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

national bereavement care pathway for pregnancy and baby loss

Miscarriage, ectopic and molar pregnancy

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 who are involved in the care of a woman who has miscarried (up to and including 23[+6] weeks) or had an ectopic or molar pregnancy, and her partner. Bereavement care is a continuing process and should be provided by all staff caring for those who have experienced miscarriage, ectopic and molar pregnancy. It is integrated with clinical care and provided by everyone within the scope of their practice – not only those with a designated bereavement remit – and doesn't start at an appointed time.

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

'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 health care professionals and staff that a parent has experienced a bereavement to enable continuity of care.
- Healthcare staff are provided with, and can access, support and resources to deliver high quality bereavement care.

When a pregnancy issue is suspected

Aim to provide kind and empathic care and give clear information sensitively. Listen carefully to the words the woman and partner use and take those words and their fertility history into consideration when responding.

Women and partners tell us this can be a very distressing and shocking experience, whatever the gestation, although occasionally the news may not be distressing and may even be a relief.

What do we need to do?

- Some women's initial contact will be with paramedics, GPs and triage staff. Acknowledge the anxiety they may feel, listen and communicate sensitively, keep to known facts and answer questions within the scope of your practice.
- Wherever possible, prior to speaking with the woman, familiarise yourself with her history and any previous pregnancies or pregnancy loss.
- When seeking consent from the woman for a scan or another examination or test, sensitively explain the potential need for a second opinion and/or repeat scan.
- Be aware that the woman and partner may be anticipating challenging news because of signs or symptoms, an earlier assessment, a letter or phone call (e.g. molar pregnancy) or a previous pregnancy. However, for many the news will come as a complete shock.
- Do not make assumptions about how the woman and partner feel about the pregnancy or the news – communicate empathically and follow their lead on terminology and language.
- If you suspect or identify a problem on examination and need to consult or confirm with a colleague outside the room, explain this before you leave the room. Be aware of your body language and non-verbal signals and be sensitive to the woman's or partner's reaction.
- Find a quiet and private place to deliver the news and/or to explain it further. This might mean giving the news in the scan room but explaining next steps elsewhere.
- If the woman is alone for the diagnosis, ask if she would like someone else to be present for further explanation.
- Share the known facts about the diagnosis and make sure the woman and her partner know what will happen next.
- Use clear, straightforward language. Avoid medical terms, abbreviations (e.g. ERPC) or euphemisms (e.g. 'not in your tummy').
- If the news is being given at an ultrasound scan, ask the woman and partner if they want you 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.
- If the diagnosis is unclear – e.g. a pregnancy of unknown location or of uncertain viability or a suspected molar pregnancy – explain the need for further assessment and acknowledge how difficult the period of uncertainty can be.
- If one or more babies in a multiple pregnancy dies but one or more is still viable, be sensitive to the feelings that the woman and partner may have. The continuing pregnancy or pregnancies may still be at risk and even if continuing, may be no compensation for the baby/babies that died.

"There was a lack of empathy, everyone too busy but one nurse squeezed my hand and that small gesture was remembered and appreciated through all the turmoil."

- If the pregnancy is heterotopic – one ectopic and one intrauterine – and the intrauterine pregnancy is viable, be sensitive to the feelings that the woman and partner may have. Depending on how the ectopic is managed, the intrauterine pregnancy may still be at risk and even if continuing, may be no compensation for the baby that died.
- If you are giving the diagnosis of a molar pregnancy, ensure that you know whether the woman and partner are expecting this news (e.g. from a previous appointment, a letter or phone call). Be sensitive to the feelings they may have if they have already been coping with the diagnosis of miscarriage. Also be aware that molar pregnancy is uncommon and is a complicated diagnosis to understand.
- Give the woman and partner time to absorb the news, and answer as many questions as you are able to within your scope of practice.
- Reassure the woman and partner that sadly early pregnancy loss is not uncommon and it is very unlikely that the loss has been caused by anything they did or did not do.
- Give information about what happens next, provide written information, specific patient leaflets and a named contact with contact details (a template contact card is available from **www.nbcpscotland.org.uk/templates**).
- Offer a copy of the scan picture if there is one and offer to keep a printed copy in the notes if they would prefer.
- 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.

"I was asked by a nurse to keep the noise down, as there were other patients to consider. At A&E, there was no prioritising for patients with pregnancy issues, no compassion."

