WOMEN'S HEALTH AND PAEDIATRICS

MATERNITY UNIT

Bereavement Care in Obstetrics, Gynaecology and Neonatalogy

Amendments			
Version	**Date**	**Comments**	**Approved by**
1	July 2022		Perinatal Guidelines group

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In consultation with: Perinatal Governance Group

Ratified by: Perinatal Governance Group

Date ratified: **Month/Year**

Next review date: **Month/Year,** or if legislation, national guidance or lessons learnt indicate an earlier review

Target audience: All health professionals within the maternity services

Equality impact assessment: Perinatal Governance Group

Comments on this document to: Perinatal Governance Guideline Group

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Bereavement Care in Obstetrics and Gynaecology

1.0 Background

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

The adoption of the NBCP standards is seen as a marker of high quality bereavement care and as a hospital and department we are committed to this goal. The Bereavement, Birth Support and Birth Reflections services have existed at ASPH since their conception over 20 years ago and are vital to the women and families that suffer the loss of their baby.

The NBCP highlights the importance of each member of the professional team involving in caring for families that suffer the loss of a baby, as well as the different care that women can often receive when they lose their baby at different stages of pregnancy. For this reason, all our local pathways have been studied, and adapted where needed, to ensure we are providing the best possible service.

This document is intended to form an umbrella under which all our specific local bereavement pathways can be viewed. It is in line with the NBCP framework but also outlines the discrete methods in which this has been adopted at ASPH, as well as the rationale where discordance is currently necessary.

2.0 Terminology

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.

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

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

3.0 Key messages

3.1 Communication

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)

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

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

Be mindful of your tone and background noise if communicating over the telephone.

Be honest with parents while being as sensitive as possible. It is okay to show emotion, but the parents should not feel they need to look after your feelings.

Parents may feel shocked and may find it difficult to understand information or think clearly. Staff should speak clearly and use simple language and parents should be encouraged to ask questions.

Be aware cultural norms or personal circumstances may affect a parent's readiness to ask questions, request clarification or express their wishes.

3.1.1 Communication barriers

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).

Where an interpreter is required, staff should have easy access to trained and experienced interpreters (ideally face-to-face) when supporting parents.

'Language-line' is readily accessible in all clinical areas and should be used whenever a language barrier is noted, if a face-to-face interpreter cannot be sourced. The use of family or friends is strongly discouraged as in other contexts.

3.2 Continuity of care

Continuity of care and consistency in approach is vital.

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

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

3.3 Parent-led care

Parent-led family involvement must be supported.

"When I got to my wife, she was still out if it due to the anaesthetic and was rambling about major surgery, blood transfusions and collapsing on the ward. I didn't really believe her because the nurse had told us it would only be a minor op." (Ectopic Pregnancy Trust, 2018)

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

4.0 NBCP Standards

The NBCP has developed key standards that assess quality of care in bereavement.

4.1 A parent-led bereavement care plan is in place for all families, providing continuity between settings and into any subsequent pregnancies.

For all patients, clear documentation of the scan findings, counselling, and patient choices is paramount. Parents should be given time to discuss their options and information in a suitable format to help their decisions. Families should be involved in this as the parents wish, and their inclusion should be facilitated.

In deliveries at the threshold of viability and very early pre-term deliveries, the survival of baby at delivery can be uncertain. In these circumstances, parents will be counselled by the obstetric and neonatal teams in a combined multi-disciplinary approach before delivery wherever possible. The parents will be aware of the choices available to them, and the neonatal team will be present at delivery when >23 weeks gestation and for some deliveries at >22 weeks gestation if this has been determined by the multi-disciplinary team and the parents.

The neonatal team will assess for signs of life at birth and the parents' views should also be included in the assessment of signs of life if they wish to share them. The parents should be included in this decision, and it is recognised that there may be differing perspectives. In the extreme preterm infant <25 weeks gestation, it will be discussed with the parents that prolonged CPR and cardiac drugs will not be used as these do not improve the outcome in this group of infants.

