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



national bereavement
c a r e p a t h w a y
for pregnancy and baby loss

Neonatal Death

Bereavement Care Pathway

Our National Bereavement Care Pathway core partners



About the NBCP

The National Bereavement Care Pathway Scotland has been developed to improve the quality of bereavement care for all families, and reduce local and national inconsistencies, after

- miscarriage, ectopic and molar pregnancy
- termination of pregnancy for fetal anomaly (TOPFA)
- stillbirth
- neonatal death
- sudden and unexpected death in infancy up to 24 months (SUDI)

This pathway has been developed to assist all healthcare professionals and staff who are involved in the care of the family of a neonatal baby who dies. Bereavement care is a continuous process and should be provided by all staff caring for those who have experienced a neonatal death. It is integrated with clinical care and provided by everyone within the scope of their practice – not only those with a designated bereavement remit – and doesn't start at an appointed time.

For further guidance on this pathway, see www.nbcpscotland.org.uk/neonataldeath.

'Healthcare professionals' and 'staff' mean any practitioner who has contact with a bereaved parent. 'Parent' refers to an expectant or bereaved mother, father or partner, and 'baby' or 'fetus' is used throughout. 'Family' refers to close relatives as defined by the parents. Not everyone will want these words to be used and some women and partners may want to use the word 'parent' but not feel entitled to do so. Healthcare professionals should use the words preferred by the individual.

Please note the NBCP Scotland Pathways are being piloted with Early Adopter NHS Boards and the pathways will continue to develop in the light of Early Adopters' experiences.

www.nbcpscotland.org.uk

Bereavement care standards

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

- A parent-led approach is taken, providing continuity of care and management of transitions 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 Board 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 strategic bereavement lead in every Health Board in whose settings a pregnancy or baby loss may occur.
- All units have access to a room where bereavement care can be provided in a suitable and sensitive environment.
- All staff listen carefully to bereaved parents, offer them informed choices about their care and the care of their babies, and are guided by their wishes.
- All bereaved parents are supported to mark their loss and offered opportunities to make memories.
- A system is in place to rapidly signal to all health care 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.

If a baby may die

“I wanted care and compassion. I didn’t want medical jargon. I wanted someone by my side who genuinely cared and understood how anxious we were.”

Aim to prepare a family as thoughtfully and early as possible when a baby may die and involve them in parallel care planning for active care and end of life care.

Families are often aware when staff have concerns that their baby may die soon or at a later unpredictable time. They feel anxious if staff don’t communicate their thoughts and plans at an early stage and if there is poor continuity of care.

Families often don’t receive help on planning for the wider impact of losing a baby as care planning does not always include discussion of emotional, social, family and spiritual needs.

What do we need to do?

- Remember to keep within the scope of your practice when providing information, explaining procedures or answering questions. Be prepared to consult with or refer to suitably trained colleagues whenever necessary.
- Offer a quiet, private space to talk to the family, away from the cot and other families. Ideally this should be a comfortable, private room.
- Make sure there is an ongoing discussion with the family about trying to understand if, why and when their baby may die. If the mother is unwell or in a different unit, ensure she is included.
- Explain that it may take days or weeks to fully understand the underlying reasons. Share the known facts as they emerge, even though an underlying diagnosis or outcome has not been confirmed.
- Use a parallel care planning approach to manage active care while thinking about end of life care, taking account of the often unpredictable nature of this time. Fully involve the family in discussions and understanding their wishes about:
 - what deterioration means and how this will be managed
 - changes in care and treatment that focus on comfort near end of life
 - organ donation
 - place of end of life care and transport options
 - care for the baby and family after death
 - memory making and family support
 - communication with primary and secondary care staff involved with the family, including the primary midwife if the mother is still receiving midwifery care, and/or the health visitor.

If a lethal anomaly has been diagnosed in utero, much of this discussion can take place before birth.

“I wanted hope. I didn’t want to discuss him dying yet. He was still alive and I wanted to make this time precious by reading to him, rubbing his feet and playing music. This allowed me to spend time being his mum rather than focusing on the fact he might die.”

- Let the family know a Perinatal Mortality Review will take place.
- Ensure that family support is included in all care planning – emotional, social, family and spiritual support.
- Try to do as much planning as early as possible so that the end of the baby’s life can be as well prepared for, and as quiet and private as possible.
- Prioritise continuity of care in line with Getting It Right for Every Child (GIRFEC) and confirm a key contact (named person) who will support and coordinate care, including bereavement care, right through the family’s journey. For GIRFEC, see www.gov.scot/policies/girfec/
- Record the care plan on the baby’s record including planned continuity of care and key contact.
- Sometimes a baby dies unexpectedly and quickly. In this situation, staff should focus on explaining known facts, end of life care and memory making.
- If parents have had a multiple birth, they face the challenge of preparing for the possibility their baby/babies may die whilst caring for their other baby/babies. Support the family by focussing equally on the baby/babies who may die and the sibling or siblings.

