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

Miscarriage, Ectopic Pregnancy and Molar Pregnancy

Full Guidance Document

Led by

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In partnership with:

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

nbcpathway.org.uk

NBCP for use in England from September 2025

About the NBCP

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

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

This guidance, developed for healthcare professionals working with bereaved families, relates to one of the five pathways. The Core Group gratefully acknowledges the support and contribution of the Department of Health and Social Care (DHSC) and Teddy's Wish to the early development of the NBCP in England. **For further information, please see nbcpathway.org.uk.**

> "Bereavement care recognises that parents' experiences and feelings count, no matter how early the gestation."
>
> **Bereaved parent**

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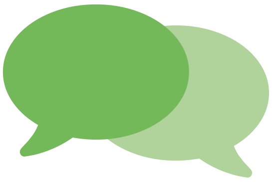
Note to the reader

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 wish the staff in day surgery had considered the operation I was in for. It wasn’t routine to us, it was the removal of our baby and all the emotions behind it.”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

“When I got to my wife, she was still out of it due to the anaesthetic and was rambling about major surgery, blood transfusions and collapsing on the ward. I didn’t really believe her because the nurse had told us it would only be a minor op.” Bereaved parent

“I wish someone had given us more time to talk about the benefits of seeing the baby and spending time with him and of inviting the other kids to come and meet him.” Bereaved parent

Bereavement care standards

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

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

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

Parent-focused standards

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

Communication and learning standards

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

Staffing standards

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

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

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

Terminology

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

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

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

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

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

Early and late miscarriage definitions

For the purposes of this document, the term 'early miscarriage' refers to pregnancy losses from conception to 13+6 weeks' gestation. 'Late miscarriages' refers to losses from 14 – 23+6 weeks' gestation.

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.
- Leaflets from the Miscarriage Association can be downloaded (or printed copies ordered) on their website, including specific information for those with a learning difficulty. Leaflets from The Ectopic Pregnancy Trust are available for parents and professionals.

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

Types of pregnancy loss covered in this pathway

Miscarriage, ectopic pregnancy, and sometimes molar pregnancy are often, but not always, diagnosed or suspected at a woman's first ultrasound examination, which may be some time earlier than a routine booking or dating scan. It is important that this information is communicated sensitively to parents as soon as possible by appropriately trained staff. Depending on the circumstances, this may be during the examination or as soon as a woman or birthing person is dressed, particularly after a transvaginal ultrasound scan. Some parents may be shocked by this diagnosis or unable to process this information. Some women and birthing people may still feel pregnant and/or have a positive pregnancy test (their hormone levels may still be continuing to rise). Other women and birthing people may have suspected something was wrong due to pain or bleeding, loss of pregnancy symptoms or having no pregnancy signs at all; and others might have already had a private scan indicating that something was wrong. Some women and birthing people, especially those with a missed or silent miscarriage, may feel guilty or ashamed that they had not realised that anything was wrong.

If the scan is inconclusive, or if protocols require a re-scan before making a definitive diagnosis, this can be very difficult for people (the woman or birthing person/couple) to bear. This scan result/findings and the reasons for it should be communicated clearly and sensitively.'

> **"It was painful to realise that for all these weeks there wasn't a baby growing inside me. It felt like we had been tricked."** Bereaved parent

Pregnancy of Unknown Location

With a Pregnancy of Unknown Location, parents should be informed that this is not a diagnosis in itself and is a term attributed until the location of the pregnancy is determined. Parents might find a Pregnancy of Unknown Location difficult to understand and the uncertainty worrying. It is important that this information is communicated sensitively to parents as soon as possible by appropriately trained staff. Some families may wish to have time and space in a quiet room. Depending on the circumstances, this may be during the examination or as soon as a woman is dressed, particularly after a transvaginal ultrasound scan. Some parents may be shocked by this news, and some may feel unable to process this information. Some women may still feel pregnant and/or have a positive pregnancy test (their hormone levels may still be continuing to rise).

Ectopic pregnancy

Ectopic pregnancies are frequently diagnosed prior to the routine 12-week scan. Women and birthing people are likely to suspect that something is wrong prior to diagnosis because of their symptoms and the need for an early scan and/or blood tests. Some find out that they are pregnant and it is ectopic at the same time, which can add to the shock. Even if a pregnancy is unplanned, parents may be shocked at the diagnosis of ectopic pregnancy and know very little about the condition. Women and birthing people may be scared for their wellbeing and by the prospect of facing their own mortality, frightened about treatment and anxious about future fertility.

Importantly, in among the physical care needed in treating an ectopic pregnancy, the possible emotional toll for a couple should not be overlooked. A range of emotions and reactions may surface, whether a pregnancy was planned or unplanned. Women and birthing people experiencing ectopic pregnancy often consider the condition to be distinct to miscarriage and, in recognition of this, care should be taken not to conflate the two conditions.

“I wish someone would have told me I would grieve the loss of my fallopian tube as much as the loss of my baby.” Bereaved parent

Molar pregnancy

Molar pregnancy is sometimes suspected at an ultrasound examination. This may be a first routine scan, a scan performed because of bleeding in early pregnancy or a scan performed due to a continuing positive pregnancy test after what is believed to be a miscarriage. If molar pregnancy is suspected, a second opinion should be sought before informing the woman or birthing person/couple of this specific suspicion. It is crucial that this information is communicated sensitively to the woman or birthing person/couple by appropriately trained and knowledgeable staff who can provide some basic information about this condition, even at the stage of a suspected molar pregnancy. If not, many women and birthing people/couples will seek information online, where a search will quickly bring up the word ‘cancer’. This can be extremely frightening so some warning of what they might see online can be helpful. You might also direct them to reliable patient information such as the Miscarriage Association leaflet ‘Molar Pregnancy’.