Further information about signs of life in the extremely pre-term infant can be found here: https://timms.le.ac.uk/signs-of-life/

In early pregnancy, where documentation is on Viewpoint, it is important for it to be immediately uploaded to Evolve as well so that this information is visible across all settings in the trust, specifically computers where Viewpoint is not available.

For any patient that is admitted directly from the outpatient setting, it is expected that the admitting clinician will discuss the patient and their wishes with the on-call team.

Key messages, patient choices and care plans should be detailed within the 'Management Plan' box on BadgerNet so this information is readily visible to all staff members in all settings.

All women suffering a pregnancy loss will be given information regarding their care in any subsequent pregnancies. This may be discussed at a perinatal follow up appointment or covered in written information in patient information leaflets.

The Early Pregnancy Support Scan clinic is a patient self-referral clinic to provide early reassurance scans for those that have had 2 or more early miscarriages, an ectopic pregnancy, a TOPFA or previous late miscarriage, stillbirth or neonatal death.

Parent feedback is sourced via the 'Maternity Bereavement Experience Measure' questionnaire and this is used to drive further change in pathways where required. The Maternity Voices Partnership is also active in reviewing our bereavement pathways and service and contributing to ensuring bereaved parents are engaged in co-designing a service for bereaved parents of the future.

4.2 Bereavement care training is offered to staff who come into contact with bereaved parents, and staff are supported to access this training.

NBCP SANDS training is offered to all staff who interact with bereaved families, on a 3-yearly basis. This includes doctors, nurses and midwives, as well as sonographers, support workers and theatre staff.

Annual mandatory training incorporates a bereavement update and feedback session for midwives.

All doctors and midwives who may be involved in the post-mortem consent process will complete SANDS post-mortem training on a 3-yearly basis.

Further bereavement education and study days are accessible to staff as part of study leave or in their own time.

4.3 All bereaved parents are informed about and, if requested, referred for emotional support and for specialist mental health support when needed.

The Bereavement Service contact information is provided to all women who experience the loss of their pregnancy from 12 weeks gestation onwards. Women can self-refer and make an

appointment. For many women, they will have direct contact with the bereavement midwives during their hospital stay and follow up already arranged.

Further support is accessible through the SANDS charities and these are signposted in written information given to women at the time of their loss.

In pregnancy loss at less than 12 weeks and ectopic pregnancy, women are signposted to the Miscarriage Association and the Ectopic Pregnancy Trust. In TOPFA, the Antenatal Choices and Results (ARC) charity is signposted. In specific cases of pregnancy loss at less than 12 weeks, support through the Bereavement service is available, and is accessed by a referral from the EPU team. When a GP may wish to refer to the ASPH Bereavement service, this will be discussed on an individual case basis. Currently due to capacity, it is not possible to accept all referrals and self-referral by patients from all gestations. Alternate support is available through local IAPT services which is patient self-referral, and Mind Matters which can be accessed through clinician referral.

Specialist mental health support can be accessed through the perinatal mental health team, which the doctor responsible for the patient can refer to. If this need arises when the patient is no longer an in-patient, the patient's GP can also refer to this service.

4.4 There is a bereavement lead in every healthcare setting where a pregnancy or baby loss may occur.

The details are as follows:

Obstetrics and Gynaecology Bereavement Lead – Miss Abigail Le Bas, O&G Consultant

Early Pregnancy Unit – Miss Ngozi Izuwah-Njoko, O&G Consultant

Early Pregnancy Support Service - Miss Catey Bass, Early Pregnancy Specialty Doctor

Emergency Department – Daniah Al-Muntafiq, Lead ED Nurse for Bereavement

Neonatal Unit- Dr Alexandra Briscoe, Neonatal Consultant

Paediatrics – Dr Evagelia Paraskevopoulou, Paediatric Consultant

Bereavement Lead Midwife – Zara Chamberlain

4.5 Bereavement rooms are available and accessible in all hospitals.

A specialist bereavement suite (Daffodil suite) is available on labour ward where all women more than 12 weeks experiencing pregnancy loss will be cared for. If this is not available or is not medically appropriate, then they will be cared for in another side room on labour ward until it does become available/appropriate. This alternative side room does not have an en-suite bathroom currently and hence sits as a discordance with the pathway in section 6.2.

