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



Miscarriage, ectopic pregnancy and molar pregnancy

Full Guidance Document

Our National Bereavement Care Pathway core partners



About the NBCP

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

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

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

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

“Bereavement care recognises that parents’ experiences and feelings count, no matter how early the gestation.”

(Quote by bereaved parent, 2018)

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Note to the reader

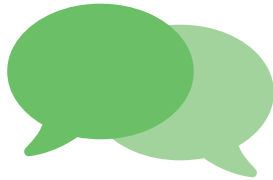
This is the first of two guidance materials we have produced for the National Bereavement Care Pathway (NBCP). This document contains detailed reference material and guidance whereas the second document is a more ‘hands on’ and practical approach to providing bereavement care for families, including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

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

Key messages

In our consultation with parents three clear messages came through:

1. Good communication is key to delivering good bereavement care



“For me the simple things make a huge difference.

Being listened to. Eye contact and someone sitting beside me – communicating they have time for me.”

(M.E., 2017)

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

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

2. Continuity of care and consistency in approach is vital

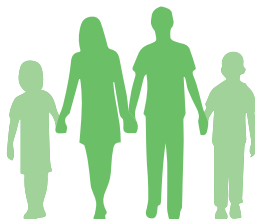


“I wish the staff in day surgery had considered the operation I was in for. It wasn’t routine to us, it was the removal of our baby and all the emotions behind it.” (Miscarriage Association, 2018)

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

Mother (Sands Guidelines, 2016)

3. Parent-led family involvement must be supported



“When I got to my wife, she was still out if 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.” (Ectopic Pregnancy Trust, 2018)

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

Bereavement care standards

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

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

- A parent-led bereavement care plan is in place for all families, providing continuity between settings and into any subsequent pregnancies.
- Bereavement care training is provided to all staff who come into contact with bereaved parents, and staff are supported by their Trust to access this training.
- All bereaved parents are informed about and, if requested, referred for emotional support and for specialist mental health support when needed.
- There is a bereavement lead in every healthcare setting where a pregnancy or baby loss may occur.
- Bereavement rooms are available and accessible in all hospitals.
- The preferences of all bereaved families are sought and all bereaved parents are offered informed choices about decisions relating to their care and the care of their babies.
- All bereaved parents are offered opportunities to make memories.
- A system is in place to clearly signal to all healthcare professionals and staff that a parent has experienced a bereavement to enable continuity of care.
- Healthcare staff are provided with, and can access, support and resources to deliver high-quality bereavement care.

Terminology

This pathway is intended for all healthcare professionals and staff who work with parents who have experienced a pregnancy or baby loss through miscarriage, ectopic pregnancy, molar pregnancy, termination for fetal anomaly, stillbirth, neonatal death or Sudden or Unexpected Death in Infancy.

The terms 'healthcare professionals' and 'staff' are used throughout to denote all of those practitioners that a bereaved parent may come into contact with.

For consistency, the term 'parents' is used to refer to expectant and bereaved mothers, fathers and partners. This is applied in a wide range of situations, including when referring to individuals who experience early miscarriage, ectopic pregnancy and molar pregnancy, late miscarriage, termination for fetal anomaly, stillbirth and neonatal death.

Many people will consider themselves parents from the time they discover they are, or were, pregnant while others will not. Therefore, it should be acknowledged that not all people who have experienced a childbearing loss would consider themselves to be, or have been, a parent. It is also important for those who do identify themselves as parents to have this recognised.

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

Similarly, the term 'baby' is used throughout to describe the child from the early stages of pregnancy through to the neonatal period. Many people will conceptualise their baby and develop strong attachments to them from the moment they discover that they are, or were, pregnant. However, others will be more comfortable with medical terminology such as 'embryo', 'fetus' or 'pregnancy' and may not find the term 'baby' to be appropriate in their situation.

Again, while we have used the term 'baby', it is important to recognise that the wishes and viewpoints of those experiencing the loss should always be the most important factor when communicating with them. Healthcare professionals will need to adapt the terminology they use accordingly.