“I thought nothing could be more devastating than losing a baby, until a month later when they told me it was a partial molar pregnancy.” Bereaved parent

Molar pregnancy is likely to be confirmed only after histological examination of pregnancy tissue, following surgical management of miscarriage. The woman or birthing person may attend the hospital after receiving a letter or phone call, possibly some days or even weeks after her miscarriage, and may know little or nothing about the reason for the visit. She may be very shocked by the diagnosis and frightened about its implications for her health; she may find it hard to process a second piece of bad news after the original diagnosis of miscarriage; and she may be distressed by the thought of a lengthy follow-up and a delay before trying again

Second trimester loss

Late miscarriage may be suspected, or more likely diagnosed at a woman or birthing person’s first ultrasound scan if this is carried out after 13 weeks’ gestation, or any time later in the second trimester. It may be diagnosed or confirmed on examination or it may be clear that a complete miscarriage is in process or has completed. It is important that all information is communicated sensitively to the woman or birthing person/couple by appropriately trained staff. Some women and birthing people may suspect that something is wrong because of pain or bleeding, loss of symptoms or lack of fetal movement, while others might have no indication that anything is wrong. Some will be only too aware that they are in the process of losing their baby and some will already have delivered their baby.

Whatever the case, they may still be shocked by the diagnosis or unable to process the information. Some may feel guilty or ashamed that they had not realised that anything was wrong.

Ultrasound examination when a problem is suspected

Women and birthing people should be advised to bring their partner or another person for support and not to bring children.

The person performing the scan should speak to parents before the scan to make sure that they understand the reasons for the scan. They should acknowledge that having a scan in these circumstances may be upsetting for parents.

Communication during an ultrasound examination

Staff should be aware that parents are often highly sensitive to non-verbal messages and body language during scans. Parents may become alarmed if the screen is turned away from them or if the sonographer's facial expression and demeanour change or if a colleague is called into the room/consulted in the absence of any explanation.

> **"The hushed discussion between the sonographers as they studied the screen is one of my most vivid memories. Without any explanation, one asked me to get dressed. This took me by surprise and I was very confused. While I put my clothes on, I had a sinking feeling that I was about to hear the worst possible news."** Bereaved parent

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

Clear, honest information about scan results should sensitively be given to parents. Additionally, staff should acknowledge any uncertainties about the findings. Parents should also be asked if they would like the sonographer to show them what they have seen on the screen.

If another ultrasound examination is recommended and the woman or birthing person consents to another scan, this should be organised as soon as possible. The reasons for any delay in this scan should be explained to parents and staff should acknowledge that waiting may be very difficult for parents.

Parents are often not expecting to hear difficult news during an ultrasound examination and should be given time to begin to absorb the results of the examination before staff offer to discuss the next steps and available options with them however, bearing in mind that some circumstances will necessitate rapid decision making.

If miscarriage is diagnosed during a private scan, staff should refer the woman or birthing person to hospital (either an Early Pregnancy Unit or her maternity unit depending on the gestation). If an ectopic pregnancy is suspected or diagnosed during a private scan, she should be referred to her local Early Pregnancy Unit immediately or the Emergency Department if out of hours.

Parents should be offered a scan photograph. Some parents will appreciate a scan photograph while others will not. A copy of the image should be added to medical notes in the event that parents request a scan photograph at a later date.

Breaking bad news

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

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.

"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

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.
- When a diagnosis or prognosis is uncertain, 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/ies for the remainder of the pregnancy.
- 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 and that, where appropriate, parents are offered religious or spiritual care. 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.

First Trimester Miscarriage

Place of care

After a miscarriage diagnosis is confirmed and depending on the circumstances, women and birthing people should be offered information about their care options. In relation to each type of management offered, women and birthing people should be given information about their options for going home (either to wait for the miscarriage to occur or while awaiting a procedure) or being allocated a room or bed on a gynaecological or surgical ward where staff are available to support them. A woman or birthing person should only be referred to a surgical ward if there is no gynaecology ward and it should never be a mixed-sex ward.

Women who are seen in A&E should be transferred to an early pregnancy or emergency gynaecology unit or ward or be offered support to go home as quickly as possible where it is safe to do so. Women and birthing people should also not be left on a trolley in a public place if they are experiencing vaginal bleeding. If there is no alternative, and certainly when being transferred or moved, women and birthing people should be offered a pad and a covering so that bleeding is not visible.

Ideally, a single room or dedicated bereavement room should be available to parents on a gynaecological or surgical ward. However, it is important that parents do not feel isolated or unsupported if they are moved to a single room on a busy ward. Staff should ensure that a designated member of staff is responsible for checking on parents (at least once every hour unless parents request otherwise) and ensuring that they know whom to contact if they need support or assistance.

If a woman or birthing person is undergoing medical or expectant management while miscarrying and is already at home or has decided to go home, she should be offered verbal and written information about what to expect, practical suggestions for managing pain and bleeding as well as pain relief, whom to contact if they have any questions, what to do in an emergency and potential options for what will happen with any pregnancy remains and follow-up care. This information is equally important for women and birthing people who are at home awaiting hospital management.

Physical care options for first trimester miscarriage

Recommendations for a woman or birthing person’s care may depend on the type of miscarriage that she is experiencing. In any circumstances, parents must be given clear information about what is happening. Personalised care should be given to each woman or birthing person based on her particular circumstances and wishes and what is possible in terms of staffing and theatre and ward space.

Providing information to parents and involving them in decisions about their care may help to increase their sense of control in a difficult situation.

Parents should be offered information about what they might expect their baby or pregnancy remains to look like depending on the gestation and the type of management used. Some parents may wish to see their baby or any remains and other parents may not. Before a surgical procedure, staff should offer to gently describe what the remains will look like. This may include sensitively telling parents whether any remains will be recognisable and/or complete. If a woman or birthing person wishes to see the remains, this needs to be clearly recorded.

