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



**national bereavement
care pathway**
for pregnancy and baby loss

Termination of Pregnancy due to Fetal Anomaly (TOPFA)

Full Guidance Document

Led by Sands



In partnership with:



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. Information on the Scotland pathway can be found at www.nbcpscotland.org.uk.

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.

The Core Group gratefully acknowledges the support and contribution of the Department of Health and Social Care (DHSC) and Teddy's Wish to the development of the NBCP.

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

“All the staff were wonderful from the moment we were given the initial news at the 12-week scan – caring, supportive, kind, professional. It helped us enormously.”

(Quote by bereaved parent)

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Note to the reader

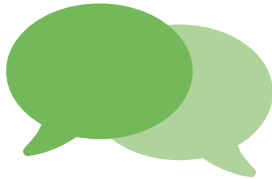
This is the first of two guidance materials we have produced for National Bereavement Care Pathway (NBCP). This document contains detailed reference material and guidance whereas the second document is a more ‘hands on’ and practical approach to providing bereavement care for families, including a number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

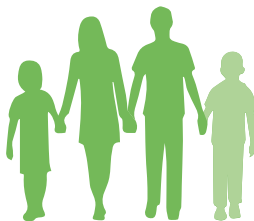
2. Continuity of care and consistency in approach is vital



“I 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. They should be private, comfortable, warm and welcoming
- 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

The NBCP (National Bereavement Care Pathway) Editorial Panel acknowledges the current debates, discussions and difficulties around terminology and language facing healthcare professionals and have attempted to unify language across the pathways to ensure a consistent approach.

The Panel also recognises that as healthcare professionals it may be easier to verbalise the correct terminology with your knowledge of the person in front of you, rather than the panel trying to cover all bases in written documents.

As such, we offer the following as overarching guidance:

- The terms 'healthcare professionals' and 'staff' are used throughout to denote all of those working with bereaved parents
- Per recent NICE guidance on induction of labour (<https://www.nice.org.uk/guidance/ng207>), we use the terms 'woman' and 'women', based on the evidence used in its development. The recommendations will also apply to people who do not identify as women but are pregnant or have given birth.
- Similarly, the term 'baby' (or 'babies' in the case of multiple pregnancies) is used throughout, 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.
- The term 'parents' is used to refer to expectant and bereaved mothers, fathers, and partners. 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 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.
- The term 'partner' is used to refer to whoever is there as a close support to the person being cared for. Not everyone will have a partner and/or may not have them with them in the clinical setting, and as such, the guidance should be adjusted accordingly – for example discussions with the birthing partner or accompanying friend/family member.
- We have used the phrase 'Trusts' because the rapid changes in the way that health services are structured and managed across the country make it impossible to use a phrase that covers all the bodies involved. In the devolved nations the term 'Board' is used. However, the pathway will also be applicable to independent healthcare establishments and to all other bodies that may be set up in the future to organise and provide care for women and families experiencing a childbearing loss.
- 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.

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

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 sections we have also used the term 'should' (for example 'staff should be trained'). Essentially this is shorthand for 'good practice suggests that'.

Communication

All communication with parents experiencing a pregnancy loss or the death of a baby must be empathic, sensitive, non-judgemental and parent-led.

Use warm, open body language by sitting near parents, facing them, making eye contact and using touch if appropriate. Be mindful of your tone and background noise if communicating over the telephone. Be honest with parents while being as sensitive as possible. It is okay to show emotion, but the parents should not feel they need to look after your feelings.

Parents may feel shocked and may find it difficult to understand information or think clearly. Staff should speak clearly and use simple language and parents should be encouraged to ask questions. Be aware 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 TOPFA Pathway, Appendix A9).

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.

The decision to end a pregnancy after a prenatal diagnosis

This pathway provides guidance on care for women and their partners who have made a decision to have a termination of pregnancy because of the implications of the scan findings or other antenatal test results. We are assuming that the parents have experienced high quality care up to this point and had access to all the information and support they needed to come to a decision.

