with no time restrictions. Family rooms may also be available in the hospice where parents can comfortably stay while spending time with their baby.

Visitors

When a baby is unlikely to live for long, there should be no or few visiting restrictions for siblings, grandparents and other family members, provided that the parents have agreed to these visits. Parents may also want friends or religious advisers to see their baby and this should be facilitated if possible. Other people may be able to be more supportive to the parents later if they too have memories of the baby to share. However, restricted space in the unit may mean that the number of visitors present at any one time has to be limited, especially with any additional COVID restrictions. It can be helpful if staff acknowledge and introduce themselves to other family members (especially siblings) when they visit the ward.

Some parents cannot spend a lot of time with their baby because they have other commitments and pressures. Others may find it too distressing or frightening. Gentle encouragement and support may help some parents to feel more confident. When caring for parents who may be apprehensive about spending time with their baby, staff could gently suggest that they will stay with parents or be present just outside the door if parents would prefer. Parents should be told that there is no rush and they should be supported to decide what feels right for them with no pressure.

Some women may also be reluctant to travel on public transport by themselves, or be physically unable to do so for some weeks after the birth.

Additionally, some women who speak little or no English may be afraid to visit without their partner or another family member. Interpreters should be arranged to support families where necessary. Women who follow the tradition of resting at home for several weeks after giving birth may also be unable to come.

It is important to reassure all parents who find it difficult to spend time in the unit that their baby is receiving the best possible care and attention from staff.

Discussing a post mortem examination with parents

The first step is to establish the parents' willingness to discuss the possibility of a post mortem examination. Some parents may ask about a post mortem examination and welcome the discussion. For other parents, there may not be a good time to discuss the topic and staff may need to gently mention a post mortem examination and give more details when parents are ready. Parents who do not wish to discuss a post mortem examination should be told that staff will check with them again later. If parents do not want to be asked again later or refuse a second time, this should be respected and recorded in the parent's medical notes. They should not be asked more than twice to avoid parents feeling pressured.

A post mortem examination could also be mentioned when staff are discussing moving to palliative care on the neonatal unit. Consent should not usually be sought until after the baby's death and at a time that is suitable for the parents. Staff should be honest and realistic when telling parents about post mortem timelines.

Location

All post mortem examinations on babies should be carried out by specialists in perinatal pathology in regional centres.

During the consent process, parents must be informed if the post mortem examination is to be carried out at another hospital and the reasons for this transfer. They should also be told where their baby's body is being sent, when and how it will be transported and when it will be returned so that parents can see their baby or arrange a funeral after a post mortem examination if they wish. Some parents may appreciate being told about who will be transporting the baby and caring for them in the mortuary.

The timing of the transfer should allow parents as much time as possible with their baby. Staff should be aware of local transport arrangements where applicable and be able to tell parents about how these might affect their time with their baby. The body should also be returned as soon as possible after the post mortem examination.

All transport arrangements and handling of the baby must be respectful and the baby's body must be clearly labelled and tracked.

Results

After the post mortem examination, the parents will have a follow-up appointment to discuss the results. If there is a delay to the post mortem examination results, it is important that this information is shared with the healthcare team supporting parents and that this information is conveyed to parents as soon as possible. It can be very distressing for parents who expect to receive results and do not receive them when expected or feel they need to chase results so good communication across teams and with parents is paramount.

Policies and practices should be in place to ensure that there are good communications between pathology staff and healthcare teams. This coordination between services will help to ensure that staff are aware of the time scale for receiving results when booking follow-up appointments with parents and help them to keep parents informed of any delays. A named contact should be designated within each pathology and neonatal team to facilitate the return of post mortem examination results and ensure that a specific person on the healthcare team is responsible for following up on results. The parents should have the medical terminology of cause of death explained to them that is written on the certificate.

Care and support for parents in the community

Hospital staff and primary care staff such as GPs, community midwives and health visitors are all important sources of ongoing care and support for many bereaved parents.

In the first few days at home, some parents may be in shock. At this time, they may also be busy with visits from family members and friends as well as organising and preparing for a funeral.

However, many parents are left to cope on their own or feel alone once other people return to their normal routines. In the days and weeks that follow, some parents may also experience their loss and grief more intensely.

Some parents may appear to be well supported by their family and friends. However, these parents may not be getting the help that they need. Some may distance themselves from family members or try to hide their grief.

Some parents may also find that friends and relatives avoid them or are unable to listen. This may be because they do not know what to say, they are experiencing their own grief for the baby or they may be experiencing renewed grief for past losses. This can add to the isolation many parents can feel following a pregnancy loss or the death of their baby.

It is important that parents receive information about the support available from their primary care team and that the primary care team have the training required to offer good bereavement care. It is also crucial that GPs and other primary care staff take the initiative to offer support to parents, rather than wait for parents to ask.

Bearing in mind that a partner's grief may manifest itself in different ways and often at a later stage, good follow up care by the GP or Health Visitor for partners is essential so that this may be recognised and supported. Further, support should be provided by the key worker as laid out in the statutory Child Death Review guidance. This person should be allocated in every instance where a baby dies.

Communication between hospital and primary care teams

Primary care staff should be promptly informed that a woman has experienced a pregnancy loss or the death of her baby. The appropriate member of staff can then contact her and ensure that she is not sent reminders for antenatal appointments and immunisation clinics.

Hospital staff should explain the benefits and importance of receiving support from their primary care team to bereaved parents. Many mothers will give consent to the hospital contacting their GP or primary care team. Other mothers may not want their GP or primary care team to be informed and it is always important to check. If a mother declines to have her primary care team informed, this decision must be respected. The mother should also be told where she can receive additional care if required. Additionally, she should be given a letter summarising her history and treatment to give to her GP or another doctor if she needs further medical care. Staff can also offer to help mothers register with a GP or change their GP if necessary.