Current NICE guidance (Ectopic Pregnancy and Miscarriage: diagnosis and initial management) recommends that women and birthing people who have had a diagnosed early miscarriage use expectant management of the miscarriage for 7–14 days before considering other management options.

Some exceptions to this recommendation include where a woman or birthing person has experienced a previous childbearing loss or is at risk of haemorrhage or infection. According to this guidance, women and birthing people should be offered medical management if expectant management is not acceptable for them.

Despite these recommendations, expectant or medical management may not be suitable care options for some women and birthing people. Additionally, women and birthing people may have a wide range of views and preferences regarding how early miscarriage is managed.

Where medically appropriate, women and birthing people should be able to decide on their place of care and whether their miscarriage care will be expectant, medical or surgical. Therefore, staff should offer all women and birthing people the opportunity to fully discuss their available miscarriage care options.

The information discussed with women and birthing people for each care option should include details of:

- How long each type of management may take and what it involves.
- What they might expect if there is any delay to medical or surgical management.
- Any associated risks and benefits (including for the woman or birthing person's future fertility).
- What they might see following each type of management.
- How heavy or severe the bleeding and pain may be, and how often emergency intervention is required..
- The possibility of needing a repeat procedure or a different management method.
- Risk of haemorrhage or infection.
- Woman or birthing person's own preference of management.
- Advise on red flags and changes to look out for and how to seek medical help.

This should be supplemented by relevant written information. Parents may also have other questions and concerns that they wish to discuss with staff. Leaflets from the Miscarriage Association can be downloaded (or printed copies ordered) on their website, including specific information for those with a learning difficulty.

Expectant and medical management

Providing information about the range of experiences that women and birthing people may have is important as some women and birthing people have felt unprepared for the amount of bleeding and pain that they experienced and the length of time that the process took.

Some parents may be anxious about miscarrying at home or seeing their baby.

Parents should also be told that they can change their mind later and decide to have medical or surgical management. Any timeline restrictions for this decision must be discussed with the woman or birthing person.

Surgical management

Some women and birthing people may prefer surgical management for their miscarriage. They may want to avoid the physical experience of miscarriage and the uncertainty of when and how it might happen.

A surgical procedure may be medically recommended for some women and birthing people experiencing miscarriage. The reasons for this recommendation should be clearly explained to parents and staff should offer to discuss any concerns that parents have about the procedure.

Any arrangements that women and birthing people may need to make to travel home afterwards should also be discussed. Written information about the procedures should be given to women and birthing people and be available in a variety of languages and formats.

Some women and birthing people may want to have the procedure without delay while others may wish to wait a while. Wherever possible, women and birthing people's preferences should be accommodated.

If there is a long delay for a procedure to take place, the potential difficulty of the situation should be acknowledged and woman or birthing person should be offered or signposted to emotional support.

Before going home, women and birthing people should be given information about signs of infection, what to do if bleeding persists or becomes heavier and any follow-up appointments that are offered. They should also be provided with written emergency contact information as well as details of a named contact whom they can contact if they have any additional questions or concerns.

Surgical management of miscarriage is sometimes also referred to as SMM or evacuation of retained products of conception (ERPC). Surgical management performed with local anaesthetic and/or sedation is called MVA – manual vacuum aspiration. In all cases, staff should refer to surgical management of miscarriage when speaking with parents.

Ectopic pregnancy

Physical care options for ectopic pregnancy

Recommendations for a woman or birthing person's care depend on the extent of symptoms she is experiencing. In terms of the three treatment routes (surgical, medical and expectant management), sometimes two or all three options may be available. Being faced with treatment choice might bring anxiety to some women and birthing people, while for others give a degree of control over their care. Conversely, there are often instances where only surgical management is available and this can be a frightening prospect. Surgery is the only route in an emergency situation or where symptoms rule out other treatment routes which can be overwhelming. People may feel a loss of control or sense of panic. This may affect their ability to take in what is happening and understand next steps. Parents should be given clear information about what is happening, treatment routes (including why certain management methods would not be suitable for some women and birthing people) and personalised care.

Guidance is available: NICE clinical guideline 126 (Ectopic pregnancy and miscarriage: Diagnosis and initial management) and RCOG Green-top Guideline no. 21 (Diagnosis and Management of Ectopic Pregnancy).

When discussing management options with women and birthing people, the following should be covered:

- Why certain management routes are being offered while others are not
- The ability, if any, to change the treatment plan and circumstances where treatment will have to change, such as beta hCG levels not falling.
- How long each type of management might take and what is involved.
- Any associated risks/benefits (including future fertility).
- What they might see/experience following each type of management.
- How heavy or severe the bleeding and pain may be.
- Risk and signs of rupture or infection.
- Woman or birthing person's own preference of management.

Each treatment route harbours its own challenges – both physically and emotionally. It can feel overwhelming in trying to make a decision about care while starting the grieving process for the loss of a pregnancy. Emotions can include denial, confusion, grief, guilt, shock and fears about one's own mortality and future fertility. It is important for staff to recognise that some parents seek for their loss to be acknowledged. Parents who experience an ectopic pregnancy may appreciate words of condolence for their experience or loss; this can sometimes be overlooked in among the clinical treatment of the condition. Some, however, do not view the experience as the loss of a baby and so it is important to be led by the individual, whether the person physically experiencing ectopic pregnancy or their partner.

Expectant and medical management

Women and birthing people should be given a clear explanation of what these care options involve and what to do or not do and expect during treatment. This should include the importance of attending regular appointments to monitor beta hCG levels, what doctors are aiming to observe regarding the rate at which beta hCG levels should fall and options if those thresholds are not achieved.

