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

national bereavement care pathway
for pregnancy and baby loss

Stillbirth

Bereavement Care Pathway

Our National Bereavement Care Pathway core partners

ARC Antenatal Results & Choices
Bliss for babies born premature or sick
Miscarriage Association The knowledge to help
Held in our Hearts Baby loss counselling and support
Scottish Early Pregnancy Network
Sands
Scottish Cot Death Trust
The Royal College of Midwives
RCPCH Royal College of Paediatrics and Child Health
Royal College of Nursing
Royal College of Obstetricians & Gynaecologists
Scottish Government Riaghaltas na h-Alba gov.scot

NBCP for use in Scotland from July 2022 onwards

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 involved in the care of parents of a stillborn baby. Bereavement care is a continuing process and should be provided by all staff caring for parents who have experienced a stillbirth. It is integrated with clinical care and provided by everyone within the scope of their practice – not only those with a designated bereavement role – and doesn't start at an appointed time.

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

'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.

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 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.

If a baby may die before birth

Aim to thoughtfully prepare a family as early as possible when a baby may die before birth and support them throughout the period when there is uncertainty about if, when and why their baby may die.

Families often know when staff are concerned that a baby may die. This causes anxiety if staff don't communicate their thoughts and plans at an early stage and if there is poor continuity of obstetric and midwifery care.

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.
- The reasons why and when a baby may die are variable, therefore it may take days or weeks to give definite answers. Share the known facts as they emerge with parents even though an underlying diagnosis or outcome has not been confirmed.
- Explain to the woman and family that confirming why and when their baby may die before birth may take days or weeks.
- During this period, make sure the family knows what will happen next and ensure:
  - continuity of obstetric and midwifery care
  - a key contact is identified who will support and coordinate care, including bereavement care, for the woman and couple right through their journey – this may be the primary midwife
  - the key contact also provides continuity during the Perinatal Mortality Review.
- Record the care plan on the mother's maternity record including planned continuity of care and key contact.
- Explain how support organisations would be able to help and offer their contact details (see useful contacts).

"When you are in a situation, with a baby that has passed away or is about to, just say - don't tiptoe. Sit down and have a sensitive conversation and come in and just say it. Don't try to butter it up into something it's not. They were dancing around the subject and we never got any straight answers. Be direct."

"Staff need to use direct and appropriate language. Don't dance around the subject. Be direct, compassionate and kind."

How will we know we have achieved our aim?

- Families will tell us they felt well supported and prepared and were aware of the facts as they emerged.
- Staff will say they feel more confident and competent involving families at an early stage.

When a fetal heartbeat is not heard

Aim to share information kindly and clearly when staff suspect there is no fetal heartbeat before birth or during labour and throughout the period until they can confirm that the baby has died.

Families often know when staff are concerned that a baby has died and remember this moment for years.

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.
- When you suspect there is no heartbeat explain this straightaway to the family and describe what will happen next.
- During this challenging time keep language and body language clear, calm and face to face.
- If the family are not already in a quiet and private place, move to an appropriate room.
- Ask parents if they would like someone else to be with them.
- Make sure the family knows what will happen next, give written information about ongoing care and ensure:
  - continuity of obstetric and midwifery care
  - a key contact is identified who will support and coordinate care, including bereavement care, for the woman and couple right through their journey whether they are going home or remaining in hospital – this may be the primary midwife
  - the key contact also provides continuity during the Perinatal Mortality Review.
- Record the care plan on the mother's maternity record including planned continuity of care and key contact.
- Ensure your guidelines on the management of an absent fetal heartbeat include information on how to confirm a diagnosis as soon as possible and by whom.
- Check that the woman and partner can get home or to the next appointment safely and, if not, help them to think about other options.
- Explain how support organisations would be able to help and offer contact details (see useful contacts).
- If there is an intrauterine death in a multiple pregnancy, parents face the challenge of simultaneously experiencing ongoing pregnancy and a baby who has died. Support the family by focusing equally on all the babies.

"They used a Doppler, put on a monitor and said maybe baby was sitting awkwardly – I knew it wasn't that. Then we went to the scan room - it felt like 30 minutes, but it was only 2 minutes. I was duly plonked in waiting room with everyone sitting with bumps. I was sitting for 15 or 20 minutes howling into my husband's chest. The scan took ages, they said 'I'm sorry' but they had to go and get someone else to confirm. I already knew but they didn't want to alarm me. We were left a while, then a junior doctor came to speak to us 'the consultant is still in theatre, but I can start a few things.'"

How will we know we have achieved our aim?

- Families will tell us they felt they were told what was happening from the first moment they realised staff had concerns and were well prepared for what happened next.
- Staff will say they feel confident and competent telling the family when they suspect and confirm there is no fetal heartbeat and explaining what happens next.

