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

national bereavement
care pathway
for pregnancy and baby loss

Neonatal Death

Full Guidance Document

Led by

sands

In partnership with:

Antenatal Results & Choices

Bliss for babies born premature or sick

iHV Institute of Health Visiting Excellence in Practice

the lullaby trust

Miscarriage Association The knowledge to help

Neonatal Nurses Association

UCL EGA Institute for Women's Health

Royal College of Midwives

RCGP Royal College of General Practitioners

Royal College of Nursing

Royal College of Obstetricians & Gynaecologists

NHS England

The Ectopic Pregnancy Trust

nbcpathway.org.uk

NBCP for use in England from September 2025

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 programme provides a dedicated, evidence-based and independently evaluated care pathway with guidance for professionals delivering bereavement care to parents and families. Whilst the programme encompasses all four nations of the UK, this document relates to England only. Information on the Scotland pathway can be found at nbcpscotland.org.uk, and for information on the emerging Wales and Northern Ireland Pathway projects email bereavementcare@sands.org.uk.

This guidance, developed for healthcare professionals working with bereaved families, relates to one of the five pathways. 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 in England. **For further information, please see nbcpathway.org.uk.**

> "Parents don't need protecting; they need the chance to be parents, provide their child dignity and create memories."
>
> **Bereaved parent**

Key messages 04
Bereavement Care Standards 05
Terminology 06
Communication 07
Diagnosis and delivering difficult news 08
Memory making 19
Post-mortem examination 25
Coroners 28
Registration and Certification 29
Sensitive disposal and funerals 29
Leaving the hospital 32
Feedback and Review 36
Emotional support 37
Another pregnancy 38
Staff support 42

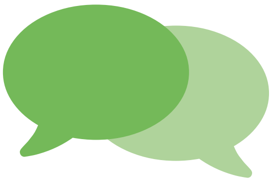
Note to the reader

This is the full version of the pathways guidance produced for the National Bereavement Care Pathway (NBCP). This document contains detailed guidance to support the care of bereaved families. The quick reference guide for this pathway is also available at nbcpathway.org.uk and contains templates and tools for you to adapt and use in the local setting. Please consult the terminology page before reading this document in full.

Key messages

There are 9 bereavement care standards (overleaf), and all of these are underpinned by three important themes since the beginning of the NBCP programme.

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." Bereaved parent

"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." Bereaved parent

2. Continuity of care and consistency in approach is vital

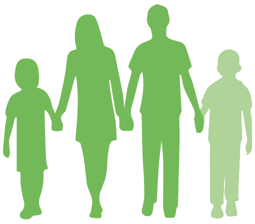
"I would have loved to have birthed the baby at home as I had had previous homebirths – but this option was not given, **and I was not aware this was a choice I had."**

Bereaved parent

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

Bereaved parent

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."

Bereaved parent

"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." Bereaved parent

Bereavement care standards

These nine standards for bereavement care underpin the NBCP guidance. A Trust that meets these standards is considered to be providing good bereavement care.

Trusts should audit their service provision against these standards to identify gaps in the care they provide, and develop plans for improvement. A self-assessment tool is available for all Trusts in England to conduct this audit, see nbcpathway.org.uk.

Implementation of these standards via the pathway will help Trusts to meet the elements of the Care Quality Commission's assessment framework for maternity.

Parent-focused standards

1. All bereaved parents and families are provided with **personalised care**.
2. All bereaved parents and families have the opportunity to use an appropriate, available and accessible **bereavement room**.
3. All bereaved parents and families are offered opportunities to **make memories**.

Communication and learning standards

4. All bereaved parents and families are informed about and, where needed, referred for **emotional support** and for specialist **mental health support**.
5. A **system** is in place to clearly **signal** to all health care professionals and staff that a parent has experienced a bereavement.
6. Bereaved parents and families are confident that **learning** from their baby's death will take place and are fully informed throughout.

Staffing standards

7. Bereaved parents and families receive their care from an **appropriately staffed** team.
8. All staff involved in the care of bereaved parents and families receive the **training and resources** they need to provide high-quality bereavement care.
9. Healthcare staff are effectively **supported** to care for bereaved parents and families.

The NBCP bereavement care standards are cited extensively in national reviews, policy and clinical guidance. A full list of citations is available on the website.

A self-assessment form is available to help you assess the quality of care in your Trust against the nine bereavement care standards. Your bereavement lead should have one of these, otherwise contact us via bereavementcare@sands.org.uk.

Terminology

The NBCP editorial panel acknowledges that language matters, and that it is complex and continually changing.

We encourage all staff to follow the principle of asking the person they care for how they would like to be referred to and to mirror the language used by families when speaking to them about their experiences.