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.

However, the pathway will also be applicable to independent healthcare establishments and to all other bodies that may be set up in the future to organise and provide care for women and families experiencing a childbearing loss.

Finally, because this is a pathway focused on improving outcomes for families, by its very nature it is quite directive and as such in a number of places 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.

Use warm, open body language by sitting near parents, facing them, making eye contact and using touch if appropriate. 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.

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

Supporting parents when communication barriers are present

Staff should never assume that they can anticipate the needs of any individual with a sensory impairment, learning difficulties or who is experiencing a language barrier. Staff should ask parents if they need additional support and about their preferences. Staff should record this information in a prominent place in parents’ medical notes (with their consent) (see Miscarriage, Ectopic Pregnancy and Molar Pregnancy Pathway, Appendix A9).

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

Communicating if there is no interpreter

- Using family and friends to interpret is strongly discouraged.
- Parents may not want the informal interpreter to know everything about them and may not feel able to discuss things fully or truthfully.
- An informal interpreter who is a family member or friend may themselves be deeply affected by the situation and their ability to interpret may also be affected if they become distressed.
- It is never acceptable to use a child or a teenager 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.
- Some parents may be accustomed to their children interpreting for them. They may have a cultural expectation that their children will interpret for them. However, staff should inform parents that it is the hospital or clinic’s policy to not allow children to interpret in order to avoid possible misunderstandings.

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

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

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

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

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

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

Diagnosis and delivering difficult news

Early miscarriage

Miscarriage is often diagnosed or suspected at a woman’s first ultrasound examination. It is important that this information is communicated sensitively to parents during the examination by appropriately trained staff. Some parents may be shocked by this diagnosis or 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). Other women 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 have a private scan indicating that something was wrong. Some women especially those with a missed or silent miscarriage, may feel guilty or ashamed that they had not realised that anything was wrong.

“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.” Parent (Miscarriage Association 2013: 7)

Ectopic pregnancy

Ectopic pregnancies are frequently diagnosed prior to the routine 12-week scan. Women 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. Nonetheless, parents may still be shocked at the diagnosis of ectopic pregnancy and know very little about the condition. Women 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. Women 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.

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 to explain ongoing tests, their role in reaching diagnosis and possible outcomes. Families may feel that their pregnancy is paused until they know more and experience feelings of numbness or confusion. Some families may wish to have time and space in a quiet room.

It is important that information is sensitively communicated to parents by appropriately trained staff as soon as possible. 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 feel guilty that they had not realised that something was wrong. Some women may still feel pregnant and/or have a positive pregnancy test (their hormone levels may still be continuing to rise).

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

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/couple of this specific suspicion. It is crucial that this information is communicated sensitively to the woman/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/couples will seek information online, where a search will quickly bring up the word 'cancer'; this can be extremely frightening.

"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." Parent (Miscarriage Association 2013: 7)

Molar pregnancy is likely to be confirmed only after histological examination of pregnancy tissue, following surgical management of miscarriage. The woman 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.

Late miscarriage

Late miscarriage may be suspected, or more likely diagnosed at a woman'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/couple by appropriately trained staff. Some women 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 or that their baby has already been born.

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.

Breaking bad news

Breaking 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.

“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.” Parent (Redshaw et al. 2014: 15)

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.” Parent (Ectopic Pregnancy Trust, 2018)

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

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 parents consent 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.

If miscarriage is diagnosed during a private scan, staff should refer the woman 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.

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.

