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

national bereavement care pathway for pregnancy and baby loss

Termination of pregnancy for fetal anomaly (TOPFA)

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 women and partners experiencing termination of pregnancy for fetal anomaly (TOPFA). Bereavement care is a continuing process and should be provided by all staff caring for those who have experienced TOPFA. 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/TOPFA**.

'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.

This document will use the term 'women'/'woman' throughout. However, it is important to highlight that it is not only those who identify as women who require access to bereavement care. For example, some transgender men, non-binary people, and intersex people or people with variations in sex characteristics may also experience pregnancy loss and/or the death of a baby. Bereavement care must therefore be appropriate, inclusive and sensitive to individual needs. The term couple is used to describe two individuals of any sexuality or gender.

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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.

Parent-focused care

Parent-led bereavement care plan: A parent-led approach is taken, providing continuity of care and management of transitions between settings and into any subsequent pregnancies.

Memory opportunities: All bereaved parents are supported to mark their loss and offered opportunities to make memories.

Bereavement space: All units have access to a room where bereavement care can be provided in a suitable and sensitive environment.

Staffing

Access to training: 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.

Leadership: There is a strategic bereavement lead in every Health Board in whose settings a pregnancy or baby loss may occur.

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

Communication

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

Informed choice: 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.

Robust signal system: 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.

When a fetal anomaly/genetic condition is suspected or diagnosed

Aim to provide kind and empathic care and to communicate clearly and sensitively when a fetal anomaly is suspected or diagnosed. Listen carefully to the words the woman and partner use and take those words into consideration when responding.

Fetal anomalies/genetic conditions can be suspected or diagnosed in any trimester. The timing of this can impact on some of the options available throughout the pathway.

Women and partners tell us that communication and support received at this point has a long term impact on their subsequent adjustment to loss.

What do we need to do?

- If possible, prepare yourself for giving difficult news by gathering information and consulting with colleagues.
- Whenever possible, prepare the woman and partner for difficult news by informing them of your findings as soon as it is possible to do so.
- Find a quiet and private place to deliver the news and/or explain it further. This might mean giving the news in the scan room but explaining next steps elsewhere. If over the phone, check the woman is in a suitable environment to have the conversation.
- If a problem is suspected during ultrasound examination:
  - Be aware of both your verbal and non-verbal communication and be sensitive to the woman's or partner's reaction.
  - Give information on scan findings. Do not give false reassurance and explain if a second opinion is required.
  - Give the woman and partner an opportunity to see the screen and offer to show them what you have seen. Ask the woman if she would like to get dressed and sit up or prefer to see the screen while you explain the findings.
  - Offer a scan photo because this may be important to memory making. If it is possible, offer to keep a printed copy in the notes if they would prefer.
- Ask the woman whether she would like partner or a support person present, or if she has brought children with her whether she would like them to stay with her or leave.

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- Use clear, straightforward language, with no euphemisms or jargon.
- Do not make assumptions about how the woman or partner may feel about a diagnosis, or any decisions she may make – communicate empathically and follow their lead on language (for example, some may prefer using 'baby' rather than 'fetus').
- Communicate with the woman and partner in a supportive and non-directive way, giving them time to absorb the news.
- Share the known facts about the diagnosis and make sure the woman and partner know what will happen next.
- Explain any reasons for a delay for further care (for example, further scans). If a referral to a different unit and travel is required, explain the reason for this. Acknowledge that uncertainty and delays can be difficult. Provide written information and signpost online information.
- Give the woman and partner a named key contact with contact details (a template contact card is available from **www.nbcpscotland.org.uk/about-us/nbcp-templates**).
- Offer to contact the primary midwife
- Explain how support organisations would be able to help and offer their contact details (see Useful contacts).
- Check the woman and partner can get home safely and if not, help them to think about other options.
- Record the care plan on the woman's maternity record including planned continuity of care and key contact.

