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

## Initial response

|  | Y/N/P  | *Resources or support needed?* |
| --- | --- | --- |
| *At all times* |
| 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 care and support to the whole family, including step and extended families.
 |  |  |
| 1. Keep an open mind about how families react. There is no right or wrong reaction to sudden death and grief, and anger is a common expression of emotion.
 |  |  |
| 1. Be aware that families often blame themselves, no matter what the circumstances – they will often already be aware of their specific risk factors.
 |  |  |
| 1. There are known risk factors for sudden infant death syndrome (SIDS), but these are not causes of death – take care to avoid suggesting guilt when discussing these. Use phrases such as ‘would you like to tell me what happened’ rather than ‘why didn’t you?’ Say you are sorry and acknowledge the distress.
 |  |  |
| 1. Keep the family informed and give realistic time scales and honest information keeping to known facts, however difficult this is.
 |  |  |
| 1. Understand that the presence of police, even when not in uniform, will have an impact on the family and the wider community, and avoid using terms such as ‘suspicious death’ and ‘crime scene’.
 |  |  |
| *When talking with families* |
| 1. Communicate sensitively and be aware of your language and non-verbal signals.
 |  |  |
| 1. Listen effectively – it is a very important skill that families will often remember.
 |  |  |
| 1. Introduce yourself, your name, your role and what you are going to do.
 |  |  |
| 1. Find out the baby’s and parents’ names and use them.
 |  |  |
| 1. Use simple direct language including the words ‘died’, avoid euphemisms and do not be overly apologetic.
 |  |  |
| 1. Give information plainly and invite questions as you go along.
 |  |  |
| 1. Don’t assume someone else has given any information to families.
 |  |  |
| 1. Establish and confirm what happens next.
 |  |  |
| *Arrival of services*  |
| 1. Most unexpected infant deaths are found by their families, who will call an ambulance. The initial 999 call will request an ambulance and also notify Police Scotland, who will also attend. Be aware that this is an extremely distressing experience for families, who will often not be expecting the police. Reassure parents that police involvement is routine.
 |  |  |
| 1. The family should be supported to attend the hospital, either travelling with their baby in the ambulance, or separately. Consider the needs of other children or family members. Attending police may be able to assist with these arrangements.
 |  |  |
| *On arrival at the hospital[[1]](#footnote-1)* |
| The SUDI toolkit provides a timeline giving an overview of how all professionals are involved in a SUDI and how they interact [www.sudiscotland.org.uk/process-overview/](http://www.sudiscotland.org.uk/process-overview/)  |  |
| 1. At the hospital, allocate a lead healthcare professional to the family and keep them fully informed, in an appropriate quiet and private space.
 |  |  |
| 1. Where resuscitation is ongoing, it is good practice to allow the parents to remain present if they wish to and ensure they are supported.
 |  |  |
| 1. Reiterate that Police and Procurator Fiscal involvement is routine in all sudden and unexpected deaths as required by law in Scotland. Families should know that these professionals will be involved from the outset and that their role is not to investigate families but to help find out what happened to their child.
 |  |  |
| 1. Working collaboratively, ensure that police presence is as discreet as it can be, given their need to be present. For example, if there are two uniformed officers present, quietly discuss the possibility of one staying close to the family without their radio whilst the other could take on the role of communicating with colleagues and is not in the room.
 |  |  |
| *When death is confirmed* |
| 1. Give families as much opportunity to be with their baby at this stage as possible.
 |  |  |
| 1. Provide a quiet, private and comfortable space away from the main clinical area if possible.
 |  |  |
| 1. Explain someone will remain with them at all times to give support so they won't be left on their own, but staff will be as discreet as possible and give them space.
 |  |  |
| 1. Give the family as much time as they need.
 |  |  |
| 1. Ensure the family hold their baby if that is possible.
 |  |  |
| 1. Wherever possible, assign two people to care for the family, as they are likely to be with them for up to 5-6 hours and staff will need to take drinking and toilet breaks.
 |  |  |
| 1. In early interviews, carefully balance the needs of the information gathering with the shock, trauma and grief of families. Wherever possible, work jointly with other professionals to save the family from needing to repeat the same information.
 |  |  |
| 1. If the baby who died was from a multiple birth, reassure the family as far as possible about their other baby or babies and explain they can be provided with an apnoea monitor by the Scottish Cot Death Trust. Where possible, the surviving baby or babies should be admitted for observation.
 |  |  |
| *Before the family leave hospital* |
| 1. Support the family with practical arrangements, such as where they will stay because they will not be able to return home immediately due to the early police investigation. Reference your own NHS board’s policy on this.
 |  |  |
| 1. Ask about any medicines or essential items which any family member may need so they can be provided by Police Scotland to the family as quickly as possible. Consider a family photograph or photograph of the baby and/or comforter toys for siblings as essential items.
 |  |  |
| 1. Explain paediatric post mortems are highly specialised and the baby will be transferred to a paediatric pathology centre and, if known at that time, say which centre that will be.
 |  |  |
| 1. Reassure the family their baby will be travelling safely to the paediatric pathology centre and handled with respect. Explain it is likely that another family member will need to formally identify the baby there – and this may require the parent/family member to travel.
 |  |  |
| 1. Provide contact details for a key healthcare professional who will answer the family’s questions and provide updates. Use the SUDI Toolkit’s ‘What happens next?’ leaflet <https://www.sudiscotland.org.uk/wp-content/uploads/2015/06/what_happens_next_parent_leaflet.pdf>
 |  |  |
| 1. Give the family contact details of support organisations and bereavement counselling and provide the leaflet (above) from the Emergency Department SUDI pack
 |  |  |
| 1. Explain the emotional support available via your hospital and primary care colleagues.
 |  |  |
| 1. Offer contact with the chaplaincy team and explain how they can support families, noting they can liaise with religious and spiritual advisers of all local faiths and humanist celebrants.
 |  |  |
| 1. **Identify the key healthcare contact for any questions the family have.**
 |  |  |
| 1. **Notify the GP (ideally by email or urgent fax) to inform the practice about the baby’s death and to request no further appointments for immunisation or developmental checks are sent out.**
 |  |  |
| 1. **Inform the hospital medical records department to ensure no clinic appointments are sent.**
 |  |  |
| 1. **Inform the family that any future routine health check or immunisation appointments will be cancelled.**
 |  |  |

