Please note this document is an extract from the pathway to be used to record your self assessment. Please use the [TOPFA Pathway](https://www.nbcpscotland.org.uk/topfa/) for all other purposes. NBCP Scotland’s self assessment tools are designed to help boards, units and services to get ready to join our early adopters who are piloting the 5 bereavement care pathways or to prepare for the national rollout. The tool can be completed individually or by a group of staff. For each item, please say if you are able to do this by putting Y for yes, N for no, P for partly. If something is not relevant to your role, unit or service, you can put NA.

|  |  |
| --- | --- |
| Job roles(s) |  |
| Unit(s) or service |  |
| Completed by |  |

1. When a fetal anomaly is suspected

|  | Y/N/P | *Resources or support needed?* |
| --- | --- | --- |
| 1. 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. |  |  |
| 1. When possible, prepare the woman and her partner for difficult news by informing them something may be wrong as soon as it is suspected. |  |  |
| 1. If possible, prepare yourself for giving difficult news by gathering information and consulting with colleagues. |  |  |
| 1. 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. |  |  |
| 1. If a problem is suspected during ultrasound examination |  |  |
| * 1. Be aware of both your verbal and non-verbal communication. |  |  |
| * 1. Give information on scan findings. Do not give false reassurance and explain if a second opinion is required. |  |  |
| * 1. Give the woman and her partner an opportunity to see the screen and offer to show them what you have seen. |  |  |
| * 1. Offer a scan photo because this may be important to memory making. Offer to keep a printed copy in the notes if they would prefer. |  |  |
| 1. Ask the woman whether she would like her partner or a support person present, or if she has brought children with her whether she would like them to leave. |  |  |
| 1. Use clear, straightforward language, with no euphemisms or jargon. |  |  |
| 1. Do not make assumptions about how the woman or her partner feels 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’). |  |  |
| 1. Communicate with the woman and her partner in a supportive and non-directive way, giving them time to absorb the news. |  |  |
| 1. Share the known facts about the diagnosis and make sure the woman and her partner know what will happen next. |  |  |
| 1. 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. |  |  |
| 1. Give the woman and her partner a named key contact with contact details - a template contact card is available from [www.nbcpscotland.org.uk/templates](http://www.nbcpscotland.org.uk/templates) |  |  |
| 1. Offer to contact the primary midwife |  |  |
| 1. Explain how support organisations would be able to help and offer their contact details (see Useful Contacts). |  |  |
| 1. Check the woman and her partner can get home safely and if not, help them to think about other options. |  |  |
| 1. Record the care plan on the woman’s maternity record including planned continuity of care and key contact. |  |  |
| *Next steps* |  |  |
| 1. Acknowledge how difficult this decision must be. Allow women and partners time to take in information and ask questions. Acknowledge that women and partners will need time to make their decision. |  |  |
| 1. Give the woman and her partner the time they need to decide what they want, 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 when your hospital stops offering the surgical method). |  |  |
| 1. Offer to refer the woman and her partner to the spiritual care/chaplaincy team. |  |  |
| 1. Make sure the woman and her partner know when and how to communicate with their key contact if they have questions or changed their minds. |  |  |