"After receiving our diagnosis at the hospital, we were given details of a support organisation by a bereavement midwife. We had a lengthy discussion around our son's diagnosis and were offered further tests for genetic disorders which we declined, we were then asked to have a think about further tests and speak about it at our next appointment."

Next steps

- Be sensitive to the woman and partners reactions and acknowledge any distress shown. Allow womenand partner's time to take in information and ask questions and also acknowledge that they may need time to make their decision.
- Give the woman and partner the time they need to consider their options, supporting them to understand the implications of their decisions, and let them know they can change their minds. Be clear about timelines if there are necessary cut-offs (such as, if available, when your hospital stops offering the surgical method).
- Offer to refer the woman and partner to the spiritual care/chaplaincy team.
- Make sure the woman and partner know when and how to communicate with their key contact if they have questions or changed their minds.

How will we know we have achieved our aim?

- Women and partners will tell us they were treated with respect and kindness by staff and received clear information that was sensitive to their individual needs.
- Staff will say they feel confident and competent when communicating difficult news to women and partners.

Termination of pregnancy

Aim to respect and support women and partners as they understand options and make decisions that will have a long term impact on their psychological adjustment to loss if they choose to end the pregnancy.

Women and partners tell us they felt were not treated with compassion by all staff they came into contact with and some felt pressurised into making decisions too quickly.

Surgical termination of pregnancy

- Allow women and partners time to take in information and ask as many questions as necessary.
- Prepare the woman and partner for what to expect and who will be involved in their care.
- Ask the woman if she would like someone to attend with her and offer to support this if possible.
- Ensure that the woman and partner are cared for in the appropriate environment by staff who are sensitive to their needs.
- Ensure that all staff supporting the woman and partner before, during and after the procedure are aware of the baby's condition and communicate sensitively, using appropriate language and terminology.
- Aim for continuity of carer where possible.
- Sensitively prepare the woman and partner that following a surgical procedure there will not be a baby to see or hold.
- Explain that a full post-mortem examination may not be possible, however other options of testing may be available eg. genetic tests.
- Be clear about whether the woman wishes someone else to attend with her, and if so, who.
- Prepare the woman for what she can expect regarding bleeding, pain and common emotional reactions and provide written information.
- Be aware that some women will want to take their baby/fetus home with them.
- Ensure the woman has a key contact in case of any questions or concerns (a template contact card is available from **www.nbcpscotland.org.uk/about-us/nbcp-templates**).
- If women and partners are not already fully aware of support organisations, explain how they can help and give contact details (see Useful contacts).
- Explain a previous pregnancy loss form could be added to the woman's notes, if she wishes (a template is available from **www.nbcpscotland.org.uk/about-us/nbcp-templates**).
- Record the care plan on the woman's maternity record including planned continuity of care and key contact.
- Make sure the woman and partner have made arrangements to get home safely and if not, help them to consider their options.

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"The midwife spoke to me about everything. She was caring, sympathetic and empathetic. She cared for me the same way I had been cared for during labour with my living son."

Medical termination of pregnancy

- Prepare the woman and partner for what to expect during labour and birth, including information on the likely appearance of the baby.
- Discuss the arrangements, including place of birth, memory making, including the option of seeing and holding the baby. Respect and support the women and partners' decisions.
- All staff providing care for the women and partner before, during and after labour and birth should be aware of the baby's condition and communicate sensitively.
- Ensure continuity of carer where possible.
- Discuss the possibility of the baby showing signs of life at birth and what this will mean.
- Depending on gestation, the option of feticide may be discussed by the fetal medicine team. Ensure the woman and partner understand why this is offered. If referral to another unit is required, ensure good communication between units.
- Enable the woman to have a partner or a support person with her at all times.
- With the woman's consent, keep partner or support person informed and be prepared to offer them emotional support.
- Prepare the woman for what she can expect regarding bleeding, pain and common emotional reactions after birth, and who to contact if she has any concerns.
- Be aware that some women will want to take their baby/fetus home with them.
- Ensure the woman has a key contact in case of any questions or concerns (a template contact card is available from **www.nbcpscotland.org.uk/about-us/nbcp-templates**).
- If women and partners are not already fully aware of support organisations, explain how they can help and give contact details (see Useful contacts).
- Explain a previous pregnancy loss form could be added to the woman's notes, if she wishes (a template is available from **www.nbcpscotland.org.uk/about-us/nbcp-templates**).