A quiet room is available in the ultrasound and early pregnancy units for sensitive discussions and support.

Women who suffer early miscarriage and opt for surgical management, or who require a surgical termination of pregnancy for fetal anomaly, are cared for in Ashford Day Surgery Unit or a surgical ward at St Peter's hospital. In Ashford, they are admitted straight to their own bed rather than the waiting room. This is a bay area with the curtains always drawn for privacy unless the patient specially requests otherwise. In St Peter's, where possible they are given a side room with en-suite. Due to capacity, it is with regret that this is not always possible. As a minimum, it is ensured that they are not in a bay with patients that have ongoing pregnancies.

4.6 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.

Parents will often need to make multiple decisions about their and their baby's care. It is important they are given adequate time and information to do this.

Some information and choices will be different according to gestation of the pregnancy. Discussion should include the potential benefits and adverse effects and limitations of each option, as well as alternatives.

Topics that should be covered include but are not limited to:

Choice of management their miscarriage if <12 weeks – conservative, medical, surgical

Choice of appropriate ectopic pregnancy management options – conservative, medical, surgical

Choice of surgical or medical TOPFA if appropriate

Information and counselling about the options and process of induction of labour, analgesia, and place of birth

Information about potential investigations for baby depending on gestation– cytogenetics, histology, placental histology, post-mortem

Information about potential investigations for the mother – bloods, swabs

Information about sensitive disposal, burial, cremation, funeral services

Information about memory making

Follow up options – perinatal postnatal appointment referral, counselling, bereavement midwives, birth reflections, health visitor, GP

4.7 All bereaved parents are offered opportunities to make memories.

All parents should be offered the option of seeing and holding their baby. Some parents may not wish to see or hold their baby straight away. Some parents may wish to see but not hold or touch their baby. All choices should be accepted and respected.

Many parents find making positive memories and generating keepsakes helpful in their grief and in the future. All memory making is optional and should be parent-led. They can choose to have memories made that they take home with them, that are kept by the hospital to access at a later date, or not at all.

All parents are offered a copy of scan photographs if they wish. These can also be kept in the confidential notes so that they may access them later if they wish.

In pregnancies less than 12 weeks, parents are not routinely offered additional memory making. Angel pockets, blankets and small moses baskets are available if they wish. They can opt to organize a funeral service themselves or to take baby home with them. If any parents have specific memory making requests, this will be facilitated wherever possible.

In pregnancies of more than 12 weeks, options include photographs of baby, photographs of parents or family with baby, hand and footprints, baby's cot card, cord clamp, keepsake clothing and nametags, as well as paired items (one that stays with baby and one that they can keep).

In the context of multiple births, with a surviving sibling, memories including the surviving sibling should be sought if wished. This may include but is not limited to photographs of the siblings together, paired hand and footprints.

Parents should be offered the opportunity to wash and dress the baby. It is recognized that in some clinical scenarios and gestations this would not be possible, and this should be explained to the parents.

4.8 A system is in place to clearly signal to all health care professionals and staff that a parent has experienced a bereavement to enable continuity of care.

The Badgernet system should be updated to show a 'tear-drop' sticker as soon as the pregnancy loss is diagnosed. This is now included in all clinical pathways.

On labour ward, all women that have a diagnosed loss that are currently in the community, are written on the handover board and discussed in the twice-daily handover to ensure the team know of them should they need to present as an emergency or to telephone the labour ward for advice.

For all expected admissions on labour ward, the labour ward receptionist is informed so that the parents do not have to explain the reason they have come and their bereavement.