The guidance below outlines important points on language use throughout the pathways:

- The terms ‘healthcare professionals’ and ‘staff’ are used throughout to denote all of those professionals working with bereaved parents.
- Throughout the pathways we use the additive language ‘women and birthing people’ to include individuals who do not identify as women.
- The term ‘baby’ (or ‘babies’ in the case of multiple pregnancies) is used throughout the pathways to refer to the first trimester of a pregnancy through to the neonatal period. In earlier losses many people will prefer to conceptualise their baby and will develop strong attachments to them from the moment they discover that they are, or were, pregnant. However, some people will be more comfortable with terminology such as ‘fetus’ or ‘pregnancy’ and will not find the term ‘baby’ to be appropriate in their situation. While we have used the term ‘baby’ throughout the guidance, it is important to recognise that not everyone who experiences a perinatal bereavement will want to refer to their loss using this language. The language preferences of those people experiencing a loss should always be mirrored when communicating with them.
- The term ‘parents’ is used to refer to expectant and bereaved people and partners. Many people will consider themselves parents from the time they discover they are, or were, pregnant. However, not everyone who experiences pregnancy loss or the death of a baby will want to be referred to as a parent. Therefore, when using this guidance staff should be sensitive to the individual preferences of those they are caring for.
- We recognise that who a ‘family’ is may involve different structures and diverse experiences. Where ‘family’ or ‘families’ are referred to in this document, we advise healthcare professionals to consider that there is not one type of bereaved family but to ensure that the individual is given opportunity to explain who they consider their family or support structure to be.
- 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, while others may be with a friend or family member, or may have more than one partner. As such, ask rather than assume who is in the room and what their relationship to the woman or birthing person is.
- 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, birthing people and families experiencing a childbearing loss.

Finally, because this is a pathway focused on improving outcomes for women, birthing people and 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.

Staff should have a conversation with parents as early as possible, to find out about their background and individual needs. This can help staff identify health inequalities and practical barriers and tailor communication to the needs of each individual family, should they experience pregnancy loss or the death of a baby. These conversations should be recorded in the woman or birthing person's medical notes (with their consent).

Use warm, open body language by sitting near parents at a similar height (not above them), facing them, making eye contact and using touch if appropriate (see differentiations below for parent(s) with specific communication needs including neurodiversity). 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 aim to be empathic, avoiding being too "cold and calculated" whilst still maintaining professional clinical boundaries. 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, use simple language and parents should be encouraged to ask questions. Staff should also provide information in writing (or other formats) where possible. 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 women and birthing people with a multiple pregnancy are 4.9 times more likely to experience neonatal death than those with a singleton pregnancy (MBRRACE 2022) 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 without first asking them. Parents may have a hospital or communication passport with them to indicate their communication preferences. Staff should have a conversation with parents about their needs and preferences as early as possible, and these should be recorded in the woman or birthing person's notes (with their consent).

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.

NHS England have created a resource pack for maternity service providers on supporting interpretation. The Office for Health Improvement and Disparities have also created guidance on language interpreting and translation.

Sands and Tommy's Joint Policy Unit have produced a report on the provision of interpreting services in maternity and neonatal care with recommendations for practice.

Communication

Communicating if there is no formal 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 distress or confusion and to adhere to safeguarding procedures.

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 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 let them know where everyone is located.

Communicating with parents who have a learning disability and/or neurodiversity

It is important to remember that parents with a learning disability and/or neurodiversity often have a hospital or communication passport with them, which indicates their communication preferences. For many neurodiverse parents, eye contact and touch can feel difficult, so the typical communication approaches outlined above may need to be adjusted. Please try and check this out however, as every parent is individual.

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 or birthing person 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 or birthing person'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 will never be transferred to a neonatal unit. Some of these will be premature babies, but some may be babies who were expected to survive but who experience an intrapartum event.

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 woman or birthing person'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.

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 explainedusing everyday language. Parents should be encouraged to ask questions and to say if they find anything difficult to understand. Staff can help to facilitate this by checking things out throughout the conversation, inviting parents to say if they want something repeating or need something to be explained in a different way. 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 delivering difficult or unexpected news to parents:

- Where possible, offer a member of staff that the family have met before to be present.
- Before delivering difficult news to parents, staff should prepare what they are going to say and ensure that they have accurate information.
- Check whether an interpreter or other support for communication is needed.
- Find the most appropriate private place available to have the conversation with parents.
- If the woman or birthing person is on their own, check whether they would like to contact their partner or another supporter who might be able to join them.
- 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.
- Use warm, open body language by sitting near parents, facing them, making eye contact and using touch if appropriate, being mindful of possible neurodiversity and individual preference.
- Use clear, straightforward communication and do not use euphemisms. It is important that the message is clear and that parents are not left with false hope.
- Express 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 difficult 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 difficult 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.
- Following delivery of difficult news, staff should let the parents know what options are available to them in case they would like to access psychosocial support, both on the neonatal unit or in the community. If there is a psychological professional on the neonatal unit, parents should be informed of this service and offered the opportunity to meet with them. Otherwise, parents should be offered the option to be referred elsewhere for specialist psychological support. It may take some time for parents to process the news and take up this offer, however it is important that staff are aware of what is on offer and that they provide all the relevant information to parents so that they can make an informed decision. It is important to remember that, for some families, it may take time to adjust to the idea of psychological support so it can help to gently revisit this over several conversations, whilst also respecting decisions if psychological support is declined.
- 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 communications.

