Please note this document is an extract from the pathway to be used to record your self assessment. Please use the [Neonatal Death Pathway](https://www.nbcpscotland.org.uk/neonatal-death/) 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** |  |

## If a baby may die

|  | 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. Offer a quiet, private space to talk to the family, away from the cot and other families. Ideally this should be a comfortable, private room.
 |  |  |
| 1. Make sure there is an ongoing discussion with the family about trying to understand if, why and when their baby may die. If the mother is unwell or in a different unit, ensure she is included.
 |  |  |
| 1. Explain that it may take days or weeks to fully understand the underlying reasons. Share the known facts as they emerge, even though an underlying diagnosis or outcome has not been confirmed.
 |  |  |
| 1. Use a parallel care planning approach to manage active care while thinking about end of life care, taking account of the often unpredictable nature of this time. Fully involve the family in discussions and understanding their wishes about
 |  |  |
| * 1. what deterioration means and how this will be managed
 |  |  |
| * 1. changes in care and treatment that focus on comfort near end of life
 |  |  |
| * 1. organ donation
 |  |  |
| * 1. place of end of life care and transport options
 |  |  |
| * 1. care for the baby and family after death
 |  |  |
| * 1. memory making and family support
 |  |  |
| * 1. communication with primary and secondary care staff involved with the family, including the primary midwife if the mother is still receiving midwifery care, and/or the health visitor.
 |  |  |
| 1. If a lethal anomaly has been diagnosed in utero, much of this discussion can take place before birth.
 |  |  |
| 1. Let the family know a Perinatal Mortality Review will take place.
 |  |  |
| 1. Ensure that family support is included in all care planning – emotional, social, family and spiritual support.
 |  |  |
| 1. Try to do as much planning as early as possible so that the end of the baby’s life can be as well prepared for, and as quiet and private as possible.
 |  |  |
| 1. Prioritise continuity of care in line with Getting It Right for Every Child (GIRFEC) and confirm a key contact (named person) who will support and coordinate care, including bereavement care, right through the family’s journey. For GIRFEC, see [www.gov.scot/policies/girfec/](http://www.gov.scot/policies/girfec/)
 |  |  |
| 1. Record the care plan on the baby’s record including planned continuity of care and key contact.
 |  |  |
| 1. Sometimes a baby dies unexpectedly and quickly. In this situation, staff should focus on explaining known facts, end of life care and memory making.
 |  |  |
| 1. If parents have had a multiple birth, they face the challenge of preparing for the possibility their baby/babies may die whilst caring for their other baby/babies. Support the family by focussing equally on the baby/babies who may die and the sibling or siblings.
 |  |  |

## B. When a baby is deteriorating and dying

|  | 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.
 |  |  |
| *First steps* |
| 1. Explain what has happened, what is known and what happens next.
 |  |  |
| 1. Review the family’s care plan and their wishes about care as their baby becomes more unwell and end of life care.
 |  |  |
| 1. Be clear about whether the baby is nearing end of life and try to give a sense of timescales if they can be predicted.
 |  |  |
| 1. If parents have had a multiple birth, they face the challenge of preparing for the possibility their baby/babies may die whilst caring for their other baby/babies. Support the family by focussing equally on the baby/babies who may die and the sibling or siblings.
 |  |  |
| *End of life care* |
| 1. Provide a quiet, private space to talk to the family and give them time to absorb the news. Ideally this should be a comfortable, private room.
 |  |  |
| 1. Check the care plan (see section A – If a baby may die)
 |  |  |
| * 1. make sure the family remain fully involved in planning
 |  |  |
| * 1. listen carefully and provide enough time for them to think about their wishes
 |  |  |
| * 1. let the family know they can change their mind and any timescales that would limit other choices.
 |  |  |
| 1. Ensure the family understands the planned changes in care up until the end of life, and that their baby will be kept pain free and comfortable throughout.
 |  |  |
| 1. Review choices about place of end of life – in the hospital, at home or a hospice or another location and transport options. If in the hospital, provide a quiet, private room.
 |  |  |
| 1. Explain what to expect in terms of the changes in the baby’s appearance and responses as the baby dies. Talk about the opportunities to cuddle, bathe and dress their baby and to use a cuddle cot.
 |  |  |
| 1. Check primary and secondary health professionals have been made aware the baby is dying and know what is happening next. Include the primary midwife if the mother is still receiving midwifery care, and/or health visitor. Remember staff from another hospital if the baby was transferred for care.
 |  |  |
| 1. Make sure all staff on the unit are aware what is happening so they can be sensitive to the family’s needs, dignity and privacy at this time.
 |  |  |
| 1. Think about other families on the unit who will be aware that a baby is dying and how to communicate and support them.
 |  |  |