In NICU if an infant is a surviving twin, a purple butterfly sticker is placed on the incubator to indicate that the twin sibling has died.

The health visitor team and GP is emailed when any woman experiences a loss in pregnancy. This now occurs for women who have not yet had their booking appointment as well. GPs are also emailed and receive a copy of the hospital discharge information.

In subsequent pregnancies, the 'tear-drop' sticker will be present in the pregnancy summary box on Badgernet to alert professionals to the previous loss.

4.9 Healthcare staff are provided with, and can access, support and resources to deliver high quality bereavement care.

Staff who feel competent and confident to deliver bereavement care have been shown to be more able to deal with the stresses that this work entails. For this reason, training is vital to a supported workforce. The training and education available is detailed in point 4.2.

All staff can access support through the Bereavement Service midwives or through the trust support pathways. This is confidential and free of charge. The Bereavement Service has a visible presence on labour ward to support midwives in their care of bereavement families and the families themselves.

5.0 Ongoing evidence of NBCP compliance

Yearly audit of training competencies

- All staff – NBCP SANDS communication training to be completed every 3 years
- All staff taking post-mortem consent – SANDS post-mortem training to be completed every 3 years

Yearly audit of parent feedback

- Maternity Bereavement Experience Measure to all bereaved families

All datix, risk events, complaints and parent feedback involving bereavement care to be reviewed by Bereavement Area Lead and escalated to Bereavement QI team if systems change required

Continuous audit of all bereavement pathways against NBCP standards as new changes and demands on the system occur.

6.0 Discordance with NBCP

6.1 Subsequent pregnancies after one early miscarriage

The NBCP ethos is that all women should have access to the same care no matter what stage of pregnancy they have their bereavement. It is recognized that early scans in subsequent pregnancies after loss, can be a welcome source of reassurance for parents and reduce anxiety. It follows that therefore early scans and pregnancy support should be available to all who have previously had a pregnancy loss.

This creates a challenge of capacity and resource to our Early Pregnancy Support Scan Clinic, however. National evidence-based guidelines suggest a standardised and structured care model to help guide the use of finite resources in a public healthcare system. At ASPH, we utilise this recognised ‘graded model’ where women are offered online and written healthcare advice and support after one or two miscarriages, and care in a medical consultant-led clinic after three miscarriages. This approach balances the need for evidence-based management and supportive care, whilst targeting health care resources appropriately. For this reason, the Early Pregnancy Support Clinic does not currently offer early scans to those women who have had one early

miscarriage or biochemical pregnancy loss only. It is accessible on a self-referral or clinician-referral basis for women who have had 2 miscarriages or more. For all women with symptoms, such as bleeding or pain in early pregnancy, they are seen through the emergency Early Pregnancy Unit pathway.

The same national guidelines advise review in a nurse or midwife-led clinic after two miscarriages. This clinic is planned but not operational yet due to staffing capacity.

6.2 Bereavement room on Labour Ward

The Daffodil room has en-suite facilities but is not suitable for women who are unwell, or babies being born with uncertain outcome. In this circumstance women are cared for in Room 1. This room does not have en-suite facilities. A bid was planned for the funds necessary for bathroom installation and redecoration of the room. However, due to the largescale works required to modify Obstetric Theatre, this was put on hold until plans are defined.

6.3 Training

There is no specific funding for the training of staff in bereavement care. The online modules are free to access for all staff. However, they are not part of mandatory training for all the appropriate staff currently, due to financial constraints on the amount of paid training time each staff member has each year. It is therefore not possible to achieve 100% of staff trained in this aspect. There are ongoing discussions with the Trust about incorporating this aspect into mandatory training for all staff interacting with bereaved families. Where staff members have admin/CPD/SPA sessions in their job plan, uptake and completion of these modules is expected.

References

www.nbcpathway.org.uk

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https://doi.org/10.1016/S0140-6736(21)00682-6