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



national bereavement
c a r e p a t h w a y
for pregnancy and baby loss

Neonatal Death

Full Guidance Document

Led by Sands



In partnership with:



NBCP for use in England from July 2022 onwards



About the NBCP

The National Bereavement Care Pathway, led by a multi-agency Core Group of baby loss charities and professional bodies, has been developed in order to improve bereavement care, and reduce the variability in bereavement care, for families suffering the loss of a baby through miscarriage, ectopic pregnancy and molar pregnancy, termination for fetal anomaly, stillbirth, neonatal death or sudden and unexpected death in infancy up to 12 months.

The project provides a dedicated, evidence-based care pathway with guidance for professionals delivering bereavement care to parents and families. As its name infers, it is a national project, although at this stage its scope is limited to England and not the devolved nations. Information on the Scotland pathway can be found at www.nbcscotland.org.uk

This booklet, developed for healthcare professionals working with bereaved families, relates to one of the five pathways which have been piloted in 32 sites and independently evaluated, the report for which can be found on the website below.

The Core Group gratefully acknowledges the support and contribution of the Department of Health and Social Care (DHSC) and Teddy's Wish to the early development of the NBCP.

For further information, please see www.nbcpathway.org.uk

“Parents don’t need protecting; they need the chance to be parents, provide their child dignity and create memories.”

(Quote by bereaved parent, 2017)



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Note to the reader

This is the first of two guidance materials we have produced for the National Bereavement Care Pathway (NBCP). This document contains detailed reference material and guidance whereas the second document is a more ‘hands on’ and practical approach to providing bereavement care for families, including a number of templates and tools for you to adapt and use in the local setting.

For more information, please see www.nbcpathway.org.uk or contact your local Bereavement Lead.

Key messages

In our consultation with parents three clear messages came through:

1. Good communication is key to delivering good bereavement care



“For me the simple things make a huge difference.

Being listened to. Eye contact and someone sitting beside me – communicating they have time for me.” (M.E., 2017)

“Why didn’t anyone check in with me afterwards?

I had been on their records and yet [there was] no call the week after to see how I was doing. [There was] no information of what to expect or where to get help.” (N.B., 2017)

2. Continuity of care and consistency in approach is vital



“I would have loved to have birthed the baby at home as I had had previous homebirths – but this option was not given, **and I was not aware this was a choice I had.**”

(M.E., 2017)

“I found it really distressing to have to explain over and over again to different members of staff that my baby had died.”

Mother (Sands Guidelines, 2016)

3. Parent-led family involvement must be supported



“I would have liked to have had been offered a couple of sessions with a midwife with my husband where we could share our story and debrief.”

(M.E., 2017)

“I wish someone had given us more time to talk about the benefits of seeing the baby and spending time with him and of inviting the other kids to come and meet him.” (M.E., 2017)

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.

Terminology

The NBCP (National Bereavement Care Pathway) Editorial Panel acknowledges the current debates, discussions and difficulties around terminology and language facing healthcare professionals and have attempted to unify language across the pathways to ensure a consistent approach.

The Panel also recognises that as healthcare professionals it may be easier to verbalise the correct terminology with your knowledge of the person in front of you, rather than the panel trying to cover all bases in written documents.

As such, we offer the following as overarching guidance:

- The terms 'healthcare professionals' and 'staff' are used throughout to denote all of those working with bereaved parents
- Per recent NICE guidance on induction of labour (<https://www.nice.org.uk/guidance/ng207>), we use the terms 'woman' and 'women', based on the evidence used in its development. The recommendations will also apply to people who do not identify as women but are pregnant or have given birth.
- Similarly, the term 'baby' (or 'babies' in the case of multiple pregnancies) is used throughout, from the early stages of pregnancy through to the neonatal period. Many people will conceptualise their baby and develop strong attachments to them from the moment they discover that they are, or were, pregnant. However, others will be more comfortable with medical terminology such as 'fetus' and may not find the term 'baby' to be appropriate in their situation. Again, while we have used the term baby, it is important to recognise that the wishes and viewpoints of those experiencing the loss should always be the most important factor when communicating with them.
- The term 'parents' is used to refer to expectant and bereaved mothers, fathers, and partners. Many people will consider themselves parents from the time they discover they are, or were, pregnant while others will not. Therefore, it should be acknowledged that not all who have experienced a childbearing loss would consider themselves to be, or have been, a parent. It is also important for those who do identify themselves as parents to have this recognised.
- The term 'partner' is used to refer to whoever is there as a close support to the person being cared for. Not everyone will have a partner and/or may not have them with them in the clinical setting, and as such, the guidance should be adjusted accordingly – for example discussions with the birthing partner or accompanying friend/family member.
- We have used the phrase 'Trusts' because the rapid changes in the way that health services are structured and managed across the country make it impossible to use a phrase that covers all the bodies involved. In the devolved nations the term 'Board' is used. However, the pathway will also be applicable to independent healthcare establishments and to all other bodies that may be set up in the future to organise and provide care for women and families experiencing a childbearing loss.
- 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.

As is set out in the pathway guidelines, healthcare professionals should use the terminology preferred by those experiencing the loss when communicating with them.

Finally, because this is a pathway focused on improving outcomes for families, by its very nature it is quite directive and as such in a number of sections we have also used the term 'should' (for example 'staff should be trained'). Essentially this is shorthand for 'good practice suggests that'.

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.

Communicating with parents who are deaf or who have a hearing impairment

In addition to offering a sign language interpreter, staff who are communicating with parents who are deaf or have a hearing impairment should ensure that:

- A quiet place is available for discussions.
- They avoid wearing a mask or covering their mouth depending on relevant COVID restrictions and local protocols.
- They avoid shouting, speaking slowly or exaggerating speech or facial expressions.
- They use clear, simple language and provide clear, simple written information.

Communicating with parents who are blind or who have a visual impairment

Staff should introduce parents who are blind or visually impaired to everyone involved in any discussion and told where everyone is located.

Communicating with parents who have learning disabilities

It is important to remember that parents with disabilities often have their 'passport document' with them, which indicates how best to communicate with them.

Diagnosis and delivering difficult news

Parents should be told as soon as it is suspected that something is wrong, even if it is not yet confirmed or certain. Parents often sense from the reactions of staff that something might be wrong and this may cause them additional distress and anxiety and reduce their trust in staff if they are not told what is happening.

Delivering difficult news can be extremely difficult and stressful for staff and it is important that all staff have the skills to sensitively inform parents when something is wrong.

It is important that all staff have training so that they have the skills to sensitively inform parents when something is wrong. For some staff groups this could include the knowledge to know what to say if they must leave to request a more senior or experienced colleague join them.

Communication during and after an ultrasound examination

Whenever possible, sonographers should explain what they are doing during an ultrasound examination as long silences may be very hard for parents. Staff should be aware that parents are often highly sensitive to non-verbal messages and body language.

If an anomaly or another reason for concern is found during a scan, the sonographer should tell the woman as soon as possible that there is something on the scan that needs to be looked at more closely. It is important not to pretend that all is well or offer false reassurance.

Parents should be offered a scan photograph. If the parents do not want a photograph, the sonographer could offer to take one and keep it in the woman's medical records so that they can ask for it later if they wish. Parents should not feel pressured to accept the offer of a photograph.

Decision making after a difficult diagnosis

Parents who have decided to continue with a pregnancy after their baby has been diagnosed with a potentially life-limiting fetal anomaly need special care and support during labour and birth. These parents should also be offered referral to a local hospice if this service is available.

At the right time, a special care baby plan should be written between specialist staff and the family to ensure all professionals know the plan moving forward for labour and birth. Part of this discussion should be around the option of referral to a hospice.

Communication when the baby dies during or very soon after birth

There will be some instances where a baby will die on the delivery suite and never make it to a neonatal unit. Some of these will be premature babies, but some may be babies who were expected to survive, but who are compromised by an intrapartum event, are born just breathing and where resuscitation is attempted on the delivery suite but unsuccessful.

Parents must be offered the opportunity to see and hold their baby for what precious minutes and moments exist before they die. Research shows these missed opportunities to be close to their baby, to parent them for even a short time before death, are important to many parents. This is particularly important if the mother's partner is not present or she has had an Emergency C-section, is alone or unsupported. Professionals, such as anaesthetists, should be included in training around supporting parents in informed decision making about seeing, holding and making memories of their baby.

Communicating on the neonatal unit: Discussions with parents about their baby's condition

Within 24 hours of admission to a neonatal unit, all parents should have a documented consultation with a senior member of the neonatal team. They should also have opportunities to talk with a senior member of staff if their baby is seriously ill or dying. The baby's weight and gestation at birth will impact on the care options available.

Additionally, parents should be kept informed and be involved in discussions about changes in their baby's condition, prognosis and care as soon as possible.

For many parents this is an important part of taking parental responsibility and their identity as a parent, especially when they feel that they have no control over the situation.

Parents should be encouraged to write down any questions and/or responses received to refer to later.

A private, comfortable room should be available for discussions with parents on the neonatal unit. It is very important that information is given sensitively to parents by staff who are trained in breaking bad news and the baby's name should be used if they have been named.

Interpreters should also be arranged when needed.

Parents need to be given clear, understandable, consistent and honest information about all tests, developments and interventions. Staff should normally avoid using technical terms or these should be explained using everyday language. Parents should be encouraged to ask questions and to say if they find anything difficult to understand. It may be necessary for staff to repeat what they have told parents on several occasions as stress and anxiety can strongly affect people's ability to take in and remember information. Parents may wish to write this information down. Some parents may also want to invite another person such as a family member or friend to be present for these discussions.