## C. Memory making

|  | Y/N/P  | *Resources or support needed?* |
| --- | --- | --- |
| 1. Introduce memory making as soon as possible and share examples of what you can offer. This can happen from the point when it is known a baby may die and any item used in the baby’s care has the potential to be part of memory making.
 |  |  |
| 1. Give the family time to reflect and decide what they want and let them know they can change their mind at any time.
 |  |  |
| 1. When the baby has died, offer the family the opportunity to hold them, if they are not already doing so.
 |  |  |
| 1. Discuss with the family
* washing and dressing their baby
* photographs
* hand and foot prints
* memory box
* other memories and mementos.
 |  |  |
| 1. Complete the informed choice form to ensure the family are provided with options but do not feel pressured. ‘Creating memories – offering choices’, a template form, is available from [www.nbcpscotland.org.uk/templates](http://www.nbcpscotland.org.uk/templates)
 |  |  |

## D. After the death

|  | Y/N/P | *Resources or support needed?* |
| --- | --- | --- |
| 1. Introduce (or revisit) the following and explain the need for these, as far as possible trying to maintain continuity of care
* registration
* post mortem
* funeral arrangements
* clinical follow up
* Perinatal Mortality Review.
 |  |  |
| 1. Ensure local guidelines set out clearly who should lead these discussions and how staff in these roles should achieve continuity.
 |  |  |
| 1. Plan at least an hour for this discussion and ensure it takes place in a quiet, private place.
 |  |  |
| 1. This is complex and challenging information for the family. After you have explained, check they have understood what is involved, for example by using the Teach Back method. See NES Knowledge Network <http://www.healthliteracyplace.org.uk/toolkit/techniques/teach-back/> Remember you may need to revisit the conversation.
 |  |  |
| 1. Document the discussion in the baby’s medical record.
 |  |  |
| 1. Try to summarise in written information the processes and forms the family will need to engage with.
 |  |  |
| 1. Begin to discuss arrangements for discharge and find out the family’s wishes.
 |  |  |
| 1. Explain that a form can be added to the mother’s record to explain to staff that her baby has died if she wishes - a template is available from [www.nbcpathway.org.uk/templates](http://www.nbcpathway.org.uk/templates)
 |  |  |
| *Review and follow up* |
| 1. Inform parents about the process of perinatal mortality review and invite them to become involved in the review process and refer to the parent engagement materials - see [www.npeu.ox.ac.uk/pmrt/parent-engagement-materials](http://www.npeu.ox.ac.uk/pmrt/parent-engagement-materials)
 |  |  |
| 1. Ensure that the family know who their key contact is for the review period and, wherever possible, ensure this person is the same key contact they had during their baby’s parallel and end of life care planning.
 |  |  |
| 1. Explain that the family will be given flexibility on the timing of when and how they contribute their thoughts, comments and questions to the review. Check that the family are comfortable with where the appointment will take place. Explain that during the review process they will be asked about their preferences on how and when they would like to receive and discuss the review report.
 |  |  |
| 1. Explain the purpose of clinical follow up, both what the family can expect and what the follow up does not cover, and who can attend. Check the family are comfortable with where the appointment will take place. Ensure enough time has been allowed for this appointment. This follow up should be led by the team providing continuity of obstetric and midwifery care. If at all possible this appointment should also include feedback from the Perinatal Mortality Review.
 |  |  |
| *Post mortem examination* |
| 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 a post mortem is recommended. You may find the NES video for professionals useful preparation [Discussing Authorised (Hospital) Post Mortem Examination after Stillbirth or Neonatal Death](http://www.sad.scot.nhs.uk/bereavement/pregnancy-loss-stillbirth-and-neonatal-death/).
 |  |  |
| 1. Tell the parents 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 the family of the likely timescales for the return of the baby’s body and the results.
 |  |  |
| 1. Identify a named contact within pathology who will be responsible for following up on results.
 |  |  |
| 1. Ensure any small objects or keepsakes such as a hat or cuddly toy that the family sent with their baby are returned following the investigation.
 |  |  |
| 1. Ensure that you are aware of relevant statutory death review processes and that these link with your Board’s internal processes – e.g. morbidity and mortality (M&M) meeting, Adverse Event Review, Perinatal Mortality Review –and inform the family as appropriate.
 |  |  |