## Memories and mementos

|  |  |  |
| --- | --- | --- |
|  | Y/N/P  | *Resources or support needed?* |
| 1. Sensitively explain to the family that no mementos can be offered in the Emergency Department due to the legal processes.
 |  |  |
| 1. Let the family know mementos will be offered by mortuary staff who will ensure that a lock of hair, hand and footprints and photographs are offered.
 |  |  |
| 1. Discuss the opportunities to see and hold baby again after the post mortem has taken place.
 |  |  |
| 1. If the pathology centre will be geographically quite far away, do not assume that families may or may not want to travel to see baby there but do say they can see and hold their baby again at their funeral directors.
 |  |  |

## After death is confirmed

|  | Y/N/P  | *Resources or support needed?* |
| --- | --- | --- |
| *Procurator Fiscal and 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 to the family that they will not be able to register the death or arrange the funeral for some time as the death will be referred to the Procurator Fiscal.
 |  |  |
| 1. Explain that the Procurator Fiscal will order a post mortem investigation, and that the family will not be able to choose whether this takes place. This may be very difficult for some families, and this should be acknowledged.
 |  |  |
| 1. Ensure families are aware they can choose to see, hold and spend time with their child again after the post mortem examination is complete.
 |  |  |
| 1. Support the family to understand that their baby’s body will not be released for funeral until certain investigations are complete.
 |  |  |
| 1. Explain a named support professional within the Procurator Fiscal service will have regular contact with the family and will update them on results awaited and likely timescales.
 |  |  |
| 1. Bear in mind that the baby’s body will often have to travel, sometimes long distances, to a specialist centre for the post mortem examination and this can be very upsetting for families.
 |  |  |
| 1. Remind families their key healthcare professional will keep them up to date with where their baby has been moved to and when the post mortem examination is going to take place. The paediatric pathologist should contact the key healthcare professional, and also parents if appropriate, to say who they are, where and when the post mortem will take place and offer to meet with them to explain results.
 |  |  |
| 1. Take care to ensure the family receives timely, sensitive responses to any questions and are supported with any decisions they need to make.
 |  |  |
| *Registration of death and funeral* |
| 1. Explain to the family that:
 |  |  |
| * 1. a funeral can only take place once an initial death certificate is issued by the pathologist, pending further investigations. Ask the pathologist for likely timing.
 |  |  |
| * 1. once all post mortem results are available, a final death certificate will be issued which may have an amended cause of death.
 |  |  |
| * 1. the Procurator Fiscal investigation and post mortem tests can take many months.
 |  |  |
| 1. It is likely that a period will now have passed since baby’s death and it is maybe a different healthcare professional working with families. These professionals should encourage families to consider the different options for a funeral. Funeral directors are experts in bereavement care and will support families to make the best decision for them in advance of the funeral.
 |  |  |
| 1. Funeral directors in Scotland offer a simple funeral free of charge. Ensure that families are aware of this and that they are also aware of any hidden costs such as order of service printing, coffin costs if the one on offer is not used, flowers and so on
 |  |  |
| 1. Verbal and/or written information should include financial support payment available to families on low income via Social Security Scotland.
 |  |  |