Women and birthing people should also be informed that they can usually change their minds if they subsequently feel that expectant or medical management is not emotionally suitable for them, provided this is clinically appropriate. Any time limits to this should also be highlighted.

Surgical management

Some women and birthing people elect for surgical management, as it is more predictable and quicker than expectant/medical management, while for others, surgery is the only treatment route available. If surgery is recommended, the reasons should be explained to parents the type of procedure explained (keyhole/open surgery/salpingectomy/salpingostomy), and staff should offer to discuss any concerns about the procedure.

Place of care

Upon leaving the sonography room, people should have access to a single/bereavement room situated away from the EPU waiting area. Ideally, couples should not have to wait in or walk past a waiting area with expectant parents on leaving the sonography room.

If surgical management is advised, a woman or birthing person should be allocated a room or bed on a gynaecological ward and be provided with information on whom to contact if they need support or information. If medical management is advised, women and birthing people should be allocated a room or bed in a gynaecological ward while they undergo patient suitability testing and be provided with information about their options for going home or remaining in hospital. Women and birthing people should also be informed of the need for repeated hospital visits for blood tests and timings until beta hCG levels fall to non-pregnant. If expectant management is advised, women and birthing people should again be provided with information about returning to hospital for ongoing beta hCG testing until hormone levels return to non-pregnant. Women and birthing people who are medically or expectantly managed should be given contact details in the event that their symptoms change and for support while undergoing treatment. Those who are surgically managed should be given information on any further blood tests needed after discharge particularly after salpingostomy.

Women and birthing people should be given information about after-care, signs of infection, what to do if bleeding persists or becomes heavier and details about follow-up appointments. They should also be furnished with details of national and local support organisations such as The Ectopic Pregnancy Trust.

Molar pregnancy

Place of care

The care for women and birthing people with a molar pregnancy is likely to be split between the initial referring hospital and one of the UK specialist follow-up and treatment centres: London, Sheffield or Dundee. Hospital staff are usually the first point of contact when molar pregnancy is suspected or confirmed, and they may see women and birthing people during the follow-up process if they come to the unit for blood tests. It is crucial that staff caring for women and birthing people at these times are fully informed about molar pregnancy so they are able to explain processes and discuss some of the key implications. If they are not, it is best to ask a more informed colleague to look after them.

It is important that staff offer emotional support to those who have a molar pregnancy. Some will feel an additional sense of loss after an earlier diagnosis of miscarriage, and some may feel uncertain as to whether to think of this as a pregnancy and a baby at all. It is important to reassure them that whatever they feel is normal and understandable. Staff should know where women and birthing people/couples can find further support and information, including the specialist centres, the Miscarriage Association and online groups, and provide that information accordingly.

Management options for molar pregnancy

The first line of management for molar pregnancy is the surgical removal of pregnancy tissue. If the diagnosis is made or confirmed after surgical management of miscarriage (SMM), the woman or birthing person will have blood tests over the next weeks and months to ensure that hCG levels have dropped. If levels do not drop, she may need further surgical management. A very small number of women and birthing people will need further investigations and treatment, which will be carried out at Charing Cross or Weston Park hospitals.

Women and birthing people with molar pregnancy are advised not to conceive until follow-up is complete, which may be many months. This can be very distressing, prolonging the experience of loss and making it harder for them to move on. If they do conceive, they need to inform their follow-up centre so that their hCG levels can be closely monitored.

Second Trimester Miscarriage

Place of care

While surgical management is possible for second trimester loss, it is not usually recommended and, most often, women will go through labour. During and after labour, it is important that parents are offered a private room away from the sounds of other women in labour and crying babies.

While women and birthing people who are experiencing second trimester miscarriage should be offered a special bereavement room on the labour ward, these facilities are not always available. Staff should acknowledge the potential difficulties of this situation for parents and offer parents support.

The labour ward may be more likely to have suitable facilities and staff who are supported to provide parents with good quality bereavement care. Parents should be cared for in an environment that provides adequate safety according to individual clinical circumstance and guideline, while meeting their needs to grieve and feel supported in doing so. Ideally, parents should be given options for their place of care regardless of gestation.

Physical care options for Second Trimester Miscarriage

The options for care depend on the stage at which the woman or birthing person presents: a diagnosis of intrauterine death with little or no outward sign (a ‘missed or silent miscarriage’); a diagnosis of intrauterine death with some pain and bleeding (an ‘incomplete miscarriage’); an evident process of miscarriage/active labour (‘spontaneous miscarriage’); or after the baby has been born.

Missed/silent/incomplete Second Trimester Miscarriage

When a baby’s death is confirmed, parents may need this information repeated gently but clearly. They may well need time to absorb this information – perhaps at home – before considering options for what happens next. When they are ready, staff should explain the options for the completion of the miscarriage and the delivery of their baby, using clear but sensitive language, appropriate to the words the woman or birthing person/couple uses (‘miscarriage’, ‘birth’, etc).

If the woman or birthing person had been aware of fetal movement before the baby’s death, she should be told that she might still feel some sensations similar to fetal movement even though the baby has died. This may cause additional distress.

In most cases, unless medically indicated otherwise, the woman or birthing person would be offered either medical management to induce or complete the process of miscarriage, or expectant management – allowing the miscarriage/labour to happen naturally. In both cases, the likely processes (including bleeding, pain and options for pain relief) should be explained clearly so that the woman or birthing person knows what to expect both during the process and after the baby is born. They may need information about what the baby or remains may look like and options for seeing or holding.

In a very small number of cases, surgical management may be considered or recommended.

Second Trimester Miscarriage away from hospital

Some women and birthing people may choose to miscarry at home, even late in the pregnancy, while others may miscarry spontaneously, whether at home or elsewhere. If they come to hospital, possibly with their baby or baby's remains, they will need sensitive care and support. If they arrive in A&E, they should be transferred as quickly as possible to their preferred place of care, either in the gynaecology or maternity department. Their baby or its remains should be transferred with them in as sensitive a way as possible.