"I was left in the waiting room at A&E for three hours with blood seeping through my clothes."

"At A&E, although in great pain no one listened to me and I was sent home to cope. That pain was like being in labour but because no one had explained what could happen, the level of pain etc. I was not prepared and had to put up with it."

- It is not uncommon for women to pass their baby/pregnancy while on the toilet. Bedpans or similar should be provided in women's toilets in A&E, early pregnancy, gynaecology and maternity settings.
- Consider NICE guidance NG126 for further information (**www.nice.org.uk/guidance/ng126**).

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 which was sensitive to their individual needs.
- Staff will say they feel confident and competent in dealing with women and partners who exhibit any of a range of emotional responses to their situation and in giving clear information.

Next steps

Aim to provide kind and empathic care, give clear information sensitively. Listen carefully to the words that the woman and partner use and take those words and their fertility history into consideration when responding.

Women and partners tell us they felt they were not always treated with compassion by all staff they came into contact with and their previous experiences were not always taken into account.

B1. Next steps – first trimester miscarriage

See following pages for next steps for second trimester miscarriage, ectopic pregnancy and molar pregnancy. Please note that many principles are shared across all four kinds of loss.

What do we need to do?

- All staff with whom a woman may be in contact about early pregnancy problems should acknowledge the anxiety she may feel and listen and communicate sensitively.
- Give clear information about what is happening and carefully discuss management options or recommendations – including risks – if appropriate.
- Provide written information and give time for decision making wherever possible.
- Discuss how the place of care – home or in hospital, early pregnancy, gynaecology or maternity ward – and geography may affect the management options available.
- Acknowledge any concerns the woman and her partner may have.
- Sensitively explain any reasons for a delay in further care – e.g. further scans, booking theatre time. Acknowledge that uncertainty and delays can be difficult. Provide written information and signpost online information where appropriate.
- In the Emergency Department, transfer a woman to the appropriate unit/ward as soon as possible or offer support to go home. Provide information about accessing and/or an appointment for further treatment or assessment.
- Provide clear information about possible pain and bleeding, and the possibility of miscarrying before the next appointment, and whom to contact if symptoms worsen before the next appointment.
- If the woman opts for expectant management or medical management at home, explain honestly what she might experience regarding pain and bleeding during and after the miscarriage. Remember to offer analgesics or advice on over-the-counter options and on the likely need for extra-absorbent sanitary pads.
- Acknowledge that waiting for the miscarriage to happen can be difficult and that the process itself may be distressing and provide details of whom she can contact if she needs support.
- In all cases, advise the woman sensitively that she may miscarry while on the toilet and offer information regarding pregnancy remains

"Lack of information, lack of respect, I was bleeding six weeks later, I didn't know if this was normal no one had mentioned this might happen or explain this is what you may see (lots of blood). No information about when you go home."

"I told the professionals my history, I knew my own body and that what was happening was not right but I was ignored and advised that I would be monitored for twenty-four hours as I was not in pain, my husband intervened and I was taken in. A surgeon later admitted to my husband I could have died from loss of blood."

(see guidance for miscarriages that occur at home, available from **www.miscarriageassociation.org.uk/information/for-health-professionals/guidance-miscarriages-occur-home**).

- Inform the woman that she can usually change her mind about the management option and provide the appropriate contact details if she does.
- Ensure that all staff seeing the woman and partner during and after the process of miscarriage are aware of what is happening and communicate sensitively, using appropriate language and terminology.
- Aim for continuity of carer where possible.
- Ask if the woman or couple are wondering what they might see when she miscarries and be prepared to talk this through. Offer to tell the woman and partner what their miscarried pregnancy might look like (see the Miscarriage Association's guidance on management of miscarriage **www.miscarriageassociation.org.uk/wp-content/uploads/2016/10/Management-of-miscarriage-2016.pdf**).
- Ask the woman if she would like the pregnancy loss form completed to alert staff who provide further or future care (a template form is available from **www.nbcpscotland.org.uk/templates**), or use another means to alert staff, e.g. a teardrop sticker or digital icon.
- Provide information about histology or post mortem examination if appropriate (see section D).
- Discuss the options for cremation and burial (see section D).
- Describe the help that support organisations can offer and provide contact details if the woman or her partner wishes to have these.