Parents should have easy access to members of staff who can answer their questions between formal discussions. Some parents may have questions and concerns at times when the consultant team is not there. Others may find it easier to talk to less senior members of staff. In both cases, parents should be encouraged to raise issues with any member of staff with whom they feel comfortable. If their questions cannot be resolved immediately, the member of staff concerned can approach the consultant team on their behalf.

All discussions with parents should be documented to ensure parents receive consistent information. In order for parents to receive consistent information, it is essential that staff work in a well-functioning multidisciplinary team where information is shared with all staff (including junior staff) and across disciplines and teams. To ensure consistency, it is good practice to have a differently coloured parent communication sheet in the front of the notes where staff can record what parents have been told.

Parents should have designated members of staff (including a named nurse) who take the main responsibility for checking that the parents feel informed and listened to and who raise and discuss sensitive and difficult issues and decisions with them.

If a baby dies suddenly on the neonatal unit

Parents should be sensitively informed as soon as possible after their baby dies if they were not present. This information should be shared with parents in a private place and in person wherever possible. The baby's death should be confirmed to parents using clear, simple, unambiguous language. Parents may need time to process this information and some parents may not be able to believe that their baby has died when the baby's death is sudden or unexpected.

Leaflets and other information from charities such as Bliss, Sands and Child Bereavement UK which contain helpful advice for parents can be offered as appropriate (see appendices for further details)

Best practice points that staff should follow when breaking bad news to parents:

- Where possible, offer a member of staff that the family have met before to be present
- Before breaking bad news to parents, staff should prepare what they are going to say and ensure that they have accurate information.
- Many parents appreciate an indication that the member of staff understands the impact of what they are saying.
- Phrases such as “I am afraid it is bad news...”; “I am sorry to say that the results are not what we expected...” or “I am afraid this is not the news you wanted...” may be helpful.
- Find the most appropriate private place available to break the news.
- If one parent is on their own, check whether they would like to contact their partner or another supporter who might be able to join them.
- Check whether an interpreter or other support for communication is needed.
- Use warm, open body language by sitting near parents, facing them, making eye contact and using (being mindful of Covid restrictions) touch if appropriate.
- Use clear, straightforward communication and do not use euphemisms. For example, when a baby’s death is confirmed during a scan, use words such as “your baby has died” and not euphemisms such as “I’m afraid your baby has gone.” It is important that the message is clear and that parents are not left with false hope.
- Be honest with parents while continuing to be as sensitive as possible.
- Express genuine concern and empathy by using phrases such as “I’m very sorry” or “What a terrible shock for you – I’m so sorry.”
- Ensure that parents have sufficient time to absorb what they have been told, check their understanding of the information they have been given and ensure they have time to express their concerns and ask any questions.
- Be honest when a baby’s diagnosis or prognosis is uncertain and acknowledge that this is likely to be very difficult for parents. If the member of staff who is with parents at the time cannot give them accurate or sufficient information, they should be honest about this and offer to arrange for parents to speak with someone more knowledgeable as soon as possible. Parents should not be given information that they may later discover is incorrect.
- Parents will likely be shocked and distressed after receiving bad news and they may find it hard to absorb and remember what they are being told. Parents may only hear the first one or two things that are said and then be unable to focus on additional information. Staff may need to repeat themselves and should check that parents have understood what they are being told. It may sometimes be helpful for staff to phrase information in different ways. While staff should provide parents with as much information as they want, they should also ask parents how they are feeling and offer to arrange a further time to discuss additional details. Repeated discussions may be necessary, particularly if there is a lot of information to convey.
- If there is a lot to discuss, staff should start by dealing with any topics that parents want to discuss and the immediate decisions that parents may need to make. Staff should be prepared to leave discussing less pressing information until later, depending on the parents’ wishes. It is important to watch for signs of distress and exhaustion and to ask parents if they would like to take a break and continue the discussion later.
- If a parent is going home alone after receiving bad news, staff should suggest that they might like to call somebody to accompany them. This can be very important if they are planning to drive home and/or live a long way from the hospital.
- Staff should ensure the cultural and religious needs of the parents and family are supported wherever possible. Staff should offer to contact the family’s spiritual/religious support or hospital chaplaincy/spiritual service. Where possible, the consideration of the parents’ religious and cultural needs should influence the timing of any planned/scheduled communications.
- Communicating with Covid restrictions in place can prove tricky - the Sands leaflets ‘sensitive and effective communication’ <https://www.sands.org.uk/professionalsprofessional-resources/sensitive-and-effective-communication> and ‘communicating while wearing PPE’ <https://www.sands.org.uk/professionalsprofessional-resources/communication-while-wearing-ppe> can be helpful

“I so wanted to hold my baby and to hear his cries, but they did not come. After a strange amount of time that seemed like a second but also like an eternity, a woman doctor came over, put a hand on my arm and said, ‘I’m sorry, but we have been unable to resuscitate your son. I’m so very sorry.’”

Mother

Parents may need time to absorb the reality of what has happened and staff should offer parents support. However, staff should also give parents as much time as they need before offering parents information about creating memories and/or asking parents to make any other decisions.

It is often helpful to provide information regarding agencies that can give unbiased opinions and support.

Care on the neonatal unit

Many parents find being in a neonatal intensive care unit frightening and threatening at a time when they are already extremely anxious and distressed. Parents may experience a wide range of emotions. They might feel scared, disempowered, angry, loving, vulnerable, detached, guilty, like they want to run away, that they can't control their emotions, unable to bond with their baby and/or inadequate for not knowing how to help their baby. These emotions may be mixed with the joy of being parents, hope and optimism. They may have little opportunity to feel that they are parents to their baby (or babies) or that their baby belongs to healthcare staff. When a baby's prognosis is uncertain or is not expected to live for long, parents may also not be able to believe or need time to accept that their baby is going to die.

Parents are likely to be exhausted after the birth and may find that their sleep is disturbed by their fears and concerns. Some parents may also experience depression, anxiety or traumatic stress symptoms. These factors may make it harder for parents to deal with the often rapid changes in the baby's condition, understand what is happening and make difficult critical care decisions. The emotional and possible financial stresses linked with having a sick baby may affect parents, their relationship and/or other family members. Staff should be aware of signs of exhaustion and strain in parents and offer sensitive help and support if necessary.

Similarly, if the diagnosis is soon after the birth there needs to be an awareness of the mother's condition if she is physically unwell/ less able to move about.

A limited window to parent their child

Parents whose baby dies on a neonatal unit have limited time to be close to and parent their baby. Neonatal units should offer a family-centred approach to care which recognises the logistical challenges parents may face in being on the unit, and supports them to be as involved as possible in their baby's care. Parents may face practical, financial and indeed emotional challenges to being on the unit, but research shows that parents whose baby goes on to die as a newborn, look back at the minutes and hours they spent with their baby as extremely 'precious' and reflect negatively on opportunities to be physically close to their baby and involved in decision making about their care, which they may feel have been denied to them.

Some parents may find it distressing or frightening to be on the unit. Some women may be reluctant to travel on public transport by themselves, and some mothers may be unable to drive themselves in the weeks after birth, particularly if they have had a caesarean section.

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 feel unable to come.

Staff should be aware of how to support families with these challenges given that that the window for parents to be with their baby while they are alive, may be limited and opportunities not to 'parent' their child may be the source of future regret. 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

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

Putting parents at the heart of their babies' care

The Bliss Baby Charter provides a comprehensive toolkit to ensure that parents are at the heart of their baby's care and given unlimited access to their baby. Parents may therefore need support in making special arrangements to enable them to stay at the hospital. For example, they may need to arrange care for other children, transportation to the neonatal unit or accommodation if they live farther away from the unit where their baby is staying. Parents who observe religious or other dietary restrictions may also need to bring in their own food and drink or have food and drink brought in for them. If there are no kitchen facilities on or near the unit, parents may find the financial costs of buying food in hospital canteens, for example, an additional burden.

Parents may find it particularly hard to spend time with their baby when the baby requires specialist care and is transferred to a neonatal unit which is many miles away from their home. It is important that parents are made aware of the financial support available to them through benefits, the health service or local charities, and that units work hard to ensure that financial barriers are overcome.

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 parents may find it difficult to be with their babies on the unit for a number of reasons. These could be practical reasons, cultural reasons, or connected to barriers that they face. These could include difficulty in travelling, either by car or on public transport, financial challenges, physical or mental illness, disabilities, restricted mobility, other caring responsibilities, or following traditions which mean they will spend several weeks at home.

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.

I just wanted to be moved to where my baby was, but instead I had to stay in a room with an empty cot... Mother

If the mother is ill

Mothers who are unwell should be enabled to spend as much time as possible with their baby.

If the mother is in the same hospital but is unable to walk to the neonatal unit, and her physical condition allows, she should be brought to the unit in a wheelchair or hospital bed. This will allow her to spend as much time as possible with her baby. If the baby is transferred to a regional unit for specialist care to be provided then every effort should be made to transfer the mother to the same hospital for her care either simultaneously or as quickly as possible after the baby's transfer. If there is any period of time before this happens when mother and baby are separated, midwifery staff at the referring hospital should be asked to phone the regional unit to check the baby's progress and pass this information on. The information should not only be about the baby's condition and prognosis but also anything the staff can tell her about the baby's personality and reactions. This may help the mother to picture her baby as an individual.

Some units take digital pictures of babies and relay them to the mother's bedside. Taking a video or using a video calling service such as FaceTime or Skype to contact the mother may also be beneficial. Others have a password-enabled site for each baby, where the mother can view computer readings from her baby and comments and observations entered by nurses. While these technologies may be beneficial, bad news should always be given face to face with both parents (if applicable) or another family member or friend present to offer support.

