A pathway to ensure high quality bereavement care after pregnancy loss or the death of a baby

national bereavement
care pathway
for pregnancy and baby loss

Stillbirth

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

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Miscarriage Association The knowledge to help

Neonatal Nurses Association

UCL EGA Institute for Women's Health

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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 with dignity and create memories."
>
> **Bereaved parent**

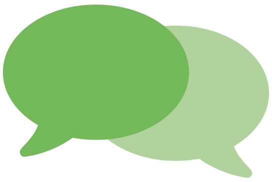
Note to the reader

This is the full version of the 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.

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.” 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

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. If the sonographer needs some time to concentrate, it may be helpful to use phrases such as, "I am going to be quiet for a moment so that I can concentrate on the screen." Staff should be aware that parents are often highly sensitive to non-verbal messages and body language.

Parents may become alarmed if the screen is turned away from them without prior warning or if the sonographer's facial expression and demeanour change. 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. This may be very difficult and distressing for the sonographer who may need a moment to compose their feelings although parents must not be kept waiting for any length of time. It is also important not to pretend that all is well or offer false reassurance.

> **"I can remember every detail of the room and the moment the chatty sonographer stopped talking and turned the screen away from me. She then asked her assistant to get a doctor. That is the moment I knew deep inside me that my baby daughter Heather had died and my heart broke."**
> Bereaved parent

Parents should also be offered a scan photograph. Some parents will appreciate a scan photograph while others will not. 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 would like to/change their mind. Parents should not feel pressured to accept the offer of a photograph.

Breaking bad news

Delivering difficult news can be extremely challenging and stressful for staff and it is important that all staff have training so that they have the skills to sensitively inform parents when something is wrong. Breaking bad news in a sensitive way cannot reduce the pain that parents feel but it can affect how they experience care from staff.

> **"Doctor said there doesn't seem to be a heartbeat and asked if I know what that means?! Why did she have to make me go through the hardship of telling her that my baby is dead, is this an exam/test? I think she should have gently explained it herself."** Bereaved parent

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.

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.

Good communication with parents is important at this time and staff should be aware of the range of reactions that parents may have when receiving this news and offer emotional support.

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. For example, when a baby's death is confirmed during a scan, use words such as "your baby has died" and not euphemisms such as "I'm afraid your baby has gone."
- 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.
- If the pregnancy is a multiple birth pregnancy and one or more of the babies have died then additional time and care needs to be taken to discuss the care of the surviving baby or babies.
- 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.
- 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.
- For further information, see the Consensus Guidelines on the communication of unexpected news via ultrasound.

> **"I so wanted to hold my baby and to hear his cries, but they did not come. After a strange amount of time that seemed like a second but also like an eternity, a woman doctor came over, put a hand on my arm and said, I'm sorry, but we have been unable to resuscitate your son. Im 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 [and/or is possible] before offering parents information about creating memories and/or asking parents to make any other decisions.

Parents who have decided to continue 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.

Delivery and birth

Stillbirth

Vaginal birth is generally the recommended type of birth for women and birthing people whose baby dies before labour begins unless there are medical reasons for recommending a caesarean birth. This is because of the risks to the woman or birthing person and potential implications for future pregnancies that are linked with caesarean births. However, all potential options for the baby's birth should be discussed with parents and the implications for the future explained clearly and sensitively There are several reasons why parents might ask for a caesarean birth, including fear of childbirth in general (INSIGHT Siassakos et al BJOG 2017). The discussion of delivery should start by eliciting the parents' concerns and wishes, before joint decision making can be reached. Parents should also be reassured that staff will be available to provide continuous support regardless of the type of birth parents choose.

Many parents may initially request a caesarean section and this option should be discussed, including that this may not always be available. Many parents, though initially shocked that they will most likely need to labour and give birth, afterwards can feel a great sense of achievement and pride in birthing their baby. Where medically appropriate, women and birthing people should be offered the option of delivering their baby in a birthing pool.

If there is time, staff should also suggest that parents may want to plan for the labour, birth and/or what they would like to happen after their baby is born. Some parents may want help and support in deciding what they would like to include in a birth plan. Any members of staff caring for parents should read this plan and be aware of parents' wishes.