Next steps

B2. Next steps – second trimester miscarriage

In addition to the guidance on first trimester miscarriage in section B1 above

What do we need to do?

- Ensure that the woman is cared for in the appropriate care environment by staff who are sensitive to her needs.
- Discuss the arrangements, including where she will deliver and possible ways of marking the loss and/or making memories (see section C).
- Prepare the woman and partner for what to expect during labour and delivery, including information about pain relief and how long the process might take.
- Offer to tell the woman and partner what they might expect their baby to look like, depending on the gestation.
- Provide a named contact in case the woman changes her mind or has any questions.
- Ensure all staff seeing the woman and partner during labour and delivery are aware of the baby's death and communicate sensitively.
- Be conscious that women are likely to need additional emotional support during labour.
- Enable the woman to have a partner or support person with her at all times.
- With the woman's consent, keep the partner or support person informed.
- Provide the partner or support person with emotional support.

B3. Next steps – ectopic pregnancy

In addition to the guidance on first trimester miscarriage in section B1 above

What do we need to do?

- Give clear and understandable information (verbally and in writing where possible) about management options, risks, benefits and any recommendations, and allow time for discussion and decision making wherever possible.
- Be sensitive to the feelings the woman and partner may have about their loss, risks to the woman and implications for her fertility. Recognise that they may have already been coping with the diagnosis of miscarriage or pregnancy of unknown location.
- If the woman opts for expectant or medical management, explain the need for continued monitoring and further appointments, and advise on the potential need for treatment, further treatment or surgery in some cases. Provide a contact name and/or number so the woman and partner can ask questions or seek advice at any time.
- If surgical management is advised/opted for, clearly and sensitively explain the steps for hospital admission, pre-operative preparation and surgical routes including any recommendations (keyhole, open) and possible outcomes, e.g. for an affected Fallopian tube.
- Provide a contact name so that the woman and partner can ask questions or seek advice.
- Offer to tell the woman and partner what they might expect the remains of their baby

"I was left alone in a room without support, no explanation."

or pregnancy to look like, depending on the gestation and the type of management used.

- Provide information about pain relief and physical and emotional care.
- Discuss the options for cremation and burial in the same way as you would following miscarriage (see section D).

B4. Next steps – molar pregnancy

In addition to the guidance on first trimester miscarriage in section B1 above

What do we need to do?

- Give clear and understandable information regarding the recommendation for surgical management if this is needed, recognising that this may be the woman's second procedure.
- Give clear information about the follow up process, why it is needed and what it will involve.
- Provide contact details of the Scottish Hydatidiform Mole Follow Up Service at Ninewells Hospital, to which the woman will be referred, so the woman and partner can ask questions or seek advice at any time.
- Be sensitive to the feelings the woman and partner may have regarding their loss, the possible risks for the woman's health and implications for future pregnancies. Provide information about organisations that can offer further support.
- Discuss the options for cremation and burial in the same way as you would following miscarriage (see section D).

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 which was sensitive to their individual needs.
- Staff will say they feel confident and competent in dealing with women and partners who exhibit any of a range of emotional responses to their situation and in giving clear information.

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 this.

Women and partners tell us that it can be helpful to have some suggestions for marking their loss should they wish to, but that they don't want to be made to feel guilty if they'd rather not.

What do we need to do?

In first or second trimester loss

- Recognise that some women and partners will choose to mark their loss or create memories in some way. Some will appreciate the offer of help to do this and others will not.
- Do not make assumptions about what she or they might want based on the gestation of their pregnancy but be aware that some options will not be possible with early loss.
- Allow time for making decisions and for the possibility of changing those decisions. 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. Respect the decision the woman and partner make.
- Depending on the condition of the baby or pregnancy remains, offer the woman and partner the opportunity to discuss:
  - seeing and/or holding their baby or remains, in a suitable container if needed – local or national organisations may be able to supply appropriate resources, offer to describe the (likely) appearance of the baby or remains first
  - a memory box, or similar, appropriate to the gestation or items for a box if they prefer
  - a copy of the scan image, if one is available and it has not already been given to the woman
  - certificate of loss - Offer to provide information on Certification of Pregnancy and Baby Loss Prior To 24 Weeks Application Form (MB1) and Guidance Notes **(nrscotland.gov.uk)**
  - entry in a book of remembrance, if available
  - photographs of the baby or remains
  - hand and footprints, if the baby's condition allows
  - other memories or mementos.