Talking to parents about their baby's condition

A private, comfortable room should be available for discussions with parents on the neonatal unit. Where possible, offer a member of staff that the family have met before to be present. As per the section on communication above, it is very important that information is given sensitively to parents by staff who are trained in breaking bad news and the baby's name should be used if they have been named. Interpreters should be arranged when needed.

Parents need to be given clear, understandable, consistent and honest information about all tests, developments and interventions. Staff should normally avoid using technical terms or these should be explained using everyday language. Parents should be encouraged to ask questions (more than once) and to say if they find anything difficult to understand. It may be necessary for staff to repeat what they have told parents on several occasions as stress and anxiety can strongly affect people's ability to take in and remember information. Parents may wish to write this information down, or to be provided with a recording of the information where appropriate. Some parents may want to invite another person such as a family member or friend to be present for these discussions. The overriding principle is that parents' understanding of the information provided should be checked. Whenever possible, parents should be offered an opportunity to privately discuss important matters together in a quiet place or room.

At the end of formal discussions, parents should also be given a time when they can meet with staff again. Parents should be encouraged to write down any questions as they occur to them so that they can ask them when the opportunity arises. However, parents should also have easy access to members of staff who can answer their questions between formal discussions. Some parents may have questions and concerns at times when the consultant team is not there. Others may find it easier to talk to less senior members of staff. In both cases, parents should be encouraged to raise issues with any member of staff with whom they feel comfortable. If their questions cannot be resolved immediately, the member of staff concerned can approach the consultant team on their behalf. It is important that all staff are trained in supporting families on the neonatal unit.

All discussions with parents should be documented to ensure parents receive consistent information. In order for parents to receive consistent information, it is essential that staff work in a well-functioning multidisciplinary team where information is shared with all staff (including junior staff) and across disciplines and teams. To ensure consistency, it is good practice to have a differently coloured parent communication sheet in the front of the notes where staff can record what parents have been told.

Parents should have designated members of staff (including a named nurse) who take the main responsibility for checking that the parents feel informed and listened to and who raise and discuss sensitive and difficult issues and decisions with them.

Making decisions about critical care

Parents should be offered the opportunity to participate in all important decisions about the care of their baby, including critical care decisions when their baby is in a very critical condition. Whenever possible, staff should avoid implementing a major change in the baby's care without first explaining it to the parents. If decisions have to be taken in an emergency and the parents cannot be reached, staff should document the reasons for their decision. Parents should then be informed as soon as possible by telephone or when they arrive at the unit about the treatment their baby has received and the reasoning for staff's decisions. Parents should be involved and should also be able to ask as many questions as required to get the information they need, which may involve speaking to more than one healthcare professional.

In some cases, it may be difficult for healthcare staff to discuss care options with parents when they are unable to predict a likely outcome. Open and honest communication with parents about their baby's condition from the time of diagnosis is important. This will allow staff to support parents who remain hopeful about their baby's prognosis to simultaneously start considering realistic care options for their baby. It is important for staff to recognise that hope may be an important coping mechanism for some parents.

Parallel or anticipatory planning may be beneficial in such instances as care plans can be discussed by staff and parents for active treatment of the baby while also planning for palliative or end-of-life care should it become necessary. This parallel planning may also help parents to avoid feeling like they are "giving up" on their baby.

Critical care decisions are guided by the baby's best interests which staff have a duty to act upon in partnership with the parents. Consideration of the parents' interests are also important as these are linked to the baby's best interests. During discussions about critical care, parents should be treated as full partners in the discussion and with respect and dignity at all times. Further helpful guidance can be found at <https://evidence.nihr.ac.uk/alert/parents-meaningfully-involved-care-decisions-critically-ill-baby-when-given-options-not-recommendations/>

Withholding or withdrawing life sustaining treatment

Even though the final decision regarding the baby's care formally rests with senior medical staff to act in the best interests of the baby, healthcare teams should always aim to make a decision in full partnership with the parents and this will hopefully help everyone feel they can live with the decision.

Parents also have a legal responsibility to be involved in critical care decision making for their child alongside medical staff. All parents should be given the opportunity to be included in the decision about whether to withdraw or withhold life-sustaining treatment for their baby. Receiving information about their baby's prognosis and care may be important for some parents as it may reduce their stress in comparison to when they do not feel informed about the situation. Remember that this is a decision that parents will live with and reflect back on for the rest of their lives, so it is vital they have all the information and time they need to consider the options in full, and are comfortable with whatever decision is reached.

Some parents feel strongly that they themselves should take on the responsibility of deciding what is best for their baby and that this is part of the rights and duties of being a parent. However, even when parents want to make the decision themselves, they should not be left feeling that they are carrying the burden alone and should receive support from healthcare staff during decision-making.

Some parents want to be fully informed about the issues but feel that they should be guided by health professionals towards a decision. Parents may feel that they lack the requisite medical knowledge and professional experience to make a decision or they may think that they don't have a say in decision-making.

Both parents and staff are likely to have views and opinions about what should and should not be done when considering withdrawing or withholding life-sustaining treatment. It is important that there is excellent communication and co-operation during these discussions and that everyone has opportunities to voice their views and feelings, listen to each other and, if possible, reach a consensus. Co-operation is important as staff offer their medical expertise, experience and reasoning while parents contribute their values, preferences, family circumstances and understanding of the situation.

Staff should offer to fully explain the baby's condition and options for care, including parents' options for symptom control and taking the baby home or to a hospice for extubation. This information may be important as some parents have lingering doubts about their decision to withdraw or withhold life-sustaining treatment if they were not convinced that there was sufficient evidence to confirm their baby's poor prognosis.

Some parents may also want to involve family members, friends or a spiritual adviser in discussions with medical staff. Support from these sources may help parents gain a sense of control, help them to reflect on their baby's best interests and encourage confidence in the healthcare team. Some parents may also feel that a chaplain or other supporter has more time to sit and talk about their concerns and they may be able to offer ongoing comfort and support. Staff should offer parents information about local resources and the Bliss website <https://support.bliss.org.uk> which is available to support parents.

Following the initial meeting about withdrawing or withholding life-sustaining treatment for a baby, parents should be given time to think about the decision. Another appointment should be arranged for them to discuss their baby's care further with a senior member of their care team. It is important that making a decision is a process rather than a singular event as parents and others involved in decision-making may better understand the available options over a period of time.

Consideration to organ donation may be given at this stage (further details are on page 24).

Palliative care

It is essential to prepare parents by offering them information about what palliative care for babies normally entails and the opportunity to be involved in their baby's care at this stage. Before life-sustaining treatment is withdrawn, staff should offer to have a private, face-to-face discussion with parents to discuss the options for their baby's care and give parents adequate time to ask questions and talk about their views and feelings. Parents may appreciate someone being able to listen to their concerns, particularly as many parents will not have seen anyone die before and may feel frightened by the prospect.

The process of moving to palliative care should be thoroughly explained to parents and they should be reassured that this does not mean that care is being withdrawn from their baby. This explanation should include a discussion of the benefits of palliative care (including keeping the baby pain-free and comfortable) and its ability to reduce harm to the baby, particularly if parents are sceptical or uncertain about the need for this care. The following information and options should also be discussed with parents before their baby starts to receive palliative care:

- The time and place for the withdrawal of lifesustaining treatment. Parents should be offered information about the available options for taking the baby home or to a hospice to receive palliative care (even if the baby is not expected to live for long). If the baby has been transferred to a unit that provides specialist neonatal care, consideration should also be given to transferring them to a neonatal unit or hospital that is closer to parents. If the mother is ill and still in hospital, the possibility of the baby receiving palliative care on the postnatal ward could also be discussed.
- Whether or not parents want to be present when life-sustaining treatment is withdrawn or their baby dies. Parents should also be told that they can change their mind about whether to be present.
- Whether or not parents wish to have a dedicated member of staff available to be with them or nearby when life-sustaining treatment is removed.
- The possibility of parents inviting family members or close friends for support.
- The baby's possible physical reactions to the change in care. It should be explained to parents that the baby may gasp or change colour when the ventilator is removed. The role of opiates in diminishing pain and distress during extubation should also be discussed with parents while acknowledging that the use of opiates may also hasten the baby's death.
- Any spiritual or religious needs or requirements that the parents may have.

To some extent, this will all depend on what the available local options are and where parents decide to have their baby receive palliative care. This could be on the neonatal unit, postnatal ward, at home or in a hospice. Depending on the unit's available facilities, the option of labour suite/bereavement suite might be given. It is important that the options discussed with parents are realistic and that they are clearly told what may or may not happen.

Providing privacy for families is essential. Whenever possible, parents who want to stay with their baby should be offered a separate family room on the neonatal unit (or a private room on the postnatal ward if the mother is still receiving care). Staff should remove as much equipment as possible from this room. The unit or hospice should also have a comfortable sitting room where parents can spend time with their baby that is large enough and has enough chairs to accommodate several people if necessary. This room should have a cot or Moses basket available, a settee and soft, non-fluorescent, side lighting.

Further information can be found at: www.togetherforshortlives.org.uk/resource/perinatal-pathway-babiespalliative-care-needs

Parents may also want to take their baby out of the neonatal unit, particularly if the baby is expected to live for a while. Some parents may want to take their baby home, into the hospital grounds or to a local park. This may help them feel that their baby has experienced more than the hospital environment and has been a part of the wider world. It may also be helpful for parents to spend time with their baby away from the public space of the hospital in a private and/ or familiar place. Some parents will feel able to do this alone while others will need some reassurance and support. This may also be helpful for other family members (especially older siblings) or people who will be important sources of support for parents in the subsequent months and years.