How will we know we have achieved our aim?

- Families will tell us they felt well supported and prepared and they had time to consider their choices.
- Staff will say they feel confident and competent involving families at an early stage and being guided by their wishes.

When a baby is deteriorating and dying

“I didn’t want to stay too long with him when he got cold and changed as we had spent weeks together when he was alive. We knew when the time was right to say goodbye. We tucked him in his Moses basket and kissed him goodnight.”

Aim to tell families early when their baby is becoming more unwell, in a kind and clear way and plan the end of their baby’s life sensitively and compassionately.

Families tell us they want to be told whenever their baby is becoming more unwell and that not knowing what this means can add to their anxiety. They say that it is very important to them to have had choices about the end of their baby’s life and for their wishes to be respected.

What do we need to do?

- Remember to keep within the scope of your practice when providing information, explaining procedures or answering questions. Be prepared to consult with or refer to suitably trained colleagues whenever necessary.


First Steps

- Explain what has happened, what is known and what happens next.
- Review the family’s care plan and their wishes about care as their baby becomes more unwell and end of life care.
- Be clear about whether the baby is nearing end of life and try to give a sense of timescales if they can be predicted.
- If parents have had a multiple birth, they face the challenge of preparing for the possibility their baby/babies may die whilst caring for their other baby/babies. Support the family by focussing equally on the baby/babies who may die and the sibling or siblings.


End of life care

- Provide a quiet, private space to talk to the family and give them time to absorb the news. Ideally this should be a comfortable, private room.
- Check the care plan (see section A – If a baby may die):
 - make sure the family remain fully involved in planning
 - listen carefully and provide enough time for them to think about their wishes
 - let the family know they can change their mind and any timescales that would limit other choices.
- Ensure the family understands the planned changes in care up until the end of life, and that their baby will be kept pain free and comfortable throughout.
- Review choices about place of end of life – in the hospital, at home or a hospice or another location and transport options. If in the hospital, provide a quiet, private room.

“I didn’t want to watch him die. I asked to hold him while my husband sat next to me and we cradled him in our arms. I told him he could go and watched him as he took his final breath. When he died he looked absolutely beautiful. No apparatus or medical attachments. He was perfect and this is how I will always remember my son.”

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- Explain what to expect in terms of the changes in the baby’s appearance and responses as the baby dies. Talk about the opportunities to cuddle, bathe and dress their baby and to use a Cuddle Cot.
 - Check primary and secondary health professionals have been made aware the baby is dying and know what is happening next. Include the primary midwife if the mother is still receiving midwifery care, and/or health visitor. Remember staff from another hospital if the baby was transferred for care.
 - Make sure all staff on the unit are aware what is happening so they can be sensitive to the family’s needs, dignity and privacy at this time.
 - Think about other families on the unit who will be aware that a baby is dying and how to communicate and support them.

How will we know we have achieved our aim?

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- Families will tell us that they understood when their baby was becoming more unwell and had this explained to them in a sensitive manner.
 - Staff will say they feel confident and competent to discuss deterioration and plan end of life care with the family.

Memory making

“The nurse made clay imprints of his feet and took hand and footprints when he was still alive. I later got these made into a necklace which I treasure. The memories last a lifetime.”

Aim to ensure that the family, including siblings, have the opportunity and time to make choices about creating memories.

Families tell us that if they have already experienced family integrated care, this helps them continue to parent through end of life care. They also say being able to make lifelong memories before and/or after the loss of their baby, to touch and to parent them, helps them adjust to their loss.

What do we need to do?

- Introduce memory making as soon as possible and share examples of what you can offer. This can happen from the point when it is known a baby may die and any item used in the baby's care has the potential to be part of memory making.
- Give the family time to reflect and decide what they want and let them know they can change their mind at any time.
- When the baby has died, offer the family the opportunity to hold them, if they are not already doing so.
- Discuss with the family:
 - washing and dressing their baby
 - photographs
 - hand and footprints
 - memory box
 - other memories and mementos.
- Complete the informed choice form to ensure the family are provided with options but do not feel pressured ('Creating memories – offering choices', a template form, is available from www.nbcpscotland.org.uk/templates).

“I sang a lullaby to him and cradled him in the room. It felt strange but natural at the same time. I wish I had been told to take more pictures or videos. The ones I have are so precious.”

How will we know we have achieved our aim?

- Families will tell us they felt they were offered the opportunity to make memories, did not feel rushed and knew they could revisit decisions.
- Staff will say they feel confident and competent discussing options for making memories and supporting families as they take time and decide what they want to do.

After the death

Aim to provide continuity of carer at this stage and sensitively lead the discussions about the investigations and processes.

Families tell us it is difficult and confusing to have different people at different times discussing investigations and processes, including people they have not met before.

What do we need to do?