Ultrasound examination when a problem is suspected

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

Best practice points that staff should follow when delivering difficult or unexpected news to parents:

- Before breaking bad news to parents, staff should prepare what they are going to say and ensure that they have accurate information.
- Many parents appreciate an indication that the member of staff understands the impact of what they are saying.
- Phrases such as “I am afraid it is bad news...”; “I am sorry to say that the results are not what we expected...” or “I am afraid this is not the news you wanted...” may be helpful.
- Find the most appropriate private place available to break the news.
- If a woman is on her own, check whether she would like to contact a partner or another supporter who might be able to join her.
- Use clear, straightforward communication and do not use euphemisms. It is important that the message is clear and that parents are not left with false hope.
- Express genuine concern and empathy by using phrases such as “I’m very sorry” or “What a terrible shock for you – I’m so sorry.”
- Ensure that parents have time to absorb any news, check their understanding of the information they have been given and ensure they have time to ask any questions.
- When the 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.
- If further tests or treatments are needed, next steps and timings should be discussed, options (if any) should be clearly communicated and parents should have the opportunity to ask questions.
- 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 further discussions to discuss additional details. Repeated discussions may be necessary.
- 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.
- If a woman is going home alone after receiving bad news, staff should suggest that she might like to call somebody to accompany her. This can be very important if she is planning to drive home and/or lives a long way from the current location.
- 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.

Early miscarriage

Place of care

After a miscarriage diagnosis is confirmed and depending on the circumstances, women should be offered information about their care options. In relation to each type of management offered, women 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 should only be referred to a surgical ward if there is no gynaecological ward.

Women who are admitted through A&E should be transferred to a ward or be offered support to go home as quickly as possible. Women should also never be left on a trolley in a public place. When being transferred or moved, women should be offered 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 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 who are at home awaiting hospital management.

Physical care options for early miscarriage

Recommendations for a woman'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 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 others 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. The woman's wish to see the remains needs to be clearly recorded.

Current NICE guidance (*Ectopic Pregnancy and Miscarriage: diagnosis and initial management*) recommends that women 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 has experienced a previous childbearing loss or is at risk of haemorrhage or infection. According to this guidance, women 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. Additionally, women may have a wide range of views and preferences regarding how early miscarriage is managed.

Where medically appropriate, women 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 the opportunity to fully discuss their available miscarriage care options. The information discussed with women for each care option should include details of:

- How long each type of management may take and what it involves.
- Any associated risks and benefits (including for the woman'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's/couples own preference of management.

This should be supplemented by relevant written information. Parents may also have other questions and concerns that they wish to discuss with staff.

Expectant and medical management

All women who are offered either expectant or medical management should be given a clear explanation of what these care options involve and what to expect during the miscarriage.

Providing information about the range of experiences that women may have is important as some women 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. It is important that parents who wish to access physical care or emotional support from staff are able to do so.

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.

Surgical management

Some women may prefer surgical management for their miscarriage as it is more predictable and the miscarriage is over more quickly.

A surgical procedure may be medically recommended for some women 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 may need to make to travel home afterwards should also be discussed. Written information about the procedures should be given to women and be available in a variety of languages and formats.

Some women may want to have the procedure without delay while others may wish to wait a while. Wherever possible, women'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 should be offered or sign posted to emotional support.

Before going home, women 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 they details of a named contact who 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'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, while for others, 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. 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 personalised care.

Guidance is available: NICE clinical guideline 154 (*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, the following should be covered:

- 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'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; this can sometimes be overlooked in among the clinical treatment of the condition.

Expectant and medical management

Women should be given a clear explanation of what these care options involve and what to expect during treatment. This should include what doctors are aiming to observe regarding the rate at which beta hCG levels should fall and options if those thresholds are not achieved. You should be able to share the success rate of Methotrexate in your unit. It is important to provide an explanation around pain and bleeding particularly as to when a woman should seek medical attention in case of possible rupture or heavy bleeding. Women should also be informed that they can usually change their minds if they subsequently feel that expectant/medical management is not emotionally suitable for them. Any time limits to this should also be highlighted.

Surgical management

Some women 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 and staff should offer to discuss any concerns about the procedure.

Place of care

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

If surgical management is advised, a woman 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 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 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 should again be provided with information about returning to hospital for ongoing beta hCG testing until hormone levels return to non-pregnant. Women who are medically or expectantly managed should be given contact details in the event that their symptoms change and for support while undergoing treatment.

Women should be given information about 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 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 during the follow-up process if they come to the unit for blood tests. It is crucial that staff caring for women 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 the woman/couple.