If they are going home before returning to a hospital or freestanding-midwifery unit, parents may also wish to consider things that they might like to bring to the hospital. For example, they may want to bring snacks, comfortable clothing, toiletries, a camera, a special toy, blanket or other item for their baby and any clothes that they may wish to dress their baby in. Parents may appreciate suggestions from staff about items that they may want to bring.

Induction

Parents should be offered information about:

- The types of medication that are available to induce labour.
- The process, and the potential benefits and risks associated with each medicine used for induction.
- The time each type of induction may take.

When parents decide to have their labour induced, they should be offered time between the confirmation of the baby's death and induction. This time may help some parents to absorb the news about their baby and the idea of labouring and giving birth to their baby who has died, make any necessary practical arrangements at home and think about how they want to say goodbye to their baby. If a woman or birthing person goes home before the induction, she should be given a 24-hour contact number for named contacts should she want any support or information. Other women and birthing people may want the induction to take place as soon as possible and may find it very distressing to carry a baby who has died. For some parents, a long delay between the confirmation of their baby's death and the birth may cause distress. It is essential that women and birthing people are supported to make a decision that is right for them.

Pain management

Women and birthing people have different experiences of pain during labour and birth. However, a woman or birthing person who is frightened, shocked, distressed or feels unsupported may feel pain more intensely. Induction of labour may also increase the pain that a woman or birthing person experiences and this should be explained to women and birthing people when discussing induction and pain management. In addition to this, many women and birthing people may not expect the pain and duration of their labour after their baby dies.

Women and birthing people whose babies have died need full information about pain relief and should be reassured that all pain relief options will be available to ensure that they are comfortable (unless they have a history of allergies or adverse reactions to certain drugs). All women and birthing people should be offered information about all available pain relief options, including advantages, disadvantages, side effects and evidence for the efficacy of each type of pain relief.

Women and birthing people should also be aware that the place where they are receiving care may affect their options for pain relief.

Place of care

The place where a woman or birthing person receives care during labour and birth after her baby dies may affect how parents experience this care. Women and birthing people and their partners (where applicable) should be provided with full information about the places where they can choose to give birth and be supported to make a decision about their place of care. Some parents may decide to give birth in the place where they had originally planned or they may change their mind.

Staff should support women and birthing people to make a decision about where they give birth to their baby who has died by giving them information about their available options, the benefits and risks of each option for the woman or birthing person and recommendations based on the woman or birthing person's medical condition and history. A woman or birthing person's preferences for the labour and birth will also affect where she gives birth. The types of pain relief that a woman or birthing person may want may also affect her decisions about place of care.

It should be possible for women and birthing people to decide whether to give birth to their baby who has died in a hospital (on a labour ward, gynaecological ward or midwifery-led unit), in a freestanding midwifery-led unit or at home. The available choices will be dependent on the woman or birthing person's medical condition and birth preferences.

Many parents find it distressing to give birth in a place where live babies are being born or they can hear the sounds of crying babies. It is recommended that labour wards have dedicated, soundproofed bereavement rooms or suites where parents can have complete privacy and comfort. However, these rooms should be a short distance from the main labour ward rooms so that staff are quickly and easily able to provide care for parents. There should also be space for partners and other birth supporters in these rooms, including a comfortable place to sleep. Where these facilities are unavailable, staff should acknowledge that this may be difficult for parents and prepare them for potentially distressing sights or sounds on the way to the room where they will receive care.

While it is less common, some women and birthing people may decide to give birth at home after their baby has died or is expected to die around the time of birth. Some women and birthing people may already have been planning a homebirth before their baby died. Other women and birthing people may decide to give birth at home after they learn that their baby has died.

If a woman or birthing person plans to give birth at home, it should be clearly documented in the woman or birthing person's hand-held maternity notes that the baby has died or is expected to die around the time of birth.

The woman or birthing person's midwife should arrange for gas and air and any other equipment to be delivered to the woman or birthing person's home as soon as possible. Any equipment that may be needed to provide care for the woman or birthing person, or comfort care for the baby, should be included in this delivery. The midwife should ensure that a delivery pack for the baby is not sent to the home unless the baby may be born alive. Staff should also double-check that these items have been delivered. Consideration should also be given to the availability of cool cots, memory making facilities and other services outside of the hospital setting. It is also important that, where appropriate, parents are offered religious or spiritual care.