If the baby is to be moved home or to a hospice to receive end of life care, it is important that the move and plans to withdraw life-sustaining treatment are well planned. It is crucial that the transport team, the neonatal unit team and any community-based care providers (for example, a GP, nurse or hospice staff) work well together and have good communication. If parents want to take their baby home or to a hospice to die, neonatal staff should give them a letter explaining the situation and containing the contact details of the unit. The community care team, including the parent's GP should also be informed. It is also important that parents are also given details about other types of community support and outreach programmes that are available to offer them support while caring for their baby at home or in a hospice.

Staff should ensure that the parents know that they can telephone or bring their baby back to the unit at any time of the day or night. They should also be told what they will need to do if the baby dies at home and be given information about how to obtain a Medical Certificate of Cause of Death (MCCD).

Information regarding communication with funeral directors and funeral arrangements can be found further down the document.

Further guidance with regard to the perinatal management of extreme preterm birth which references NBCP can be found at <https://www.bapm.org/resources/80-perinatal-management-of-extreme-preterm-birth-before-27-weeks-of-gestation-2019>

Care for parents around the time of their baby's death

Parents may want time alone with their baby in privacy before, during or after the death. Others may wish to have a member of staff present to support them, answer any questions and confirm the death when the time comes. If parents want privacy, they should be aware that the member of staff is available just outside of the room.

Some parents may want to hold their baby before the death and while they are dying. The designated member of staff supporting parents could also make gentle suggestions about parents' options to comfort their baby by holding them or putting them to the breast. They could also gently remind parents about their options for creating memories. It is important that staff make suggestions tentatively and gently as it may be particularly difficult for distressed parents to refuse if they perceive these suggestions to be instructions from staff.

Some parents may also have family members and friends with them for support and/ or to care for older children. Parents might want to offer these people the opportunity to see, possibly hold and/ or say goodbye to the baby. Staff might offer to take photographs of family members (particularly siblings) spending time with or holding the baby.

Some parents may appreciate seeing other staff members who have been most involved in caring for their baby. The staff concerned may also find this helpful.

Some parents may want to pray alone or with a chaplain or spiritual adviser. They may also want to hold a religious ceremony. Parents should be asked what they would like and staff should offer to contact whoever is needed and to help with arrangements. The parents should be offered privacy to hold any ceremony that they choose to perform. Some parents may be grateful if staff take part.

After their baby's death, parents should be able to be alone with their baby in quiet and privacy for as long as they want. They may also want to spend this time taking more photographs, making hand or footprints, washing or dressing their baby. Staff could also offer parents keepsakes from their baby's time in the neonatal unit or hospice to take away with them (for example, clothing or blankets used by their baby, wristbands, cot cards or other items used in their baby's care).

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 the neonatal 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 incubator. 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.

If the mother is ill

If the mother is in the same hospital but is unable to walk to the neonatal unit, and her physical condition allows, she should be brought to the unit in a wheelchair or hospital bed. This will allow her to spend as much time as possible with her baby. If the baby is transferred to a regional unit for specialist care to be provided then every effort should be made to transfer the mother to the same hospital for her care either simultaneously or as quickly as possible after the baby's transfer. If there is any period of time before this happens when mother and baby are separated, midwifery staff at the referring hospital should be asked to phone the regional unit to check the baby's progress and pass this information on. The information should be not only about the baby's condition and prognosis but also anything the staff can tell her about the baby's personality and reactions. This may help the mother to picture her baby as an individual. Some units take digital pictures of babies and relay them to the mother's bedside.

“I just wished my twins could have had cots next to each other. It would have made such a difference.” Redshaw *et al.* 2014: 33

Taking a video or using a video calling service such as FaceTime or Skype to contact the mother may also be beneficial. Some units have a password-enabled site for each baby, where the mother can view computer readings from her baby and comments and observations entered by nurses. While the use of technology may be beneficial, bad news should always be given face-to-face with both parents (if applicable) or another family member or friend present to offer support (if possible).

Parents with more than one baby

Parents should be encouraged to spend time with healthy babies and babies that are sick or unlikely to live.

Many hospitals will also try to keep babies together. 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 have died with or near the surviving baby or babies; some trusts use a butterfly sticker to put on a cot to indicate that this baby is the surviving twin / multiple of one who died.

“I have a precious photo of my whole family, taken when Sharon came out of the ventilator before she died. All my three children together for the first and last time.” Mother

“The nurses and doctors who cared for Charlie and Joshua were wonderful. We cannot thank them enough for all that they did for our twins. The neonatal unit helped to provide us with our wonderful memories and allowed us to get to know Charlie and Joshua as individual characters.” Mother

Providing care for parents around the time of their baby's death

Some parents may want to hold their baby before the death and while they are dying. Parents may be anxious of holding their baby and staff should offer support to parents who may want to, but lack the confidence to do so. The designated member of staff supporting parents could also gently remind parents about their options for creating memories.

It is important that staff make suggestions tentatively and gently as it may be particularly difficult for distressed parents to refuse if they perceive these suggestions to be instructions from staff.

Some parents may also have family members and friends with them for support and/or to care for older children. Parents might want to offer these people the opportunity to see, possibly hold and/or say goodbye to the baby. Staff might offer to take photographs of family members (particularly siblings) spending time with or holding the baby.

After their baby's death, parents should be able to be alone with their baby in quiet and privacy for as long as they want. They may also want to spend this time taking more photographs, making hand or footprints, washing or dressing their baby. Staff could also offer parents keepsakes from their baby's time in the neonatal unit or hospice to take away with them.

Seeing and holding their baby

It is important for healthcare professionals to offer all parents the option of seeing and holding their baby after death while recognising and respecting that some parents may decline this offer.

When the baby has an anomaly

If there is a visible anomaly, some parents may want to see the anomaly. They may find this important for understanding why their baby died. Other parents may want to keep the anomaly covered if this is possible. It is important to respect the parent's choice and follow their lead while also providing them with opportunities to discuss how they feel.

When parents are undecided about seeing or holding their baby after death

Some parents will want to see and hold their baby straight away while others may want time to decide. Some parents may choose to see but not to touch or hold their dead baby.

Some parents will decide that they do not want to see or hold their baby after they have died, and their decision should be accepted and respected. They should be told where the baby's body will be kept and that they can ask to see their baby if they change their minds. If there are time limits, this should be explained (such as due to a post mortem or investigation).

Careful notes must be kept about what has been offered to parents and what has or has not been done to avoid parents feeling pressured or not being offered options at all (See Neonatal Pathway document, Appendix A4).

Naming the baby

Parents often decide to name their baby. This may help parents and their family to talk about the baby while in the neonatal unit and in the future. A name may also be important for existing and future siblings, especially in a multiple birth where one or more babies survive. Staff should always use the baby's name when they have been given one by the parents. However, staff should bear in mind that some parents will not want to name their baby.

Creating memories. It is important that staff ensure:

- Parents are offered genuine choices.
- Parents are given time to reflect and decide what they want.
- Parents who have declined previous offers are not asked repeatedly if they have changed their minds; however parents should be gently offered different options more than once to enable them to change their minds if they choose to do so.
- Any views the parents may have expressed earlier are recorded and acknowledged.
- The condition of the baby is considered when discussing memory making with parents.
- Assumptions are not made about what a parent might want depending on gestation or cultural/religious background.

Photographs

“The community midwife suggested that I pack a camera to take pictures of our baby – I can remember thinking how terrible to take pictures of a dead baby. The pictures we now have of him are truly precious: vivid and beautiful memories of our treasured son. I’m so grateful she mentioned something so simple, important and caring.” Father

Photographs should never be taken without the parents' knowledge and permission. Parents' wishes must be respected if they say clearly that they do not want any photographs taken. Some parents may simply find the idea unacceptable or may not feel it is necessary. Some parents may regard it as forbidden to make an image of a person and may not want photographs or hand and footprints taken. However, staff should never assume for any reason that any parents will not want photographs of their baby. Photographs should always be offered.

Many parents treasure the photographs taken of their baby and of the time they spent together. Some parents may want photographs of their baby dressed and undressed, or with them and other members of their family or with friends. If parents have decided to wash and dress their baby, they may want photographs taken of these experiences, so they can remember them later on.

Where there is a loss in a multiple pregnancy, it is important to offer photographs of all of the babies together and with the parents. Many parents will take their own photographs with the phones or cameras, but where staff are taking photographs they must discuss with the parent whether they want photographs to include any visible anomaly/ies.

If parents are undecided about having photographs, staff can offer to take photographs and keep them sealed in the mother's paper or electronic notes in case they want them at a later date. Photographs must only be taken with permission of the parent.

Photographs taken as part of the post mortem examination should not be considered as a substitute for the photographs described above. However, some parents may request these photos and find them helpful.

Other keepsakes

Other keepsakes parents may want to take home include:

- Hand and foot prints.
- A record of the baby's weight and measurements.
- The baby's scan picture.
- The baby's cot card.
- The baby's identification bracelet.
- The baby's cord clamp.
- An identical set of the clothes the baby has been dressed in.
- Cards and ribbons from any flowers received.
- Clinical items used to care for their baby.
- A copy of baby's certificate(s).
- The blanket the baby has been wrapped in or toy they have been given.

These choices are very personal and only the parent can know what is right for them. Parents may feel unclear about what they want, and may need time to think about it. Some parents will think differently to their partner, or may keep changing their mind. It is important that parents are given the time they need to make the decisions that feel right for them.

Memorials

Many parents want to create a lasting memorial to their baby. Sometimes parents choose to do this shortly after their baby's death while others may decide to make a memorial later – sometimes many years after the baby died. Parents may welcome reassurance from staff that it is never too late to commemorate and show their love and grief for their baby.

There are many other public and private ways in which parents can create memorials to their babies. Some parents may welcome memorial suggestions from healthcare staff or want to contact a bereavement support group (see Neonatal Pathway, Appendix A14) to find out what other parents have done.