We expect all units to have carefully co-ordinated care pathways in place to provide support to women and couples whether they decide to continue or end their pregnancy, whatever the diagnosis. For parents continuing when they know their baby is going to die, it will be helpful to also consult the Neonatal Death Pathway. <https://nbcpathway.org.uk/professionals/nbcpathways-material>

It is important to recognise that if one baby from a multiple pregnancy has a fetal anomaly that the decision to have a TFMR can impact that surviving twin or triplets, particularly if they are identical.

Termination of pregnancy for fetal anomaly

It is important that there is good communication between all staff and that staff read a woman's notes before meeting with her to ensure that they are aware of her situation and provide appropriate care. Women should be offered continuity of carer when they have decided to terminate a pregnancy.

It is important that parents receive supportive, empathetic, non-judgemental care and information from staff so that parents can make decisions that are right for them. Empathetic care is crucial for parents who can fear being judged for their decision. Parents may experience additional distress if they perceive staff to be unsupportive or disapproving of their decision to terminate the pregnancy.

Once parents have decided to have a termination, staff should offer to discuss the woman's options for her care including the termination procedures. Parents need to be given adequate information so that they know what to expect and can make informed choices about their care. It is important that staff offer to repeat information to parents and that parents have a named contact who is available to discuss any questions and concerns the parents may have.

Staff should acknowledge the difficulty for parents who are planning a termination for a wanted baby. They should also ensure that they use the language that parents use when referring to their baby. For example, the word "baby" or "fetus." Some may be distressed by terms like "products of conception."

Staff should sensitively offer to discuss parents' options for seeing, touching, holding and/or creating memories with their baby and normalise these choices when speaking to parents. Some parents may want to have a blessing or other type of ceremony for the baby before or after the termination procedure.

Some parents may want to discuss other concerns with staff. If parents have decided not to tell family members and friends about the termination, it is extremely important that staff are aware of this decision and reassure parents that complete confidentiality will be maintained.

Most women who are considering a termination after 14 weeks' gestation are offered a medical termination in a hospital setting and may be unaware or surprised that they are expected to labour and give birth to their dead baby. This information should be sensitively explained to women when they are being given information about medical procedures. Women who opt for a medical termination should also be offered information about their choices for the labour, birth and pain relief and they may want to plan for this experience.

Women should be offered access to a surgical termination if she would prefer this procedure as this can be accommodated by independent sector providers who are contracted by the NHS. Women who decide to have a surgical termination of pregnancy should be gently prepared for waking up after the surgery and no longer being pregnant and the potential effects of the general anaesthetic.

It is important that women seeking terminations receive accurate, realistic and accessible information about the termination methods available to them, what each procedure involves, what to expect before and after procedures and the potential risks and complications of each procedure. This information should include the relevant information about the expected length of each procedure, how long a woman will need to stay in a hospital or clinic and any arrangements that she needs to make to travel home afterwards.

Women should also be told where procedures will be performed (for example, in a gynaecological ward, day clinic, independent clinic or on labour ward) and whether other women will be having different procedures in the same place (including terminations for other reasons).

Parents should also be gently offered information about post mortem examinations and how the termination procedure used may affect their post mortem examination options for their baby.

Termination before 21 weeks + 6 days' gestation

It is uncommon for a baby to be born alive following a medical termination before 21 weeks + 6 days' gestation. However, women who undergo a medical termination before 21 weeks + 6 days' gestation should be prepared for this possibility. These women should be gently and sensitively told that the baby may make movements at birth but that this does not mean that the baby could survive even with intensive care.

In circumstances where the baby is born alive, parents should be offered palliative comfort care for the baby. Parents should also be told that they can see, touch and hold the baby if they wish, regardless of whether the baby is born alive or dead.

Staff should check with regard to relevant protocols relating to recording of the death.