1. Termination of pregnancy

|  | Y/N/P | *Resources or support needed?* |
| --- | --- | --- |
| **Surgical Termination of Pregnancy** | | |
| 1. 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. |  |  |
| 1. Prepare the woman and her partner for what to expect and who will be involved in their care. |  |  |
| 1. Ensure that the woman and partner are cared for in the appropriate environment by staff who are sensitive to their needs. |  |  |
| 1. 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. |  |  |
| 1. Aim for continuity of carer where possible. |  |  |
| 1. Sensitively prepare the woman and partner that following a surgical procedure there will not be a baby to see or hold. |  |  |
| 1. Explain that a full post mortem examination will not be possible, however some tests e.g. genetic may still be available. |  |  |
| 1. Be clear about whether the woman wishes someone else to attend with her, and if so, who. |  |  |
| 1. Allow women and partners time to take in information and ask as many questions as necessary. |  |  |
| 1. Prepare the woman for what she can expect regarding bleeding, pain and common emotional reactions and provide written information. |  |  |
| 1. Be aware that some women will want to take their baby/fetus home with them. |  |  |
| 1. 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/templates](http://www.nbcpscotland.org.uk/templates) |  |  |
| 1. If women and partners are not already fully aware of support organisations, explain how they can help and give contact details (see Useful Contacts). |  |  |
| 1. Explain a previous pregnancy loss form could be added to the woman’s notes, if she wishes - a template is available from [www.nbcpathway.org.uk/templates](http://www.nbcpathway.org.uk/templates) |  |  |
| 1. Record the care plan on the woman’s maternity record including planned continuity of care and key contact. |  |  |
| 1. Make sure the woman and her partner have made arrangements to get home safely. |  |  |
| **Medical termination of pregnancy** | | |
| 1. 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. |  |  |
| 1. Prepare the woman and her partner for what to expect during labour and delivery, including information on the likely appearance of the baby. |  |  |
| 1. 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. |  |  |
| 1. Ensure all staff seeing the women and partners before, during and after labour and birth are aware of the baby’s condition and communicate sensitively. |  |  |
| 1. Ensure continuity of carer where possible. |  |  |
| 1. Discuss the possibility of the baby showing signs of life at birth and what this will mean. |  |  |
| 1. Depending on gestation, the option of feticide may be discussed by the fetal medicine team. Ensure the woman and her partner understand why this is offered. If referral to another unit is required, ensure good communication between units. |  |  |
| 1. Enable the woman to have a partner or a support person with her at all times. |  |  |
| 1. With the woman’s consent, keep her partner or support person informed and be prepared to offer them emotional support. |  |  |
| 1. Prepare the woman for what she can expect regarding bleeding, pain and common emotional reactions after delivery, and who to contact if she has any concerns. |  |  |
| 1. Be aware that some women will want to take their baby/fetus home with them. |  |  |
| 1. 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/templates](http://www.nbcpscotland.org.uk/templates) |  |  |
| 1. If women and partners are not already fully aware of support organisations, explain how they can help and give contact details (see Useful Contacts). |  |  |
| 1. Explain a previous pregnancy loss form could be added to the woman’s notes, if she wishes - a template is available from [www.nbcpathway.org.uk/templates](http://www.nbcpathway.org.uk/templates) |  |  |
| 1. Record the care plan on the woman’s maternity record including planned continuity of care and key contact. |  |  |
| 1. Make sure the woman and her 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** | | |
| 1. 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. |  |  |
| 1. Prepare the woman and her partner for what to expect, depending on the gestation. |  |  |
| 1. If the woman and her partner need to attend another unit, explain why and ensure good communication between units. |  |  |
| 1. Ensure the woman and her 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. |  |  |
| 1. Ensure a follow up appointment has been arranged for the woman and her partner. |  |  |
| 1. Acknowledge the potential difficulty of having a baby who has died remaining alongside the living baby or babies. |  |  |
| 1. Prepare the woman and her partner for what they can expect during the remainder of the pregnancy, labour and birth. |  |  |
| 1. Tell the woman and her 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. |  |  |
| 1. 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 |  |  |
| 1. Offer referral for specialist psychological support if there are signs that might indicate PTSD or clinical depression. |  |  |

1. Marking the loss, making memories

|  | Y/N/P | *Resources or support needed?* |
| --- | --- | --- |
| 1. All women and partners regardless of gestation should be sensitively offered the opportunity to mark their loss and create memories. |  |  |
| 1. Do not make assumptions about what women and partners may want based on the gestation of their pregnancy, the anomaly diagnosed or the decision to end their pregnancy. |  |  |
| 1. Give women and partners time to reflect and decide what they want. |  |  |
| 1. Let women and partners know they can change their mind but respect a decision when one has been made. |  |  |
| 1. 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. |  |  |
| 1. 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. |  |  |
| 1. 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. |  |  |
| 1. 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/templates](http://www.nbcpscotland.org.uk/templates) |  |  |
| 1. Options to discuss with women and partners, if appropriate  * washing and dressing the baby * photographs * hand and footprints * certificate of loss - a template certificate is available from [www.nbcpscotland.org.uk/templates](http://www.nbcpscotland.org.uk/templates) * other mementos * memory box. |  |  |
| 1. 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. |  |  |

1. After the loss

|  | Y/N/P | *Resources or support needed?* |
| --- | --- | --- |
| *Post mortem examination and histology* | | |
| 1. 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. |  |  |
| 1. Sensitively explain why post mortem is offered. |  |  |
| 1. 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. |  |  |
| 1. Make sure the discussion about post mortem takes place in a quiet and private place, at an appropriate time and is not rushed. |  |  |
| 1. Inform the woman and partner if the post mortem examination will take place at a different hospital and explain where and why. |  |  |
| 1. Explain that all transport arrangements and handling of the baby will be respectful and caring and who will be responsible for this. |  |  |
| 1. 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 |  |  |
| 1. Make sure anatomical pathology technicians and/or pathologists are aware of any specific cultural or religious requirements or special requests from the family. |  |  |
| 1. Ensure any small objects or keepsakes such as a hat or cuddly toy that accompany the baby are returned following the investigation |  |  |
| 1. Identify named key contacts within pathology and maternity who will be responsible for following up on results. |  |  |
| *Registration and certification* | | |
| 1. Offer to provide a ‘certificate of loss’ from the hospital - a template is available from [www.nbcpathway.org.uk/templates](http://www.nbcpathway.org.uk/templates) |  |  |
| 1. If delivery 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/](http://www.miscarriageassociation.org.uk/information/for-health-professionals/guidance-miscarriages-occur-home/) |  |  |
| 1. If the baby is stillborn after 24 weeks’ gestation, provide the women and partners with a medical certificate of stillbirth. |  |  |
| 1. 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. |  |  |
| 1. 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 her partner that the cause of death will be recorded as termination of pregnancy for fetal anomaly. |  |  |
| *Cremation, burial and funerals* | | |
| 1. 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 her partner may also make private arrangements outwith the hospital including burial at home. |  |  |
| 1. Provide the woman and her 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. |  |  |
| 1. If the woman and her 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. |  |  |
| 1. Verbal and/or written information should include |  |  |
| 1. The choices they have if they want the hospital to make arrangements and the costs, if any. |  |  |
| 1. The choices they have if they want to manage the arrangements, including burial at home information on local funeral directors if available. |  |  |
| 1. The time frame for making and communicating that decision. |  |  |
| 1. The hospital process if they do not make or communicate that decision within that time frame. |  |  |
| 1. Bear in mind and facilitate where possible different personal, religious and cultural needs and do not make assumptions. |  |  |
| 1. Discuss the options for urgent burial and cremation where appropriate. |  |  |
| 1. Offer to refer the woman and her partner to the spiritual care/chaplaincy team if contact has not already been offered. |  |  |
| 1. Record all decisions made by the woman in her maternity record, including where information is declined or no decision is made. |  |  |
| 1. See also Scottish government guidance on the sensitive disposal of pregnancy losses up to & including 23 weeks and 6 days gestation <http://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](http://www.rcn.org.uk/professional-development/publications/pub-007321) |  |  |