- Introduce (or revisit) the following and explain the need for these, as far as possible trying to maintain continuity of care:
 - registration
 - post-mortem
 - funeral arrangements
 - clinical follow up
 - Perinatal Mortality Review.
- Ensure local guidelines set out clearly who should lead these discussions and how staff in these roles should achieve continuity.
- Plan at least an hour for this discussion and ensure it takes place in a quiet, private place.
- This is complex and challenging information for the family. After you have explained, check they have understood what is involved, for example by using the Teach Back method. See NES Knowledge Network www.healthliteracyplace.org.uk/toolkit/techniques/teach-back/. Remember you may need to revisit the conversation.
- Document the discussion in the baby's medical record.
- Try to summarise in written information the processes and forms the family will need to engage with.
- Begin to discuss arrangements for discharge and find out the family's wishes.
- Explain that a form can be added to the mother's record to explain to staff that her baby has died if she wishes (a template is available from www.nbcpathway.org.uk/templates).

Review and follow up

- Inform parents about the process of perinatal mortality review and invite them to become involved in the review process and refer to the parent engagement materials (see www.npeu.ox.ac.uk/pmrt/parent-engagement-materials).
- Ensure that the family know who their key contact is for the review period and, wherever possible, ensure this person is the same key contact they had during their baby's parallel and end of life care planning.
- Explain that the family will be given flexibility on the timing of when and how they contribute their thoughts, comments and questions to the review. Check that the family are comfortable with where the appointment will take place. Explain that during the review process they will be asked about their preferences on how and when they would like to receive and discuss the review report.
- Explain the purpose of clinical follow up, both what the family can expect and what the follow up does not cover, and who can attend. Check the family are comfortable with where the appointment will take place. Ensure enough time has been allowed for this appointment. This follow up should be led by the team providing continuity of obstetric and midwifery care. If at all possible this appointment should also include feedback from the Perinatal Mortality Review.

Post-mortem examination

- Remember to keep within the scope of your practice when providing information, explaining procedures or answering questions. Be prepared to consult with or refer to suitably trained colleagues whenever necessary.
- Sensitively explain why a post mortem is recommended. You may find the NES video for professionals useful preparation **Discussing Authorised (Hospital) Post Mortem Examination after Stillbirth or Neonatal Death.**
- Tell the parents if the post mortem examination will take place at a different hospital and explain where and why.
- Explain that all transport arrangements and handling of the baby will be respectful and caring and who will be responsible for this.
- During the authorisation process, inform the family of the likely timescales for the return of the baby's body and the results.
- Identify a named contact within pathology who will be responsible for following up on results.
- Ensure any small objects or keepsakes such as a hat or cuddly toy that the family sent with their baby are returned following the investigation.
- Ensure that you are aware of relevant statutory death review processes and that these link with your Board's internal processes – e.g. morbidity and mortality (M&M) meeting, Adverse Event Review, Perinatal Mortality Review – and inform the family as appropriate.

Registration and certification

- Provide the family with the medical certificate certifying the neonatal death, having carefully checked that the information is accurate.
- In addition to providing written information, sensitively explain the national death registration process, including where and how to register, and the need to register both the birth and the death.
- Ensure the family have any other information the registrar will need.

Funerals

- Provide the family with information around the legal requirements and local funeral directors.
- Explain that baby funerals are free in Scotland, although there may be a charge for a plot and there will be a charge for a headstone.
- Let the family know that a financial support payment is available to families on low income via Social Security Scotland (see useful contacts).
- Bear in mind, and facilitate where possible, different personal, religious and cultural needs. Do not make assumptions.
- Discuss the options for urgent burial and cremation with the family where appropriate.
- Offer to refer the family to the spiritual care/chaplaincy team.
- Inform all primary and secondary healthcare staff involved in the care of the family and baby that the baby has died, including any referring units before discharge and within 24 hours.
- Record a neonatal death on the risk reporting system.
- Record all decisions made in the baby's record, including where information is declined, or no decision is made.

How will we know we have achieved our aim?

- Families tell us they felt the right person spoke to them, in the right way, and they understood what the processes were, why they happened and the choices they had.
- Staff will say they feel confident and competent when discussing investigations and processes after death.

Preparing for discharge

Aim to support families as they leave hospital and adjust to going home without their baby.

Families tell us leaving the baby in the hospital is difficult, they feel unsure who is caring for the baby and for themselves, and who will be providing contact and support.

What do we need to do?