Termination at or after 21 weeks + 6 days' gestation

The RCOG recommends that feticide is offered for terminations that take place after 21 weeks + 6 days' gestation, except where the fetal anomaly is so severe as to make early neonatal death inevitable, regardless of the gestational age at delivery.

Despite this recommendation, it is not a legal requirement for women to have feticide for a termination of pregnancy that is performed at or after 21 weeks + 6 days' gestation and women should not be pressured to have this procedure. Women who decline feticide should be informed that it is possible that their baby may have signs of life and that some midwives may consider neonatal review is necessary.

When feticide is discussed, it is very important that the woman is told what the procedure involves, where it will be performed and what she may feel during and after the procedure. The woman also needs to know when and where her labour will be induced after the feticide procedure.

Travelling to a fetal medicine unit for feticide

Women may need to travel to have feticide performed by a fetal medicine specialist. If this is the case, staff should acknowledge travel may cause parents additional distress.

A woman travelling to a different unit should be given a map and clear information about how to get there. The staff in the unit should be expecting her so that they can welcome her without her having to explain why she has come. If she is planning to travel alone, staff should discuss with her whether she might like to travel with her partner or another supporter. Women who plan to travel by car should be told that they should not drive themselves. If possible, funding should also be available to help with travel costs for parents on low incomes.

During the termination procedure

When a woman arrives for a termination procedure, all staff should be aware of the reason for her appointment so that she does not need to explain her situation and to avoid inappropriate comments from staff. Good co-ordination and communication is needed between staff making the referral and the unit or clinic (including independent sector services) where the procedure is being performed to ensure that women receive the best care possible.

Privacy is important for many parents and each woman should be offered a private room where she will be cared for during and after the termination regardless of the type of procedure that is being performed or the location.

Selective termination and feticide

Women having a multiple pregnancy may be offered selective termination or feticide if one or more of their babies is diagnosed with a fetal anomaly. Parents who are considering selective termination or feticide should be offered full information about the procedures offered for the gestation, chorionicity and amniocity of the pregnancy. It is important that the risks to other babies are explained for each procedure including the risk that the procedure may also cause the death of other babies. Parents may need time to consider the available options and should be offered support to discuss their concerns.

The woman should also be told about any physical changes that she might notice after the baby has died and any potential side effects of drugs that may be offered to prevent premature labour. Some parents may find the idea of the dead baby remaining in the womb beside the living baby or babies disturbing, while other parents may find the thought comforting. The woman should also be told about what to expect during the remainder of the pregnancy, labour and birth.

If feticide is to be carried out after 24 weeks' gestation, parents must also be told that they are required to register the stillbirth of the baby who has died.

Once the feticide has been carried out, staff should inform their colleagues who will be providing the woman's ongoing maternity care. This will help staff to avoid making inappropriate comments and ensure that the woman does not need to explain what has happened. Informing the relevant staff requires a careful communication plan, especially if the feticide has taken place at a specialist centre that is not linked to the obstetric or midwifery teams who are providing the woman's maternity care.

Multifetal pregnancy reduction

Parents should be offered clear, unbiased information about all options and any associated risks so that they can make a fully informed choice about multifetal pregnancy reduction. Staff should also offer parent information about fetal reduction procedures. Parents should be made aware that the fetuses that have died will remain in the uterus but will not harm the surviving baby or babies and that there are unlikely to be any visible remains after the birth of the surviving baby or babies if the procedure is carried out in early pregnancy.

Parents must then be given as much time as they need to consider their options and make a decision that is right for them. While making their decision, parents should be offered support from staff and information about support organisations.

Parents who decide to have fetal reduction should be offered sensitive care and emotional support from staff before, during and after the procedure.

For parents who have had fertility treatment, it may also feel particularly bizarre and frightening to decide to terminate one or more fetuses after their struggle to become pregnant.