1. Before discharge

|  | Y/N/P | *Resources or support needed?* |
| --- | --- | --- |
| 1. Recognise the complexity when discussing the woman’s continuing care and physical changes to her body. |  |  |
| 1. Depending on gestation, discuss lactation and milk suppression. |  |  |
| 1. Discuss physical changes to the woman’s body and who to contact if she has any concerns. |  |  |
| 1. 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. |  |  |
| 1. Discuss with the woman or partner the difficult emotions they may experience to reassure them that feelings of grief and loss are common. |  |  |
| 1. Sensitively explain that physical postnatal checks are not routinely offered but the woman can ask to see the GP. |  |  |
| 1. 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. |  |  |
| 1. 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 be added to her notes - a template is available from <http://www.nbcpathway.org.uk/templates> |  |  |
| 1. 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. |  |  |
| 1. Consider NICE guidance on antenatal/postnatal mental health <http://www.nice.org.uk/guidance/qs115>and SIGN guidance on perinatal mood disorders <https://www.sign.ac.uk/our-guidelines/management-of-perinatal-mood-disorders/> |  |  |
| **Feedback** | | |
| 1. Discuss with the woman and her partner the channels available for giving feedback about the bereavement care they receive. Ensure any verbal feedback is recorded. |  |  |
| 1. Ensure women and partners are asked for feedback on the care they have received at their follow up appointments and by their key contact. |  |  |

1. Support in the community

|  | Y/N/P | *Resources or support needed?* |
| --- | --- | --- |
| 1. Offer women and partners a telephone call and/or home visit when they are back in the community. GPs should consider writing a letter expressing sorrow and offer an appointment. |  |  |
| 1. The loss should be coded in the GP notes and references to an ongoing pregnancy cancelled. |  |  |
| 1. Ensure good follow up care is provided for the partner as well as woman. |  |  |
| 1. Allow enough time to offer emotional support as well as check the mother’s physical health. |  |  |
| 1. Discuss with the woman or partner the difficult emotions they may experience to reassure them that feelings of grief and loss are common. |  |  |
| 1. Offer to discuss with women and partners how to talk about the baby who died with existing siblings. |  |  |
| 1. Ensure ongoing care is available where it is needed. |  |  |
| 1. 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/templates](http://www.nbcpscotland.org.uk/templates) |  |  |
| 1. 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. |  |  |
| 1. 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. |  |  |
| 1. Offer referral for specialist psychological support if there are signs that might indicate PTSD or clinical depression, and, if appropriate, for mental health assessment. |  |  |
| 1. Consider NICE guidance on antenatal/ postnatal mental health [www.nice.org.uk/guidance/qs115](http://www.nice.org.uk/guidance/qs115) and SIGN guidance on perinatal mood disorders <https://www.sign.ac.uk/our-guidelines/management-of-perinatal-mood-disorders/> |  |  |
| **Follow up meeting** |  |  |
| 1. Remember to keep within the scope of your practice when providing information, explaining procedures or answering questions. |  |  |
| 1. Help the woman and her partner to consider questions they want to ask before this meeting. |  |  |
| 1. Allow enough time for women and partners to understand information and ask their questions. |  |  |
| 1. Pay attention to the woman and her partner’s emotional wellbeing as well as physical needs |  |  |
| 1. Discuss care for potential future pregnancies and what, if anything, can be done to reduce risk |  |  |
| 1. 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. |  |  |
| 1. Provide women and partners with a letter summarising their follow up meeting and send a copy to their GP. |  |  |