- Give the family time to ask questions about who is caring for their baby, where their baby is being cared for, and who to contact when they have left the hospital.
- If appropriate psychological support is available, immediately and longer term, offer the opportunity to take the baby home or out of the hospital environment (a template form is available from www.nbcpscotland.org.uk/templates). Refer to local guidelines on taking a baby home, e.g. informing Police Scotland.
- Sensitively discuss the options for donating or suppressing milk.
- Offer to cancel the Baby Box delivery if it has already been requested, and the woman, partner or a family member wishes. The box can be cancelled by calling 0800 030 8003. The call can be made either by the parent, a family member or a nominated health professional. However there is no need to cancel if they prefer to have the box.
- Discuss the emotions the family may experience and let them know they are common. Make sure the family knows how to access emotional support, have information and offer to help make contact if they wish. Information includes:
 - their key contact, ongoing plan of care, and follow up appointment
 - how to contact the spiritual care/chaplaincy team, offer to contact on their behalf
 - how to access emotional support available from NHS Boards and primary care team
 - contacts for support organisations and how they can help (see useful contacts)
 - offer to help make contact if they wish.
- Consider NICE guidance on antenatal/postnatal mental health (www.nice.org.uk/guidance/qs115) and SIGN guidance on perinatal mood disorders www.sign.ac.uk/our-guidelines/management-of-perinatal-mood-disorders/.
- Check all primary and secondary healthcare staff, including referring units have been informed that the baby has died. This should be within 24 hours of the neonatal death.
- Make sure that staff have reported a neonatal death through the Board's risk reporting system.
- Document final agreed arrangements in the baby's medical record and communicate these to primary care colleagues.
- Make sure there is a clear handover from the paediatric team to primary care teams. This should be in written form and documented on the baby's medical record.
- Make sure the family know whom to contact for their healthcare needs from this point onwards.

“The hardest part was leaving my baby in the hospital. There are no words to describe how difficult this was. He was my baby and every part of me wanted to stay with him. The nurse brought a beautiful Moses basket into the room and this allowed us to leave him looking like he was sleeping and with someone who we trusted. I left with a bundle of information and no signposting for community care. I felt very alone.”

Feedback

- Explain to the family that feedback about their care helps the Board understand if they received the appropriate care and that staff will ask families about their experience at follow up appointments. Ensure any verbal feedback is recorded. Explain how anonymous feedback could be given, if preferred.
- If they are comfortable about being asked for feedback then let them know how and when they will be contacted. Document if a family are in agreement with this.
- Consider using the Maternity Bereavement Experience Measure (MBEM) to capture parent feedback (www.sands.org.uk/maternity-bereavement-experience-measure-mbem).
- Be clear with the family that feedback they give for this purpose is not part of a review of the baby's death nor a complaints process.

How will we know we have achieved our aim?

Families will tell us they felt well supported as they left hospital and knew who was responsible for their care once they were at home.

Staff will say they feel confident and competent supporting families as they leave hospital. Primary care staff will say they were given full information and were informed in a timely way.

Support in the community

“Community care was a lot better than the hospital. My community midwife had volunteered with a support organisation so knew what to say, there’s not a script and asked “Have you phoned?” She followed up a few times.”

Aim to keep ongoing clinical and emotional care of the family at the centre during and following handover from secondary to primary care and ensure families have the emotional support they need.

Families tell us they get lost between services and their expectations about follow on appointments, review and further support are not met.

What do we need to do?

- On hearing of the neonatal death:
 - the GP should send a letter expressing sorrow to the family and offer an appointment, preferably a home visit
 - if the mother is still receiving midwifery care, the primary midwife should arrange a home visit as soon as possible.
- Check the family has all the information on the different types of emotional and bereavement support available and how to make contact. Continue to offer to help them make contact if they wish.
- Check the family knows who their primary healthcare team is and who they should contact.
- Check the family knows when the clinical follow up appointments are and if they need any help to consider questions they want to ask before their appointment. Remind them what the follow up does and does not cover, and who can attend. Offer to attend the appointment with them.
- Offer referral for specialist psychological support if there are signs of PTSD or clinical depression and, if appropriate, for mental health assessment for the family including siblings.
- Consider NICE guidance on antenatal/postnatal mental health (www.nice.org.uk/guidance/qs115) and SIGN guidance on perinatal mood disorders (www.sign.ac.uk/our-guidelines/management-of-perinatal-mood-disorders/).

Perinatal Mortality Review

- Confirm the family’s wishes about being involved in the perinatal mortality review process, and when and how they can contribute. Check whether and how they want to be informed of the outcomes of the review of their baby’s death.
- Prompt the family to think about their questions and comments beforehand. A form to help the family do this is available from the Parent Engagement Materials on the Perinatal Mortality Review Tool (PMRT) website www.npeu.ox.ac.uk/pmrt/parent-engagement-materials.
- Ensure the review looks at the family’s clinical and emotional care, and covers the whole pathway of care, with input from community healthcare professionals.

“The minute I stepped out of the hospital that was me. I had a few visits. She (the midwife) was in more shock than me, I had seen her the day before. When visiting me at home, she said technically I shouldn’t be coming any more, but I can come if you want. My follow up at the GP 6 weeks later, ‘What are you doing here?’”

- Meet with the family to consider their clinical and emotional care, discuss any results of investigations, explain the Perinatal Mortality Review report and answer their questions. Wherever possible, this meeting should be with the senior paediatrician who has provided continuity of care.
- Continue to check a family has information about support services and how to contact them and offer to help with this.
- Carefully share ongoing information between the GP and health visitor (and primary midwife if involved), with the family’s key contact acting as coordinator.
- Ensure primary care staff are aware of the timing of and outcomes from clinical follow up and the Perinatal Mortality Review.
- Arrange a final handover from the paediatric team to primary care team when appropriate and make sure the family know whom to contact from this point onwards.