Care for labour and birth

Labour ward staff should be expecting parents who arrive at a hospital for an induction after their baby has died. Wherever possible, separate entrances/exits to those used for livebirths should be used. Staff should be available to welcome parents and ensure that they do not have to explain why they are there. This also applies if labour has started following expectant management and parents have called ahead to inform staff that they are coming in to the labour ward or midwifery-led unit. These parents should not be expected to wait at home until contractions are closer together unless they wish to do so.

Parents should be shown to a private room as soon as possible after arrival. If labour has not begun when the death is diagnosed, parents should not be expected to wait for a scheduled induction or caesarean section under these circumstances unless it is absolutely necessary.

Before caring for parents, all staff should ensure that they have read the woman or birthing person's medical notes and birth plan if one has been prepared.

All women and birthing people should be offered continuous support and care from the same carers throughout the labour and birth as this may affect their well-being and their experience of care. This continuity will help to ensure that parents do not need to repeatedly build new relationships with staff at such a difficult time and it may also affect the quality of care that staff can provide. Wherever possible, staff should be able to arrange for parents to be supported in hospital by a known midwife who cared for them in the community.

Staff can sensitively mention cremation, burial and funerals with parents before the baby is born to give them time to think about their options before a full discussion after death. Some parents will not want to discuss this before the baby is born, whilst others will.

The other staff on the unit should be told about the baby's death or expected death. This will help to prevent inappropriate comments being made by well-meaning staff. It may also help to ensure that the staff caring for parents whose baby has died are offered support from their colleagues. After parents arrive at the labour ward or midwifery unit, the patient board should be marked with a special symbol to notify all staff that a woman or birthing person is in labour whose baby has died. All staff should be familiar with this symbol-including administrative, cleaning and support staff. This symbol will give staff information about what room parents are in and make them aware that they will have different support needs from other parents on the unit. Some units have told us that they have a symbol, for example a laminated butterfly sign, on the door of the room to remind staff going along the corridor that the bereavement room is in use and to be sensitive to noise – e.g. to avoid chatting and laughing in the corridor.

Many women and birthing people have concerns or fears about labour and birth and how they will cope. These feelings may be intensified when the baby has died and there is no reward of meeting a healthy baby at the end. Women whose babies have died are likely to need extra encouragement and support to keep going during the labour and birth. For any women whose babies are expected to die around the time of birth, please refer to the Neonatal death pathway.

Offering this support may be challenging for staff as the usual words of encouragement that focus on the positive experience of the baby being born cannot be used with parents whose baby has died. It may be tempting for staff to focus on the future in these situations. However, it is important that staff stay focused on the present situation as focusing on the idea of a future baby may cause additional distress for parents or cause them to feel isolated.

Babies who are born premature may be delivered very quickly and this may come as a shock to the parents. It is important to explain that this may happen before the birth so as to reduce distress.

Parents who have had previous deliveries will have different expectations and it is worth discussing with them what may be different

During the birth, parents may need extra emotional support. In particular, this may be the case for parents whose baby is expected to die as a result of the process of giving birth.

After the birth, parents may not be expecting the silence that follows and may be in shock or be very distressed. Staff should be present to support parents following the birth. Staff are also able to offer parents opportunities to meet their baby at this time and provide valuable guidance for parents around seeing, holding and creating memories with their baby. Later sections of this pathway provide suggestions as to how the baby who has died may physically appear and it is important to gently describe this in advance where possible.

Care for partners and supporters

A woman or birthing person should be able to have her partner and/or another supporter with her at all times. Some women and birthing people may want to have more than one person with them and this should be accommodated.

Even if a woman or birthing person has someone else with her, it is important that staff offer support and make it clear that they are available whenever needed. Some women and birthing people do not wish to be left alone at any time and should not be left on their own. Other women and birthing people may prefer to be alone, provided they know they can get help immediately if it is needed.

Any partners or supporters who are present should be kept fully informed and involved whenever possible (with the woman or birthing person's consent). This is important as it may add to their distress if they do not feel informed about what is happening.

Partners and supporters may also feel protective towards the woman or birthing person and may become very anxious that staff should be doing more to help her and, where appropriate, the baby. In some cases, this may lead to aggression towards staff. Acknowledging the partner's concerns and giving clear explanations may help to reassure them that everything possible is being done. Of course if this aggression continues staff should deal with it in the normal way recommended by the Trust, being mindful of the well being of all involved.