After the surviving babies are born, staff should be aware that parents may also experience immediate and/or long term grief. With the woman's consent, staff should inform the woman's midwife, GP and/or health visitor of the fetal reduction so that they can offer ongoing support and care'.

Parents should be made aware that they will be offered funeral choices for the deceased baby/babies and it may be more appropriate to discuss and complete the paperwork as soon as possible rather than after the birth of the live baby. (See later section on funerals for further information).

The Purple Butterfly sticker may be introduced at the time of the loss to help communication. It is important that staff are aware of the purple butterfly symbol and its meaning, posters should be displayed in prominent areas to alert people to the symbol.

Memory making

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

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

Some parents may find the idea of creating memories strange and unnecessary for a variety of reasons. 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:

- 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.
- Parents are offered genuine choices.
- Parents are given time to reflect and decide what they want.
- Parents who have declined previous offers are not asked repeatedly if they have changed their minds; however parents should be gently offered different options more than once to enable them to change their minds if they choose to do so.
- Any views the parents may have expressed earlier are recorded and acknowledged.



Seeing and holding their baby

When having a medical termination of pregnancy, seeing and holding their baby may be important to parents regardless of the size, condition or gestation of their baby. Where possible, staff should offer parents the option of seeing and holding their baby while recognising and respecting that some parents will decline this offer. It should be explained to the parent what the baby will look like, to prepare them. For example, some parents will not know that a baby is formed by 12 weeks. Some parents may not realise their baby will be a fully formed, tiny baby and have not brought any clothes with them. Ensure the hospital has alternatives and something to dress baby in, if required.

When the baby has an anomaly or is macerated

If there is a visible anomaly or maceration, parents should be gently told what to expect and be offered a description of their baby's appearance before deciding whether to see the baby. If parents accept the offer of a description, it is important that the explanation is factual and without judgement. Sometimes, it may help if the baby is wrapped in a blanket or dressed and the parents look first at the baby's other features.

Some parents may want to see the anomaly. They may find this important for understanding why their baby died. Other parents may want to keep the anomaly covered if this is possible. It is important to respect the parents' choice and follow their lead while also providing them with opportunities to discuss how they feel.

Multiple births

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

Staff should offer parents scan images of all the babies together, where possible. It may be helpful for any surviving siblings to see these images later on. It is important to consider that bereavement support may be needed for a long time after the babies are born. Twins Trust bereavement group offers support after the TFMR of one or more of a multiple any time after loss.

Naming the baby

Parents sometimes decide to name their baby, or have a nick-name for their baby from early pregnancy. 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 use the baby's name when one has been given by the parents. Some parents will not want to name their baby.

Washing and dressing the baby

Parents may want to wash their baby or assist or watch a member of staff washing 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 very tiny babies and some that are macerated, washing may not be appropriate and this needs 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. For very tiny babies who can be difficult to dress, a small knitted poncho is often a good alternative.

Photographs

Photographs should never be taken without the parents' permission. Parents' wishes must be respected. Some parents may find the idea unacceptable or may not feel it is necessary. Some parents may regard it as forbidden to make an image of a person and may not want photographs or hand and footprints taken. However, staff should never assume for any reason that any parents will not want photographs of their baby. Inform parents of outside charities that provide a free photography service, for example Remember My Baby. They are trained to take sensitive photos such as hands or tiny feet only. Photographs should always be offered. Where appropriate and where possible, if there is more than one baby, parents should be offered photos of all their babies together.

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

Other keepsakes

Other keepsakes parents may want to save include:

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

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

Memorials

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

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

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

Taking the baby or remains out of the clinical environment

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

Some parents may also want to take their baby's body or remains home as they may wish to spend time in the home where he or she would have lived and grown up. Others may want to take the baby's body or remains to a place that has special significance for them.

Some areas may have a local hospice with a cold room where parents can spend time with their baby if they do not wish to take the baby home.