Termination of pregnancy

Medical termination of pregnancy continued

- Record the care plan on the woman's maternity record including planned continuity of care and key contact.
- Make sure the woman and partner have made arrangements to get home safely and if not help them think about options.

Additional considerations for selective termination or multifetal pregnancy reduction

- Prepare the woman and her partner for what to expect, depending on the gestation.
- If the woman and partner need to attend another unit, explain why and ensure good communication between units.
- Ensure the woman and partner know who their key contact is, if they have not already been identified, and when and how they can communicate with them if they have any questions.
- Ensure a follow up appointment has been arranged for the woman and partner.
- Acknowledge the potential difficulty of having a baby who has died remaining alongside the living baby or babies.
- Prepare the woman and partner for what they can expect during the remainder of the pregnancy, labour and birth.
- Advise the woman and partner there are unlikely to be any visible remains after the birth of the surviving baby or babies if the procedure is carried out in early pregnancy.
- When recording on the woman's care plan, offer to use the 'Butterfly Sticker', available from the Twins Trust, and ensure staff recognise this as identifying women and partners of a surviving baby who have suffered the loss of a baby/babies from a multiple pregnancy.
- Offer referral for specialist psychological support if there are signs that might indicate PTSD or clinical depression.

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"I felt that both myself and my son were just not important to her on that shift. She took everything the first midwife had done and destroyed it, all my fears around being treated differently were coming true at that moment."

How will we know we have achieved our aim?

- Women and partners will tell us they were treated with respect and kindness by all staff and felt well informed and supported when making difficult decisions.
- Staff will say they feel confident and competent in caring for and supporting women and partners having to make difficult decisions about ending their pregnancy.

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Marking the loss, making memories

Aim to offer all women and partners information about possibilities for marking their loss or creating memories, while respecting that not everyone will want to do this. Be aware that some options may not be possible depending on gestation.

Women and partners tell us they can feel that they have no right to make memories because they have made the decision to end their pregnancy.

What do we need to do?

- All women and partners regardless of gestation should be sensitively offered the opportunity to mark their loss and create memories. Some may take this opportunity and some may not, it is important that all feel supported and respected in their choice.
- Do not make assumptions about what women and partners may want based on the gestation of their pregnancy, the condition diagnosed or the decision to end their pregnancy.
- Give women and partners time to reflect and decide what they want. This is especially important if a couple feel differently about marking loss and memories. Note that some options will be time-limited and make clear any time frame for making decisions.
- Let women and partners know they can change their mind but respect a decision when one has been made.
- Consider the gestational age and condition of the baby when offering options and discuss ways of marking the loss and making memories e.g. scan photos.
- Acknowledge where there are no physical remains and be aware of how this may affect opportunities for memory making, if this is something they would like to do.
- Offer women and partners the opportunity to see and hold their baby. If women and partners are uncertain, offer to describe the baby's appearance first.
- Complete the informed choice form to ensure women and partners are provided with options, but do not feel pressured (a template form, 'Creating memories – offering choices', is available from **www.nbcpscotland.org.uk/about-us/nbcp-templates**).
- Options to discuss with women and partners, if appropriate, and dependant on gestational age:
  - seeing and/or holding their baby
  - washing and dressing the baby
  - photographs/scan images
  - hand and footprints if the baby's condition allows.
  - provide leaflet for the memorial book of pregnancy and baby loss prior to 24 weeks **(www.nrscotland.gov.uk/registration/the-memorial-book/)**, to enable women to consider applying at a time most appropriate to them. Emphasise that this may be now or in the future. Ensure information leaflets are available in the hospital.
  - a memory box, or similar, appropriate to the gestation, or items for a box if they prefer.
  - other appropriate memory making options that may be available in your unit.