Staff should also offer emotional support to any supporters as they are likely to be experiencing their own grief for the baby as well as fear for the woman or birthing person. Additionally, they may feel powerless and worried if they see that the woman or birthing person is distressed and in pain.

It may be helpful for staff to acknowledge that partners may feel there is very little they can actively do. However, staff can emphasise the support they are offering by being there. It is also important to acknowledge that most people find it very difficult to "just" be there.

Multiple pregnancies

When one or more babies have died during a multiple pregnancy and one or more babies has also survived, parents may experience mixed feelings during the labour and after birth. Some parents may feel torn between experiencing joy for the impending birth of any surviving babies and intense grief for the baby or babies who have died. Some parents may not feel able to grieve until after their babies are born when they are able to say goodbye to the baby or babies who have died. They may also have been concerned that their grief would affect any surviving babies before the birth. Staff should acknowledge the baby who has died and try to focus on both the baby or babies who have survived and the baby or babies who have died. Staff should also offer parents opportunities before, during and after the labour and birth to discuss how they are feeling. It is important to ensure babies are labelled correctly, for example 'Twin 1' for the first born. It is important to discuss this with the family as the smaller baby noted on scan who was expected to be born first, Twin A, and may have moved and may not have been born first (Twin A may become Twin 2).

If there is likely to be a body, recognisable remains of the baby or babies who have died or a fetus papyraceous, staff should offer to gently describe to parents how the baby or babies may look. Many parents do not regret seeing their baby or babies even if their appearance has deteriorated or they have a visible anomaly. The Twins Trust provide butterfly stickers which can be placed on the surviving baby's/ babies' cots to indicate they are the sibling of one who died. Further guidance can be found in the Twins' Trust's helpful supplementary NBCP guidance leaflet.

Memory making

Seeing and holding their baby

Seeing and holding their baby may be important to parents regardless of the size, condition or gestation of their baby. For parents, gestation is not an indicator of feeling for or attachment to their baby and it is important that all babies are handled respectfully and with care.

It is important for healthcare professionals to offer all parents the option of seeing and holding their baby while recognising and respecting that some parents may decline this offer. It is important to anticipate and support different parents' wishes to seeing and holding the baby. One parent may wish to see they baby, and the other may not. In such circumstances the second parent often, but not always, may then decide to see and hold the baby as well, as they feel reassured.

Multiple births

Women and birthing people expecting multiples were 2.2 times more likely to experience stillbirth than singletons according to the MBRRACE 2019 report. Special consideration is needed for the parents of twins or multiple babies. It is important that staff acknowledge the importance of the baby (or babies) who have died, and avoid focusing only on the baby or babies that are alive. If parents want to see the baby or babies who have died, it may be helpful to see and perhaps hold the living and the dead babies together if this is possible. Without this opportunity it may be difficult for parents to grasp the reality of what has happened. Later on, the parents may value the memory of being with all their babies together. It is important to ensure that other ward staff are aware that the surviving baby/ies is/are part of a multiple birth. Health professionals should use all of the babies names where possible, including the baby that has died.

> **"The emotions that swamped us over the next few days were completely overwhelming. How does one integrate the feeling of grief for one baby with the feeling of joy for the other? After all we had only wanted one healthy baby and we still had that. So why did we feel so terrible?"**
> Bereaved parent

Baby's condition

If there is a visible anomaly or maceration, the parents should be gently told what to expect and be offered a description of their baby's appearance before deciding whether to see the baby. Parents may need extra support from healthcare professionals. If parents accept the offer of a description, it is important that the explanation is factual and without judgement or any implication that the baby looks unpleasant. Parents often see the beauty of their baby regardless of the baby's actual appearance. Sometimes, it may help if the baby is wrapped in a blanket or dressed and the parents look first at the baby's other features. Some parents may want to see the anomaly. They may find this important for understanding why their baby died. If the pregnancy was terminated for medical reasons, seeing the anomaly may help parents to understand the decision they made to end the pregnancy. 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

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 baby.

Some parents will decide that they do not want to see or hold their baby, 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.

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 Stillbirth Pathway, Appendix A4).