All women with late miscarriage should be offered information about follow-up care, post-mortem examinations and options for sensitive disposal. They should also be offered information about further support available after their discharge, for example the Miscarriage Association or Sands. It is important to recognise that some parents will prefer to think of their late miscarriage as a stillbirth and prefer referral to Sands rather than to the Miscarriage Association.

Information on second trimester loss is available from the Miscarriage Association.

Spontaneous Second Trimester miscarriage

Some women and birthing people may experience a late miscarriage that starts in a way that is similar to going into labour. For some women and birthing people, the labour may progress quickly and they may give birth at home or in another place. Women and birthing people should be offered a physical assessment for themselves and their baby even if no healthcare professionals were present when the baby was born.

Other women and birthing people's labours may take longer and they may come to the hospital. In these situations, women and birthing people should be offered a physical assessment and information about what is happening, options for their care and pain relief. If there is a fetal heartbeat, parents should be offered information about any care that would be offered for the baby if they are born alive. In these instances, some parents may see late miscarriage and premature labour as being very similar even if some staff may view these as very different situations.

Experiencing a spontaneous late miscarriage may be a very distressing and frightening experience for many women and birthing people and their partners. Staff should offer parents care and emotional support during the labour and birth. If parents are offered care on a gynaecological ward, it is important that they are offered a private room and that staff are available to provide sensitive, empathetic care.

After the birth, staff should offer parents emotional support and an opportunity to discuss their experience in addition to offering physical care and information about recommended follow-up care, sensitive disposal, post-mortem examinations and funeral options.

Multiple pregnancies

When one or more babies from a multiple pregnancy has died, parents may be advised to continue the pregnancy for the benefit of any surviving babies. Waiting to give birth may be difficult for parents who feel fearful for their surviving baby. Some parents may also be distressed about the idea of the dead baby remaining with any surviving baby or babies. However, other parents may find this thought comforting.

Additionally, some parents may feel that they are unable to start grieving for their baby or babies who have died until after birth. Some parents may also have concerns that their fear and grief may affect the surviving baby or babies.

It may be helpful for discussions to be commenced after diagnosis of a twin IUD with regards to funeral arrangements. Parents will need to understand if the baby was under 24 weeks, it will still be classed as miscarriage even though it will be born after 24 weeks as the healthy baby's pregnancy continues however if the IUD diagnosis was over 24 weeks, the baby will be diagnosed as stillbirth. It is important that funeral choices and registration are discussed before the birth of the healthy baby so the family are not confronted with this shock at the birth. This may also help them come to terms with the loss of their baby and be part of their grieving process.

Staff should acknowledge the potential difficulties for parents who have a multiple pregnancy where one or more babies have died and offer parents emotional support. It may be relevant to explain that they will have regular fetal medicine scans and blood tests to survey the healthy baby. Staff should acknowledge that anxiety may also be increase during the pregnancy and so the perinatal mental health team can be considered for extra psychological support.

Support from staff will be particularly important if some family members and friends discount the reality of the loss and focus only on the surviving baby or babies. It would be good practice to have a way to signal to staff that this was a multiple pregnancy post-delivery of the living sibling.

Memory-making

Parents may find making memories following the loss of their pregnancy or death of their baby valuable and sharing these memories may be beneficial to the grieving process. Staff should offer parents opportunities to create memories and physical keepsakes where possible.

When discussing with 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 some 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. However, no assumptions should be made on the basis of people's background, ethnicity or the gestation of their loss. 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:

- That they do not make assumptions based on the type or gestation of the loss or the parents' cultural and/or religious background.
- The condition of the baby or pregnancy remains is considered when discussing memory-making with parents.
- 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.
- That, where appropriate, parents are offered religious or spiritual care.

Seeing pregnancy remains

Seeing their baby or its remains may be important to the parents regardless of its size, condition or gestation. For some people, the only chance they might have to see their pregnancy or baby is on an early scan at 6/7 weeks' gestation. If there are no remains that can be seen or parents prefer not to see them, staff might sensitively ask if they have or would like a copy of an earlier scan picture.

Holding their baby or pregnancy remains

Holding their baby or its remains may be important to the parents regardless of its size, condition or gestation. Where possible, staff should offer parents this option while recognising and respecting that some parents may decline. If the baby or remains are very fragile and the parents wish to see and/or hold them, place the baby or remains on gauze or cotton material and in a suitable container, rather than a disposable bedpan. However, It may not be possible for parents to hold their baby or pregnancy remains when they have experienced a first trimester loss. This needs to be sensitively talked through with the parents.

When the baby has an anomaly or is macerated

If there is a visible anomaly or maceration, 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. If parents accept the offer of a description, it is important that the explanation is factual and without judgement. 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. Other parents may want to keep the anomaly covered if this is possible. It is important to respect the parental choice and follow their lead while also providing them with opportunities to discuss how they feel.

Naming the baby

Parents sometimes decide to name their baby, or have a nick-name for their baby from early pregnancy. If so, and they use the name, staff should ask the woman or birthing person/couple whether they would like them to use the that name too.

Caring for the baby

Whatever the gestation, staff should treat the baby or pregnancy remains with respect and dignity. Even if the baby is very tiny and fragile, it may still be possible to wrap him/her in tiny cotton or flannel garments which some parents and organisations provide to hospitals. It is important to ensure such garments are available before offering this.

It is equally important to recognise that some women and birthing people will not want this kind of care and that this is no reflection of how they feel about their loss.