> **“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 or birthing person 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.’”** Bereaved parent

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 optmism. 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 trained to identify parental wellbeing needs and help parents to access psychosocial support, when needed.

Similarly, if the diagnosis is soon after the birth there needs to be an awareness of the woman or birthing person’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. According to the principles of Family Integrated Care, neonatal units should offer an individualised approach to care which recognises the logistical challenges parents may face in being on the unit and empowers them to become confident, knowledgeable and independent primary caregivers. 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 and birthing people may be reluctant to travel on public transport by themselves, and some woman or birthing persons may be unable to drive themselves in the weeks after birth, particularly if they have had a caesarean section.

Additionally, some women and birthing people 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 and birthing people 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 practical framework to encourage healthcare professionals to empower parents to be primary caregivers through joint decision-making and hands-on care, as well as understanding families' needs and availability in order to provide truly individualised care. The Charter advocates for all parents to have unrestricted access to their baby; parents may therefore need support in making arrangements to enable them to stay at the hospital. 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..."** Bereaved parent

If the woman or birthing person is ill

Woman or birthing persons who are unwell should be enabled to spend as much time as possible with their baby.

If the woman or birthing person 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 woman or birthing person 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 woman or birthing person 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 woman or birthing person to picture her baby as an individual.

Some units take digital pictures of babies and relay them to the woman or birthing person's bedside. Taking a video or using a video calling service such as FaceTime or Skype to contact the woman or birthing person may also be beneficial. Others have a password-enabled site for each baby, where the woman or birthing person 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. Parents may benefit from access to a psychological professional who are trained to support parents when navigating difficult decisions about their baby's care.

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. The National Institute for Health and Care Research provides further guidance on strategies for critical care discussions with parents.

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 and support their agency 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. Input from a linked psychological professional (or broader psychosocial support services if a psychologist is not available) should also be offered to parents at this time. 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. Additionally, Parents should be supported by a psychological professional if needed. Staff should offer parents information about local resources and the Bliss website 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 woman or birthing person 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.
- Other sources of support for parents/siblings/family include access to a designated psychological professional/psychosocial support.

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 woman or birthing person 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.

Together for Short Lives have produced a Perinatal Pathway for Babies with Palliative Care Needs to support health care professionals in caring for families. A palliative care framework published by BAPM is also available for further support and guidance.

Bliss have produced guidance for parents on coping with uncertainty and loss, which includes an information booklet for parents about perinatal palliative care.

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 on the perinatal management of extreme preterm birth is available from BAPM.

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."** Bereaved parent

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. Woman or birthing persons may wish to put the baby to the breast for comfort rather than only for feeding.

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

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

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

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

Visitors

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

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

Some women and birthing people 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 and birthing people 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 and birthing people 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 woman or birthing person is ill

If the woman or birthing person is in the same hospital but is unable to walk to the neonatal unit, and their physical condition allows, they should be brought to the unit in a wheelchair or hospital bed. This will allow them to spend as much time as possible with their 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 woman or birthing person to the same hospital for their care either simultaneously or as quickly as possible after the baby's transfer. If there is any period of time before this happens when parent 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 them about the baby's personality and reactions. This may help the woman or birthing person to picture their baby as an individual.

Some units take digital pictures of babies and relay them to the woman or birthing person's bedside. Taking a video or using a video calling service such as FaceTime or Skype to contact them may also be beneficial. Some units have a password-enabled site for each baby, where the woman or birthing person can view computer readings from their baby and comments and observations entered by nursing staff. 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).

"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 woman or birthing person may also be beneficial. Some units have a password-enabled site for each baby, where the woman or birthing person 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." Bereaved parent

"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." Bereaved parent

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. Whatever choice a parent makes, this should be respected whilst also ensuring that support is available should a parent wish to hold their baby but are feeling anxious or otherwise concerned about this.

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.

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.
- That, where appropriate, parents are offered religious or spiritual care.
- That, where appropriate, parents are offered or signposted to psychosocial support.

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 woman or birthing person'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, neonatal deaths and deaths from SIDS. The HTA also provides guidance relating to the handling of remains following losses prior to 24 weeks' gestation.

There is a triage framework for perinatal post-mortem and the final decision for the investigation(s) to take place lies with the perinatal pathologist. It is important the parents are kept informed throughout the post-mortem process. The Royal College of Pathologists has issued autopsy guidelines for perinatal post-mortem.

Transporting the baby's body and remains outside the hospital

When a baby is transferred from home to hospital with the woman or birthing person, 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 woman or birthing person'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 woman or birthing person) 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. post-mortem. Placental examinations should be discussed with all parents and, where relevant and possible, 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.