It is important that staff offer emotional support to women/couples who have a molar pregnancy. Some women/couples 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/couples can find further support and information, including the specialist centres, the Miscarriage Association and online groups, and provide that information accordingly.

Physical care 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 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 will need further investigations and treatment, which will be carried out at Charing Cross or Weston Park hospitals.

Women 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 women/couples to move on. If they do conceive, they need to inform their follow-up centre so that their hCG levels can be closely monitored.

Late miscarriage

Place of care

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 who are experiencing late 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. However, it is important to remember that some women experiencing late miscarriage may also prefer to give birth on the gynaecological ward or at home. Ideally, parents should be given options for their place of care regardless of gestation.

Physical care options for late miscarriage

The options for care depend on the stage at which the woman 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 late miscarriage

When a baby's death is confirmed, the woman/couple 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 the woman/couple is 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/couple uses ('miscarriage', 'birth', etc).

If the woman 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 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/couple 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.

Spontaneous late miscarriage

In some cases late miscarriage starts in a way that is similar to going into labour. This may be a very distressing and frightening experience, especially once it is clear that the baby is not going to survive. Staff should offer particularly sensitive support and information throughout the process, including options for pain relief and place of care. If there is a fetal heartbeat the woman/couple should be told about any care that might be given to the baby if s/he is born alive. Staff should recognise that some women/couples may see this process as a premature labour rather than a miscarriage, regardless of the gestation.

Late miscarriage away from hospital

Some women 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.

Spontaneous late miscarriage

Some women may experience a late miscarriage that starts in a way that is similar to going into labour.

For some women, the labour may progress quickly and they may give birth at home or in another place. Women 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's labours may take longer and they may come to the hospital. In these situations, women 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. 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.

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. 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.

Memory-making

Parents may find making memories following the 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. Some women/couples will appreciate the offer of some kind of memory-making and others will not.

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. For example, this may be the case for parents who have grown up in parts of the world with high infant mortality rates. However, no assumptions should be made on the basis of people’s background or origins. 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 woman/couple’s cultural 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.

Seeing and holding their baby or pregnancy remains

It may not be possible for parents to see and hold their baby or pregnancy remains. when they have experienced an early loss. This needs to be sensitively talked through with the parents.

Seeing and holding their baby or its remains may be important to the woman/couple regardless of its size, condition or gestation. Where possible, staff should offer parents the option of seeing and holding their baby while recognising and respecting that some parents may decline this offer. If the baby or remains are very fragile and the woman/couple wishes to see and/or hold them, try to place the baby or remains on gauze or cotton material and in a suitable container, rather than a disposable bedpan.

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 parent's 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 the woman/couple uses the name, staff should tentatively use that name too, e.g. "George" or "your peanut".

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 to the woman/couple.

It is equally important to recognise that some women/couples 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/couples will appreciate the offer of a photograph being taken of their baby or the pregnancy remains even in a very early 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 women [or parents] appreciate having a photograph of their baby [or whatever word the woman/couple uses]. I wonder if this is something you would like.” The woman/couple’s wishes are paramount and must be respected.

If a woman has had an ectopic pregnancy, she may wish to keep a copy of the ultrasound scan picture. Sensitivity should be exercised in showing images from surgery. A woman 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 and women 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 poncho 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 clinical environment

Some parents find it very helpful to have time with their baby and say goodbye away from a clinical setting. 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 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.

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 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 return to the hospital mortuary chapel of rest. For mothers 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 unidentifiable 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 it back to the hospital or making their own funeral arrangements.