Some parents choose to write in the hospital or another book of remembrance, some will attend memorial services hosted by their local hospital or a local support group.

Parents may want to create a memorial or remember their baby in some of the following ways:

- Making a book or memory box about the pregnancy, birth and/or the baby's life and death.
- Pressing flowers from their baby's funeral to keep or to display in a frame.
- Making, buying, or commissioning a special picture, sculpture, engraving, embroidery or piece of patchwork or piece of jewellery.
- Lighting a candle on anniversaries or other special days.
- Buying a special vase and having flowers on anniversaries or at other times.
- Planting a tree or shrub in a special place, where the baby is buried or where the ashes have been scattered (if this is permitted).
- Writing a poem or letter to the baby or choosing a piece of writing or a poem to be framed.
- Writing an account of their experience of loss. Charities that support bereaved parents, such as [Sands](#), the [Miscarriage Association](#) and [ARC](#) sometimes publish parents' stories in their newsletters or other publications.
- Adding the baby to a family tree.

Organ donation

Newborn organ donation is not currently common practice in the UK. It is feasible though, and there have been positive outcomes for transplants from neonatal donors. Some parents may take comfort from knowing that their baby's organs will help another child.

When a baby has anencephaly or has been confirmed as having severe hypoxic ischemic encephalopathy, it may be appropriate to discuss the option of organ donation with parents or they may ask about this possibility. Organ donation should not be discussed with parents or confirmed as a possibility until staff have determined this option is possible following multidisciplinary discussions that include transplant teams. If parents have asked about donation and it is not possible, the reasons for this should be explained to parents. Parents should be reassured that their baby's care will not be affected if they decide to consider donating their baby's organs. To allow parents to make a fully informed choice, they should also be told how donating their baby's organs will affect their options regarding end of life care, post mortem examinations or spending time and creating memories with their baby after their baby dies. Parents' decisions regarding organ donation must always be respected.

All staff who are discussing neonatal organ donation with parents should receive training around how to communicate sensitively with parents.

Post mortem examination

In England, the Human Tissue Act 2004 and the Human Tissue Authority (HTA) Codes of Practice govern how the bodies and remains of babies are handled and stored by institutions, including during and after post mortem examinations. The legislation applies to stillbirths and neonatal deaths and deaths from SIDS. The HTA also issues guidance relating to the handling of remains following losses prior to 24 weeks' gestation.

Transporting the baby's body and remains outside the hospital

When a baby is transferred from home to hospital with the mother, the baby's body or remains should never be placed in a clinical waste bag. This is inappropriate and could also lead to the remains being lost or accidentally disposed of as clinical waste.

Any transfer of the baby outside the hospital should be discussed and agreed with parents beforehand. Drivers should know what they are carrying and should be given appropriate documentation when transporting babies' bodies.

Before storage or transferring a baby, the baby's body or remains should be labelled with the mother's name and NHS number or unique identification number, the baby's date and time of birth and/or death, the baby's name if they have been named, the baby's sex (if known) and the name and details of the person who verified the death. Items that parents want to accompany the baby should also be listed. Babies' bodies and remains should be appropriately covered, kept in the best possible condition and protected against accidental damage and avoidable deterioration.

If the case has been referred to coroners all tubes/lines etc. should be left in place and parents informed of this and why.

Placental examination (where relevant)

Consent for histological examination of the placenta is not covered by the Human Tissue Act 2004 as this is considered to be examination of tissue from the living for diagnostic purposes. That is, placental tissue is considered to be from a living person (the mother) rather than from a deceased person (the baby), in this case used for diagnostic purposes. While consent for examination is not legally required, it is good practice to seek consent for examination of the placenta, umbilical cord, membranes or amniotic fluid from parents. However, whether parents have consented to post mortem examination or not, placental examinations should be discussed with all parents and, wherever possible, all placentas from babies who have died should be sent for examination by a specialist pathologist.

If there is to be a post mortem examination, the placenta should always be sent fresh (rather than in formalin) with the baby's body, unless otherwise agreed with the pathologist. If parents do not want the placenta to be examined for any reason, the placenta is usually treated as a surgical specimen in the same way as following a live birth. Some parents may want to bury the placenta for personal, cultural or religious reasons. The parents do not need permission to do this, nor is there a need to inform any other authority.

Post mortem examination consent

Asking parents whether they would like a post mortem investigation to be carried out, and providing them with information about the procedure, is an area that many healthcare professionals find challenging. There are some key principles that can assist professionals in approaching these conversations:

- All parents should have the option of discussing whether to have a post mortem examination of their baby.
- No assumptions should be made about who will and who will not consent to a post mortem on the basis of, for example, religion and ethnicity.
- All parents should be given the information they need to make their own decisions.
- Obtaining consent for a post mortem examination is a process. The responsibility for giving information and answering questions lies with the consent taker. A form is only a record of what parents have decided.
- Parents should never be given a consent form without some preliminary discussion. They should never be left on their own to complete it unless they specifically request this.

Consent should be sought by a member of staff who has received training in seeking post mortem examination consent and the process and who has a good understanding of the procedures for which they are seeking consent. They should ensure they are up to date with their trust's requirement for updates regarding consent (i.e. yearly updates). It is a process that should involve careful listening and discussion. It should be unhurried (a minimum of one hour should be allocated for this process) and should help parents to reach decisions that are right for them. All discussions should take place in a quiet, private place where parents and staff will not be disturbed.

Seeking consent for a post mortem examination may differ from consent for other types of procedures as staff are often not performing or involved with the investigations themselves. It is vital that the person requesting consent has a thorough understanding of local policies and procedures for post mortems in their hospital and that they are familiar with the consent form so that they can confidently take parents through it. They should be aware of the potential benefits of a post mortem investigation and able to explain these to parents, but also that no definite cause of death may be found, particularly for earlier gestation losses.

It is important that the member of staff seeking consent knows how to clearly and accurately complete the consent form to avoid delays that might arise if the pathologist is unclear about the information provided. All staff who discuss consent for post mortem examinations with families should be in contact with the pathologist and/ or mortuary involved. They should regularly exchange information in order to ensure best practice is followed, as well as to optimise care and support for parents. The NBCP good practice website includes examples of helpful checklists relating to care at the mortuary.

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.

Coroners

The doctor must report the death of a baby to coroner if:

- The cause of a neonatal death is uncertain
- It is possible that a stillborn baby or a fetus that underwent termination for fetal anomaly was born alive
- The baby was not receiving care from a doctor while they were alive.

When a baby's death is reported to the coroner, the parents must always be informed and the reasons for reporting the death should be explained. Staff should acknowledge that this may be difficult for parents and they should be offered support.

There is no statutory requirement to notify the coroner of all child deaths, including newborns. Deaths must be notified to a senior coroner where a Medical Certificate of Cause of Death (MCCD) can't be issued. This would be under clause (c) of 'The Notification of Deaths Regulations 2019' which says:

(c) the registered medical practitioner —

(i) is an attending medical practitioner required to sign a certificate of cause of death in relation to the deceased person; but

(ii) despite taking reasonable steps to determine the cause of death, considers that the cause of death is unknown;

After a baby's death is reported, the coroner may or may not decide that a post mortem examination should be carried out to try to establish the cause of death. A coroner ordered post mortem examination is usually carried out as soon as possible but may occasionally delay the baby's burial, cremation or funeral and this should be discussed with parents. The coroner must also ensure that options for disposing of any retained tissue samples and any retained organs are discussed with and consented to or authorised by parents. The coroner's office should inform parents and their GP about the date and location of the post mortem examination.

Parents' consent is also not required to perform a post mortem examination ordered by a coroner. If parents want to object to a coroner ordered post mortem examination for any reason, they should be advised to contact the coroner's office immediately to discuss their objections and the situation. In some areas, the coroner or one of their officers can be contacted 24 hours a day. A coroner has the legal right to go ahead with a post mortem examination. However, they may be able to arrange for the post mortem examination to be performed as quickly as possible if time is a concern for parents. If a post mortem examination is ordered after parents object, they can apply to the High Court to try to prevent this post mortem examination. Staff should acknowledge that it may be very distressing for parents when a post mortem examination is carried out despite their objections and support should be offered.

In these circumstances, the baby's body will be restored to the same standard as following a hospital post mortem examination. When the coroner authorises the release, it will then be handed to the parents, funeral director or hospital for burial or cremation. The family may also wish to see the baby or create other memories when the baby's body is released following the post mortem examination.

If the coroner is not satisfied with the results of the post mortem examination, they may hold an inquest. In some cases, the baby's body may not be released until after the inquest. (Where a perinatal death review is carried out there must be an option for parents to feed in and receive follow-up information.)

Child Death Review Statutory Guidance can be found here: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/859302/child-death-review-statutory-and-operational-guidance-england.pdf. It includes flow diagrams for decision making/actions after a death.

Registration and Certification

Registration of birth and death

If a baby is born alive at any gestation and dies within 28 days of birth, a birth and death certificate must be issued for the baby. The doctor who provided medical care for the baby or mother before death should issue Medical Certificate of Cause of Death (MCCD) which certifies the death. These certificates must be taken to the registrar of births and deaths.

If no doctor saw the baby whilst the baby was still alive or the baby's death was unexpected, the death cannot be medically certified until it has been reported to the coroner. The parents must be informed that their baby's death has been referred to the coroner and the procedure and the reasons should be sensitively explained to them.

Before parents leave the hospital, staff should ensure that:

- They have discussed the information about registering the baby's death with parents and that parents understand what is required of them.
- Parents are given written information leaflets about registration and organising a funeral.
- They have given the parents the medical certificate and any other information the registrar will need.
- Parents who need an interpreter know whether the register offices can provide an interpreting service and how to book it.