- Where there is a loss or death in a multiple pregnancy, consider discussing the options for marking the loss with surviving siblings.
- Consider offering information about other remembrance events within or outwith the hospital or healthcare setting.
- Complete the informed choice form to indicate that the woman and partner have been offered options, but without pressuring them (a template form, 'Creating memories – offering choices', is available from **www.nbcpscotland.org.uk/templates**).

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 in offering and discussing possibilities for marking loss and making memories, without making assumptions or imposing their own values.

After the loss

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

Women and partners tell us they didn't always understand the benefits and limitations of the examinations and tests. They were not always given the option 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 right for them.

What do we need to do?

Histology and post mortem

- 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.
- Ensure that all discussions take place in a quiet, private place.
- If histological examination of pregnancy remains or the placenta is recommended, ensure the woman and partner understand why and also the limitations of the examination.
- If seeking consent for histological examination, aim to do so when obtaining consent for surgical management.
- Ensure that the woman and partner understand 'fetal karyotyping' or other investigations if being offered.
- Offer to explain options for cremation and burial of pregnancy remains.
- 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 limited post mortem and know how to complete the form.
- Allow sufficient time for discussing post mortem and gaining authorisation if appropriate.
- During the authorisation process, inform the woman and partner of the likely timescales for the return of their baby and how and when the results will be communicated and be as realistic as possible about these.
- 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. Identify a named pathology or maternity contact who will be responsible for following up on the results.
- 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.
- Provide information about cremation and burial (see section D).

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 the miscarriage occurred at home, refer to the guidance for miscarriages that occur at home **www.miscarriageassociation.org.uk/information/for-health-professionals/guidance-miscarriages-occur-home/**.

- 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.

Cremation, burial and funerals

- Advise that a minimum standard by a hospital for sensitive disposal of pregnancy loss under 24 weeks is shared cremation. Individual cremation or burial may also be considered. The individual may also make private arrangements outwith the hospital, including burial at home.
- Advise that signed authorisation is required before the hospital can sensitively dispose of the pregnancy loss.
- Provide the woman and partner with written information about these options, including information about the recovery of ashes, but recognise that some women and partners will not want to read or discuss it or to make a decision. In this situation they may authorise someone else to make the decision or authorise the hospital to arrange for shared cremation.
- 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:
    - choices they have if they want the hospital to make arrangements and the costs, if any
    - choices they have if they want to manage the arrangements, including burial at home and 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 and do not make assumptions.
- Discuss the options for urgent burial and cremation where appropriate.
- Inform the woman and partner about the spiritual care/chaplaincy team as a source of additional support or advice.
- Record all decisions made by the woman in her medical records, 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 Miscarriage Association guide **www.miscarriageassociation.org.uk/wp-content/uploads/2020/08/Talking-about-sensitive-disposal-of-pregnancy-remains-Good-practice-guide.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 this information was sensitively and clearly given, at a time and in a format (written or verbal) that was 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 women and partners understand possible or likely physical symptoms and know whom they can contact – as well as when and how – whether a healthcare professional or support organisation.

Women and partners often tell us they are shocked and distressed by the intensity of symptoms that they had not been prepared for, and they were not always clear who could support and care for them following discharge.

What do we need to do?

- Ensure the woman is told about the possibility or likelihood of continuing or increasing pain and bleeding, which she may find distressing, and when and how to contact a healthcare professional. Discuss lactation and milk suppression if appropriate.
- Provide information on continuing care/follow up for this pregnancy loss and, if known and appropriate, on the hospital's policy for offering investigations into possible causes.
- Provide information, if appropriate, on the hospital's policy for early scanning or testing in pregnancy after this loss.
- Discuss with the woman and partner the emotions they may experience, so they know that feelings of grief and loss are common and understandable, but so too is acceptance and in some cases, relief. Avoid the word 'normal' in case they don't feel this way.
- Offer contact with the spiritual care/chaplaincy team.
- Promptly inform primary care staff and all relevant departments that the woman has experienced a miscarriage, ectopic or molar pregnancy, so that future associated appointments are cancelled.
- Offer to mark the woman's notes to alert staff who provide further or future care, e.g. with a teardrop sticker or digital icon. If the loss was from a multiple pregnancy, 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.
- Ask the partner if they would like their own GP to be informed and if so, take details and action this.
- Before the woman and partner leave the hospital, give them the contact details for primary care and secondary care staff and local and national support organisations (see Useful contacts).
- Advise all women and partners on how to request a follow up appointment with the unit (if available) and/or their GP. If you offer a follow up appointment, explain what to expect from it and if possible, book the appointment allowing sufficient time for the woman and partner to ask questions and talk about their experience.
- Offer referral to a recurrent miscarriage clinic if appropriate.
- 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.
- 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/**.

