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

national bereavement care pathway
for pregnancy and baby loss

Stillbirth

Full Guidance Document

Our National Bereavement Care Pathway core partners

ARC Antenatal Results & Choices
Bliss for babies born premature or sick
IHV Institute of Health Visiting Excellence in Practice
the lullaby trust
MISCARRIAGE ASSOCIATION The knowledge to help
NEONATAL NURSES ASSOCIATION
THE ROYAL COLLEGE OF MIDWIVES
RCGP Royal College of General Practitioners
Royal College of Nursing
Royal College of Obstetricians & Gynaecologists
NHS England
Sands Stillbirth & neonatal death charity

NBCP for use in England from April 2019

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 infant death 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

"Parents don't need protecting; they need the chance to be parents, provide their child dignity and create memories."
(Quote by bereaved parent, 2017)

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Note to the reader

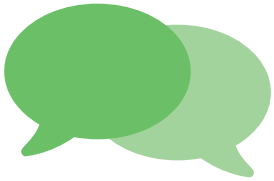
This is the first of two guidance materials we have produced for the National Bereavement Care Pathway (NBCP). This document contains detailed reference material and guidance whereas the second document is a more 'hands on' and practical approach to providing bereavement care for families, including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

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

Key messages

In our consultation with parents three clear messages came through:

1. Good communication is key to delivering good bereavement care



"**For me the simple things make a huge difference.** Being listened to. Eye contact and someone sitting beside me – communicating they have time for me."
(M.E., 2017)

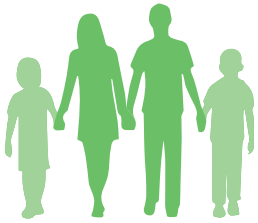
"Why didn't anyone check in with me afterwards? I had been on their records and yet [there was] no call the week after to see how I was doing. [There was] no information of what to expect or where to get help." (N.B., 2017)

2. Continuity of care and consistency in approach is vital

"I would have loved to have birthed the baby at home as I had had previous homebirths – but this option was not given, **and I was not aware this was a choice I had.**"
(M.E., 2017)

"I found it really distressing to have to explain over and over again to different members of staff that my baby had died."
Mother (Sands Guidelines, 2016)

3. Parent-led family involvement must be supported



"I would have liked to have had been offered a couple of sessions with a midwife with my husband where we could share our story and debrief."
(M.E., 2017)

"I wish someone had given us more time to talk about the benefits of seeing the baby and spending time with him. 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 and 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 'fetus' and may not find the term 'baby' to be appropriate in their situation.

Again, while we have used the term baby, it is important to recognise that the wishes and viewpoints of those experiencing the loss should always be the most important factor when communicating with them. 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…'

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 back-ground 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 that 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 Stillbirth Pathway, Appendix A10).

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

Communicating if there is no interpreter

- Using family and friends to interpret is strongly discouraged.
- Parents may not want the informal interpreter to know everything about them and may not feel able to discuss things fully or truthfully.
- An informal interpreter who is a family member or friend may themselves be deeply affected by the situation and their ability to interpret may also be affected if they become distressed.
- It is never acceptable to use a child or a 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

Breaking bad news

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

"Doctor said there doesn't seem to be a heartbeat and asked if I know what that means?! Why did she have to make me go through the hardship of telling her that my baby is dead, is this an exam/ test? I think she should have gently explained it herself. Parent." (Redshaw et al. 2014: 15)

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.

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

Communication during an ultrasound examination

Whenever possible, sonographers should explain what they are doing during an ultrasound examination as long silences may be very hard for parents. If the sonographer needs some time to concentrate, it may be helpful to use phrases such as, "I am going to be quiet for a moment so that I can concentrate on the screen." Staff should be aware that parents are often highly sensitive to non-verbal messages and body language.

Parents may become alarmed if the screen is turned away from them without prior warning or if the sonographer's facial expression and demeanour change. If an anomaly or another reason for concern is found during a scan, the sonographer should tell the woman as soon as possible that there is something on the scan that needs to be looked at more closely. This may be very difficult and distressing for the sonographer who may need a moment to compose their feelings although parents must not be kept waiting for any length of time. It is also important not to pretend that all is well or offer false reassurance.