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

When parents are not comfortable or there are good clinical reasons to discourage parents from taking their baby's body home, parents should be offered a longer stay in hospital. For mothers with existing mental health problems, advice should be sought from a mental health professional if necessary and extra support should be offered in the community.

If parents plan to take the baby's body home, it is important to take any post mortem examination or other investigations into account. A post mortem examination may be carried out first. In these instances, parents should be told about the condition of the body 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's body 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. Depending on the baby's gestation, another suitable container may be used to transport the baby's remains. The type of container offered should be discussed with parents who may wish to use an alternative receptacle of their choice. Staff might suggest using an opaque container for unidentifiable remains.

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

There is no legal reason to inform the police if parents take their baby's body 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 TOPFA 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.

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.
- 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 and histology

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

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. Whether the placenta can be tested will depend upon the gestation.

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

Post mortem examination consent

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

Consent should be sought by a member of staff who has received training in seeking post mortem examination consent. They should be aware of the potential benefits of a post mortem investigation and be able to explain these to parents, but also explain that no definite cause of death may be found, particularly for earlier gestation losses.

Consent is a process that should involve careful listening and discussion. It should be unhurried and should help parents to reach a decision that is right for them. All discussions should take place in a quiet, private place where parents and staff will not be disturbed.

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

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

Discussing a post mortem examination with parents

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. 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.

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

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. Some parents may appreciate being told about who will be transporting the baby and caring for them in the mortuary.

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

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

Results

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

Good coordination between services will help to ensure that staff are aware of the time scale for receiving results when booking follow up appointments with parents. A named contact should be designated within the pathology team and the relevant care unit to facilitate the return of post mortem examination results.

Registration and Certification

Registration of birth and death

Read this section in association with the RCN guideline: <https://www.rcn.org.uk/professional-development/publications/managing-the-disposal-of-pregnancy-remains-uk-pub-009-942>

TOPFA (pre 24 weeks)

Once the termination has taken place, the doctor responsible for initiating it fills out an abortion notification form, which is sent in confidence to the Chief Medical Officer for England.

You should discuss with the parents whether they would like a certificate or form from the hospital recognising the birth (see TOPFA Pathway, Appendix A2).

TOPFA (after 24 weeks)

Once the termination has taken place, the doctor responsible for initiating it fills out an abortion notification form, which is sent in confidence to the Chief Medical Officer for England.

If the baby is born dead after the termination, the doctor or 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 certificate must be taken to the registrar of births and deaths for the stillbirth to be registered.

TOPFA if a baby is born alive and then dies

If a baby is born alive following a termination of pregnancy at any gestation and subsequently dies, both the birth and the death of the baby must be registered with the registrar of births and deaths.

The doctor who witnessed the definite signs of life will issue a birth certificate for the baby and a Medical Certificate certifying the baby's death. If no doctor was present while the baby was alive, a doctor will discuss the situation with the healthcare professionals who were present and sensitively with the parents. In some cases (albeit unlikely,) there may be a need to inform the coroner. Staff need to check with regard to relevant protocols relating to recording of the death. It should be noted that this will be distressing for the parents and they should be offered support accordingly.

Sensitive disposal and funerals

Legal requirements

There is no legal requirement to bury or cremate fetuses terminated or miscarried before 24 weeks' gestation. The legal options for disposal in England are burial, cremation or sensitive incineration.

For terminations that take place after 24 weeks' gestation parents have a legal responsibility to bury or cremate their baby's body, though they can consent to have a Trust carry this out on their behalf. Most Trusts have the option for support in decision making in this area (bereavement officers).

Providing information on what happens to fetal remains

Women who have a termination for fetal anomaly should be given the opportunity to discuss and make choices about their available options for the disposal of fetal remains. Parents should be informed whether burial or cremation options provided by the hospital are individual or shared. For terminations before 24 weeks' gestation, the differences between cremation and sensitive incineration, particularly concerning the impossibility of collecting ashes through incineration, should be explained sensitively.