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"We didn't know that we could do things differently and with that sadness comes enormous regret as that was our only opportunity, and we now have to live our lives trying to reconcile ourselves with the fact that that opportunity is lost and gone, and we can't go back and change things."

- Where there is a death from a multiple pregnancy, discuss with women and partners the options around marking loss and memory making. Offer to use the 'Butterfly Sticker', available from the Twins Trust, and ensure staff recognise this as identifying women and partners of a surviving baby who have suffered the loss of a baby/babies from a multiple pregnancy.

How will we know we have achieved our aim?

- Women and partners will tell us they were offered information on marking loss and making memories sensitively and their wishes were respected.
- Staff will say they feel confident and competent when offering and discussing possibilities for marking loss and making memories, and able to do so without making assumptions or imposing their own values.

After the loss

Aim to sensitively provide information about investigations and tests which may be recommended or can be offered, and about options for cremation/burial and certification/ registration.

Women and partners tell us they didn't always understand the benefits and limitations of investigations and tests offered. They were not always advised about the possibility of certification and the explanation of cremation and burial was not always clear and objective or given at a time and in a format that was accessible or at an appropriate time.

Post-mortem examination and histology

- Make sure the discussion about post-mortem takes place in a quiet and private place, at an appropriate time and is not rushed.
- Sensitively explain why post-mortem is offered.
- Ensure staff discussing post-mortem examination with the woman and partner are trained to do so and are fully aware of the protocol for offering a full or partial post-mortem and any other tests available including examination of the placenta.
- Inform the woman and partner 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 women and partners of the likely timescales for the return of their baby and the results and be realistic about these.
- Make sure anatomical pathology technicians and/or pathologists are aware of any specific cultural or religious requirements or special requests from the family.
- Ensure any small objects or keepsakes such as a hat or cuddly toy that accompany the baby are returned following the investigation.
- Identify named key contacts within pathology and maternity who will be responsible for following up on results.

Registration and certification

- Offer to provide information on Certification of Pregnancy and Baby Loss Prior To 24 Weeks Application Form (MB1) and Guidance Notes **(nrscotland.gov.uk)**
- If birth occurs at home following the initial stage of the medical termination, refer to guidance for miscarriages that occur at home (**www.miscarriageassociation.org.uk/information/for-health-professionals/guidance-miscarriages-occur-home/**).
- If the baby is stillborn after 24 weeks' gestation, provide the woman and partner with a medical certificate of stillbirth.
- If a baby was born after 24 weeks' gestation but it is known or can be proven that the baby died before 24 weeks, the death cannot be recorded or registered as a stillbirth.
- Explain that if a baby is born alive following a termination of pregnancy at any gestation and subsequently dies, both the birth and death of the baby must be registered. Sensitively explain to the woman and partner that the cause of death will be recorded as termination of pregnancy for fetal anomaly.

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Cremation, burial and funerals

- Explain that the minimum standard for sensitive disposal of pregnancy loss under 24 weeks is shared cremation. Individual cremation or burial may also be considered. The woman and partner may also make private arrangements outwith the hospital including burial at home.
- Provide the woman and partner with information about their options but recognise that some people will not want to read or discuss it or to make decisions. In this situation they may authorise someone else to make the decision or authorise the hospital to make the arrangements.
- If the woman and partner do not want the information, explain that they can get back in touch if they change their minds and provide the time frame for doing so.
- Verbal and/or written information should include:
  - The choices they have if they want the hospital to make arrangements and the costs, if any.
  - The choices they have if they want to manage the arrangements, including burial at home and information on local funeral directors if available.
  - The time frame for making and communicating that decision.
  - The 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 and do not make assumptions.
- Discuss the options for urgent burial and cremation where appropriate.