## Continuing care

|  | Y/N/P  | *Resources or support needed?* |
| --- | --- | --- |
| *Follow up meetings and contact* |  |  |
| 1. **Explain that although routine health check or immunisation appointments have been cancelled, any that are computer generated, may already be in the process of being sent. Acknowledge that these may be distressing to receive and that any which do arrive can be returned**
 |  |  |
| 1. The key healthcare contact, identified before the family left the hospital, should reach out and ideally offer to meet face to face in addition to having scheduled phone calls.
 |  |  |
| 1. When arranging updates for the family, either about their baby’s death or the support and care they have received:
 |  |  |
| * 1. give as much notice of meetings as possible, and an indication of what each meeting is about
 |  |  |
| * 1. allow plenty of time for families to ask questions and consider how to invite the family to prepare their questions in advance.
 |  |  |
| * 1. having liaised with key professional partners (e.g. Procurator Fiscal), share results of investigations with families face to face rather than in the post or via email.
 |  |  |
| * 1. ensure the family understand the information that is given to them and have access to professionals who can explain each part.
 |  |  |
| * 1. offer to liaise with other agencies on the family’s behalf.
 |  |  |
| * 1. offer information about organisations and services offering emotional and psychological support.
 |  |  |
| 1. Explain that a SUDI review is for infants aged between 0 -24 months and that this may take place several months after the baby or infant has died. See [www.sudiscotland.org.uk/sudi-review](http://www.sudiscotland.org.uk/sudi-review)
 |  |  |
| 1. Inform the family as appropriate of other child death review processes e.g. Perinatal Mortality Review (PMR), and your local internal processes for example the Morbidity and Mortality [M&M] meeting, Significant Adverse Event (SAE) review and significant case review [SCR].
 |  |  |
| 1. Make sure the family know how they can give feedback on the care and support they have received to hospitals and other care services and advise they could share their stories via Care Opinion [www.careopinion.org.uk](http://www.careopinion.org.uk)
 |  |  |
| *Support in the community* |
| 1. Know the family’s circumstances and the stage of the investigation before you make any contact.
 |  |  |
| 1. Offer the family a telephone call and/or an appointment when they are back in the community. GPs should consider writing a letter expressing sorrow.
 |  |  |
| 1. Provide details of support services, locally and nationally, at every available contact. There can often be long periods where there is no information, and families can find these quiet times the most difficult to get through.
 |  |  |
| 1. Encourage families to seek support from their health visitor or primary midwife if they are particularly struggling with issues such as sleep or re-living the time when their baby died.
 |  |  |
| 1. Be conscious of additional needs for the whole family and that that the death may trigger other issues including housing, schooling, employment and financial problems. Be prepared to help families get appropriate advice.
 |  |  |
| 1. Depending on the previous involvement with the family, and especially if there are other pre-school children, tailor ongoing health visiting care.
 |  |  |
| 1. Do not assume multi-agency communication is happening (although it is an essential part of the process) or that everyone, including you, has the most up-to-date information.
 |  |  |
| 1. Refer families to specialist counselling and bereavement support at any time. The process following the sudden death of a baby is often so traumatic that families may not seek specialist support for several weeks or months, once the contact from professionals has become less frequent. Be mindful that counselling therapy/ trauma therapy offered by support services may be more quickly available than NHS services.
 |  |  |
| 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 for parents/siblings.
 |  |  |
| 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/>
 |  |  |

## SUDI Review

|  |  |  |
| --- | --- | --- |
|  | Y/N/P  | *Resources or support needed?* |
| The SUDI toolkit sets out the review process [www.sudiscotland.org.uk/sudi-review/](http://www.sudiscotland.org.uk/sudi-review/) |
| 1. [Inform the family that a SUDI Review is taking place. The meeting is held shortly after the final post mortem examination report is available, which may be several months after the infant has died.](http://www.lullabytrust.org.uk/childdeathreview)
 |  |  |
| 1. Explain that although the family would not usually be involved in the discussion between professionals, they will be kept informed and should be asked to contribute their feedback and questions if they choose to.
 |  |  |
| 1. Actively encourage the family to ask questions and give feedback about their concerns or experiences through a midwife, health visitor, GP or paediatrician, making it clear their experience will be integral to the learning outcomes from the meeting
 |  |  |

1. In rare cases, a baby can die suddenly and unexpectedly on the postnatal ward. Although families can go home immediately, the same bereavement care set should be used. [↑](#footnote-ref-1)