If there are likely to be any problems with registration, the parents or, if they prefer, the member of staff who is caring for them should telephone the registrar for advice.

Sensitive disposal and funerals

Legal requirements

All babies who die in the neonatal period must be buried or cremated by law. Parents have a legal responsibility to bury or cremate their baby's body although they can consent to have a Trust carry this out on their behalf.

Providing information on sensitive disposal to parents

Parents should be given the opportunity to discuss and make choices about their available options for the disposal of the body, based on the options provided locally. Parents should be informed (where applicable) whether burial or cremation options provided by the hospital are individual or shared. Staff who talk to parents should have a thorough understanding of the available local options and should know what is possible at local cemeteries and crematoria.

Some parents may decline information about these options or involvement in decision-making processes regarding the disposal of the body and this should be respected. Parents should be informed of what option will be used if they do not make a decision, and told who they can contact if they change their minds, or would like more information in future. They should also be informed of any time frame in which they would need to do this, and who to contact if they want to find out more details at a later date.

Some parents may also wish to arrange a funeral or other ceremony for their baby. Staff should offer to discuss the various funeral options available with all parents.

All parents should be offered written information, covering:

- What choices they have if they want the hospital to make the arrangements.
- What choices they have and what they need to do if they want to make their own arrangements or use the services of a funeral director.
- What costs are involved (if any).

Some parents will want to discuss the arrangements and the options available to them. These discussions should not be rushed as parents may need to take time to decide what they want. Some parents may find it difficult to make decisions, especially if they are experiencing shock or grief. Other parents may want to discuss their options with family, friends or a spiritual advisor. Offer to put them in contact with the Chaplaincy team, if they would like this.

Staff should also mention any additional options available to parents, such as an entry in the hospital remembrance book or an individual or shared memorial service.

Parents on a low income

Parents of babies who die in the neonatal period may be eligible for a Funeral Payment. To be eligible, one or both parents must be receiving at least one benefit or tax credit. More information and claim forms are available in the Funeral Payments section of the UK Government website – www.gov.uk/funeral-payments. Details are emerging of a new Children's Funeral Fund, please see www.gov.uk/government/news/childrensfuneral-fund-for-england.

Cultural considerations

Staff should be aware of, and open to, different personal, religious and cultural needs. Assumptions should not be made, however, about what any individual will want on the basis of their heritage or religion. There may also be differences in practice between different denominations and traditions of the same religion.

It is important that staff do not question parents' choices unless there are legal reasons why their wishes cannot be carried out.

Parents should be informed that the Chaplaincy team are available to discuss any issues they want to cover, and that the Chaplaincy team would be able to put them in touch with a representative of their faith, wherever possible.

Whilst focused on the impact of bereavement on staffing groups, the NHS guide to bereavement and cultural practice can be helpful in this regard: <https://www.england.nhs.uk/wp-content/uploads/2021/01/Bereavement-Practices-Jan-2021.pdf>

Urgent burial and cremation

For some parents, personal circumstances or religious considerations may mean that they need to organise an urgent burial or cremation for their baby. This may not always be possible, particularly when the baby's death has been referred to the coroner. However, staff should do what they can to support parents who wish to organise an urgent burial or cremation for their baby.

When an urgent burial is needed for religious reasons, a community or religious leader may be able to help with the necessary arrangements. The local registrar may also be able to provide an out of hours service where burial or cremation is required urgently. However, staff should verify whether this service is available locally.

Although registration must normally take place before a body can be buried, the local registrar should make arrangements to provide the necessary documents before registration so that urgent burials can take place wherever possible. A certificate for cremation can be issued before registration in the same way. This may be needed if the death occurs on or just before a weekend or public holiday. Families may need help from healthcare staff with getting the documentation completed as quickly as possible and with contacting the registrar out of hours.

It is important that staff are aware of local arrangements for out of hours services and know about how to deal with these circumstances in areas where urgent burials are not frequently requested. Staff should look on their local council's website and contact their local registrar if they have any questions about local procedures.

If an urgent burial is required, the registrar will normally issue a certificate of burial to allow burial to go ahead, unless the death needs to be referred to the coroner. Formal registration of the death after burial can take place up to 5 days after a neonatal death (this can be extended to 14 days in certain circumstances).

Taking the baby home

There is no legal reason why parents should not be able to take their baby from the hospital and make their own arrangements (unless the death has been referred to the coroner). They should be offered a Moses basket, if required. No documentation is legally required but a form should be issued by staff to accompany the baby to protect the parents and avoid misunderstandings. If parents plan to take the baby's body home, it is important to take any post mortem examination arrangements into account. A post mortem examination may be carried out first. In these instances, parents should be told about the condition of the body and how to handle it after the post mortem. Alternatively, it may be possible for parents to take their baby's body home for a short time and then back to the hospital for post mortem examination.

If parents are considering a post mortem examination they should receive clear information from an appropriately trained member of staff about the impact that taking their baby out of the hospital environment may have on the accuracy of the results, if any.

Parents also need to know that it is important to keep the body cool. They may be able to borrow a cold cot from the hospital. It is important that staff know what local resources are available before offering options to parents. If parents plan to return the body to the hospital before the funeral, they also need to know when and where they should go. Alternatively, the funeral director (if applicable) can collect the baby's body from the parents' home before the funeral.

Staff should refer to local practice and arrangements.

Record keeping

Any decisions that parents make regarding their options should be documented in the mother's medical records. It should also be documented if the woman has declined information on these options or involvement in these decisions.

Ask the partner if they would like their GP to be informed about the loss so it can be added to their notes, and record their consent if they did.

Discharge and aftercare

Leaving the hospital

Leaving the insulated environment of the hospital and going home to face the world without their baby can be frightening and painful. Some parents may want to leave soon after their baby's death. Others prefer to stay a little longer but some may feel unable to stay. This may be because facilities are inappropriate or they do not feel that they have received sensitive care. For example, parents may not have the degree of privacy or contact with others that they would like, they may feel pressured to leave if their bed is needed for another patients or staff may be unable to listen and provide support. Parents should not automatically be sent home as soon as possible.

It may be helpful to discuss the place and time of leaving the hospital with the parents. All parents should be told who will contact them and when, and the services and support available to them once they are at home. Staff knowledge of local support options should be up to date, and this knowledge should be passed on to families. Some may be reassured if they know that a member of the primary healthcare team will visit or contact them shortly after their discharge from hospital if this has been scheduled.

Before parents leave the hospital staff should discuss with them the ongoing physical symptoms the mother may experience (for example bleeding, lactation and pain) and when they should contact a healthcare professional. Staff should also discuss milk donation and suppression.

Milk donation and milk suppression

Some women may choose to donate their milk to a breast milk bank. While discussing milk donation may be difficult, staff should sensitively give women information about donating their milk. Some mothers may want to donate their milk to a milk bank and other mothers may not.

UKAMB (United Kingdom Association for Milk Banking) can provide more support if there is not a local milk bank. UKAMB offers support for staff and bereaved mothers across the UK who are looking for information about donating milk. (See Neonatal Pathway Appendix A14).

Healthcare staff can help a woman to determine if she is eligible to donate her milk to a milk bank and explain how to express and store her milk for donation. The woman should also be told about the necessary blood tests, local milk bank dietary and alcohol intake requirements and any emotional and practical support that is available to her when she is donating milk.

The mother should receive information about milk suppression, any medication and its side-effects and the gestation from which this medication can be used. Staff should discuss pain relief and time frames with the mother. The mother should be given a contact name and number in case of any questions or concerns.

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.

With the mother's consent:

- A designated member of staff at the hospital should phone her GP, community midwife and Health Visitor when the woman is discharged. This is important as letters may take several days to arrive.
- When the mother has been discharged, prior to the death of the neonate, a designated member of staff at the hospital should phone her GP, Health Visitor and if still receiving maternity care, the community midwife.
- The hospital or clinic should also immediately send a summary of the woman's obstetric history and care to her GP when she is discharged. Depending on the gestation at which the loss occurred, the summary should also be sent to the community midwife and the health visitor.
- The woman should be given a summary of her care that she can give to her GP at their first appointment.
- The GP and community midwifery team (where applicable) should also be informed where the mother will be staying after she is discharged from hospital. This is particularly important if the mother is going to stay with relatives or on the neonatal unit so that the primary care team know where and how to contact her or arrange for her care.

If different members of the primary care team are involved with the woman and her partner (if applicable), it is important that they communicate with each other. This helps to ensure that someone continues to visit for as long as the parents want and that the parents do not receive conflicting information.

It can be helpful if the GP, community midwife, health visitor (or other staff who may view the records and interact with families) marks bereaved parents' electronic and hard copy medical records with an alert or sticker to notify other healthcare professionals to their bereavement.

Follow up appointments

All parents should be offered follow-up appointments for postnatal care and to discuss any results from tests or post mortem investigations. It is important that parents do not fall through the gaps.

It is important to make sure that the parents know the purpose of each follow-up appointment. This will ensure that parents know what to expect at the appointment as they may experience distress if their expectations are not met. For example, parents may arrive at an appointment expecting to hear post-mortem results but learn that the appointment is for a physical check-up which may cause frustration, disappointment or distress. Letters that are sent to confirm the appointment with parents should clearly state the purpose of the appointment.

It is also important to ensure confidentiality in situations where other family members may not know about the loss or about post mortem investigations. Staff who telephone should check they are speaking directly to the mother. The envelope of any letters that are sent should be marked "Private and confidential."

Parents should be offered for their named bereavement support to be present. If possible, parents should see a professional they have met previously.