Before induction or onset of labour and delivery

Aim to support and prepare women for their induction and delivery whether they are going home or remaining in the hospital.

Women tell us that this time can be difficult because they know their baby has died and it won't be apparent to others. They can feel lost and uncertain about what is happening next and who they could contact.

What do we need to do?

- Make sure all health professionals who have a role with the family know what has happened as soon as possible. Aim to contact the GP, midwife and local obstetric consultant within 24 hours.
- Prepare parents for what to expect during induction, labour and birth. Describe the place of birth, likely appearance of the baby, and common emotional reactions.
- Provide written information.
- If a woman wishes to wait for her labour to start naturally, a consultant will need to explain the risks to her health, the possible deterioration in the baby's appearance and reduced ability to identify the cause of death.
- Update the birth plan to reflect what is important to the woman and so she is in control as much as possible.
- Begin or continue the conversation about planning for memory making, and the option to take the baby home or out of the hospital environment (see Section G before discharge).
- Where possible, offer a choice of place of care depending on mother's medical condition and wishes.
- Make sure the family know:
  - who their key contact is if they have not already been identified
  - when and how they can communicate with their key contact if they have any questions or change their mind
  - how continuity of obstetric and maternity care is being provided.

"Get things personalised, our experience was mostly positive. Personal touches stay with you the most."

"You don't want to feel that you're just another woman having a stillbirth. It's my care and my care alone. Not following a crib sheet. It's all about personalised communications."

How will we know we have achieved our aim?

- Families will tell us they felt well prepared and supported for the delivery of their baby.
- Staff will say they feel confident and competent when preparing and supporting women for the delivery.

D

Labour and birth

Aim to provide an appropriate environment and sensitive, compassionate care from all staff attending to the woman and her family as she delivers her baby.

Families tell us they are not always treated sensitively. Staff are often not aware that the baby has died and not always conscious of the different needs they have.

What do we need to do?

- Ensure a room suitable for the woman, her family and their bereavement care is available and ready for them when the mother's medical condition permits.
- Maternity services should aim to provide a dedicated bereavement/family room, away from the labour ward, and consult local support organisations on design and facilities.
- Ensure continuity of carer through to delivery where possible and if a change in staff is necessary, introduce them sensitively.
- Ensure all staff seeing parents during labour and birth are aware of the baby's death and communicate sensitively.
- If she wishes, enable the woman to have a partner or support person with her at all times. Check the woman is happy for you to keep her partner or support person informed. Provide the partner or support person with emotional support.
- Begin or continue the conversation about and planning for memory making.
- If there is a stillbirth in a multiple pregnancy, parents face the challenge of simultaneously experiencing a live born baby and a baby who has died. Support the family by focusing equally on the baby who has died and the surviving sibling or siblings.

"We were then brought back in 2 days later and the care was perfect. I was in just after 9am, didn't get started until 1pm. I can't fault the staff and paperwork was done well – I wanted an epidural. We were in the family room, not the labour ward. She was born at 12:30. She was perfect – my husband held her until the warmth left her. We got loads of pictures and cuddles. Had the whole day with her."

"Even when I was labouring, the baby's heart was strong, but under viability – he was going to die. Just as I was getting ready to push, one staff member said he might die during labour."

How will we know we have achieved our aim?

- Families will tell us they felt well supported during labour and birth, were cared for in an appropriate environment and all staff were sensitive to their needs.
- Staff will say they feel confident they were able to provide an appropriate place of care for labour and delivery, and able to integrate bereavement and clinical care.

Memory making

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

Families tell us that being able to make memories helps them adjust to the loss of their babies.

What do we need to do?

- Offer parents the opportunity to see and hold their baby. Offer to describe the baby's appearance.
- Give parents time to reflect and decide what they want and let parents know they can change their mind.
- Complete the informed choice form to ensure parents are provided with options but do not feel pressured ('Creating memories – offering choices', a template form, is available from **www.nbcpscotland.org.uk/templates**).
- Consider the condition of the baby when offering memory making options.
- Discuss with parents:
  - washing and dressing the baby
  - photographs
  - hand and footprints
  - memory box
  - other mementos and memories.

"My only regret was I never got to see her feet. Her skin had deteriorated – her feet were wrapped in cling film. I was never offered to wash and reclothe her."

"The family room should be your privilege to help families to make memories. All these families leaving with their child, they have the chance over a lifetime to make memories. Midwives can't shy away from supporting families facing bereavement."

"There may be quite a few women out there in my situation. I didn't have any photos. I didn't get to hold the baby. She was taken away. I got a call, 10 days later. I had nightmares about where she was and what had happened to her."

How will we know we have achieved our aim?