"Lack of information when you go home, basic change pad but nothing else what do I do? Surely they could provide a booklet with different scenarios in it. Something explicit, both verbal and a written leaflet with more detail."

"The miscarriage clinic gave me information but only after three miscarriages, support group posters in GP surgeries would help."

"I was referred to a psychologist after my second miscarriage who referred me to a bereavement counsellor. Why couldn't the GP have done this earlier? GPs did not know about support groups."

Feedback

- Discuss with the woman and partner how they can give feedback about the bereavement care they received.

  If the woman and partner give consent to be contacted for feedback, let them know how and when they will be contacted about this and document consent to participate.

- Let women and partners know they can give feedback to hospitals and other healthcare services and share their stories via Care Opinion (**www.careopinion.org.uk**).

How will we know we have achieved our aim?

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

Support in the community

"The support organisation has been good for me, hearing other people's stories helped me. I felt guilty about being upset over a miscarriage."

Aim to offer women and partners the aftercare and emotional support they need, respond to their concerns, and provide information about and/or referral to other sources of help as needed.

Women and partners tell us they found it hard to cope after their loss and to find appropriate support.

What do we need to do?

- Once notified of the loss the GP practice, primary midwives or health visitors should consider contacting the woman to acknowledge the loss and offer further contact if she wishes.
- The loss should be coded in the GP notes and references to an ongoing pregnancy cancelled.
- At follow up and subsequent appointments:
  - pay attention to the woman's emotional wellbeing as well as physical needs
  - listen to the words the woman and partner use and take those words and their fertility history into consideration when responding
  - be ready to answer questions about potential future pregnancies and whether anything can be done to reduce risk
  - make sure women and partners know whom to contact if they would like preconception advice where appropriate.
- Ensure you are aware of the types of bereavement support available within the NHS and from support organisations and provide details (see Useful contacts).
- Offer referral for specialist psychological support if there are signs that might indicate PTSD or clinical depression.
- 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/**.

"Three weeks after an ectopic pregnancy I started back to work, it was too early but they gave me full sick pay and that helped me cope.."

"It took me one year to get back to normal, I felt I was coping but depression and anxiety kicked in and I fell apart. I felt there was a stigma about going to the GP asking for anti-depressants, I was afraid to mention depression, memories and loss."

"It can be difficult for partners - it hit my husband six months later. He had a history of mental health and self-referred to a local service. Now he is more open and talks about it."

How will we know we have achieved our aim?

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

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.
- If appropriate, discuss what, if anything, the woman and partner can do to reduce the risk of another loss.

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

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)

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 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** •
- Ensure the previous history is disclosed on the ultrasound request, with consent, to avoid miscommunication.
- If possible, offer the option of an additional ultrasound scan or scans, appropriate to the timing of the previous loss.
- Staff should explain reasons for additional tests with their benefits and any risks in declining. This is important for early scans where women have previously experienced an ectopic pregnancy.
- It may be appropriate to offer additional reassurance at the 12-week scan if all is well and the previous loss was in the first trimester but recognise that anxiety may continue long after that time.

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 for example
  - becoming sensitive to triggers that would not normally upset you
  - becoming overcritical or defensive of yourself or others
  - questioning your own and others' values
  - sleeping poorly or much longer than usual
  - drinking more alcohol or eating more or less than usual.
- Find out about wellbeing from the NES Support Around Death website **www.sad.scot.nhs.uk/wellbeing/**

How will we know we have achieved our aim?

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

Outcome measures

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

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, including 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 and partners who experience miscarriage, ectopic or molar pregnancy 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 all staff in direct contact with women and partners experiencing miscarriage, ectopic or molar pregnancy loss have access to 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 marking loss and memory making
  - discharge planning.
- Review how frequently units and services provide resources for memory making such as scan images.
- 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 will have named senior staff with responsibility for the quality and consistency of bereavement care following miscarriage, ectopic or molar pregnancy, are listening to all women, partners and staff and are implementing improvement plans.