The Royal College of Pathologists has guidance on placental histology.

Post-mortem examination consent

Consent should be sought by a senior member of staff who has received training in seeking post-mortem examination consent and has a good understanding of relevant processes and procedures. Consent takers need to have up-to-date information about local circumstances and how these will impact on what parents will experience (for example, transporting the baby, local wait times), in order to support parents to make an informed decision. It is a process that should involve careful listening and discussion. The Sands perinatal post-mortem consent package provides guidance on the post-mortem consent process.

Asking parents whether they wish for 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 examination 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.

For guidance on where support needs to be in place for parents, see the Parent Pathway included in NHSE's perinatal post-mortem investigation policy.

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. The discussion 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 and align with their values. All discussions should take place in a quiet, private place where parents and staff will not be disturbed.

It is vital that the person requesting consent has a thorough understanding of local policies and procedures for post-mortem examinations 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. They must have up-to-date information about local circumstances, including where the post-mortem will be carried out (if known), transportation, timelines for returning the baby, and the likely timeline for receiving the post-mortem report. There are a range of circumstances where a full post-mortem may not be carried out, and staff should be able to discuss this sensitively and knowledgeably with parents. They must also be aware of the options for post-mortem investigation available, for example Minimally Invasive Autopsy is not available in every perinatal pathology unit.

Parent's wishes about post-mortem should be acknowledged and held at the centre of the perinatal post-mortem process. The consent taker should ensure parents understand their consent is for a maximum level of post-mortem investigation. The pathologist will not exceed this level, and will determine the most appropriate investigations(s), which may be a less invasive investigation than parents have consented to.

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.

Anyone taking consent must have undertaken training as required by their Trust and this training needs to be regularly updated. Information on options for post-mortem consent training is available via the Sands website.

Parents who consent to a post-mortem must be given the name of a main and a secondary contact for the period of time from the baby being sent for the post-mortem investigation through to the parents receiving the post-mortem report. The names of these contacts and their contact details must be listed on the post-mortem consent form. The key contacts must stay in touch with parents, keeping them informed about details such as where their baby is, arrangements for the baby after the post-mortem is complete, and when they will receive the post-mortem report.

Model consent forms, which can be adapted for local requirements, can be accessed via the HTA website.

Discussing a post-mortem examination with parents

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 asked if they would be happy for staff to approach them to discuss this after having some space to think. 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.

Staff should be aware and ready to make any necessary adaptations for parents with an identified learning disability to ensure that parents fully understand. Staff should also ensure that if an interpreter is needed, this is arranged prior to the discussion.

Sands training is available on conducting sensitive and compassionate conversations with bereaved parents about perinatal post-mortem examinations.

Location

All post-mortem examinations on fetuses and 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. Additionally, a family may be able to use the mortuary viewing room to spend more time with their baby and mortuary staff should liaise with bereavement teams to ensure that this is possible.

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. This can take several months and, in some cases, more than 6 months. It is important staff are aware of likely timelines and are able to give parents a realistic estimate. Parents must be given the name of a main key contact and second key contact who they can get in touch with to ask any questions during this period. The names and contact details must be included on the consent form. The key contacts to proactively keep parents in formed of progress wherever possible. If there is a delay to the post-mortem examination results, it is important that this information is shared with the healthcare team supporting the parents and with the 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 is good communication 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.

Coroners

Medical examiner

If a baby dies neonatally at any gestation, on the maternity or neonatal unit, including any baby showing signs of life following a medical termination, the medical examiner will need to be informed. The medical examiner will consider the cause of death given by the doctor, review the medical notes and speak to the family before deciding whether to issue a MCCD or if a referral to the coroner is needed. The baby will not be able to be released until it has been decided if coronial involvement is needed. If the medical examiner issues a MCCD, the body can be released back to the family, so they are able to spend more time with their baby and begin to prepare for a funeral. This can be an extremely distressing time for parents, and it is important that parents are given clear written and verbal information about the process so they can manage expectations. Parents should be updated about where their baby is at all times and given opportunity to ask questions or raise any concerns with the medical examiner. Staff should offer parents information about what emotional support is available.

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 baby 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. Parents should be advised on what memory making is possible before the baby is taken for the post-mortem as this may be limited due to the coroner's timescales. 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 is available and includes flow diagrams for decision making and actions following 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 woman or birthing person 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.

Burial and cremation

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 to parents

Parents should be given the opportunity to discuss and make choices about their available options based on the those 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

More information and claim forms are available in the funeral payments section of the UK Government website. Further information on the cost of child funerals is also available on the UK Government website. The Child Funeral Charity provides further information for parents on arranging a child funeral.

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.

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 whenand 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 woman or birthing person's medical records. It should also be documented if the woman or birthing person 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.