Photographs

It can be difficult for staff to know whether or not to offer to take photographs of a miscarried baby or pregnancy remains. Some women and birthing people will appreciate the offer of a photograph being taken of their baby or the pregnancy remains even in a very first trimester loss, while others might find the suggestion distressing, unacceptable or not needed even with a later loss. The offer should be made only with great sensitivity, perhaps preceded by words such as 'Some people [or parents] appreciate having a photograph of their baby [or whatever word they use]. I wonder if this is something you would like.' Their wishes are paramount and must be respected.

Regardless of the type of loss, a woman or birthing person may wish to keep a copy of the ultrasound scan picture. Sensitivity should be exercised in showing images from surgery. A woman or birthing person should always be asked first if she would like to view such images and whether she would prefer to do so with her partner/another family member present. Copies of images should be kept with medical notes (if they are not there already) and women and birthing people should be informed that they can view them at a follow-up appointment, if they wish.

Multiple births

It is important that staff acknowledge the importance of the baby (or babies) who have died, and avoid focusing only on a surviving baby or babies.

Staff should offer parents scan images of all the babies together, where possible. It may be helpful for any surviving siblings to see these images later on.

Other keepsakes

Other keepsakes parents may want to save include:

- Baby's scan picture.
- Hand and foot prints.
- A record of baby's weight and measurements.
- An identical set of the clothes the baby has been dressed in.
- Cards and ribbons from any flowers received.
- A copy of any certificate(s).
- The blanket or material baby has been wrapped in.

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

Taking the baby or remains out of the hospital

Some parents find it very helpful to have time with their baby and say goodbye away from a clinical setting where appropriate. 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's body or remains 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's body or remains to a place that has special significance for them. Some may wish to take the baby's body or remains home to make their own arrangements, which could be burial in their garden or in a planter.

Some areas may 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. 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.

There are no legal reasons to prevent parents from taking their baby's body or remains home unless the death has been referred to the coroner. There may be clinical reasons (for example, infection) and these need to be sensitively discussed with parents.

When parents are not comfortable or there are good clinical reasons to discourage parents from taking their baby's body or remains home, parents should be offered a longer stay in hospital or be able to return to the ward/bereavement room to see the baby or remains or return to the hospital mortuary chapel of rest. 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.

If parents plan to take the baby's body or remains home, it is important to take any post-mortem examination or other investigations into account. A post-mortem examination may be carried out first. In these instances, parents should be told about the condition of the body or remains and how to handle it after the post-mortem examination.

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

Parents can take the baby or remains home by car in a Moses basket secured by a seatbelt or in the parents' arms. Depending on the baby's gestation, another suitable container may be used to transport the baby's remains. The type of container offered should be discussed with parents who may wish to use an alternative receptacle of their choice. Staff might suggest using an opaque container for remains.

If necessary, parents could arrange to take the baby or remains home in a taxi or minicab if this is agreed by the parents with the driver in advance, although using other forms of public transport is not advisable.

There is no legal reason to inform the police if parents take their baby's body or remains 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 or remains. The form should confirm that the body or remains has been released to the parents and that they will be taking them 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 Miscarriage Pathway, Appendix A5)

If the parents are collecting the baby's body or remains from the mortuary rather than the ward, the ward should also give them a mortuary release form.

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 loss while others decide to make a memorial later. Parents may welcome reassurances that it is never too late to commemorate their baby.

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

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

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

- Planting a tree, shrub or flowers in a special place; this could be a small planter
- Buying or making an ornament, a special item or a piece of jewellery in memory
- Making and/or putting items into a memory box
- Creating a journal about their pregnancy and their baby
- Lighting a candle on anniversaries or other special days
- Having flowers on anniversaries or other special days
- 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 for themselves or to share with others. The Miscarriage Association, The Ectopic Pregnancy Trust and other charities often publish parents' stories.
- Pressing flowers from their baby's funeral, if there is one, or flowers they have received after their loss
- Adding the baby's name to a family tree

Post-mortem examination and histology

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. Whilst the legislation does not apply to miscarriage, the HTA 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.

Histology

Women and birthing people are often offered histopathology for their pregnancy losses. Some women and birthing people who are offered it may assume that it will provide information about a possible cause of their miscarriage or ectopic pregnancy or identify the baby's gender. Women and birthing people should be informed about what the histology examination involves and what insights it can and cannot provide. For instance, they may be advised that routine histology of first and early second trimester loss aims to confirm pregnancy tissue and rule out molar pregnancy, or that with ectopic pregnancy sometimes pregnancy tissue is not always found in testing even where the ectopic pregnancy was seen at surgery.

After the histology, the woman or birthing person will have a follow-up appointment or phone call to discuss the results. If there is a delay to the histology results, it is important that this information is shared with the healthcare team supporting them and that this information is conveyed to them as soon as possible.

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 or remains.

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 death, the baby's name if they have been named, the baby's sex (if known) and the name and details of the person who verified the death. Items that parents want to accompany the baby should also be listed. Babies' bodies and remains should be appropriately covered, kept in the best possible condition and protected against accidental damage and avoidable deterioration.

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. Whether a placenta can be tested will depend on the gestation.

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, wherever possible, all placentas from babies who have died should be sent for examination by a specialist pathologist.

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

The Royal College of Pathologists has guidance on placental histology.

Post-mortem examination consent

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

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

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

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

Seeking consent for a post-mortem examination may differ from consent for other types of procedures as staff are often not performing or involved with the investigations themselves. The discussion should be unhurried (a minimum of one hour should be allocated for this process) and should help parents to reach decisions that are right for them and align with their values. All discussions should take place in a quiet, private place where parents and staff will not be disturbed.