Some women may decline information about these options or involvement in decisionmaking processes regarding the disposal of fetal remains and this should be respected. Parents should be informed of what option will be used if they do not make a decision, and told who they can contact if they change their minds, or would like more information. They should also be informed of any time frame in which they would need to do this. Parents need to be told that they have time to explore the options and ask questions before they make their decision. Parents often feel they have to make their decision in that moment.

Some parents may also wish to arrange a funeral or other ceremony for their baby, although they are not required to have a funeral. If a family approach a registered funeral director, there should be no charge. The Child Funeral Fund (<https://www.gov.uk/child-funeral-costs>) is available to ensure funerals for babies of neonatal deaths and children up to 18yrs of age are free of charge.

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.

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 (including necessary documentation).
- What costs are involved (if any).

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

Cultural considerations

Some parents who elect for a termination may not be able to speak to family or friends about what is happening. Staff should ensure these parents receive sensitive, supportive care.

Staff should be aware that some cultures and religions do not traditionally hold funerals or other ceremonies for babies born before 24 weeks' gestation. It should not be assumed however that this will be the case, and all parents should be offered information on the disposal methods and options for hospital-arranged or private funerals available locally.

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

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 or involvement in decisions.

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

Discharge and aftercare

Leaving the hospital

Leaving the clinical environment and going home without their baby can be frightening and painful. Some women want to leave soon after the loss. Others prefer to stay a little longer. Women should not automatically be sent home as soon as possible. Some women may feel abandoned and support may not be available at home. Before parents leave the hospital staff should sensitively inform them about information regarding access to benefits, the need for time off work (for both parents, where appropriate) and the length of time for post mortem results to become available.

Where possible, parents should be given an alternative route out of the birth centre/hospital from their room. Walking through a busy labour ward/birth centre with empty arms is hugely distressing and the memory can impact them forever.

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, some will not want this contact, but a visit from a relevant healthcare professional should always be offered.

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 discuss milk donation and suppression.



Milk donation and milk suppression

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

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

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

Women should receive information about milk suppression, any medication and its side effects and the gestation from which this medication can be used. Staff should discuss pain relief and time frames with parents. For example, that of a Community midwife, bereavement midwife or GP and number in case they have any questions or concerns.

Care and support for parents in the community

Hospital staff and primary care staff such as GPs, community midwives and health visitors can all be important sources of ongoing care and support for bereaved parents.

During the first few days and weeks at home, some parents may be busy with visits from family members and friends as well as organising and preparing for a funeral. However, many parents are left on their own or feel isolated once others return to their normal routines.

Some parents may appear to be well supported by their family and friends. However, they may not be getting the help that they need. Some parents may find that friends and relatives avoid them or are unable to listen. This can add to their feelings of isolation. TOPFA parents often don't tell even close family/friends of their experience straight away and so are more likely to be more isolated and lacking in support. After ending a pregnancy parents feel judgement from others, also guilt, sometimes feeling they don't 'deserve' the help and support.

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, especially as not all primary care staff will be familiar with the particular emotional grief journey associated with TOPFA losses.

Communication between hospital, clinics 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. The woman should also be told where she can receive additional care if required.

With the woman's consent:

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

- 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 given a summary of her care that she can keep or give to her GP at their first appointment.
- The GP and community midwifery team (where applicable) should also be informed where the mother will be staying after she is discharged from hospital. This is particularly important if the mother is going to stay with relatives or on the neonatal unit so that the primary care team know where and how to contact her or arrange for her care.
- Ask the partner if they would like their GP to be informed about the loss so it can be added to their notes, and record their consent if they did.

It can be helpful if the GP, community midwife or health visitor marks bereaved parents' electronic and hard copy medical records with an alert or sticker to notify other healthcare professionals to their bereavement (see TOPFA Pathway, Appendix A9).



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.