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

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

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 one parent is on their own, check whether they would like to contact their partner or another supporter who might be able to join them.
- Check whether an interpreter or other support for communication is needed.
- Use warm, open body language by sitting near parents, facing them, making eye contact and using touch if appropriate.
- Use clear, straightforward communication and do not use euphemisms. For example, when a baby's death is confirmed during a scan, use words such as "your baby has died" and not euphemisms such as "I'm afraid your baby has gone." It is important that the message is clear and that parents are not left with false hope.
- Be honest with parents while continuing to be as sensitive as possible.
- Express genuine concern and empathy by using phrases such as "I'm very sorry" or "What a terrible shock for you – I'm so sorry."
- Ensure that parents have sufficient time to absorb what they have been told, check their understanding of the information they have been given and ensure they have time to express their concerns and ask any questions.
- Be honest when a baby's diagnosis or prognosis is uncertain and acknowledge that this is likely to be very difficult for parents. If the member of staff who is with parents at the time cannot give them accurate or sufficient information, they should be honest about this and offer to arrange for parents to speak with someone more knowledgeable as soon as possible. Parents should not be given information that they may later discover is incorrect.
- Parents will likely be shocked and distressed after receiving bad news and they may find it hard to absorb and remember what they are being told. Parents may only hear the first one or two things that are said and then be unable to focus on additional information. Staff may need to repeat themselves and should check that parents have understood what they are being told. It may sometimes be helpful for staff to phrase information in different ways. While staff should provide parents with as much information as they want, they should also ask parents how they are feeling and offer to arrange further discussions to discuss additional details. Repeated discussions may be necessary, particularly if there is a lot of information to convey.
- If there is a lot to discuss, staff should start by dealing with any topics that parents want to discuss and the immediate decisions that parents may need to make. Staff should be prepared to leave discussing less pressing information until later, depending on the parents' wishes. It is important to watch for signs of distress and exhaustion and to ask parents if they would like to take a break and continue the discussion later.
- If a parent is going home alone after receiving bad news, staff should suggest that they might like to call somebody to accompany them. This can be very important if they are planning to drive home and/or live a long way from the hospital.

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

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

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

Labour and birth

Stillbirth

Vaginal birth is generally the recommended type of birth for women whose baby dies before labour begins unless there are medical reasons for recommending a caesarean birth. This is because of the risks to the mother and potential implications for future pregnancies that are linked with caesarean births. However, all potential options for the baby's birth should be discussed with parents. Parents should also be reassured that staff will be available to provide continuous support regardless of the type of care parents choose.

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

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

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

Induction

Parents should be offered information about:

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

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

Pain management

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

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

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

Place of care

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

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

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

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

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

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

The woman's midwife should arrange for gas and air and any other equipment to be delivered to the woman's home as soon as possible. Any equipment that may be needed to provide care for the woman or comfort care for the baby should be included in this delivery. The midwife should ensure that a delivery pack for the baby is not sent to the home unless the baby may be born alive. Staff should also double-check that these items have been delivered.

Care for labour and birth

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

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

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

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

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

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

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

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

During the birth, parents may need extra emotional support when pushing the baby out. This may particularly be the case for parents whose baby is expected to die as a result of the process of giving birth.

After the birth, parents may not be expecting the silence that follows and some parents may be in shock or be very distressed. Staff should be present to support parents following the birth. Staff are also able to offer parents opportunities to meet their baby at this time and parents may value guidance from staff around seeing, holding and creating memories with their baby.

Care for partners and supporters

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

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

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

Partners and supporters may also feel protective towards the woman and may become very anxious that staff should be doing more to help her and, where appropriate, the baby. In some cases, this may lead to aggression towards staff. Acknowledging the partner's concerns and giving clear explanations may help to reassure them that everything possible is being done.