- All families will tell us they felt supported to make memories, did not feel rushed and knew they could revisit decisions.
- All 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

"One of the midwives took the time to write a checklist - these are the things that you need to think about, general guidance. We were in shock, your brain is all over the place and it helped to have someone sit down with you – e.g. do I want a post-mortem? Do I want the hospital to make funeral arrangements?"

Aim to provide continuity of obstetric and midwifery care, and to jointly and sensitively lead the discussions about investigations and processes following a stillbirth.

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

What do we need to do?

- Introduce and explain the need for the following as far as possible with the same obstetrician and midwife providing continuity of care:
  - registration processes
  - 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 families. After you have explained, check families have understood what is involved by, for example, 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 mother's maternity 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 a previous stillbirth form could be added to the woman's record, if she wishes (a template is available from **www.nbcpathway.org.uk/templates**).

Registration and certification

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

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 needed. 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 in 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.

"The midwife came in and sat cuddling her and warmed her for me. I didn't want to hold her for a final cuddle, as she was cold and I didn't realise what the midwife was doing while she was chatting to me. I will be forever grateful to her. It was very personalised care – the midwife holding her, it was really clear that woman really, really cared."

- During the authorisation process, inform parents of the likely timescales for the return of the baby's body and the results.
- Identify a named contact within pathology and maternity who will be responsible for following up on results.
- Ensure any small objects or keepsakes such as a hat or cuddly toy that parents sent with the 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 parents as appropriate.

Funerals

- Provide parents with information around the legal requirements and options.
- Discuss what is available through the Board and other local options. Allow the parents time to make their decision. They may wish to consider options at home.
- Verbal and written information should include:
  - choices they have if they want the hospital to make arrangements and the costs, if any
  - financial support payment available to families on low income via Social Security Scotland (see useful contacts)
  - choices they have if they want to manage the arrangements, including information on local funeral directors if available
  - time frame for making and communicating that decision
  - hospital process if they do not make or communicate that decision within that time frame.
- 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 parents where appropriate.
- Offer to refer parents to the spiritual care/ chaplaincy team.
- Record all decisions made by the woman in her record, including where information is declined or no decision is made.

Clinical follow-up

- Explain the purpose and timing of clinical follow up, both what parents can expect, what the follow up does not cover, and who can attend. Ensure enough time has been allowed for this appointment. Maintain continuity of obstetric and midwifery care at this appointment.

Perinatal Mortality Review

- Inform parents about the process of perinatal review and invite them to become involved in the review process and refer to parent engagement (see **www.npeu.ox.ac.uk/pmrt/parent-engagement-materials**).
- Explain that the key contact will remain in touch with them during the review process. Give them information on the review process.

How will we know we have achieved our aim?

- All 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.

Before 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 about who is caring for their baby, where care will take place, and who will be providing contact and support for the family after they leave.

What do we need to do?

- Give the family time to ask questions about who is caring for baby, place of care of baby and who to contact when they leave 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.
- Recognise the added complexity when discussing the woman's postnatal care and physical changes to her body. Sensitively discuss the options for donating or suppressing milk.
- Discuss the emotions parents may experience and let them know these are common.
- 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.
- Ensure the family understand and have written information on their key contact, ongoing plan of care, and follow up appointment.
- Communicate these arrangements to the primary midwife.
- Update the primary health care team so they are aware when the woman is returning home. The GP, midwife and local obstetric consultant should be informed within 24 hours.
- Offer parents contact with the spiritual care/ chaplaincy team if this had not already happened.
- Provide parents with details of the emotional support available from your Board and primary care team. Explain how support organisations can help and give contact details (see useful contacts).

  Consider NICE guidance QS115 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/**).

"The minute it happens, at the hospital, they need to inform the GP etc. You shouldn't have to explain yourself when it's already a stressful and traumatic situation. Shouldn't turn up at the 6 week check up and be asked "How old is your baby?" It should be in notes and communications."

"They need more knowledge and trauma informed practice. Just approach it – what can I do? How can I help you? Refer to baby by their name."

Feedback

- Discuss with parents the channels available for giving feedback about the bereavement care they receive. Ensure any verbal feedback is recorded.
- Let them know that they will be asked for feedback on the care they have received at their follow up appointments and by their key contact.
- Consider using the Maternity Bereavement Experience Measure (MBEM) to capture parent feedback **www.sands.org.uk/maternity-bereavement-experience-measure-mbem**.
- Be clear with parents 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 were sure who would be contacting and supporting them after they left the hospital, and knew how their baby would be cared for.
- Staff will say they feel confident and competent telling families, before they leave the hospital, who would be responsible for contact and support and explaining how their baby will be cared for.

Support in the community

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 that their expectations about follow on appointments, review and further support are not met.

What do we need to do?