"We walked out the hospital leaving our baby - on the way home it broke my heart, she was our daughter, we would not have left her grandma. Having a funeral created memories, and anchored her in our lives."

- Offer to refer the woman and partner to the spiritual care/chaplaincy team if contact has not already been offered.
- Record all decisions made by the woman in her maternity record, including where information is declined or no decision is made.
- See also Scottish government guidance on the sensitive disposal of pregnancy losses up to and including 23 weeks and 6 days gestation (**www.sehd.scot.nhs.uk/cmo/CMO(2015)07.pdf**) and RCN guidance on managing disposal of remains (**www.rcn.org.uk/professional-development/publications/pub-007321**).

How will we know we have achieved our aim?

- Women and partners will tell us information was sensitively and clearly given, at a time and in a format (written or verbal) that is right for them.
- Staff will say they feel confident and competent in providing information clearly, sensitively and able to do so at an appropriate time and in a suitable format.

Before discharge

Aim to ensure the woman and partner understand possible emotional reactions and know how they can contact a healthcare professional or support organisation.

Women and partners tell us they are shocked and distressed by their loss and they were not clear who could support and care for them following discharge.

What do we need to do?

- Recognise the complexity when discussing the woman's continuing care and physical changes to her body.
- Depending on gestation, discuss lactation and milk suppression.
- Discuss physical changes to the woman's body and who to contact if she has any concerns.
- Promptly inform primary care staff including midwife, GP and health visitor that the woman has experienced the loss of her baby, and where she will be staying when she leaves hospital.
- Discuss with the woman or partner the difficult emotions they may experience to reassure them that feelings of grief and loss are common and understandable.
- Sensitively explain that physical postnatal checks are not routinely offered but the woman's GP will be informed and she can request an appointment if wished.
- Ask the partner if they would like their own GP to be informed and if so, take details and action this.
- Ensure all women and partners are given a follow-up appointment. Ensure women and partners know what to expect from this appointment, the location and who can attend. Ensure that timing of appointment is realistic e.g. if awaiting post-mortem results.
- 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 woman, partner, a family member or a nominated health professional. However there is no need to cancel if they prefer to have the box.
- Be aware of what is available locally to mark the woman's notes to alert staff to her previous loss. If the woman wishes, a previous pregnancy loss form can added to her notes (a template is available from **www.nbcpscotland.org.uk/about-us/nbcp-templates**).
- Explain about the emotional support available to them via your Board, primary care colleagues and via support organisations and provide contact details (see Useful contacts). Never refer to 'post-abortion' counselling services unless you are confident they are completely non-judgemental and without anti-abortion bias.
- 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/**.

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Feedback

- Discuss with the woman and partner the channels available for giving feedback about the bereavement care they receive. Ensure any verbal feedback is recorded.
- Ensure women and partners are asked for feedback on the care they have received at their follow up appointments and by their key contact.

How will we know we have achieved our aim?

- Women and partners will tell us they felt informed and knew what they might happen next and who and how to contact for any further care and support they needed.
- Staff will say they feel confident and competent to provide clear information, and when identifying contacts for further care and signposting support organisations.

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Support in the community

"My husband is finding it hard to cope still. It's not just about support for women themselves, there needs to be support for partners themselves."

Aim to provide good communication between all health professionals and ensure that women and partners continue to receive the aftercare and emotional support they need in the community setting.

Women and partners tell us they found it hard to cope after their loss and often could not find appropriate support.

What do we need to do?