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

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

Multiple pregnancies

When one or more babies have died during a multiple pregnancy and one or more babies has also survived, parents may experience mixed feelings during the labour and after birth. Some parents may feel torn between experiencing joy for the impending birth of any surviving babies and intense grief for the baby or babies who have died. Some parents may not feel able to grieve until after their babies are born when they are able to say goodbye to the baby or babies who have died. They may also have been concerned that their grief would affect any surviving babies before the birth. Staff should acknowledge the baby who has died and avoid focussing on the baby or babies who have survived during and after the labour and birth. Staff should also offer parents opportunities before, during and after the labour and birth. Staff should also offer parents opportunities before, during and after the labour and birth to discuss how they are feeling.

If there is likely to be a body, recognisable remains of the baby or babies who have died or a fetus papyraceous, staff should offer to gently describe to parents how the baby or babies may look. Many parents do not regret seeing their baby or babies even if their appearance has deteriorated or they have a visible anomaly.

Memory making

Seeing and holding their baby

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

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

Multiple births

Special consideration is needed for the parents of twins or multiple babies. It is important that staff acknowledge the importance of the baby (or babies) who have died, and avoid focusing only on the baby or babies that are alive. If parents want to see the baby or babies who have died, it may be helpful to see and perhaps hold the living and the dead babies together if this is possible. Without this opportunity it may be difficult for parents to grasp the reality of what has happened. Later on, the parents may value the memory of being with all their babies together. It is important to ensure that other ward staff are aware that the surviving baby/ies is/are part of a multiple birth.

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

When the baby has an anomaly or is macerated

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

When parents are undecided about seeing or holding their baby

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

Some parents will decide that they do not want to see or hold their baby, and their decision should be accepted and respected. They should be told where the baby's body will be kept and that they can ask to see their baby if they change their minds. If there are time limits, this should be explained.

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

"I could have been better prepared for how my baby would look after he was born. I was so scared… I didn't know if I could hold him… I needed to be given time… I felt that someone was going to swoop in at any moment and take him away to the morgue. I would have loved more time."
Parent (Redshaw et al. 2014: 22)

Naming the baby

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

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

Creating memories

Perinatal loss involves losing someone who may be very important and who may have already changed their parents' lives in many fundamental ways. However, there are generally few or no tangible memories of the baby or babies and often there are no memories that can be shared with other people. In most cases, the parents have never seen their baby alive.

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

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

Some parents may find the idea of creating memories strange and unnecessary. 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 ever 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:

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

Washing and dressing the baby

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

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

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

If the baby is going for a post mortem examination, discuss with the parents if they wish the baby's clothes to be preserved for after the examination as there may be some staining of the clothes if put on immediately afterwards. Offer the parents a baby gown (often lovingly made by volunteers) for the time to and from the examination, and the baby can be dressed again in the clothes on return. If the parents are keen to keep clothes that the baby has worn it is really important that the baby does not go straight into these clothes after the post mortem examination as they will need washed which may remove the smells which the parents wish to remember.

Photographs

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

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

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

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

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

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

Other keepsakes

Other keepsakes parents may want to take home include:

- Hand and foot prints.
- A record of baby's weight and measurements.
- Baby's scan picture.
- Baby's cot card.
- Baby's identification bracelet.
- Baby's cord clamp.
- An identical set of the clothes the baby has been dressed in.
- Cards and ribbons from any flowers received.
- Sympathy cards.
- A copy of baby's certificate(s).
- The blanket baby has been wrapped in.

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

Taking baby out of the hospital environment

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

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

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

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

Wherever possible, parents should be given the choice to take their baby home or out of the hospital. When parents are not comfortable or there are good clinical reasons to discourage parents from taking their baby home, parents should be offered a longer stay in the hospital. For 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.

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

Sensitive and efficient procedures should be in place that enable staff to provide good support to parents who wish to take their baby's body out of the hospital. If parents plan to take the baby home, it is important to take any post mortem examination arrangements into account. A post mortem examination may be carried out first. In these instances, parents should be told about the condition of the body and how to handle it after the post mortem examination.