> **"I could have been better prepared for how my baby would look after he was born. I was so scared… I didn't know if I could hold him… I needed to be given time… I felt that someone was going to swoop in at any moment and take him away to the morgue. I would have loved more time."**
> Bereaved parent

Naming the baby

Parents often decide to name their baby. This may help parents and their family to talk about the baby 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 after asking the parents if they prefer so. Many do appreciate using the name, but some parents choose not to use it in discussions. However, staff should bear in mind that some parents will not want to name their baby. See also the later section on registration within this document.

If there is any doubt about the sex, the parents may want to wait for definite confirmation before they choose a name. Some parents may still want to give their baby a name, even if it is not possible to identify the baby's sex. They may want to choose a name that could be used for either sex or a name with a special meaning to them.

Creating memories

While perinatal loss is a significant loss to a family there are generally few or no tangible memories of the baby or babies and often there are no memories that can be shared with other people. In most cases, the parents have never seen their baby alive.

Parents may find making memories following the death of their baby valuable and sharing these memories may be beneficial to the grieving process. Staff may be able to help by offering parents opportunities to create positive memories and physical keepsakes.

When suggesting to parents that they might want to create memories of their baby, staff should remember that parental choice is paramount. It is essential to offer genuine choice and not to steer parents towards a particular course of action in the belief that it will help them. However, it is important to let parents know that they can change their minds later if they decline to create memories and to "normalise" the options for creating memories that are available to parents by mentioning that many parents find this helpful. Parents should be reassured that whatever choice they make is okay.

Some parents may find the idea of creating memories strange and unnecessary. It is important to listen to individual parents and find out what they would like to do in their own time.

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.
- They do not stand between parents and the baby.
- That, where appropriate, parents are offered religious or spiritual care.

Washing and dressing the baby

Parents may want to wash their baby or assist or watch a member of the staff washing the baby. It may be beneficial if staff wait until after they have asked the parents twice if they would like to wash the baby themselves before staff wash the baby. Some parents may feel that washing and dressing their baby provides them with an opportunity to "parent" or care for their baby as well as look more closely at their baby.

If there is maceration, skin slippage should be explained first to prevent further distress to the parents. For babies that are macerated, washing may not be appropriate and this may need to be discussed with parents.

Some parents may want to dress their baby in clothes they have chosen. They may need help to dress their baby or may want to ask someone to do it for them. Some hospitals provide clothes but it is still important that parents are able to choose what their baby wears. Some parents prefer to wrap their baby in a shawl.

If the baby is going for a post-mortem examination, discuss with the parents if they wish the baby's clothes to be preserved for after the examination as there may be some staining of the clothes if put on immediately afterwards. Offer the parents a baby gown (often lovingly made by volunteers) for the time to and from the examination, and the baby can be dressed again in the clothes on return. If parents wish to keep the clothing that the baby has worn, staff should sensitively and gently offer whether the parents would like the clothes washed before returning to parents so that they are clean. However, this will also remove any smells which the parents wish to remember.

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."** Bereaved parent

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, others may have objections on religious or cultural grounds, and will 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. If parents decline photographs being taken, there should be clear documentation as such in the clinical records.

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 and maceration.

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, or store on a SD card, depending on local processes and procedures, 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 baby's weight and measurements.
- Baby's scan picture.
- Baby's cot card.
- Baby's identification bracelet.
- Baby's cord clamp.
- A lock of baby's hair
- An identical set of the clothes the baby has been dressed in.
- Cards and ribbons from any flowers received.
- Sympathy cards.
- A copy of baby's certificate(s).
- The blanket baby has been wrapped in.

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.

Taking baby out of the hospital environment

Some parents find it very helpful to have time with their baby and say goodbye away from a clinical setting. If the parents wish, this can also be an opportunity for siblings, relatives and friends to see the baby, create memories and grieve with the parents.

Some parents may also want to take their baby home as they may wish to spend time in the home where he or she would have lived and grown up. Others may want to take the baby to a place that has special significance for them. Some areas may also have a local hospice with a cold room where parents can spend time with their baby if they do not wish to take the baby home.

There are no legal reasons to prevent parents from taking their baby home unless the death has been referred to the coroner.

In some cases taking the baby out of the clinical environment may not be an option, for example where there is an infection. This should be sensitively discussed with the parents and they should be enabled to spend more time with their baby within the hospital or hospice environment.