- Once notified of the loss, the GP practice, primary midwife or health visitor should consider contacting the woman and partner to acknowledge the loss and offer further support.
- The loss should be coded in the GP notes and references to an ongoing pregnancy cancelled.
- Ensure good follow up care is provided for the partner as well as woman.
- Allow enough time to offer emotional support as well as check the mother's physical health.
- Discuss with the woman or partner the difficult emotions they may experience to reassure them that feelings of grief and loss are common.
- Offer to discuss with women and partners how to talk about the baby who died with existing siblings.
- Ensure ongoing care is available where it is needed.
- Give women and partners 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/ about-us/nbcp-templates**).
- If not already fully aware of this, explain about the emotional support available to women and partners via support organisations (see Useful contacts). Never refer to 'post-abortion' counselling services unless you are confident they are completely non-judgemental and without anti-abortion bias.
- Make sure you know who can offer psychological support to bereaved women and partners and their wider family and if professional referral is required, offer to do so.
- Offer referral for specialist psychological support if there are signs that might indicate PTSD or clinical depression, and, if appropriate, for mental health assessment.
- 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/**.

"I was told in the hospital that I would receive a date for a follow up appointment with the consultant in about six weeks after birth. Six weeks came and went and there was nothing - it only adds to the stress of the situation. If there is some issue that appointments cannot be carried out in said time frame, then communication is the key."

Follow up meeting

- Help the woman and partner to consider questions they want to ask before this meeting.
- Allow enough time for women and partners to understand information and ask their questions.
- Pay attention to the woman and partner's emotional wellbeing as well as physical needs.
- Discuss care for potential future pregnancies and what, if anything, can be done to reduce risk.

- If the baby had a condition which gives an increased risk for future pregnancies, and if genetic counselling is required, offer a referral. If appropriate, discuss what women and partners can do to reduce risk e.g. folic acid supplementation. Give information on any screening/testing that may be available in future pregnancies and ensure women and partners are aware of how to access this.
- Provide women and partners with a letter summarising their follow up meeting and send a copy to their GP.

How will we know we have achieved our aim?

- Women and partners will tell us their emotional needs were recognised and they were given appropriate advice on getting the care and support they wanted.
- Staff will say they feel able to recognise the loss and they are confident and competent when identifying contacts for further care and signposting support organisations.

Follow on pregnancies

Aim to be aware at all stages that many women and partners who have experienced loss or losses at any gestation, will have additional emotional needs in future pregnancies so it is important to ensure these are met throughout any subsequent pregnancy.

Women and partners tell us pregnancy after loss – including the decision to try again – can be a highly anxious time, no matter the length of time since they had their previous loss or losses. A subsequent pregnancy will often trigger memories of difficult, distressing and even traumatic times. They say that acknowledging their previous experiences and the impact on the new pregnancy, being listened to and being given compassionate care are all important.

At all stages

- Review the maternity/medical records. Or, if there was a previous pre 12 week or SUDI loss, the case notes. Answer questions the woman and partner may have, as well as providing advice.
- Support the woman and partner to make informed choices around if/when to try for another baby.

Preconception

- If the baby had a condition which gives an increased risk for future pregnancies ensure that the woman and partner fully understand this risk and refer for appropriate counselling if necessary.
- If the option of early prenatal screening/ diagnosis is available and the woman and partner wish to consider this, ensure that they know how to access this in future pregnancies.
- Be clear about the specialist support for any future pregnancies and opportunities for additional antenatal appointments and scans.
- Listen to and acknowledge the woman and partner's fears and concerns.
- If any previous pregnancy/baby 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 form** is available **www.nbcpscotland.org.uk/about-us/nbcp-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.
- If appropriate, ensure early referral for screening/ diagnostic testing.
- Make an early appointment with the obstetric team whenever appropriate
- Discuss options and women and partners' preferences for care providers and place of birth and accommodate as far as possible. Where their wishes cannot be accommodated, explain why not. Record their preferences in the birth plan.
- 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.
- 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.
- Ensure the previous history is disclosed on the ultrasound request, with consent, to avoid miscommunication

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"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)

- Offer regular contact with staff wherever possible. Plan care around the woman's physical needs and both her own and partner's emotional and mental health needs with the frequency of the visits reflecting individual care needs and wishes as far as possible.
- 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 supportive 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, an appropriate previous pregnancy loss form can be added to her notes - a template form is available. **www.nbcpscotland.org.uk/about-us/nbcp-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)

NBCP for use in Scotland from January 2026 onwards

Follow on pregnancies

Labour and birth

- Be aware of the additional care and emotional support that may be needed to both the woman and partner 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.
- If appropriate, offer the woman and 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 woman'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 partner the contact details of a healthcare professional they can contact for information and support - a *template contact card* is available

"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)

www.nbcpscotland.org.uk

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"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.