Parents also need to know that it is important to keep the body cool. They may be able to borrow a cold cot from their hospital, a local support group or 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 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 from the parents' home before the funeral.

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

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

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

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

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

Memorials

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

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

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

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

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

Post mortem examination

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

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.

Before storage or transferring a baby, the baby's body or remains should be labelled with the mother's name and NHS number or unique identification number, the baby's date and time of birth and/or death, the baby's name if they have been named, the baby's sex (if known) and the name and details of the person who verified the death. Items that parents want to accompany the baby should also be listed. Babies' bodies and 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. However all placentas should go for investigation for stillbirth (with parental consent). 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 wish for a post mortem investigation to be carried out, and providing them with information about the procedure, is an area that many healthcare professionals find challenging. There are some key principles that can assist professionals in approaching these conversations:

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

Consent should be sought by a member of staff who has received training in seeking post mortem examination consent and 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.

Seeking consent for a post mortem examination may differ from consent for other types of procedures as staff are often not performing or involved with the investigations themselves. It is vital that the person requesting consent has a thorough understanding of local policies and procedures for post mortem examinations in their hospital and that they are familiar with the consent form so that they can confidently take parents through it. They should be aware of the potential benefits of a post mortem investigation and able to explain these to parents, but also that no definite cause of death may be found, 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 staff who discuss consent for post mortem examinations with families should be in contact with the pathologist and/or mortuary involved. They should regularly exchange information in order to ensure best practice is followed, as well as to optimise care and support for parents.

Discussing a post mortem examination with parents

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

Mentioning the possibility of a post mortem examination as soon as possible and in advance of seeking consent may be beneficial. For some parents, this discussion may be appropriate antenatally when parents have decided to have a termination for fetal anomaly or an intrauterine death has been diagnosed. Thinking about a post mortem examination before a termination for fetal anomaly may be important as this may affect the choice of method of termination. A post mortem examination could also be mentioned when staff are discussing moving to palliative care on the neonatal unit. Consent should not usually be sought until after the baby's death and at a time that is suitable for the parents.

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. It can be very distressing for parents who expect to receive results and do not receive them when expected or feel they need to chase results so good communication across teams and with parents is paramount.

Policies and practices should be in place to ensure that there are good communications between pathology staff and healthcare teams. This coordination between services will help to ensure that staff are aware of the time scale for receiving results when booking follow-up appointments with parents and help them to keep parents informed of any delays. A named contact should be designated within each pathology and midwifery team to facilitate the return of post mortem examination results and ensure that a specific person on the healthcare team is responsible for following up on results.

Sensitive disposal and funerals

Legal requirements

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

Providing information on sensitive disposal to parents

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

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

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

All parents should be offered written information, covering:

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

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

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

Parents on a low income

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

Cultural considerations

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

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

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

Urgent burial and cremation

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

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

Although registration must normally take place before a body can be buried, the local registrar should make arrangements to provide the necessary documents before registration so that urgent burials can take place wherever possible. This may be needed if the stillbirth occurs on or just before a weekend or public holiday. Families may need help from healthcare staff with getting the documentation completed as quickly as possible and with contacting the registrar out of hours. A certificate for cremation, however, cannot be issued prior to registration for a stillborn baby.

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

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

Taking the baby home

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

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

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.

Coroners

The doctor must report the death of a baby to the coroner if the cause of a neonatal death is uncertain, it is possible that a stillborn baby or a fetus that underwent termination for fetal anomaly was born alive, or the baby was not receiving care from a doctor while they were alive. When a baby's death is reported to the coroner, the parents must always be informed and the reasons for reporting the death should be explained. Staff should acknowledge that this may be difficult for parents and they should be offered support.

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

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

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

If the coroner is not satisfied with the results of the post mortem examination, they may hold an inquest. In some cases, the baby's body may not be released until after the inquest.