Some parents may want to bring a partner, relative or friend to appointments. If applicable, both parents should be encouraged to attend appointments together. When the appointment is booked, parents should also be encouraged to write down any questions and worries and to bring the list with them to the appointment. Additionally, they should be told whom to contact if they need to talk to someone urgently in the time before the appointment and be given contact details.

In addition to the initial follow-up appointment, an offer of ongoing care should be made to all bereaved parents. This offer should also be repeated some weeks later if parents initially decline the offer. Parents may find that they need support later and/ or be surprised by a lack of support offered by friends, family or other services.

Follow-up appointments may take place at home, in the GP's surgery or at the hospital. Some parents may find it too distressing to go back to the place where their baby died. If this is the case, arrangements should be made for follow-up appointments to take place in another suitable setting or outside normal clinic hours. Bereaved parents should not have to sit with other parents with healthy babies or attend an appointment in an antenatal or postnatal clinic.

Discussions at follow up appointments

Parents often have very high expectations of follow-up appointments. They may be hoping for clear answers about why their baby died that will help them make sense of what has happened. If it is not possible to provide these answers, healthcare professionals should acknowledge that this may be difficult for parents and recognise any emotions that parents may feel.

While parents should be told the purpose of an appointment or visit, it is always important to avoid imposing a set agenda and to respond to their needs. Some examples of things parents may want from follow-up appointments may include:

- To ask questions about what has happened and to check their understanding of the information they were given at the hospital.
- To discuss the events surrounding the pregnancy loss or baby's death so that they can clarify and confirm what happened.
- To discuss how they are feeling. It is important to ask parents how they feel and to offer them an opportunity to talk. Grief should not be treated as a mental health concern but parents should also be assessed for mental health problems that may be compounding their grief.
- Help in preparing questions for their consultant or GP.
- Suggestions about dealing with the reactions and questions of other family members (for example, other children, their partner, grandparents, a pregnant relative, etc.), friends and neighbours.
- Information and advice about registration and certification.
- Help with decisions about and arranging a funeral for their baby.
- Advice about sex and contraception.
- To discuss the timing of another pregnancy, their chances of having a live healthy baby and how they can reduce or manage any risks. They may also want to talk about any related implications for any existing children.
- To discuss concerns about coping with anxiety in another pregnancy or the possibility of never having a child.
- Information about local or national support organisations.
- Advice about parental leave and claiming benefit payments.
- Advice about coping with or returning to work, including what to say to colleagues and how to deal with their reactions.
- Advice about bereavement counselling that is available to parents and other family members.
- Referral for further investigations including genetic counselling. If they do not want genetic counselling immediately, they should be told how to access these services at a later date.

At the end of the appointment, parents should be told whom to contact if they have further questions, problems or worries. They should be given a named contact and a telephone number and/or email address for that person. In some cases it may be appropriate to offer another appointment. Also, a written summary of the discussion should be sent to the woman, her GP and to the referring hospital if appropriate. They should also be offered information about relevant local and national support organisations.

Feedback and review

Parent feedback

The majority of bereaved parents want to give feedback about the bereavement care they received when their baby died and feel it is appropriate for them to be sensitively asked about the care they received.

Good feedback mechanisms provide parents with opportunities to inform service improvements and feel listened to. Receiving feedback from parents in a structured and supported way gives room for reflection and learning and also promotes the sharing of best practice. Local Maternity Voice Partnerships (MVPs) can be helpful in this regard.

When parents have had a good experience of care at this often very difficult time, it can be important for the staff who cared for them to know that the care they provided was beneficial.

“We would have liked to have fed back how grateful we were for the time they gave us and how understanding they were.” Parent, Sands Survey 2016

Conversely, it may feel difficult to listen to parents who didn't receive optimal care. It is important that staff are supported to do this so that they are able to listen to parents in these circumstances. This feedback allows for reflection and learning and promotes service improvements.

All feedback from parents should be taken as an opportunity to learn and develop bereavement care services.

Before implementing a feedback mechanism for bereaved parents, it is important to have the correct structures, policies and procedures in place to ensure appropriate use of the information collected.

The Perinatal Mortality Review Tool is now fully rolled out and can be accessed here:

<https://www.npeu.ox.ac.uk/pmrt>.

“Preparing the framework or wider infrastructure for receiving feedback is essential to ensure that improvements are made in a sustainable way. Feedback may uncover common themes that need to be addressed, or issues may arise from a smaller number of respondents which provides valuable insight. As well as ensuring an effective feedback mechanism for improvement it is also important to celebrate positive feedback when things are done well.” Maternity Bereavement Experience [Measure](#), p8.

Reviewing the death of every baby in a standardised, high quality way is important. There are multiple review processes. Parents should be invited to be involved in all reviews regardless of country, system or speciality. Parents should be offered the opportunity to give their questions, concerns and perspectives of care to the review panel. You need to be flexible about how and when this is done.

The parents' perspective may add to the clinical picture. Understanding what happened may impact the parent's grieving and the narrative they share with family and friends for the rest of their lives. Parents must be informed of review outcomes, whether or not they wanted to be involved in the process.

The Child Death Review Process is the only one that is statutory, and it aims to learn from the deaths of all live born babies and children in England who die before their 18th birthday. Parents views and perspectives are collected as an essential part of this process. This happens through the local Child Death Review Meeting (CDRM). Further information can be found via this link. (add this hyperlink to the word 'link' and the word CDRM - https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/859302/child-death-review-statutory-and-operational-guidance-england.pdf)

Emotional support

Ongoing emotional support

The grief experienced by a parent when a baby dies cannot be predicted by the gestation or the type of loss they have experienced. Both immediate and long-term follow-up care and emotional support should be available to all parents who experience a pregnancy loss or the death of a baby.

Services should be accessible to parents from different backgrounds and systems and standard practices should not discriminate against parents. Services should be flexible so that they can be adapted wherever possible to meet the needs of all parents.

Good communication between staff and healthcare teams is essential to providing good bereavement care and ensuring appropriate continued emotional support is available.

Policies should be in place to ensure that there are efficient processes for keeping all staff informed (with a woman's consent) about a pregnancy loss, a diagnosis of a fetal anomaly or the death of a baby and any treatment or care that has been received or decided upon. These policies should be developed and agreed to by primary and secondary care staff.

If a woman consents, it is important that her medical notes are appropriately marked (with a Sands teardrop logo for example) to alert all primary and secondary care staff that her baby has died. This is to ensure sensitive communication when contact is made, and flag the need for ongoing emotional support.

Before leaving the clinical care environment parents should be offered information about the emotional support available to them through their care provider and otherwise.

Information to highlight

Staff should communicate with parents about the difficult emotions they might experience, and reassure them that it is okay and normal to not feel okay. Parents should be reassured that they can be in touch with their healthcare team if they need further support and should be given a contact name and number for this purpose.

Staff should flag:

- That chaplaincies should have contacts with religious and spiritual advisers of all local faiths and spiritual organisations.
- A contact to provide ongoing emotional support via the care provider (for example, a bereavement lead or community midwife).
- Counselling services available via the care provider.
- Access to counselling and further support via secondary care (for example, GPs and health visitors).
- National and local support organisations.

The death of a baby will be experienced differently by each parent. There might be recognisable themes, but staff should not make assumptions about how a parents is feeling at any point, or about what they may need in terms of ongoing support.

Mental health

Policies and practices should be in place to offer bereaved parents ongoing follow-up care, further assessment and treatment for mental health problems.

Mental health assessment and treatment should be offered to women as well as their partners, other children and family members (where applicable) after any type of baby loss.

Sufficient time must be available in follow-up appointments with bereaved parents to enquire about their emotional well-being and offer assessments for mental health conditions where necessary.

Good communication is crucial between staff and healthcare teams regarding parents who may be at risk of developing or who have been diagnosed as having mental health problems after a baby loss.

Parents should be offered continuity of carers during pregnancies, labour and birth that they experience following a loss. The option of having their notes clearly marked may also help to ensure that parents do not need to explain their situation repeatedly. For example, staff might label parents' notes with the **Sands Teardrop Sticker**.

Ensuring that there is good communication between staff (including across teams and departments) is essential in subsequent pregnancies. All staff who care for bereaved parents in subsequent pregnancies should be well-informed about parents' history so that they can respond sensitively to any anxieties or concerns that parents may express.

Another pregnancy

Parents should feel well supported in any pregnancy following a pregnancy loss and the death of a baby. All staff in primary and secondary care settings seeing bereaved parents before, during and after a pregnancy following a loss must be aware of and acknowledge the potential difficulties and challenges these parents might face.

Parents should be offered continuity of carer during pregnancies, labour and birth that they experience following a loss. The option of having their notes clearly marked may also help to ensure that parents do not need to explain their situation repeatedly. For example, staff might label parents' notes with the Sands Teardrop Sticker.

Ensuring that there is good communication between staff (including across teams and departments) is essential in subsequent pregnancies. All staff who care for bereaved parents in subsequent pregnancies should be well-informed about parents' history so that they can respond sensitively to any anxieties or concerns that parents may express.

All staff who care for bereaved parents in subsequent pregnancies should be well-informed about the parent's history so they can respond sensitively to any anxieties or concerns the parents may express.

Offering parents continuity of carers and the option of having their notes clearly marked (Neonatal Pathway Appendix A11) may help to ensure that parents do not need to explain their situation repeatedly.

If the baby who died had a medical or genetic condition that could affect subsequent babies, the chance of another loss may feel too difficult for some parents to consider. Some parents will decide not to try for another baby for other reasons. Other parents may not be able to conceive again.