It is vital that the person requesting consent has a thorough understanding of local policies and procedures for post-mortem examinations in their hospital and that they are familiar with the consent form so that they can confidently take parents through it. They should be aware of the potential benefits of a post-mortem investigation and able to explain these to parents, but also that no definite cause of death may be found, particularly for earlier gestation losses. They must have up-to-date information about local circumstances, including where the post-mortem will be carried out (if known), transportation, timelines for returning the baby, and the likely timeline for receiving the post-mortem report. There are a range of circumstances where a full post-mortem may not be carried out, and staff should be able to discuss this sensitively and knowledgeably with parents. They must also be aware of the options for post-mortem investigation available, for example Minimally Invasive Autopsy is not available in every perinatal pathology unit.

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

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

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

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

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

Discussing a post-mortem examination with parents

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

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.

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

Parents should be informed that they can request an official Baby Loss Certificate for a loss before 24 weeks at any time through the UK Government website.

Additionally, parents could be offered an unofficial certificate of birth, certificate of pregnancy loss or similar from the hospital to recognise what has happened (see Miscarriage Pathway, Appendix A2), but this should not be insisted upon if the parents decline. Unofficial certificates are also available from charities such as the Miscarriage Association or Sands.

If parents plan to take their baby or remains home or transport them to a funeral director, it is helpful to offer an official form or letter that confirms that the loss or delivery took place took place before 24 weeks' gestation and that there were no signs of life. Parents may need this to arrange a private cremation or burial, even though there are no legal regulations for burying or cremating pregnancy remains.

If a miscarriage occurs at home or outside of a medical setting without the presence of a healthcare professional, parents may have difficulty in obtaining a letter or form confirming that their baby was born dead before 24 weeks' gestation. In these instances, it is recommended that parents should take the remains to their hospital or GP to and request a letter or form confirming that the loss occurred prior to 24 weeks' gestation (Miscarriage Association et al, 2015). Staff should recognise that this can be an extremely distressing situation, and accommodate the request. If there are questions around the gestation, staff should consult with a colleague.

Babies born at or after 24 weeks, but who had died in utero before 24 weeks

If it is known or can be proven that a baby died in utero before 24 weeks based on the fetal stage of development, but was delivered at or after 24 weeks, they should not be certified or registered as a stillbirth. This is the accepted interpretation of registration law (RCOG, 2010).

This situation can arise where there is a delay between the diagnosis of an intrauterine death and delivery. It should be acknowledged that this may be very distressing for parents and all information should be explained sensitively.

If the baby showed signs of life before death, please refer to the NBCP neonatal pathway section on registration and certification.

Sensitive disposal and funerals

Legal requirements and parents' options

Make sure that women and birthing people who are treated outside of the hospital context are made aware of the options for disposal and funeral arrangements.

There is no legal requirement to bury or cremate fetuses terminated or miscarried before 24 weeks' gestation. The HTA recommends that burial, cremation, sensitive incineration, or the return of the pregnancy remains to the woman or birthing person should all be available options before 24 weeks' gestation. Some women or birthing people may choose to have no involvement with regard to disposal at all.

The HTA and Royal College of Nursing provide further guidance on managing the disposal of pregnancy remains.

Providing information on sensitive disposal to parents

Women and birthing people who experience a miscarriage, ectopic or molar pregnancy should be given the opportunity to discuss and make informed choices about their available options for the disposal of pregnancy remains. Parents should be informed whether burial or cremation options provided by the hospital are individual or shared and how many babies would be cremated at the same time. The differences between cremation and sensitive incineration, particularly concerning the impossibility of collecting ashes through incineration, should be explained sensitively.

It is also important to clearly explain to parents that some choices may incur a financial cost which is not covered by the hospital.

Some women and birthing people may decline information about these options or involvement in decision-making processes regarding the disposal of pregnancy remains 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. They should also be informed of any time frame in which they would need to do this. Parents' wishes, or choice to opt out of decision making must be clearly recorded.

There is no requirement for a funeral for a baby lost before 24 weeks, but some parents may want to arrange this or another ceremony. All parents should be offered written information, covering:

- What choices they have if they want the hospital to make the arrangements and the costs (if any).
- 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 including necessary documentation (see Miscarriage Pathway Appendices A4, A6 and A13, and visit ICCM, Miscarriage Association and Sands websites for further guidance).
- The time frame for making and communicating that decision.
- The hospital process if they do not make or communicate that decision within that time frame.
- What costs are involved (if any).

Acknowledge that many women find it very difficult to decide what to do and may find it difficult to process all the information at once; they may therefore need time to decide, as well as being provided with a clear presentation of the options, in both verbal and written form. Staff should also mention any additional options available to parents, such as an entry in the hospital remembrance book or an individual or shared memorial service. The Royal College of Nursing provides further information in its guidance.

Cultural considerations

Staff should be aware that some cultures and religions do not traditionally hold funerals or other ceremonies for babies who have died or pregnancies lost before 24 weeks' gestation. It should not be assumed however that this will be the case, and all parents should be offered information on the disposal methods and options for hospital arranged or private funerals available locally. Staff should also be aware that cremation/sensitive incineration would not be appropriate in some religious/cultural contexts.

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 if they have one, 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.

Taking the baby or pregnancy remains home

There is no legal reason why parents should not be able to take the pregnancy remains from the hospital and make their own arrangements. They should be offered a suitable container, if required. Hospitals should also ensure they are able to provide a bag to take the container home in such as plain, appropriate, strong paper bags with handles. No documentation is legally required but a form should be issued by staff to accompany the remains to protect the parents and avoid misunderstandings. The Miscarriage Association provides guidance for parents on things to consider when taking remains home.

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.

If sensitive incineration is used, this should be recorded in the woman's notes along with the date of incineration or collection. As most hospitals arrange for incineration to take place off-site, it may not be possible to provide more details, especially the location where it took place. There is more information in the RCN guidance on managing the disposal of pregnancy remains.

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. The Miscarriage Association provides information on employment rights after pregnancy loss.

Where possible, parents should be given an alternative route out of the birth centre or hospital from their room, and staff could offer to walk with them.