How will we know we have achieved our aim?

Families will tell us they knew who had responsibility for their bereavement care after they left hospital and felt confident about the support available to them. They will say they felt well prepared for the Perinatal Mortality Review, and that the investigations and the reports were sensitively explained to them.

Staff will say they feel confident and competent coordinating care and support, referring families for support, sharing information between services and engaging with parents about the review.

Next pregnancies

Aim to be aware at all stages that many women and partners, including those who experienced loss or losses under 24 weeks, will have additional emotional needs following a previous loss and ensure these are met throughout a subsequent pregnancy.

Women and partners tell us a subsequent pregnancy will bring back memories and can trigger anxieties. They say that acknowledging their previous experiences, the impact on the new pregnancy, being listened to and given compassionate care is important.

At all stages

- Remember to keep within the scope of your practice when providing information, explaining procedures or answering questions. Be prepared to consult with or refer to suitably trained colleagues whenever necessary.
- Prioritise continuity of care and carer wherever possible.
- If the woman and partner are not already aware of them, explain how support organisations can help and give the woman and her partner the contact details.
- Offer support to partners (including those who did not experience the previous loss or losses themselves) and any birth supporters who are with the woman.
- Be aware of the need some women and partners have for additional support in pregnancy after loss and consider offering referral to appropriate mental health services.
- Listen to and acknowledge the woman and partner's fears and concerns.
- If a previous pregnancy loss or stillbirth or neonatal loss form has not been added to the woman's notes, explain this can be done if she wishes - a template is available from **www.nbcpscotland.org.uk/templates**
- If the woman and partner are not already fully aware of support organisations, explain how they can help and give contact details.

Antenatal care

Preconception

- Review the maternity record or, if there was a previous pre 12 week or SUDI loss, the case notes. Answer questions the woman and her partner now have, as well as providing advice.
- Be clear about the specialist support for any future pregnancies and opportunities for additional antenatal appointments and scans.
- Support the woman and partner to make informed choices around if/when to try for another baby.
- Recognise that high levels of anxiety are common in pregnancy after any kind of loss. If the loss was in pregnancy, these feelings may continue even beyond the gestation at which the previous loss occurred.
- At booking, discuss the woman and partner's wishes in relation to their previous loss or losses – what they would want staff to know and what staff should say or not say, for example using words like loss, baby or the baby's name.
- If possible, refer women and partners to another unit or another consultant if requested and/or offer a different scan room from the one where a previous concern was identified or confirmed or an anomaly was diagnosed.
- Offer regular contact with staff wherever possible. Plan care around the woman physical needs and both her own and her partner's emotional and mental health needs with the frequency of the visits reflecting individual care needs and wishes as far as possible.

She was a different midwife but she knew the history and offered support. She gave me extra check-ups for extra reassurance ... although his death had nothing at all to do with my pregnancy. (SUDI)

- Outline any additional antenatal support offered, including additional scans or appointments and why these have been offered. Remember not all women and partners will want this support. Allocate extra time for these appointments and remind women and partners they can bring a support person to attend these appointments.
- Discuss and acknowledge with women and partners, where appropriate, certain stages, events or significant dates during the pregnancy that may be particularly difficult for them (for example, scan appointments). Discuss ways they might be reassured, for example meeting staff or a ward tour.
- Prioritise continuity of obstetric and midwifery care and ensure that the birth plan reflects this. Note that those who experienced first trimester loss may have concerns during second or third trimester.
- Consider using a clinical alert or any other marker that is available locally in the woman's notes to alert staff to her previous loss and history before admission. If the woman wishes, a previous pregnancy loss or stillbirth or neonatal loss form can be added to her notes - a template is available from www.nbcpscotland.org.uk/templates

You're still having to explain yourself, still in your third pregnancy. You have to go through your whole story again. It should be as important, if not more. (Stillbirth)

Next pregnancies

Labour and birth

- Be aware of the additional care and emotional support that may be needed during labour and after the baby is born and be prepared to offer this.
- Be sensitive to the feelings the woman and partner may have after the birth. They may be thinking of the baby or babies lost in previous pregnancies or earlier in this pregnancy or after birth - previous multiple pregnancies may involve loss(es) and a surviving baby or babies. Let the woman and partner know mixed feelings are common and be ready to talk about the previous pregnancy loss/es or the baby or babies who died. Show understanding, compassion and empathy.
- Be particularly sensitive to any specific family issues or circumstances such as additional needs, cultural or language considerations, and/or care arrangements to be followed after the birth.
- Offer the woman and her partner contact with the spiritual care/chaplaincy team.
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- Allow enough time to offer emotional support as well as to check the mother's physical health.
- Discuss how or if to talk about the pregnancy loss or losses or the baby/babies who died and the new baby with existing and subsequent siblings.
- Ensure ongoing care is available if needed. Offer to refer women and partners for additional care when necessary.
- Give the woman and her partner the contact details of a healthcare professional they can contact for information and support - a template contact card is available from www.nbcpscotland.org.uk/templates