Leaving the hospital

Leaving the clinical environment and going home no longer pregnant or without their baby can be extremely distressing. Some women and birthing people may want to leave as soon as possible. Others may prefer to stay a little longer and this should be enabled where possible. Before discharging a woman or birthing person home, the availability of support at home should be discussed with them and assessed, taking into consideration the environment they are returning to and the support network they are able to have in place. Staff should provide information regarding statutory entitlements and access to benefits where applicable, the opportunity for parents to access time off work, and the length of time for investigation results to become available. Where possible, parents should be given an alternative route out of the birth centre/hospital from their room.

It is important staff talk to parents about how they would like to say goodbye to their baby when leaving the hospital considering if they would prefer their baby to be taken from the room or for them to leave first. Parents will need to be informed about preparing and transferring their baby depending on where their baby is going and if they are going to have a post-mortem or further investigations.

All parents should be told about who will contact them and when, and the services and support available to them once they are at home. Some hospitals may also have a Sands Hospital Liaison volunteer (HLV) who will be best placed to provide information on what is available locally. 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, some will not want this contact, but contact from a relevant healthcare professional should always be offered.

Before the woman or birthing person leaves the hospital, staff should discuss with them the ongoing physical symptoms they may experience, for example bleeding, pain or lactation, and when they should contact a healthcare professional. Staff should also provide information on when the woman can return to physical activities and exercise. As appropriate, staff should provide information on pelvic floor exercises.

Milk donation and milk suppression

Some women and birthing people may choose to donate their milk to a milk bank, while others will prefer to supress lactation. Staff should sensitively provide information about both options.

UKAMB (United Kingdom Association for Milk Banking) offers support for staff and bereaved women and birthing people across the UK who are looking for information about donating milk and can provide more support if there is not a local milk bank. The Milk Bank at Chester also provides parent-facing guidance on donating milk after loss . The BAPM framework for practice provides guidance for professionals on supporting women and birthing people through lactation and loss.

Healthcare staff can support a woman or birthing person to explore if they are eligible to donate their milk to a milk bank. Staff should be able to provide guidance on how to express and store milk for donation. Women and birthing people should be informed about screening processes, and any emotional and practical support that is available to them when they are donating milk. Blood tests and health questionnaires can be completed at a place and time that is convenient for them after they make a decision.

Women and birthing people should also receive information about the available options they have to stop their milk production, including information on milk suppression, medication and its side effects and the gestation from which this medication can be used. Staff should discuss pain relief options and time frames for stopping lactation with women and birthing people.

Women and birthing people should be given a contact name and number in case they have 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.

It is important that staff recognise the complex emotional journey that a parent may be experiencing and ask open, non-judgemental questions to ensure they can provide personalised care. Staff should not make assumptions about the support that parents may be receiving and should ask parents about what support networks they have in place and where they may need further support. 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. This includes ensuring that the woman or birthing person's physical health and recovery needs are met and resources on physical recovery that are sensitive to loss are available from The PABL Project.

Third sector organisations may be able to provide additional and longer term support and these can be found in the 'useful contacts' section of the quick reference pathways. Bliss can offer bereaved parents both on the unit and post discharge one to one conversations via video call through Bliss Champions volunteers. In addition, parents can email hello@bliss.org.uk to receive emotional and practical support. Some hospitals may also have a Sands Hospital Liaison volunteer (HLV) who will be best placed to provide information on what is available locally.

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 when a pregnancy loss or the death of a baby has occurred. The appropriate member of staff can then contact the bereaved woman or birthing person and ensure that they are 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. If a bereaved parent declines to have their primary care team informed, this decision must be respected, though their ongoing well-being must be considered paramount. They should also be told where they can receive additional care if required. Additionally, they should be given a letter summarising their history and treatment to give to their GP or another doctor if they need further medical care. Staff can also offer to help with registering with a GP or changing their GP if necessary.

If different members of the primary care team are involved, 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.

With the woman or birthing person's consent:

- A designated member of staff at the hospital should phone the GP and community midwife prior to discharge. This is important as letters may take several days to arrive.
- The hospital or clinic should also immediately send a summary of pregnancy and obstetric history and care to the GP at discharge.
- Depending on the gestation at which the loss occurred, the summary should also be sent to the community midwife and the health visitor.
- The bereaved woman or birthing person should be given a written summary of their care that they can keep or give to their GP at their first appointment.
- The GP and community midwifery team (where applicable) should also be informed where the bereaved woman or birthing person will be staying after discharge from hospital. This is particularly important if they are going to stay with relatives nearby (or in some cases on the neonatal unit), so that staff know where to contact them.
- 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.
- It can be helpful if the GP, community midwife or health visitor marks bereaved woman or birthing person's electronic and hard copy medical records with an alert or sticker to notify other healthcare professionals of their bereavement (see NBCP Appendix A9).