| *Registration and certification* |
| 1. Provide the family with the medical certificate certifying the neonatal death, having carefully checked that the information is accurate.
 |  |  |
| 1. In addition to providing written information, sensitively explain the national death registration process, including where and how to register, and the need to register both the birth and the death.
 |  |  |
| 1. Ensure the family have any other information the registrar will need.
 |  |  |
| *Funerals* |
| 1. Provide the family with information around the legal requirements and local funeral directors.
 |  |  |
| 1. Explain that baby funerals are free in Scotland, although there may be a charge for a plot and there will be a charge for a headstone.
 |  |  |
| 1. Let the family know that a financial support payment available to families on low income via Social Security Scotland.
 |  |  |
| 1. Bear in mind, and facilitate where possible, different personal, religious and cultural needs. Do not make assumptions.
 |  |  |
| 1. Discuss the options for urgent burial and cremation with the family where appropriate.
 |  |  |
| 1. Offer to refer the family to the spiritual care/chaplaincy team.
 |  |  |
| 1. Inform all primary and secondary healthcare staff involved in the care of the family and baby that the baby has died, including any referring units before discharge and within 24 hours.
 |  |  |
| 1. Record a neonatal death on the risk reporting system.
 |  |  |
| 1. Record all decisions made in the baby’s record, including where information is declined, or no decision is made.
 |  |  |

## E. Preparing for discharge

|  | Y/N/P  | *Resources or support needed?* |
| --- | --- | --- |
| 1. Give the family time to ask questions about who is caring for their baby, where their baby is being cared for, and who to contact when they have left the hospital.
 |  |  |
| 1. If appropriate psychological support is available, immediately and longer term, offer the opportunity to take the baby home or out of the hospital environment - a template form is available from [www.nbcpscotland.org.uk/templates](http://www.nbcpscotland.org.uk/templates) Refer to local guidelines on taking a baby home, e.g. informing Police Scotland.
 |  |  |
| 1. Sensitively discuss the options for donating or suppressing milk.
 |  |  |
| 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 parent, a family member or a nominated health professional. However there is no need to cancel if they prefer to have the box.
 |  |  |
| 1. Discuss the emotions the family may experience and let them know they are common. Make sure the family knows how to access emotional support, have information and offer to help make contact if they wish. Information includes
 |  |  |
| * 1. their key contact, ongoing plan of care, and follow up appointment
 |  |  |
| * 1. how to contact the spiritual care/chaplaincy team, offer to contact on their behalf
 |  |  |
| * 1. how to access emotional support available from NHS Boards and primary care team
 |  |  |
| * 1. contacts for support organisations and how they can help
 |  |  |
| * 1. offer to help make contact if they wish.
 |  |  |
| 1. Consider NICE guidance QS115 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 [www.sign.ac.uk/our-guidelines/management-of-perinatal-mood-disorders/](http://www.sign.ac.uk/our-guidelines/management-of-perinatal-mood-disorders/)
 |  |  |
| 1. Check all primary and secondary healthcare staff, including referring units have been informed that the baby has died. This should be within 24 hours of the neonatal death.
 |  |  |
| 1. Make sure that staff have reported a neonatal death through the Board’s risk reporting system.
 |  |  |
| 1. Document final agreed arrangements in the baby’s medical record and communicate these to primary care colleagues.
 |  |  |
| 1. Make sure there is a clear handover from the paediatric team to primary care teams. This should be in written form and documented on the baby’s medical record.
 |  |  |
| 1. Make sure the family know whom to contact for their healthcare needs from this point onwards.
 |  |  |
| *Feedback* |  |  |
| 1. Explain to the family that feedback about their care is helps the Board understand if they received the appropriate care and that staff will ask families about their experience at follow up appointments. Ensure any verbal feedback is recorded. Explain how anonymous feedback could be given, if preferred.
 |  |  |
| 1. If they are comfortable about being asked for feedback then let them know how and when they will be contacted. Document if a family are in agreement with this.
 |  |  |
| 1. Consider using the Maternity Bereavement Experience Measure (MBEM) to capture parent feedback <http://www.sands.org.uk/maternity-bereavement-experience-measure-mbem>
 |  |  |
| 1. Be clear with the family that feedback they give for this purpose is not part of a review of the baby’s death nor a complaints process.
 |  |  |