Registration and Certification

Registration of birth and death

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

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

Before parents leave the hospital, staff should ensure that:

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

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

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

Discharge and aftercare

Leaving the hospital

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

It may be helpful to discuss the place and time of leaving the hospital with the parents. All parents should be told about the services and support available to them once they are at home. Some may be reassured if they know that a member of the primary healthcare team will visit or contact them shortly after their discharge from hospital if this has been scheduled.

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

Staff should also discuss milk donation and suppression.

Milk donation

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

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

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

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 GP's, community midwives and health visitors are all important sources of ongoing care and support for many bereaved parents.

In the first few days at home, some parents may be in shock. At this time, they may also be busy with visits from family members and friends as well as organising and preparing for a funeral. However, many parents are left to cope on their own or feel alone once other people return to their normal routines. In the days and weeks that follow, some parents may also experience their loss and grief more intensely.

Some parents may appear to be well supported by their family and friends. However, these parents may not be getting the help that they need. Some may distance themselves from family members or try to hide their grief. Some parents may also find that friends and relatives avoid them or are unable to listen. This may be because they do not know what to say, they are experiencing their own grief for the baby or they may be experiencing renewed grief for past losses. This can add to the isolation many parents can feel following a pregnancy loss or the death of their baby.

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

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

It is important where applicable to also notify the community team of multiple birth status, especially when there is a surviving baby.

Communication between hospital and primary care teams

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

Hospital staff should explain the benefits and importance of receiving support from their primary care team to bereaved parents. Many women will give consent to the hospital contacting their GP or primary care team. Other women may not want their GP or primary care team to be informed and it is always important to check. If a woman declines to have her primary care team informed, this decision must be respected. The woman should also be told where she can receive additional care if required. Additionally, she should be given a letter summarising her history and treatment to give to her GP or another doctor if she needs further medical care. Staff can also offer to help women register with a GP or change their GP if necessary.

With the woman's consent:

- A designated member of staff at the hospital should phone her GP and community midwife when the woman is 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 obstetric history and care to her GP when she is discharged. Depending on the gestation at which the loss occurred, the summary should also be sent to the community midwife and the health visitor.
- The woman should be offered a summary of her care for her own information.
- 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 if going to stay with relatives or on the neonatal unit so that the primary care team know where and how to contact her or arrange for her care.

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

It can be helpful if the GP, community midwife 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.

Follow up appointments

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

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

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

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

In addition to the initial follow-up appointment, an offer of ongoing care should be made to all bereaved parents.

This offer should also be repeated some weeks later if parents initially decline the offer. Parents may find that they need support later and/ or be surprised by a lack of support offered by friends, family or other services.

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

Discussions at follow up appointments

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

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

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

Feedback

Parent feedback

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

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

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. As well as ensuring an effective feedback mechanism for improvement it is also important to celebrate positive feedback when things are done well." Maternity Bereavement Experience Measure, p8.

The Maternity Bereavement Experience Measure (MBEM)

The MBEM is a resource to support healthcare professionals in gathering 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. 450 parents responded to a Sands survey in 2016 to inform the content of this resource (See Stillbirth 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

Review

It is important that all stillbirths are carefully reviewed through appropriate processes in order to provide answers for families about why their baby died, and to identify improvements in care for future families. Regulation 20: Duty of Candour means that if any investigation reveals incidences of poor care leading to harm, Trusts and Health Boards have a 'duty' of openness to share this information with families.

Currently units across the UK use different methodologies and tools for conducting perinatal review from Root Cause Analysis (RCA) to tools such as SCOR and only conduct them in some instances of stillbirth, usually those which are designated Serious Incidents (Sis) or equivalent.

Attendance, quality and timings of perinatal review meetings, although often monthly, are also variable. Calls for standardising review for all deaths from 22 weeks (>500grammes) have resulted in the commissioning of a national Perinatal Mortality Review Tool (PMRT), available to use for free by the end of 2017 in Scotland, Wales and England.

Reviewing the death of every baby in a standardised, high quality way is important. There are multiple review processes. Parents should be invited to be involved in all reviews regardless of country, system or specialty.