Follow up appointments

Women and birthing people should be offered follow up appointments to talk through what happened, to share any information or test results and to discuss next steps, such as when or whether to try again. Some will appreciate this opportunity, but others may find the prospect stressful.

All women and birthing people 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.

Staff must make sure that women and birthing people know the purpose of each follow-up appointment so that their expectations are managed and met. Letters sent to confirm the appointment should clearly state the purpose of the appointment for example, a physical check-up, or to talk through what happened or to discuss results of, or referral for, any tests. If there is a clinical need for follow-up, this should be expressly stated. If there is any need for interpreting or translation services, then best practice should be followed and this arranged prior to any meetings.

It is useful to ask parents what questions they would like to have answered prior to attending and also encourage them to write down any questions or worries and bring the list to the appointment. It is also helpful to invite them to contribute their recollection of events or point of view prior to or at the discussion as part of the investigation and root cause analysis discussion. Parents 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.

Letters sent to confirm the appointment with women and birthing people should clearly state the purpose of the appointment for example, a physical check-up, or to talk through what happened or to discuss results of, or referral for, any tests. If there is a clinical need for follow-up, this should be expressly stated.

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

Some women or birthing people may want to bring a partner, or another support person to appointments. If the meeting is to be online, the correct protocols regarding confidentiality, privacy and other considerations should be followed. If there is any need for interpreting or translation services, then best practice should be followed and this arranged prior to any meeting. An offer of ongoing care (beyond the initial follow-up appointment) should be made to all bereaved women and birthing people. This offer should be repeated some weeks later if they initially decline the offer. Some parents may find that they need support later and/or be surprised by a lack of support offered by friends, family or other services. It is important that any partner is also given information about how they can access further support, this may be via their GP or third sector organisations.

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 they lost their pregnancy or 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

Bereaved parents can 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. In addition to the initial follow up appointment, an offer of ongoing care should be made to all bereaved parents. Follow up appointments are a chance for the woman or birthing person to discuss their diagnosis and treatment and have any issues listened to and, as far as possible, addressed.

Some examples of things parents may want from follow-up appointments may include the following:

- 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 difficulties 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 ask about medical care with future pregnancies, such as having early and/or additional scans.
- 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, including signposting to information on gov.uk regarding statutory maternity and bereavement leave, and neonatal care and leave pay. Please be aware that rights and benefits will vary by gestation.
- 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.
- Where appropriate, advice about postpartum physical recovery after neonatal death, including how and when to return safely to activity and exercise.

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 or birthing person, their 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

Many bereaved parents feel it is appropriate for them to be sensitively asked about the maternity and bereavement care they received and would welcome the opportunity to give feedback on their care. Providing parents with opportunities to inform service improvements, feel listened to and to have their questions or concerns answered not only helps drive improvements, but can also support parents in their bereavement journeys.

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 and Neonatal Voice Partnerships (MNVPs) 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.

It is important that parents understand how valuable their feedback is. Being on the receiving end of care they are in a unique situation to highlight to staff the areas that were helpful and also what can be improved upon. Many parents want to make a positive difference to those coming after them.

> **“We would have liked to have fed back how grateful we were for the time they gave us and how understanding they were.”** Bereaved parent

Conversely, it is important staff are supported and trained to listen to parents even when parents find issues with their care. Even negative 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.

If parents provide critical feedback about their care, it is important that the correct structures, policies and procedures are in place to ensure appropriate use of the information collected. In addition, it is also paramount that feedback mechanisms are accessible to all bereaved parents, including those who don’t speak English or may face other barriers when it comes to providing feedback. Different ways of collecting feedback should be thought of and implemented in collaboration with parents.

> **“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.

Review

Reviewing the death of a baby is part of standard NHS care. It is a vital part of helping parents understand as much as possible about what happened and why their baby died.

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 of their and their baby's care, regardless of the type of review or investigation being carried out, or which department is responsible for the investigation.

Parents should be offered the opportunity to give their questions, concerns and perspectives of care to the review panel. It is important to provide a variety of ways that parents can contribute taking into consideration any adjustments that will need to be made to ensure that they are able to share their version of what happened.

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 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). The child death reviews of babies who die within 28 days after they are born are carried out using the Perinatal Mortality Review Tool (PMRT).

Parents should be engaged throughout the process of PMRT review, any Patient Safety Incident Investigations (PSII) and/or MNSI investigation. They should be kept up to date with any progress or delays. Sands provides information, timelines, template letters and other useful resources to engage parents in the review of their baby's death. There are also resources available to share with parents to support them in understanding the PMRT process.