It is important to:

- Listen to and acknowledge parents' fears and concerns.
- Support parents to make informed choices around if/when to try for another baby.
- Outline any additional antenatal support offered.
- Be clear about the available support from staff and other organisations.
- Familiarise yourself with the parent's notes

It is important not to:

- Offer false reassurances to parents about having a healthy baby.
- Minimise parents' previous experiences and current concerns.
- Make assumptions about how a parent might feel at any stage.
- Assume parents attended antenatal classes in previous pregnancies.
- Exclude partners and other family members.

Pre-conception care

The timing of subsequent pregnancies, the risks involved, concerns about their ability to conceive, sexual difficulties and the chances of having a live, healthy baby may be some of the concerns for parents who are thinking about becoming pregnant again. Parents may need an opportunity to discuss their concerns with healthcare staff before trying to conceive.

Some bereaved parents will want to discuss what, if anything, they can do to prevent another loss.

Having experienced a previous loss, many parents will have been in touch with other bereaved parents and heard about their experiences too. This may increase anxiety around situations that were not relevant to their own experience.

Antenatal care

Antenatal care in subsequent pregnancies may involve offering parents extra antenatal appointments, screening options, scan appointments and/or opportunities to discuss an antenatal care plan and birth preferences. It is important to stress that it will not safeguard against any subsequent loss. If there is a specific condition that doctors are aware of, and are screening for, extra testing will be part of the patient's care.

Staff should allocate extra time for these appointments. Parents should also be able to bring another support person to attend these appointments with them.

It is crucial that there is good communication between staff providing antenatal care for parents in a subsequent pregnancy so that parents do not have to retell their story if they do not wish to do so.

Some parents may welcome more frequent contact with healthcare staff during subsequent pregnancies and will want all available screening and diagnostic tests. Many parents, however, may not need or want extra care. Parents should have the contact details for a named contact in case they have any concerns.

Some parents may find additional appointments, screening and tests stressful and decline some or all of this care. Staff should explain the reason why parents have been offered additional tests or checks. However, parents' decisions about care should be respected.

Parents should be offered regular contact with staff, emotional support and screening for mental health difficulties.

“She was pregnant... again. What should have been fantastic news filled me with sheer terror. I did not know if I could go through this again.” Father

“When I got pregnant after 8 months, I wanted to be delighted but I didn’t dare let myself in case all our hopes were dashed again.” Mother

It is never possible to predict how individual parents will feel during subsequent pregnancies. For some parents, the main feelings during another pregnancy may be grief, anxiety and distress. These feelings may surface in all subsequent pregnancies.

One of the most important things that staff can offer parents is sensitive support to help them deal with the range of feelings and worries that they have.

Certain stages, events or dates during the pregnancy may be particularly difficult for parents, depending on what happened during the previous pregnancy. For example, parents may be very anxious and distressed in the period leading up to the gestational week or date when the previous baby died or an anomaly was diagnosed.

Some parents may feel less frightened after this point if all is well. Other parents may remain fearful until after the new baby is born or some time after their birth for those who experienced the sudden unexpected death of their baby.

Some parents may worry that they will be unable to love the new baby or that they will be disloyal to the baby or babies who died by loving the new baby.

Parents may also worry about the effects of the fear and anxiety they are feeling on the well-being of this baby. It is important that staff acknowledge the validity of parents’ concerns and take them seriously.

In addition to the mother, it is important to ensure that partners are offered support. Partners may wish to support the mother and may also want reassurance for themselves. Some partners may be reluctant to voice their fears in the mother’s presence as they are concerned about distressing her. Staff should offer partners an opportunity to speak with staff on their own.

Some parents may prefer to avoid discussing their emotions or previous loss with staff and try to focus on the practical tasks at hand. Other parents are grateful for opportunities to talk about their feelings and their baby or babies who died. Parents should be encouraged to discuss their feelings about their previous loss(es) with staff and be offered counselling or information about other support available.

It is important not to offer false reassurance as this may increase parents’ sense of isolation and prevent them from talking openly about their fears. Staff should also be aware that statistical probabilities may not provide comfort for parents.

“I didn’t want to love the baby I was carrying. I was so afraid that she would die as well and I knew I wouldn’t be able to cope with the pain.” Mother

Place of care

Parents who have a good relationship with staff in a particular hospital may want to return there for their antenatal care.

It is sometimes necessary to rebuild parents' trust. Rebuilding trust may be particularly needed if parents are unhappy about aspects of the care they or their baby received when their baby died.

Some parents may prefer to be cared for in a different hospital, GP or by different members of staff, even if their previous care was good. Parents may fear that traumatic memories will be triggered if they return to the place where their baby died or see staff who had cared for them at that time. Healthcare staff should refer parents to another unit or another consultant if requested.

At the first antenatal visit, each woman should be allocated a named midwife and consultant obstetrician. These practitioners should provide most of the woman's care throughout her pregnancy, birth and the postnatal period. They should carefully read the woman's notes thoroughly before the first appointment and ask parents if it is okay to refer to the baby who died by name if one has been given. Depending on parents' wishes, it may be appropriate for both the named midwife and consultant to attend some appointments.

Labour and birth

Staff should be prepared for parents' possible emotional reactions during labour and at the birth. Staff should be available to offer support if needed. Women should be aware that support is always available and know how to access staff members. It is also important that support is offered to any partners or birth supporters who are with the woman.

"I felt disconnected during the labour and just couldn't believe that everything would be OK."

Mother

Some parents may be surprised and confused if they experience renewed grief for the baby or babies who have died, have mixed feelings or find life difficult when a healthy baby is born. Some parents may not feel they are able to love this baby immediately and it may take a while before they start to experience these feelings. Some parents may feel guilty if they love their new baby.

"My partner was disconnected during my pregnancy, but now our son is born, his dad looks at him every day and cries. He's a lot more emotional now than I am. This baby has really brought his grief out." Mother

Care in the community

Parents who experienced the sudden and unexpected death of their baby may not feel reassured by the birth of a healthy baby and anxiety may continue for some time after the baby is born. It is important to have structured support in place in the community for these parents.

Staff should offer sensitive support to parents after their baby is born. They should normalise parents' feelings and acknowledge that such feelings are shared by many parents and that they usually pass. If these feelings continue for long periods of time after the baby is born, staff should also offer parents a referral for specialist support.

All parents should be offered a telephone call and/ or house visit from a primary care professional to check their physical health and also to offer emotional support. Not all parents will want this, but those who do can really value this contact.

Primary care staff or support groups may be able to offer parents longer-term support and an opportunity to discuss their ongoing concerns.

Parents may want to discuss how to talk about the baby who died with existing and subsequent siblings.

A few parents who go on to have another pregnancy, may experience the death of another baby. This can be deeply shocking and distressing for the parents and staff who are caring for them. These parents may need additional immediate and long-term support from staff.

Staff care

When health and social care professionals are properly supported to provide high quality bereavement care, working with women and families experiencing the death of their baby can be special and rewarding.

There must be appropriate provision for staff support and training. It is also important that staff recognise they have a professional responsibility to access support and training when they feel they need it.

All staff should be supported practically and emotionally so they feel comfortable, confident and competent in this area of care.

Training

Often healthcare staff are expected to cope with distressing events and highly emotional situations without appropriate education and training. Undergraduate, postgraduate and in-service training and updating in bereavement care should be provided for all staff. Provisions should also be made to ensure that staff can be released for this training.

Training can help staff to feel more confident in the care they provide and help to reduce staff stress.

Support and training are essential to ensure staff well-being and avoid staff burn out. Bereavement care training can help staff to develop skills in communicating more sensitively and empathetically with parents and increase their awareness of the needs of bereaved parents.

Good training and support for staff improves the quality of bereavement care offered to parents when a baby dies.

Support

There are many reasons why it can be stressful and demanding to care for parents during a pregnancy loss or when a baby dies. These reasons will be individual and may include staff having to manage their own emotions following their own experience(s) of loss; a feeling of professional failure following a baby death and anxiety caused by wanting to 'get it right' knowing this is a difficult time for parents.

To provide parents with high quality, individualised care, staff must be well-supported and have time for breaks; an open and supportive work environment; opportunities to share stories and experiences and scheduled multidisciplinary debriefs and reviews. This applies to all members of staff – at all levels and in all disciplines, including all primary care staff who may have long-term relationships with the family and who may be working in greater isolation. This support for staff should be built into the systems in which they work.

The type and amount of support that staff need can vary depending on the individual and the situation. It is important to have different support options available for members of staff to use as they need.

Stigma and concerns about not appearing to be coping with their job may cause some staff to avoid coordinated professional counselling and this should be offered as a confidential service through the central hospital human resources team.

Managers and senior staff have a duty to provide encouragement, support and training for staff, to watch for signs of strain or difficulty in individuals and within teams and to facilitate discussion between colleagues, teams and centres.

Managers and senior staff should also make sure they themselves get support so they can support their staff.

Where staff are bereaved, the NHS guide to bereavement and cultural practice can be helpful to managers:

<https://www.england.nhs.uk/wp-content/uploads/2021/01/Bereavement-Practices-Jan-2021.pdf>

Self care

As well as organisational, systemic support structures, individual healthcare professionals also need to be mindful of attending to their own needs. Working long hours, shift work and working in often challenging environments and circumstances means that healthcare professionals need to think about what they need to do to look after themselves. This may include making sure they get enough sleep, eating healthily, exercising, relaxation, booking annual leave, watching a favourite film or spending time with a friend or on a hobby or in green space/outdoors.

Keep checking back to the NBCP website to see tips and hints, tools and resources regarding self-care for staff.



For more information visit:
nbcpathway.org.uk

www.sands.org.uk

Sands (Stillbirth and Neonatal Death Society)
Company Limited by Guarantee Number: 2212082
Charity Registration Number: 299679
Scottish Charity Registration Number: SC042789