It is important for 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 have a Hospital Liaison Volunteer (HLV) who will be able to provide information on what is available locally.

Some parents may be reassured if they know that a member of the healthcare team will visit or contact them shortly after their discharge from hospital. While some will not want this contact, this contact should always be offered. If appropriate, offer referral to a recurrent miscarriage clinic. Parents should be informed as to whether a member of their GP practice will be in touch once they are at home and asked whether they would like this contact.

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. If a woman or birthing person has experienced an ectopic pregnancy, sex and contraception should be sensitively discussed and they should be informed of the need to book an early scan for future pregnancies. Staff should also provide information on when the woman or birthing person can return to physical activities and exercise. As appropriate, staff should provide information on pelvic floor exercises.

Offer the woman or birthing person a 'fit note' and ask what they would like writing on it as the reason for their absence from work. Be aware that some women and birthing people will not wish to disclose a pregnancy to their employer and may prefer the note to read, for example, 'gynaecological condition' or something less specific. However, staff should make no assumptions or decisions on their behalf; let them know it is an option and let them decide.

Milk donation and supression

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 bereaved parents.

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 feel very isolated and not have family or friends they are able to share their loss with and others may feel they are getting the help they need. 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.

Parents should receive information about the support available from their primary care team and that the primary care team has the support and 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. Some hospitals may also have a Sands Hospital Liaison Volunteer (HLV) who will be best placed to provide information on what is available locally.

A partner's grief may manifest itself in different ways and often at a later stage; good follow up care by the GP or health visitor for partners is essential so that this may be recognised and supported.

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).

It can be helpful if the GP, community midwife or health visitor marks bereaved parents' electronic and hard copy medical records with an alert or sticker to notify other healthcare professionals to their bereavement (see Miscarriage Pathway, 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 returning to work, including what they may wish to say to colleagues and their reactions. The Miscarriage Association and the Ectopic Pregnancy Trust have helpful guidance for employees.
- Advice about physical recovery after miscarriage, 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 would welcome the opportunity to give feedback on their care. Providing parents with opportunities to inform service improvements, feel listened and to have their questions or concerns answered not only helps drive improvements, but can also help 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."** 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.

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. National and local support organisations such as the Miscarriage Association and The Ectopic Pregnancy Trust.

Mental health

Parents should be reassured that feelings of grief and loss are normal for many people after pregnancy or baby loss. While grief does not necessarily result in mental health concerns, there may be cases where women and birthing people/couples should be assessed for mental health issues that may be compounding their grief.

It can be helpful for staff to explain the symptoms of depression, anxiety and post-traumatic stress disorder. They should be aware to look out for signs of these – such as a strong sense of worthlessness or hopelessness, withdrawing from friends and family, sleeping difficulties, flashbacks to, or avoidance of reminders, of the events surrounding the loss. These symptoms indicate the need for further assessment and formal treatment. Healthcare providers should also be aware that there is an increased risk of suicide following pregnancy loss, and any suicidal ideation should prompt immediate assessment. Consideration could also be given to screening women and birthing people for PTSD 3 months after miscarriage or ectopic pregnancy.

Mental health assessment and treatment should be offered to women and birthing people and their partners as well as other children and family members (where applicable) after any type of pregnancy or baby loss. Partners can experience post-traumatic stress after pregnancy loss with some still suffering nine months afterwards.

Studies highlight the impact of pregnancy or baby loss on emotional and mental health, for example:

> *Farren J, Jalmbrant M, Falconieri N, et al. Posttraumatic stress, anxiety and depression following miscarriage and ectopic pregnancy: a multicenter, prospective, cohort study. Am J Obstet Gynecol 2020;222:367.e1-22. DOI: https://doi.org/10.1016/j.ajog.2019.10.102*
>
> *Farren J, Jalmbrant M, Falconieri N, et al. Differences in post-traumatic stress, anxiety and depression following miscarriage or ectopic pregnancy between women and birthing people and their partners: multicenter prospective cohort study. Ultrasound Obstet Gynecol. 2021 Jan;57(1):141-148. doi: 10.1002/uog.23147. PMID: 33032364.*

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 pregnancy loss or the death of a baby.

The NHS guide Supporting mental healthcare in a maternity and neonatal setting 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.

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

This may be the first labour and birth experience for this parent, depending on their previous experience. For others, the birth of their previous baby may also have been when their baby died.

Staff should be prepared for parents' possible emotional reactions during labour and at the birth. Staff should be available to offer support if needed. Women and birthing people may wish to make a birth plan which could include a planned induction of labour or caesarean birth depending on their individual circumstances. Women and birthing people should be aware that support is always available and know how to access staff members. It is also important that support is offered to any partners or birth supporters who are with the birthing parent.

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

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

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

Care in the community

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

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

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

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

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

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

Staff Support

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

Training

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

Bereavement care training can help staff to develop skills in communicating more sensitively and empathetically with parents and increase their awareness of the needs of bereaved parents.

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

Staff wellbeing

To provide parents with high quality, personalised care, workplaces must be supportive environments where staff feel valued. This applies to all members of staff – at all levels and in all disciplines – including all primary care staff who may have long term relationships with the family and who may be working in greater isolation.

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

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

Staff wellbeing should be prioritised and monitored as a key part of a safe, effective and high-quality healthcare service. Managers and senior staff have a duty to provide encouragement, support and training for staff, to watch for signs of strain or difficulty in individuals and within teams and to facilitate discussion between colleagues, teams and centres. It is important to note that stigma and concerns about not appearing to be coping with their job may cause some staff to avoid seeking support.

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

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

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

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for pregnancy and baby loss

For more information visit:
nbcpathway.org.uk

sands.org.uk

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Registered Address: 10–18 Union Street, London, SE1 1SZ.