The PMRT tool supports

- Systematic, multidisciplinary, high-quality reviews of the circumstances and care leading up to each stillbirth and neonatal death.
- A structured process of review, learning, reporting and actions to improve future care.
- Coming to as clear an understanding as possible of why each baby died; this will involve a grading of the care provided.
- Communication with parents to ensure they are told that a review of their care and that of their baby will be carried out and how they can contribute to the process.
- Production of a report for parents which includes a meaningful, plain English explanation of why their baby died and whether, with different actions, the death might have been prevented.
- Other reports to enable organisations providing and commissioning care to identify emerging themes across a number of deaths to support learning and changes in the delivery and commissioning of care to prevent future avoidable deaths.
- National reports of themes and trends of perinatal deaths to enable national lessons from the nationwide system of reviews. For more information go to: npeu.ox.ac.uk/pmrt

Considerations for involving parents in perinatal mortality reviews:

- Ensure all parents are informed if a review will be taking place after their baby's death
- Share the outcomes of the review of their baby's death in a sensitive and timely manner.
- Do not make assumptions about whether parents will want to contribute to a review process but ensure that they are fully informed and understand the process and what to do if they change their mind.
- Give parents opportunities to ask questions which they would like the review to address both verbally and in writing.
- Allow for flexibility of when they contribute to the review process clearly explaining timescales so that parents are fully informed of when they will no longer be able to contribute.
- Provide a variety of ways that parents can contribute taking into consideration any adjustments that will need to be made to ensure that they are able to share their version of what happened.
- Explain that the review will look at both clinical and bereavement care and give opportunity to comment on both aspects of their care.
- Reassure parents that they are able to give both negative and positive feedback on their care and that the review process will influence future learning for professionals.
- Ensure that the review covers the whole pathway of care from antenatal to postnatal including input from community HCPs.
- Ensure that staff are aware of relevant statutory death review processes (for example, the Child Death Overview Panel [CDOP]) and that these link with your Trust's internal processes (for example, the morbidity and mortality [M&M] meeting or Patient Safety incident Investigations [PSI]) and inform the family as appropriate. There may also be MNSI referral, with consent, for those babies who were born at 37 weeks or over gestation and died within 7 days of being born.

Emotional support

Ongoing emotional support

The emotions experienced by parents during and after pregnancy loss or the death of a baby cannot be determined by the gestation or type of loss and staff should be sensitive to this. Follow up care and emotional support should be available for all those who experience a pregnancy loss or the death of a baby if they wish to access it. This should be delivered by professionals with the relevant skill set and training.

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 or birthing person'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 or birthing person consents, it is important that their medical notes are appropriately marked to alert all primary and secondary care staff that they have experienced pregnancy loss or the death of a baby. This is to ensure sensitive communication when contact is made, and flag the potential need for ongoing emotional support.

Services should be flexible so that they can be adapted wherever possible to meet the needs of all parents. Pregnancy loss or the death of a baby will be experienced differently by each parent. Staff should not make assumptions about how a parent is feeling, or about what they may need in terms of ongoing support.

Before leaving the clinical care environment parents should be offered information about the emotional support available to them through their care provider and by other key local and national resources. Staff should ensure parents are aware of what psychosocial services are on offer and are offered the opportunity to speak to a psychological professional on the unit or referred to one in the community. The information should be provided verbally and, wherever possible, in writing so that they can seek these immediately or at a later date.

Many parents find it helpful to be in contact with other parents who have been through a similar loss. There are support groups available in the community which parents can be directed to if they would find this helpful.

Staff should communicate with parents about the difficult emotions they might experience and reassure them that these emotions are commonly experienced by many bereaved parents. 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 support available:

- Chaplaincies should have contacts with religious and spiritual advisers of different faiths and spiritual organisations.
- A contact to provide ongoing emotional support via the care provider (for example, a bereavement lead or community midwife).
- Access to counselling and further support via secondary care (for example, GPs and health visitors).
- Specialist psychological services, including maternal mental health services.
- National and local support organisations, such as Sands.

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 and birthing people 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 difficulties 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 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

Women and birthing people should feel well supported in any pregnancy following a pregnancy loss or 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.

All staff who care for bereaved women and birthing people in subsequent pregnancies should be well informed about their history so they can respond sensitively to any anxieties or concerns they may express. Early pregnancy units, scan departments and others seeing women or birthing people early in pregnancy need to be informed about their previous loss(es).

Offering women and birthing people continuity of carer and the option of having their notes clearly marked (See Miscarriage Pathway, Appendix A9) may help to ensure that they do not need to explain their situation repeatedly. Where available and appropriate, Professional Midwifery Advocates (PMAs) could be helpful in supporting the family. It may also be helpful to share information in a team debrief so all staff are aware.

The possibility of another loss may be too difficult for some parents to consider. In particular, this may be the case where their baby who died had a medical or genetic condition that could affect subsequent pregnancies. 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:

- Familiarise yourself with the woman or birthing person’s notes.
- Listen to and acknowledge parents’ fears and concerns.
- Support parents to make informed choices around if/when to try for another baby, including timings after specific treatments or testing.
- Outline any additional antenatal care (such as early scans) and support offered.
- Be clear about the available support from staff and other organisations.

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 or 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 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 reduce the risk of another loss, or steps they need to take to prepare for another pregnancy.