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

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

Some women may want to bring a partner, or another support person to appointments. When the appointment is booked, parents should be encouraged to write down any questions and worries and to bring the list with them to the appointment. Additionally, they should be given a contact in case they need to talk to someone urgently before the appointment. If the meeting is to be online, due to COVID or other circumstances, the correct protocols regarding confidentiality, privacy and other considerations should be followed.

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

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



Discussions at follow up appointments

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

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

- To ask questions about what has happened and to check their understanding of the information they were given at the hospital.
- To discuss how they are feeling. It is important to ask parents how they feel and to offer them an opportunity to talk.
- Help in preparing questions for their consultant or GP.
- Suggestions about dealing with the reactions and questions of other family members.
- Information and advice about registration and certification.
- Help with decisions about a funeral for their baby.
- Advice about sex and contraception.
- To discuss the timing of another pregnancy, their chances of having a 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 returning to work, including what to say to colleagues and their reactions, or taking time off.
- 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 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.” Maternity Bereavement Experience Measure, p8.

The Maternity Bereavement Experience Measure (MBEM)

The MBEM is a resource to support healthcare professionals to gather feedback from families following the death of their baby or babies.

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

<https://www.sands.org.uk/maternity-bereavement-experience-measure-mbem>

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. Services should be flexible so that they can be adapted wherever possible to meet the needs of all parents.

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

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

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

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

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

Staff should flag support available to families

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

Mental health

While grief should not be treated as a mental health concern, parents should be assessed for mental health problems that may be compounding their grief.

Women and their partners may be at risk of depression, anxiety and post traumatic stress disorder (PTSD). Healthcare professionals should be aware to look out for signs of these – such as a strong sense of worthlessness or hopelessness, withdrawing from friends and family, sleeping difficulties, flashbacks, or avoidance of reminders, of the events surrounding the loss. These symptoms indicate the need for further assessment and formal treatment. Healthcare providers should also be aware that there is an increased risk of suicide following pregnancy loss, and any suicidal ideation should prompt immediate assessment.

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

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

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

Another pregnancy

Parents should feel well supported in any pregnancy following a pregnancy loss or 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 the potential difficulties and challenges these parents might face.

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

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

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

It is important to:

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

Pre-conception care

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

Some bereaved parents will want to discuss what, if anything, they can do to prevent the same thing happening again. 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 appointments, screening options, scan appointments and/or opportunities to discuss an antenatal care plan and birth preferences.

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

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

Some parents may welcome more frequent contact with healthcare staff during subsequent pregnancies and will want all available screening and diagnostic tests. Some parents may find additional appointments, screening and tests stressful and decline some or all of this care. Staff should explain the reason why parents have been offered additional tests or checks. However, parents' decisions about care should be respected. Parents should have the contact details for a named contact in case they have any concerns.

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

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

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

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

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

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

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

Parents may also worry about their effects of the fear and anxiety 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 partners are offered support. Some 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. Ensure that partners are offered support, in particular around time off from work, access to GP, signposting to counselling and support (for example local groups or national 'fathers' groups as appropriate).

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 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 by a different hospital, GP or by different members of staff, even if their previous care was good. Parents may fear that traumatic memories will be triggered if they return to the place where 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.

Labour and birth

This may be the first labour and birth experience for this parent, depending on their previous experience.

Staff should be prepared for parents’ possible emotional reactions during labour and at the birth. Staff should be available to offer support if needed. Women should be aware that support is always available and know how to access staff members. It is also important that support is offered to any partners or birth supporters who are with the woman.

“I felt disconnected during the labour and just couldn’t believe that everything would be OK.” Mother

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

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

Care in the community

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

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

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

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

Staff care

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

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

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

Training

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

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

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

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; the ethical dimension of TOPFA losses and anxiety caused by wanting to 'get it right' knowing this is a difficult time for parents.

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

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

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

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

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

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 or in green space/outdoors.





For more information visit:
nbcpathway.org.uk

www.sands.org.uk



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