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

Memorials

Many parents want to create a lasting memorial to their baby. Sometimes parents choose to do this shortly after their baby's death while others decide to make a memorial later. Parents may welcome reassurances that it is never too late to commemorate and show their love and grief for 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:

- Making a book or memory box about the pregnancy.
- Pressing flowers from their baby's funeral.
- Making, buying, or commissioning a special picture, sculpture, engraving, embroidery or piece of patchwork or piece of jewellery.
- Lighting a candle on anniversaries or other special days.
- Buying a special vase and having flowers on anniversaries or at other times.
- Planting a tree or shrub in a special place, where the baby is buried or where the ashes have been scattered (if this is permitted).
- Writing a poem or letter to the baby or choosing a piece of writing or a poem to be framed.
- Writing an account of their experience of loss. Charities that support bereaved parents, such as the Miscarriage Association, the Ectopic Pregnancy Trust, Sands and ARC sometimes publish parents' stories in their newsletters or other publications.
- Adding the baby 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 also issues guidance relating to the handling of remains following losses prior to 24 weeks' gestation. Whilst post mortem examinations may not be possible for earlier gestations, they may be able to determine the cause of later miscarriages. In addition, tests such as placental examination may be able to provide further insight.

Fetal karyotyping, may also be offered to parents. Ensure that parents understand that routine histology will not provide information about a possible cause of miscarriage or identify the baby's gender. This is possible only through post mortem testing or fetal karyotyping.

Transporting babies' bodies and remains outside the hospital

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

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

Before storage or transferring a baby, the baby's body or remains should be labelled with the mother's name and NHS number or unique identification number, the baby's date and time of 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 mother) rather than from a deceased person (the baby), in this case used for diagnostic purposes.

While consent for examination is not legally required, it is good practice to seek consent for examination of the placenta, umbilical cord, membranes or amniotic fluid from parents. However, whether parents have consented to post mortem examination or not, placental examinations should be discussed with all parents and, wherever possible, all placentas from babies who have died should be sent for examination by a specialist pathologist.

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

Post mortem examination consent

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

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

The consent taker 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, particular for earlier gestation losses.

It is important that the member of staff seeking consent knows how to clearly and accurately complete the consent form to avoid delays that might arise if the pathologist is unclear about the information provided.

- All parents should have the option of discussing whether to have a post mortem examination of their baby.
- No assumptions should be made about who will and who will not consent to a post mortem on the basis of, for example, religion and ethnicity.
- All parents should be given the written and verbal 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.

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. Mentioning the possibility of a post mortem examination as soon as possible and in advance of seeking consent may be beneficial.

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.

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

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

Results

After the post mortem examination, the parents will have a follow-up appointment to discuss the results. If there is a delay to the post mortem examination results, it is important that this information is shared with the healthcare team supporting parents and that this information is conveyed to parents as soon as possible. Good communication across teams and with parents is paramount.

Good coordination between services will help to ensure that staff are aware of the time scale for receiving results when booking follow-up appointments with parents and help them to keep parents informed of any delays. A named contact should be designated within the pathology team and the relevant care unit to facilitate the return of post mortem examination results and ensure that a specific person on the healthcare team is responsible for following up on results.



Registration and Certification

The birth of babies born dead before 24 weeks' gestation are not required or permitted by law to be officially certified or registered. Whilst some parents do not want to register a miscarriage, others may find this upsetting.

Parents should be offered an unofficial 'certificate of birth' or 'certificate of pregnancy loss' from the hospital to recognise what has happened (see Miscarriage Pathway, Appendix A2), but this should not be insisted upon if the parents decline.

A doctor, registered midwife or nurse who was present at the birth, and/or has examined the baby, needs to issue a form or letter confirming that the baby was born dead at less than 24 weeks' gestation. This should be provided to parents as they may need it 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 had died 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

There is no legal requirement to bury or cremate pregnancy remains before 24 weeks' gestation, although the legal options for disposal in England are burial, cremation or sensitive incineration. All options should be discussed with parents.

Providing information on sensitive disposal to parents

Women 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. The differences between cremation and sensitive incineration, particularly concerning the impossibility of collecting ashes through incineration, should be explained sensitively.

Some women 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 timeframe 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 women/couples 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).

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.

Cultural considerations

Staff should be aware that some cultures and religions do not traditionally hold funerals or other ceremonies for babies born 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.