Postnatal care in the community

- Be aware of the pregnancy history before postnatal visits or appointments.
- Be sensitive to the mixed feelings the woman and partner may have after the birth, which may last for some time. They may be thinking of the baby or babies lost in

I continued to ask for extra scans, Echo, tracing etc. and got great support from my new health visitor, who knew the whole story as did the midwife. (Neonatal death)

I got pregnant again but I was not happy, anxious, crying yet relief at being pregnant. I was waiting for something bad to happen. (Miscarriage)

I had a fear of bonding with my baby constantly, was feeling fine but advised to take time off work. I thought I was coping well but just fell apart later. (Miscarriage)



How will we know we have achieved our aim?

- Women and partners will tell us they felt understood and supported, their anxieties and distress and ongoing bereavement journey were acknowledged, and their wishes and preferences respected. If it was not possible to meet their wishes and preferences, they will tell us they were given clear reasons in a supportive way.
- Staff will say they feel able to recognise that a previous loss can cause high levels of anxiety in a new pregnancy and feel confident and competent when having open conversations about loss or losses and the impact on this pregnancy, and when providing additional care or explaining when wishes and preferences are not possible.

Staff care

Aim to provide an emotionally supportive environment for staff where challenges can be discussed openly and individual needs are acknowledged and met.

Women and partners tell us they recognise bereavement can be challenging for staff and want those caring for them to feel well supported.

What do we need to do?

Staff support

- Managers and senior staff have a duty to:
 - check how staff feel before they finish their shift
 - organise debriefs and provide reflective spaces
 - encourage, support and provide training for staff
 - watch for signs of strain or difficulty in individuals and within teams
 - facilitate discussion between colleagues and teams.
- Be aware of the stresses and challenges faced by your colleagues and, where appropriate, talk about support arrangements and services with them.
- Look after yourself:
 - make sure you have the opportunity to take regular breaks at work
 - protect your time away from work during non-working days and annual leave
 - attend to your own emotional and spiritual needs.
- Talk to your manager or a colleague if you feel you are experiencing signs of stress, 'burnout' or mental health difficulties for example
 - becoming sensitive to triggers that would not normally upset you
 - becoming overcritical or defensive of yourself or others
 - questioning your own and others' values
 - sleeping poorly or much longer than usual
 - drinking more alcohol or eating more or less than usual.

Find out about wellbeing from the NES Support Around Death website

www.sad.scot.nhs.uk/wellbeing/



How will we know we have achieved our aim?

- Staff will say they feel confident they are working in a supportive environment and can openly express their own needs with colleagues and senior staff.

Outcome measures

Aim to ensure the Board and all units and services regularly assess the quality and consistency of their bereavement care and act to improve the experiences of all women and families.

Women and partners tell us consistent, high quality care matters throughout their bereavement journey and poor experiences undermine confidence in other staff.

Outcome 1 Leadership and listening are effective


What do we need to do?


- Identify who is responsible for the quality and consistency of bereavement care at a unit, service and Board level.
- Ensure multiple channels are available for women, partners and families to give feedback on each stage of their bereavement care for example via conversations at discharge and follow up appointments, contact with the service's or Board's feedback service, and external channels such as Care Opinion www.careopinion.org.uk
- Check feedback is actively sought, for example by prompting women, partners and families to think about points they want to raise before they attend follow up appointments.
- Ensure feedback is recorded, shared and responded to.
- Ensure all staff who come into contact with women, partners and families who experience a neonatal death are aware of and understand their role in the National Bereavement Care Pathway.
- Enable and support staff to give feedback on providing bereavement care for example via team meetings and debriefs.
- Ensure key staff, in particular paediatric and paediatric/neonatal medical and nursing staff, have undertaken communication training.

Outcome 2 Improvement measures are in place

What do we need to do?

- Carry out a baseline assessment of quality and consistency at each stage of bereavement care in your unit, service or Board. You may find the Bliss Baby Charter www.bliss.org.uk/health-professionals/bliss-baby-charter useful.
- Review evidence from all channels for listening to feedback from women, partners and families, on all stages of their bereavement care, at least once a year.
- Review recorded data to establish the quality and consistency of:
 - continuity of care
 - parallel and end of life care planning
 - key contacts
 - choice of place of end of life care
 - bereavement discussions including memory making
 - discharge planning and follow up
 - whether the family's healthcare team was alerted within 24 hours of a baby's death.
- Review how frequently units and services provide resources for memory making such as memory boxes, hand and footprints, and Cuddle Cots.
- Review how effectively units, services and Boards are engaging with local support organisations.