NBCP for use in Scotland from January 2026 onwards

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.

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
  - watch for signs of strain or difficulty in individuals and within teams
  - facilitate discussion between colleagues and teams.
  - ensure staff have appropriate time for breaks while delivering bereavement care
- Ensure all staff have access to and attend bereavement care training.
- Resources for staff and family should be up to date and accessible.

Self-care

- You should be aware of your own triggers and know where to access support.
- If, at any time, you don't feel sufficiently experienced in bereavement care and are worried, ask someone more experienced to help you.
- Be aware of your own training needs or seek advice from peers.
- Recognise your own support needs and be open about them with your manager.
- 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:
  - 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:
  - 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, units and services regularly assess the quality and consistency of their bereavement care and act to improve all women's and partners' experiences.

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 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 TOPFA 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 and partners, 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 marking loss and memory making
  - discharge planning
  - national standards for referral following suspected anomaly on scan and results of screening and diagnostic testing.
- 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 time frame 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 TOPFA, are listening to all women, partners and staff, and are implementing improvement plans.

www.nbcpscotland.org.uk

Useful contacts

Key support organisations

Antenatal Results and Choices (ARC)
Provides support for people making decisions about antenatal screening and diagnosis and whether or not to continue a pregnancy this support continues after a termination.

www.arc-uk.org/for-parents

ARC also provides support and training for health professionals.

www.arc-uk.org/for-professionals

Sands
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

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

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

British Pregnancy Advisory Service (BPAS)
Offers advice on termination of pregnancy in the UK and provides terminations in England.

www.bpas.org

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

Fertility Network UK
Provides support for people dealing with infertility.

www.fertilitynetworkuk.org

www.fertilitynetworkuk.org/life-without-children

Jobcentre Plus – Bereavement Services Helpline
Provides information about benefits claims.

Telephone: 0345 608 8601
www.gov.uk/contact-jobcentre-plus

Money Advice Service
Provides free and impartial money advice, including information for bereaved parents about benefits and entitlements after the death of their baby.

www.moneyadviceservice.org.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

Registration: National Records for Scotland
www.nrscotland.gov.uk/registration/registering-a-birth

www.nrscotland.gov.uk/registration/registering-a-stillbirth (stillbirth only)

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

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

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
Revised guidance on Disposal of Pregnancy Loss prior to 24 weeks	download	**www.sehd.scot.nhs.uk/cmo/CMO(2015)07.pdf**
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**
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**
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**
Held In Our Hearts Parent to parent post-mortem authorisation	video	**Parent to Parent Post Mortem Authorisation**

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**
Helping parents with mental health issues	webpage	**www.bestbeginnings.org.uk/helping-parents-with--mental-health-issues**
ARC advice for professionals	webpage	**www.arc-uk.org/for-professionals**
Staff resilience	webpage	**www.sad.scot.nhs.uk/resilience/**
Teach Back Method	webpage	**www.healthliteracyplace.org.uk/toolkit/techniques/teach-back/**
SIGN guidance on perinatal mood disorders	webpage	**www.sign.ac.uk/our-guidelines/management-of-perinatal-mood-disorders/**
Held In our Hearts advice for professionals	webpage	**www.heldinourhearts.org.uk/hospital-support**
Values based reflective practice	webpage	**www.knowledge.scot.nhs.uk/vbrp.aspx**
NICE guidance antenatal and postnatal mental health	webpage	**www.nice.org.uk/guidance/qs115**
At a loss support search	website	**www.ataloss.org/find-support/search**

nbcp
for pregnancy and baby loss

For more information visit:
nbcpscotland.org.uk

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