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

Antenatal care

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. For others, there may be relief that they are pregnant again. Many will veer frequently between hope and anxiety. It is important to recognise the diversity of experience, circumstances and demographics. 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. The team providing care should carefully read the woman or birthing person'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.

Antenatal care in subsequent pregnancies may involve offering women and birthing people extra appointments, screening options, scan appointments and/or opportunities to discuss an antenatal care plan and birth preferences. Joint decision-making should take place between the woman or birthing person and consultant regarding frequency of review and timing and mode of delivery. Women and birthing people report attending a specialist pregnancy after loss service (e.g. Rainbow Clinic) improves mental health outcomes and reduces the risk of adverse outcome.

Staff should allocate extra time for these appointments. The woman or birthing person 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 women and birthing people in a subsequent pregnancy so that they do not have to retell their story if they do not wish to do so. Many healthcare professionals would benefit from additional training on managing this compassionately. The quality of communication between hospitals and primary care teams following loss can reduce the need for parents to keep repeating their experience in subsequent pregnancies. Some women and birthing people may welcome more frequent contact with healthcare staff during subsequent pregnancies and will want all available screening and diagnostic tests.

Some women and birthing people may find additional appointments, screening and tests stressful and decline some or all of this care. Staff should explain the reason why a woman or birthing person has been offered additional tests or checks and any risks in declining them, if relevant. However, their decisions about their care should be respected and relevant antenatal information should be provided to ensure they know when to contact their care providers. Women and birthing people should have the details for a named contact in case they have any concerns or change their mind.

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."** Bereaved parent
>
> **"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."** Bereaved parent

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.

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.

Women and birthing people 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 their concerns and take them seriously, as well as offering specialist psychological support to manage these feelings, as necessary.

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

Some parents may try to protect themselves from feeling overwhelmed by fear and anxiety by distancing themselves from what is happening, either throughout the pregnancy or until the point at which they feel their baby is safe, which can be some time after birth depending on their previous experience.

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.

> **“Having had a miscarriage, followed by an ectopic, I am in a very negative mind-set. I panic that something is going to happen to the baby.”** Miscarriage Association

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.

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 needed if parents are unhappy about aspects of the care they or their baby received.

Some parents may prefer to be cared for by 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 they had their loss or their baby died or see staff who had cared for them at that time. Healthcare staff should refer women and birthing people to another unit or another consultant if requested.

At the first antenatal visit, each woman or birthing person should be allocated a named midwife and consultant obstetrician. These practitioners should provide most of the woman or birthing person’s care throughout their pregnancy, birth and the postnatal period.

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 and birthing people may wish to make a birth plan which could include a planned induction of labour or caesarean birth depending on their individual circumstances. Women and birthing people 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 birthing parent.

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

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. Parents should be offered specialist psychological support and a space to process these feelings, as necessary.

"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." Bereaved parent

Care in the community

Parents who experience a pregnancy loss or the 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 women and birthing people 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 women and birthing people 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 specialist staff.

Staff support

Healthcare staff should be effectively supported to provide high quality bereavement care for bereaved parents and families. When staff are properly supported, working with families experiencing the death of their baby can be special and rewarding. Good training and support for staff improves the quality of bereavement care offered to parents when a baby dies.

Training

All staff involved in the care of bereaved parents and families must receive the training and resources they need to provide high-quality bereavement care. Bereavement care training should be mandatory for all staff who may come into contact with bereaved parents and families, including those in non-clinical roles. Staff should receive training on induction and annual refresher training, and must be able to access this training in working hours. Staff should also have access to up-to-date and relevant bereavement care resources.

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.

Training can help staff to feel more confident in the care they provide and help to understand their emotions. Support and training are essential to ensure staff well-being and avoid staff burn out.

Staff wellbeing

To provide parents with high quality, personalised care, workplaces must be supportive environments where staff feel valued. 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.

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 may include staff having their own experience(s) of loss; a feeling of personal and professional failure following a baby death; anxiety caused by wanting to ‘get it right’ knowing this is a difficult time for parents; working in understaffed and unsupportive work environments.

A trauma-informed approach should be taken to providing support for staff. Staff should have access to wellbeing services and specialist psychological support and have opportunities to debrief. It is important to have different support options available for members of staff to use as they need.

Staff wellbeing should be prioritised and monitored as a key part of a safe, effective and high-quality healthcare service. 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. It is important to note that stigma and concerns about not appearing to be coping with their job may cause some staff to avoid seeking support.

Trusts should also ensure that managers and senior staff have access to appropriate support, both for themselves and so they can support their staff. Where staff are bereaved, this NHS guide to bereavement and cultural practice can be helpful to managers.

For further resources, see the NBCP toolkit on staff wellbeing.

The Sands helpline is available for anyone affected by pregnancy loss or the death of a baby, including healthcare staff.

Notes

For more information visit:
nbcpathway.org.uk

sands.org.uk

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