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- Review staff training offered, percentage completed and training evaluations at a unit, service and Board level.
 - Having established a baseline, set SMART targets for improvement:
 - Specific – a very clear statement of the changes you are trying to achieve
 - Measurable – has a numerical target that can be measured
 - Achievable – is realistic and attainable in the time allowed
 - Relevant – is linked to the neonatal death pathway outcomes
 - Time-bound – has a clearly defined timeframe within which the aim should be achieved



How will we know we have achieved our aim?

- All units, services and Boards have named senior staff with responsibility for the quality and consistency of bereavement care following neonatal death, are listening to all families and staff and are implementing improvement plans.

Useful contacts

Key support organisations

Sands, (stillbirth and neonatal death charity)

Provides support and information for anyone affected by the death of a baby, through an accredited national helpline, a range of trained peer support services delivered face-to-face in local communities, on-line and printed resources including a bereavement support app and a moderated online forum.

www.sands.org.uk/support

Sands also provides guidance and an accredited training programme for professionals.

www.sands.org.uk/professionals

Bliss

Support for families of premature and sick babies.

www.bliss.org.uk/parents/support

Bliss also offers support for health professionals, campaigns and carries out research www.bliss.org.uk

Children's Hospices Across Scotland (CHAS)

Provides full family support for babies, children and young people with life-shortening conditions.

www.chas.org.uk

Held In Our Hearts (formerly Sands Lothians)

Held In Our Hearts provides baby loss counselling and support. Counselling is free and open ended and other services include one to one befriending, group, telephone and online support.

www.heldinourhearts.org.uk

Held In Our Hearts also offers education, training and support to professionals.

SiMBA

Support groups and online support for anyone who has gone through the death of a baby at any stage of pregnancy or after birth, including family members.

www.simbacharity.org.uk/support/support-groups

SiMBA also provides memory boxes, family rooms in hospitals, and bespoke remembrance events.

www.simbacharity.org.uk

Tommy's

Information and support following neonatal death.

www.tommys.org/baby-loss/neonatal-death-information-and-support

Twins Trust Bereavement Support Group (formerly TAMBA)

Offers support for families who have lost one or more children from a multiple birth during pregnancy, birth or at any time afterwards.

www.twinstrust.org/bereavement

Twins Trust also works to improve care for multiple birth mums and babies. www.twinstrust.org.uk

Other organisations

Action on Pre-eclampsia (APEC)

Helps and supports women and their families who are affected by or worried about pre-eclampsia and aims to raise public and professional awareness of pre-eclampsia.

www.action-on-pre-eclampsia.org.uk

Baby Mailing Preference Service (MPS) online

Free site where parents can register online to stop or help reduce baby-related mailings.

www.mpsonline.org.uk/bmpsr

Child Benefit Office

Parents can contact the Child Benefit Office at HM Revenues and Customs for information about eligibility, claiming and stopping Child Benefit.

www.gov.uk/government/organisations/hm-revenue-customs/contact/child-benefit

Child Bereavement UK (CBUK)

Provides support for families when a baby or child has died or is dying and offers support for children faced with bereavement. Offers training for professionals.

www.childbereavementuk.org

Each Baby Counts

The Royal College of Obstetricians and Gynaecologists' programme to reduce the number of babies who die or are severely disabled as a result of incidents occurring during term labour in the UK.

www.rcog.org.uk/eachbabycounts

Fertility Network UK

Provides support for people dealing with infertility.

www.fertilitynetworkuk.org

www.fertilitynetworkuk.org/life-without-children

Funeral Assistance

Funeral support payment available to families on low income via Social Security Scotland.

www.mygov.scot/funeral-support-payment

Jobcentre Plus – Bereavement Services Helpline

Provides information about benefits claims.

Telephone: **0345 608 8601**

www.gov.uk/contact-jobcentre-plus

Milk Bank Scotland

Provides screened donor milk to babies who have no or limited access to their own mother's milk, often to babies born prematurely.

www.nhsggc.org.uk/your-health/health-services/milk-bank-scotland/

Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK (MBRRACE-UK)

Provides surveillance of maternal, perinatal and infant deaths in the UK.

www.npeu.ox.ac.uk/mbrance-uk

Also provides an online reporting system for healthcare units to report maternal, perinatal and infant deaths.

www.mbrance.ox.ac.uk

Multiple Births Foundation (MBF)

Provides support and information for multiple birth families (including bereavement support) and information for professionals.

www.multiplebirths.org.uk

National Association of Funeral Directors

Provides support and guidance for funeral firms and bereaved families using their services.

www.nafd.org.uk

The Natural Death Centre

Offers support, advice and guidance for families and other individuals who are arranging a funeral, including information about environmentally-friendly funerals and woodland burial sites.

www.naturaldeath.org.uk

Our Missing Peace

Resources for bereaved families and a helpful repository of information under 'useful links' across the four Home Nations.

www.ourmissingpeace.org

Registration: National Records for Scotland

www.nrscotland.gov.uk/registration/registering-a-birth

<https://www.nrscotland.gov.uk/registration/registering-a-death>

Relationships Scotland

Provides relationship counselling to anyone over the age of 16.

www.relationships-scotland.org.uk/relationship-counselling

Remember My Baby

UK based charity who have professional photographers who voluntarily provide remembrance photography services to parents who lose a baby at 20 weeks or later gestation, and during or shortly after birth.

www.remembermybaby.org.uk

Samaritans

Offers confidential support that is available 24 hours a day to people who need to talk.