## F. Support in the community

|  | Y/N/P  | *Resources or support needed?* |
| --- | --- | --- |
| 1. On hearing of the neonatal death
 |
| * 1. the GP should send a letter expressing sorrow to the family and offer an appointment, preferably a home visit
 |  |  |
| * 1. if the mother is still receiving midwifery care, the primary midwife should arrange a home visit as soon as possible.
 |  |  |
| 1. Check the family has all the information on the different types of emotional and bereavement support available and how to make contact. Continue to offer to help them make contact if they wish.
 |  |  |
| Check the family knows who their primary healthcare team is and who they should contact. |  |  |
| Check the family knows when the clinical follow up appointments are and if they need any help to consider questions they want to ask before their appointment. Remind them what the follow up does and does not cover, and who can attend. Offer to attend the appointment with them. |  |  |
| 1. Offer referral for specialist psychological support if there are signs of PTSD or clinical depression and, if appropriate, for mental health assessment for the family including siblings. Consider NICE guidance QS115 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 [www.sign.ac.uk/our-guidelines/management-of-perinatal-mood-disorders/](http://www.sign.ac.uk/our-guidelines/management-of-perinatal-mood-disorders/)
 |  |  |
| *Perinatal Mortality Review* |  |  |
| Confirm the family’s wishes about being involved in the perinatal mortality review process, and when and how they can contribute. Check whether and how they want to be informed of the outcomes of the review of their baby’s death. |  |  |
| 1. Prompt the family to think about their questions and comments beforehand. A form to help the family do this is available from the Parent engagement materials on the Perinatal Mortality Review Tool (PMRT) website [www.npeu.ox.ac.uk/pmrt/parent-engagement-materials](http://www.npeu.ox.ac.uk/pmrt/parent-engagement-materials)
 |  |  |
| 1. Ensure the review looks at the family’s clinical and emotional care, and covers the whole pathway of care, with input from community healthcare professionals.
 |  |  |
| 1. Meet with the family to consider their clinical and emotional care, discuss any results of investigations, explain the Perinatal Mortality Review report and answer their questions. Wherever possible, this meeting should be with the senior paediatrician who has provided continuity of care.
 |  |  |
| 1. Continue to check a family has information about support services and how to contact them and offer to help with this.
 |  |  |
| 1. Carefully share ongoing information between the GP and health visitor (and primary midwife if involved), with the family’s key contact acting as coordinator.
 |  |  |
| 1. Ensure primary care staff are aware of the timing of and outcomes from clinical follow up and the Perinatal Mortality Review.
 |  |  |
| 1. Arrange a final handover from the paediatric team to primary care team when appropriate and make sure the family know whom to contact from this point onwards.
 |  |  |