Wherever possible, parents should be given the choice to take their baby home or out of the hospital. When parents are not comfortable or there are good clinical reasons to discourage parents from taking their baby home, parents should be offered a longer stay in the hospital. For woman or birthing persons with existing mental health problems, advice should be sought from a mental health professional if necessary and extra support should be offered in the community.

> **"It was especially helpful to be able to bring Louisa's body home for a few days to the house where she was meant to live and grow up. We let our elder daughter, Natasha, who was then aged three, hold and care for Louisa, as she was bursting to do. She sang to Louisa, carried her into every room to "show her round", brushed her hair and did This Little Piggy with her toes. It was heartrending but beautiful at the same time."**
> Bereaved parent

Sensitive and efficient procedures should be in place that enable staff to provide good support to parents who wish to take their baby's body out of the hospital. If parents plan to take their baby 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 examination.

Parents also need to know that it is important to keep the body cool. They may be able to borrow a cold cot from their hospital, a local support group or hospice. It is important that staff know what local resources are available before offering these options to parents. To ensure parents consistently have this option, repairs for cold cots can be undertaken for free by The Luca Foundation. If parents plan to return the body to the hospital before the funeral, they need to know when and where they should go. Alternatively, the funeral director (if applicable) can collect the baby from the parents' home before the funeral.

Parents can take the baby home by car in a Moses basket secured by a seatbelt or in the parents' arms.

If necessary, parents could arrange to take the baby home in a taxi or minicab if this is agreed with the driver in advance, although using other forms of public transport is not advisable. Local funeral directors may also be willing to help transport the baby home or to a hospice.

There is no legal reason to inform the police if parents take their baby's body home or out of the hospital. However, for the protection of the parents and to prevent misunderstandings, Trusts should issue a form to accompany the body. The form should confirm that the body has been released to the parents and that they will be taking it back to the hospital or making their own funeral arrangements.

It should include the name and contact details of the member of staff who can be contacted if any difficulties arise (for example, in the unlikely event of a traffic accident). (see Stillbirth Pathway, Appendix A5.)

If the parents are collecting the baby's body from the mortuary rather than the ward, the ward should also give them a mortuary release form. The parents are legally responsible for ensuring that the body is lawfully buried or cremated if the baby died after 24 weeks' gestation.

If the parents do choose to take their baby home, it is important for a member of the bereavement team to follow up to provide support and advice.

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 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 Twins Trust, The Miscarriage Association and ARC sometimes publish parents' stories in their newsletters or other publications.
- Adding the baby to a family tree.

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 babies' bodies 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 should be appropriately covered, kept in the best possible condition and protected against accidental damage and avoidable deterioration.

Placental examination

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. Placental examinations should be discussed with all parents and all placentas from babies who have died should be sent for examination by a specialist pathologist.

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

The Royal College of Pathologists has guidance on placental histology.

Post-mortem examination consent

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.

Consent should be sought by a member of staff who has received training in seeking post-mortem examination consent and has a good understanding of relevant processes and procedures. It is a process that should involve careful listening and discussion. It should be unhurried (a minimum of one hour should be allocated for this process) and should help parents to reach decisions that are right for them. All discussions should take place in a quiet, private place where parents and staff will not be disturbed.

Seeking consent for a post-mortem examination may differ from consent for other types of procedures as staff are often not performing or involved with the investigations themselves. It is vital that the person requesting consent has a thorough understanding of local policies and procedures for post-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. This is especially important in order to minimise undue 'false hopes' pinned to a post-mortem. In some Trusts, as part of internal training programmes, staff attend a perinatal post-mortem in order to better understand the process.

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.

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.

Mentioning the possibility of a post-mortem examination as soon as appropriate and in advance of seeking consent may be beneficial. Staff should be honest and realistic when telling parents about post-mortem timelines.

It can be helpful to explain to parents that when no specific cause of death is identified, this may offer important information , as it suggests that no major, recurring condition has been found.

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.

Registration and Certification

Registration of birth and death

The doctor or the registered midwife who attended the delivery or examined the baby's body after the birth gives the parents a Medical Certificate certifying the stillbirth. This will need to be taken to the registrar of births and deaths by the parents.

Healthcare staff can help parents by offering to explain what the registration process involves and alerting them to decisions they may want to make before going to the register office. For example, parents may wish to name the baby as the name cannot be changed after registration.

Before parents leave the hospital, staff should ensure that:

- They have discussed the information about registering the baby's stillbirth 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 registry 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.