Telephone: **116 123 (UK) or 116 123 (ROI) for free.**

www.samaritans.org

Society of Allied and Independent Funeral Directors (SAIF)

Independent funeral directors' national organisation.

www.saif.org.uk

Winston's Wish

Offers support to bereaved children, their families and professionals.

www.winstonswish.org.uk

Provides information about parents' rights at work and to benefits after they experience miscarriage, stillbirth and neonatal death.

Working Families

www.workingfamilies.org.uk/articles/miscarriage-stillbirth-and-neonatal-death-your-rights-at-work/

Their Family Friendly Working Scotland website offers free help and advice for working parents and carers

www.familyfriendlyworkingscotland.org.uk/employees

Training and support resources

Resource	Type	Link
Guidance on adverse events Being Open principles	download	www.healthcareimprovementscotland.org/our_work/governance_and_assurance/learning_from_adverse_events/being_open_guidance.aspx
Audit of bereavement care provision UK neonatal units 2018	download	www.sands.org.uk/audit-bereavement-care-provision-uk-neonatal-units-2018
Audit of bereavement care provision UK maternity units 2016	download	www.sands.org.uk/professionals/professional-resources/audit-bereavement-care-provision-uk-maternity-units-2016
PMRT parent engagement 'Saying sorry'	download	www.npeu.ox.ac.uk/downloads/files/pmrt/engagement/Saying%20Sorry%20is%20not%20a%20Blame%20Game.pdf
Maternity Experience Bereavement Measure	download	www.sands.org.uk/maternity-bereavement-experience-measure-mbem
PMRT parent engagement materials	downloads	www.npeu.ox.ac.uk/pmrt/parent-engagement-materials
Perinatal Mental Health Resources	downloads	www.inspiringscotland.org.uk/perinatal-mental-health-services/
Bereavement following Pregnancy Loss and the Death of a Baby	elearning	www.knowledge.scot.nhs.uk/maternalhealth/learning/bereavement-following-pregnancy.aspx
Sands modules	elearning	www.sands.org.uk/professionals/training-and-consultancy/online-learning
One chance to get it right: bereavement care	elearning	www.ilearn.rcm.org.uk/enrol/index.php?id=583
NES nursing & AHP clinical supervision 1 - includes supportive resilience	elearning	learn.nes.nhs.scot/3653/clinical-supervision/clinical-supervision-unit-1-fundamentals-of-supervision
NES Discussing authorised post mortem after still-birth or neonatal death	video	Discussing Authorised (Hospital) Post Mortem Examination After Stillbirth or Neonatal Death
NES Dealing with unsuccessful neonatal resuscitation	video	Dealing with unsuccessful neonatal resuscitation

Held In Our Hearts Parent to parent post mortem authorisation	video	Parent to Parent Post Mortem Authorisation
NES Supporting Families around the Resuscitation of a Baby or Child	video	Supporting Families around the Resuscitation of a Baby or Child
NES Talking to parents about their decisions around burial or cremation	video	Talking to parents about their decisions around burial or cremation after the death of their baby
The Parent Voice: PMRT	video	www.youtube.com/watch?v=Nq4eFQYOqCA
NES Talking to children who are bereaved	video	Talking to children who are bereaved
Supporting neonatal parents mental health	webpage	www.bliss.org.uk/parents/support/impact-mental-health-premature-sick-baby/supporting-parents-mental-health-information-for-neonatal-healthcare-professionals
Bliss Baby Charter	webpages	www.bliss.org.uk/health-professionals/bliss-baby-charter
Helping parents with mental health issues	webpage	www.bestbeginnings.org.uk/helping-parents-with-mental-health-issues
SIGN guidance on perinatal mood disorders	webpage	www.sign.ac.uk/our-guidelines/management-of-perinatal-mood-disorders/
Staff resilience	webpage	www.sad.scot.nhs.uk/wellbeing/
Teach Back Method	webpage	www.healthliteracyplace.org.uk/toolkit/techniques/teach-back/
Held In our Hearts advice for professionals	webpage	heldinourhearts.org.uk/hospital-support/
Sands advice for professionals	webpage	www.sands.org.uk/professionals
Values based reflective practice	webpages	www.knowledge.scot.nhs.uk/vbrp.aspx
NICE guidance ante natal and postnatal mental health	webpages	www.nice.org.uk/guidance/qs115
PMRT information for parents	webpages	www.npeu.ox.ac.uk/pmrt/information-for-bereaved-parents



For more information visit:
nbcpscotland.org.uk

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