Useful contacts

Key support organisations

Miscarriage Association
Provides support and information to anyone affected by miscarriage, ectopic pregnancy or molar pregnancy and offers a helpline, online support, live chat and support groups.

www.miscarriageassociation.org.uk/how-we-help

The Miscarriage Association also provides resources including elearning and guidance for professionals **www.miscarriageassociation.org.uk/information/for-health-professionals**

Ectopic Pregnancy Trust
Provides support and information for people who have had or been affected by an ectopic pregnancy.

www.ectopic.org.uk

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

www.heldinourhearts.org.uk

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

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-you/support

Sands also provides guidance and an accredited training programme for professionals **https://www.sands.org.uk/professionals**

Scottish Care and Information on Miscarriage
Provides support and information for early and late loss.

www.miscarriagesupport.org.uk/how-we-can-help/miscarriage-support-and-information

SiMBA
Drop in groups for anyone who has gone through the death of a baby at any stage of pregnancy or close to the time of birth, including all family members

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

SiMBA also provides memory boxes, family rooms in hospitals and bespoke remembrance events **www.simbacharity.org.uk**

Tommys
Information and support following miscarriage

www.tommys.org/pregnancy-information/pregnancy-complications/baby-loss/miscarriage-information-and-support

Twins Trust Bereavement Support Group (formerly TAMBA)
Offers support for families who have lost one or more children from a multiple birth during pregnancy, birth or at any time afterwards.

www.twinstrust.org/bereavement

Twins Trust also works to improve care for multiple birth mums and babies

www.twinstrust.org.uk

Other organisations

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

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

Antenatal Results and Choices (ARC)
Provides support for people making decisions about ante natal 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**

Association of Early Pregnancy Units
Annual conference, information and networking for anyone working in early pregnancy.

www.aepu.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 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

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

www.nafd.org.uk

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

www.naturaldeath.org.uk

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

www.ourmissingpeace.org

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 their photography services to parents who lose a baby at 20 weeks or later gestation, or 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

Scottish Early Pregnancy Network (SEPN)
SEPN is a network for professionals working in early pregnancy in Scotland. They run an annual conference and provide support and information for all staff.

www.miscarriage-matters.co.uk/sepn/index.php

Scottish Hydatidiform Mole Follow up Service
Specialist follow up, information and counselling, based at Ninewells Hospital.

www.nss.nhs.scot/specialist-healthcare/specialist-services/hydatidiform-mole

Society of Allied and Independent Funeral Directors (SAIF)
Independent funeral directors' national organisation.

www.saif.org.uk

Winston's Wish
Offers support to bereaved children, their families and professionals.

www.winstonswish.org.uk

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**
Ambulance crews good practice guide	download	**www.miscarriageassociation.org.uk/wp-content/uploads/2019/08/Ambulance-Crews-first-responders-Good-Practice-Gude.pdf**
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**
Caring for women experiencing pregnancy loss	elearning	**www.miscarriageassociation.org.uk/information/for-health-professionals/e-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**
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**

Miscarriage Association - Ambulance call out	video	**https://youtu.be/iU1qtt09qho**
Helping parents with mental health issues	webpage	**www.bestbeginnings.org.uk/helping-parents-with--mental-health-issues**
Staff resilience	webpage	**www.sad.scot.nhs.uk/resilience/**
Certification (miscarriage)	webpage	**www.miscarriageassociation.org.uk/information/for--health-professionals/certification/**
Miscarriage at home guidance	webpage	**www.miscarriageassociation.org.uk/information/ for-health-professionals/guidance-miscarriages-oc-cur-home/**
Teach Back Method	webpage	**www.healthliteracyplace.org.uk/toolkit/techniques/ teach-back/**
Miscarriage Association advice for professionals	webpage	**www.miscarriageassociation.org.uk/information/for--health-professionals/**
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	**https://heldinourhearts.org.uk/hospital-support/**
Ritual Respect Project	webpage/ video	**https://futurehealthandwellbeing.org/ritualrespect**
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**

nbcp
for pregnancy and baby loss

For more information visit:
nbcpscotland.org.uk

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