A stillbirth should be registered within 42 days, though this may be able to be extended under certain circumstances. Contact the local registry office, if this may be necessary.

There are lots of training modules that have been developed to address the issues registrars and healthcare professionals have identified to enable them to improve services for bereaved families.

These can be found via the Sands Training webpage, the NBCP website and by searching for 'bereavement care' on the e-learning for healthcare site, RCM i-learn and other such portals.

Burial and cremation

Legal requirements

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

Providing information on sensitive disposal to parents

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

Some women and birthing people 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.

Funeral Costs

Parents of babies who are stillborn at or after 24 weeks' gestation may be eligible for a Funeral Payment. To be eligible, one or both parents must be receiving at least one benefit or tax credit. More information and claim forms are available in the funeral payments section of the UK Government website. 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 in this regard:

Prompt burial and cremation

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

When a prompt 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. 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 prompt burials can take place wherever possible. This may be needed if the stillbirth 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.

A certificate for cremation, however, cannot be issued prior to registration for a stillborn baby.

If a prompt burial is required, the registrar will normally issue a certificate of burial to allow burial to go ahead, unless the stillbirth needs to be referred to the coroner. Formal registration of the death after burial can take place up to 42 days after a stillbirth.

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.

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 the death of their baby. Socially isolated parents or those with minimal family or social support may need additional social/psychological input.

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. ome 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. Offer parents support to deal with grief in other family members such as existing children and grandparents. Some parents wish to have guidance on how to explain the death to siblings and how to help them mourn. See also the later section on mental health.

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. 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.
- Advice about physical recovery after stillbirth, 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

Parent feedback

Many bereaved parents feel it is appropriate for them to be sensitively asked about the maternity and bereavement care they received and 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.

The Maternity Bereavement Experience Measure (MBEM)

The MBEM is a resource to support healthcare professionals to gather feedback from families following the death of their baby or babies. The MBEM survey can be adapted for local use to gather feedback from those who have experienced any pregnancy loss or the death of a baby during or shortly after birth. It is also important to adapt the survey for different types of loss.

Review

Reviewing the death of a baby is part of standard NHS care. Ensuring that all stillbirths receive a robust, multi-disciplinary review can help provide answers for families about why their baby died and help to identify improvements in care for future families.

The Perinatal Mortality Review Tool (PMRT) is the most widely-used, standardised system for reviewing the deaths of babies who are stillborn after 22 weeks of gestation. It is an online tool which is used throughout the whole of the UK.

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. The NPEU website contains further information.

In addition to a PMRT, if a baby was at least 37 weeks gestation, alive at the start of labour, but died before they were born (an intrapartum stillbirth), then a Maternity and Neonatal Safety Investigation (MNSI) will happen if parents agree to one.

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.

Considerations for involving parents in perinatal mortality reviews:

1. Ensure all parents are informed that a review will be taking place after their baby's death
2. Share the outcomes of the review of their baby's death in a sensitive and timely manner.
3. 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.
4. Give parents opportunities to ask questions which they would like the review to address both verbally and in writing.
5. 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.
6. 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.
7. Explain that the review will look at both clinical and bereavement care and give opportunity to comment on both aspects of their care.
8. 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.
9. Ensure that the review covers the whole pathway of care from antenatal to care during labour and postnatal care. Also include input from community HCPs.

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.

The NHS guide ‘supporting mental health in maternity and neonatal settings’ is for commissioners and staff involved in maternity and neonatal care. It aims to guide thinking about how best to provide services that will support mental health in the maternity and neonatal context. It also considers the role of specialist maternal mental health services (MMHS) in supporting this function.

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. Parents should be informed that the chance of complications in a subsequent pregnancy after stillbirth is higher than for mothers who had a live baby. Parents should be informed that the duration of interpregnancy interval does not affect the likelihood of problems in a subsequent pregnancy.

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, the NHS England National pregnancy and baby loss people policy framework has guidance on providing support.

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.

Support

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

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

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

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

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

Managers and senior staff should also make sure they themselves get support so they can support their staff. Where staff are bereaved, the NHS guide to bereavement and cultural practice can be helpful to managers:

Self care

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

Notes

nbcp
for pregnancy and baby loss

For more information visit:
nbcpathway.org.uk

sands.org.uk

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