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

Removing remains from the hospital

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. No documentation is legally required but a form should be issued by staff to accompany the remains to protect the parents and avoid misunderstandings. Sands and the Miscarriage Association provide 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's medical records. It should also be documented if the woman has declined information on these options or involvement in these decisions.

If sensitive incineration is used, pregnancy remains or tissue should be packaged in suitable containers, stored and incinerated separately from clinical waste. The date of collection and the location of incineration should be recorded in the woman's medical notes should she wish to access this information later.

Discharge and aftercare

Leaving the hospital

Leaving the hospital environment and going home no longer pregnant or without the baby can be extremely distressing. Some women/couples may want to leave as soon as possible. Others prefer to stay a little longer and this should be enabled if possible.

All women/couples should be told about the services and support available to them once they are at home. They should be informed as to whether a member of the primary healthcare team will be in touch once they are at home and asked whether they would like this contact.

Before the woman leaves the hospital, staff should discuss with her the ongoing physical symptoms she may experience, for example bleeding, pain or lactation, and when she should contact a healthcare professional. If a woman has experienced an ectopic pregnancy, sex and contraception should be sensitively discussed and she should be informed of the need to book an early scan for future pregnancies. If appropriate, staff should discuss milk donation and suppression.

Milk donation

After a late miscarriage some women may choose to donate their milk to a breast milk bank. While discussing milk donation may be difficult, staff should sensitively give women information about donating their milk.

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

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

Milk suppression

Women should receive information about milk suppression, including about any medication and its side-effects and the gestation from which this medication can be used. Staff should discuss pain relief and timeframes with parents. Women should be given a contact name and number in case she has 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.

Some parents may appear to be well supported by their family and friends. However, they may not be getting the help that they need. Some parents may find that friends and relatives avoid them or are unable to listen. This can add to their feelings of isolation.

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

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

Communication between hospital and primary care teams

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

Hospital staff should explain the benefits and importance of receiving support from their primary care team to bereaved parents. The woman should also be told where she can receive additional care if required.

With the woman's consent:

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

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 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 women/couples will appreciate this opportunity, but others may find the prospect stressful.

Staff must make sure that parents know the purpose of each follow-up appointment so that their expectations are managed and met. Letters sent to confirm the appointment with parents should clearly state the purpose of the appointment for example, a physical check-up or to discuss results. If there is a clinical need for follow-up, this should be expressly stated.

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

Some women may want to bring a partner, or another support person to appointments. When the appointment is booked, parents should be encouraged to write down any questions and worries and to bring the list with them to the appointment. Additionally, they should be given a contact in case they need to talk to someone urgently before the appointment.

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

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



Discussions at follow-up appointments

Women/couples often have very high expectations of follow-up appointments or they may not know what to expect. They may be hoping for clear answers about why their baby died or they had a pregnancy loss 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.

Any follow-up appointment must respond to the woman's and (where applicable) her partner's needs. Some examples of things parents may want from follow-up appointments may include:

- To ask questions about what has happened and to check their understanding of the information they were given at the hospital.
- To discuss the events surrounding the pregnancy loss or baby's death.
- To discuss how they are feeling. It is important to ask parents how they feel and to offer them an opportunity to talk.
- Help in preparing questions for their consultant or GP.
- Advice about sex and contraception.
- To discuss the timing of another pregnancy, their chances of having a healthy pregnancy and if they can reduce or manage any risks.
- To discuss concerns about coping with anxiety in another pregnancy or the possibility of never having a child.
- Information about local or national support organisations.
- Advice about parental leave and claiming benefit payments.
- Advice about returning to work, including what to say to colleagues and 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.
- To ask about medical care with future pregnancies, such as booking an early scan if a woman has had an ectopic pregnancy.

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

Feedback

Parent feedback

Some bereaved women/couples may want to give feedback about their care and there may be opportunities to ask sensitively about the bereavement care they received.

Good feedback mechanisms provide parents with opportunities to inform service improvements and feel listened to. Receiving feedback from parents in a structured and supported way gives room for reflection and learning and also promotes the sharing of best practice.

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

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

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

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

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

“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.