- On hearing of the stillbirth, the GP (or duty doctor/practice manager) should send a letter expressing sorrow and offer an appointment.
- The loss should be coded in the GP notes and references to an ongoing pregnancy cancelled.
- Carefully share information between the community midwife, GP and health visitor (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 clear final handover from the obstetric and community midwifery teams to primary care teams and make sure the family know who to contact from this point onwards.
- Ensure you and your colleagues are aware of the types of bereavement support available from local organisations and provide details as appropriate.
- At the GP follow up:
  - pay attention to the mother's physical and emotional wellbeing as well as providing routine follow up for the mother
  - arrange follow up care for her partner.
- At the obstetric follow up:
  - discuss care for potential future pregnancies and what, if anything, can be done to reduce risk
  - make sure families know who to contact for a preconception discussion.
- Offer referral for specialist psychological support if there are signs that might indicate PTSD or clinical depression, and, if appropriate, for mental health assessment for parents and/or 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/**

"There are people that slip through the net – when you leave the hospital, you might not read the bereavement pack."

"Once the shock and numbness wears off, then you are so vulnerable – not ready to leave the house or share your story."

"We got a lot of written information, and you need verbal explanation as well. If no one follows up, you are left to it. You leave the hospital with a memory box and have nothing, no other contact. You are forgotten about and already feeling so isolated. "

Clinical follow up

- Check that the family have received an appointment for clinical follow up. Help them consider questions they want to ask before their follow up appointment. Remind parents what the follow up does and does not cover, and who can attend.

Perinatal Mortality Review

- Key contact should confirm parents' wishes about having their questions answered in the review. Prompt parents to think about their questions and comments beforehand. A form to help parents 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**
- Check whether and how they want to be informed of the outcomes of the review of their baby's death.
- Ensure the review looks at parents' clinical and emotional care, and covers the whole pathway of care, both antenatal and postnatal, with input from community healthcare professionals.

How will we know we have achieved our aim?

- Families tell us they knew who had responsibility for their bereavement care after they left hospital and felt confident about the support available to them.
- Staff will say they feel confident and competent coordinating care and support, sharing information and referring families for support.

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.

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.
- 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

- 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.

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 previous pregnancies or earlier in this pregnancy or after birth. 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.
- 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**

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.

Self-care

- If, at any time, you don't feel sufficiently experienced in bereavement care and are worried, ask someone more experienced to help you.
- Recognise your own support needs and be open about them with your manager.
- Identify your training needs or seek advice from colleagues or peers.
- Communicate these needs with management and colleagues – other staff may have similar needs.
- Ensure you are aware of the support arrangements and services in place within your hospital or health board, including the spiritual care/chaplaincy team.
- 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, e.g.
  - 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/** from the NES Support Around Death website.

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 – prompt 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 stillbirth 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 sonographers, triage and midwives, 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.
- 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
  - key contacts
  - bereavement discussions including memory making
  - discharge planning
  - time taken from when no fetal heartbeat is suspected until death is confirmed
  - choice of place of care for delivery of stillborn babies
  - whether women's healthcare team was alerted within 24 hours of a pregnancy loss or baby/infant's death.
- Review how frequently units and services provide resources for memory making such as memory boxes, hand and footprints, and cold cots.

- Review how effectively units, services and Boards are engaging with local support organisations.
- 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 strategic aims of bereavement care across Scotland
    - 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 will have named senior staff with responsibility for the quality and consistency of bereavement care following stillbirth, 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, online 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

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, bespoke remembrance events and many volunteering opportunities. **www.simbacharity.org.uk**

Tommy's

Information and support following stillbirth.

www.tommys.org/pregnancy-information/pregnancy-complications/baby-loss/stillbirth-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**

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

International Stillbirth Alliance (ISA)
International alliance of organisations and individuals working to prevent stillbirth and improve bereavement care worldwide.

www.stillbirthalliance.org

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/mbrrace-uk

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

www.mbrrace.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
Provide 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

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

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
Offer support to bereaved children, their families and professionals.

www.winstonswish.org.uk

Working Families

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

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 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 midwives clinical supervision 1 - includes supportive resilience	elearning	**www.nes.scot.nhs.uk/media/3963029/CSM%20Unit%201.pdf**
NES Discussing authorised post mortem after stillbirth or neonatal death	video	**Discussing Authorised (Hospital) Post Mortem Examination After Stillbirth or Neonatal Death**
Held In Our Hearts Parent to parent post mortem authorisation	video	**Parent to Parent Post Mortem Authorisation**

NES Breaking the news of intrauterine death	video	**Breaking the news of intrauterine death**
Abigail's Footsteps The Deafening Silence - Stillbirth through a Mother's Eyes	video	**The Deafening Silence (from Abigail's Footsteps)**
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**
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	**www.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 antenatal 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**

nbcp
for pregnancy and baby loss

For more information visit:
nbcpscotland.org.uk

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