Parents should be offered the opportunity to give their questions, concerns and perspectives of care to the review panel. You need to be flexible about how and when this is done.

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

The tool will support:

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

There is currently no evidence-based process for engaging parents in perinatal review, but research in this area is being conducted by MBRRACE-UK and the PARENTS team collaborators at Bristol and Manchester Universities, as part of the development of the PMRT.

In the meantime, based on current evidence (ref), Sands and the Bristol University PARENTS research teams developed some tips for engaging parents in perinatal mortality reviews. To find these go to: **www.sands.org.uk/our-work/fewer-baby-deaths/our-work-parents**

Top tips

1. Parents are not aware of perinatal review – either that their baby's death was or should have been reviewed.
2. Parents want to know about the outcomes of the review of their baby's death.
3. Most parents want to contribute their perspective to the review process BUT some do not and only want to know about the outcomes. Assumptions should not be made as to what individual parents want.
4. Parents want to be able raise questions for the review to address.
5. Parents want flexibility on the timing of WHEN they contribute to the review process.
6. Parents want flexibility on HOW they contribute their version of what happened, including in a meeting or a written account, which may be free text or with some guidance.
7. Parents want the review to look at their clinical AND emotional care.
8. Parents want to use the review to give negative and positive feedback on their care.
9. Parents want the review to cover the whole pathway of care, both antenatal and postnatal, with input from community HCPs.

Emotional support

Ongoing emotional support

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

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 (see Stillbirth Pathway, Appendix A10) to alert all primary and secondary care staff that her baby has died. This is to ensure sensitive communication when contact is made, and flag the need for ongoing emotional support.

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

Staff should flag with families:

- Chaplaincies that should have contacts with religious and spiritual advisers of all local faiths and spiritual organisations.
- A contact to provide ongoing emotional support via the care provider (for example, a bereavement lead or community midwife).
- Counselling services available via the care provider.
- Access to counselling and further support via secondary care (for example, GPs and health visitors).
- National and local support organisations to: **www.npeu.ox.ac.uk/pmrt**

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

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

Mental health

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

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

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

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

Another pregnancy

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

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

Offering parents continuity of carers and the option of having their notes clearly marked (See Stillbirth Pathway, Appendix A10) may help to ensure that parents do not need to explain their situation repeatedly.

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

It is important to:

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

It is important not to:

- Offer false reassurances to parents about having a healthy baby.
- Minimise parents' previous experiences and current concerns.
- Make assumptions about how a parent might feel at any stage.
- Assume parents attended antenatal classes in previous pregnancies.
- Exclude 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 parents who are thinking about becoming pregnant again. Parents may need an opportunity to discuss their concerns with healthcare staff before trying to conceive.

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

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

Antenatal care

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

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

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

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

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

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

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

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

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

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

Certain stages, events or dates during the pregnancy may be particularly difficult for parents, depending on what happened during the previous pregnancy. For example, parents may be very anxious and distressed in the period leading up to the gestational week or date when the previous baby died or an anomaly was diagnosed. Some parents may feel less frightened after this point if all is well. Other parents may remain fearful until after the new baby is born or sometime after their birth for those who experienced the sudden unexpected death of their baby.

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

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

In addition to the mother, it is important to ensure that 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.

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

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

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

At the first antenatal visit, each woman should be allocated a named midwife and consultant obstetrician. These practitioners should provide most of the woman's care throughout her pregnancy, birth and the postnatal period. They should also carefully read the woman's notes thoroughly before the first appointment and ask parents if it is okay to refer to the baby who died by name if one has been given. Depending on parents' wishes, it may be appropriate for both the named midwife and consultant to attend some appointments. In the case of sudden unexpected death, parents should be given information about the Care of the Next Infant (CONI) scheme run by the Lullaby Trust and the contact details or a referral to the appropriate health visitor or team.

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

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

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

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

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

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

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

Staff care

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

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

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

Training

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

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

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

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

Support

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

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

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

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

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

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

Self-care

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

Further reading

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.

Notes

nbcp
for pregnancy and baby loss

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