It includes information and advice for staff around implementing a feedback mechanism. The MBEM also provides an appropriate way of capturing parents' feedback, which importantly, was informed by bereaved parents from the outset. 437 parents responded to a Sands survey in 2016 to inform the content of this resource (See Miscarriage Pathway, Appendix A8).

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.

The MBEM can be accessed here:

www.londonscn.nhs.uk/wp-content/uploads/2017/06/mat-bereavement-mbem-062017.pdf

Emotional support

Ongoing emotional support

The emotions experienced by a woman/couple during and after pregnancy or baby loss 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 women/couples who experience a pregnancy loss or the death of a baby.

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

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

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

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

Before leaving the clinical care environment women/couples should be offered information about the emotional support available to them through their care provider and by other key local and national resources. The information should be provided verbally and, wherever possible, in writing so that they can seek these immediately or at a later date.

Staff should flag with families:

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

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

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

Mental health

Women/couples 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/couples should be assessed for mental health issues that may be compounding their grief.

It can be helpful 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 for PTSD 3 months after miscarriage or ectopic pregnancy.

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

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

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

Another pregnancy

Parents 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 parents in subsequent pregnancies should be well-informed about the parents' history so that they can respond sensitively to any anxieties or concerns the parents may express. Early pregnancy units, scan departments and others seeing women early in pregnancy need to be informed about a woman's previous loss(es).

Offering parents continuity of carers and the option of having their notes clearly marked (See Miscarriage Pathway, Appendix A9) may help to ensure that parents do not need to explain their situation repeatedly.

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

It is important to:

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

It is important not to:

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

Pre-conception care

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

Some bereaved women/couples will want to discuss what, if anything, they can do to reduce the risk of another loss.

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

Antenatal care

Antenatal care in subsequent pregnancies may involve offering parents extra antenatal appointments, screening options, scan appointments and/or opportunities to discuss an antenatal care plan and birth preferences.

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

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

Some parents may welcome more frequent contact with healthcare staff during subsequent pregnancies and will want all available screening and diagnostic tests. Some parents may find additional appointments, screening and tests stressful and decline some or all of this care. Staff should explain the reason why a woman has been offered additional tests or checks and any risks in declining them, if relevant (e.g. early scans for women who have previously experienced ectopic pregnancy). However, parents' decisions about care should be respected. Parents should have the contact details for a named contact in case they have any concerns.

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

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

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

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

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

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

Some parents may feel less frightened after this point if all is well. Other parents may remain fearful until after the new baby is born.

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

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

In addition to the mother, it is important to ensure that fathers and partners are offered support. Fathers and partners may wish to support the mother and may also want reassurance for themselves. Some fathers and partners may be reluctant to voice their fears in the mother's presence as they are concerned about distressing her. Staff should offer fathers and 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 2018

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 when their baby died.

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

At the first antenatal visit, each woman should be allocated a named midwife, or to a small team of midwives, and consultant obstetrician. These practitioners should provide most of the woman's care throughout her 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 other women, 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 should be aware that support is always available and know how to access staff members. It is also important that support is offered to any partners or birth supporters who are with the woman.

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

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

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

Care in the community

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 offer parents a referral for specialist support.

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 another loss or the death of another baby. This can be deeply shocking and distressing for the parents and staff who are caring for them. These parents may need additional immediate and long-term support from staff.

Staff care

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

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

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

Training

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

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

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 that they provide and help to reduce staff stress. Support and training are essential to ensure staff well-being and avoid staff burn out.

Support

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

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

The type and amount of support that staff need can vary depending on the individual and the situation. It is important to have different support options available for members of staff to use as they need. Support for staff should be built into the systems in which they work.

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

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

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

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

Please make your suggestions in here – this is a further resources list, (not a reference list).

Please include links to useful online learning, resources, papers, etc.



For more information visit:
nbcpathway.org.uk

Lead organisation and ©:

Sands (Stillbirth & Neonatal Death Charity)
Victoria Charity Centre
11 Belgrave Road
London, SW1V 1RB

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