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

national bereavement care pathway for pregnancy and baby loss

Sudden, unexpected death in infancy (SUDI)

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 families of a baby who has died suddenly and unexpectedly in infancy up to 24 months of age. Bereavement care is a continuing process and should be provided by all staff caring for those who have experienced SUDI. 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/SUDI**.

'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.

Initial response

Aim to ensure everyone, including first responders, understands the significance of their communication with the family and one another and acts with care and compassion. Be familiar with the processes and refer to the SUDI Scotland toolkit for guidance.

Families tell us the way staff speak and act at this initial stage has a lasting impact on their bereavement journey. It is a traumatic situation and one in which they feel vulnerable. They need staff to tell them sensitively what is happening, why it happens and what will happen next.

What do we need to do?

At all times

- 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.
- Offer care and support to the whole family, including step and extended families.
- 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.
- Be aware that families often blame themselves, no matter what the circumstances – they will often already be aware of their specific risk factors.
- 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.
- Keep the family informed and give realistic time scales and honest information keeping to known facts, however difficult this is.
- 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

- Communicate sensitively and be aware of your language and non-verbal signals.
- Listen effectively – it is a very important skill that families will often remember.
- Introduce yourself, your name, your role and what you are going to do.
- Find out the baby's and parents' names and use them.
- Use simple direct language including the words 'died', avoid euphemisms and do not be overly apologetic.
- Give information plainly and invite questions as you go along.
- Don't assume someone else has given any information to families.
- Establish and confirm what happens next.

Arrival of services

- 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.

"Our baby son died in the car travelling. Death was confirmed by the doctor at a local hospital, where we stopped and discovered he was dead. An ambulance was called and drove ahead of us to show us the way to the hospital. Apart from the doctor who was a GP who was called in, I don't remember seeing any staff at all and we had to just drive back."

- 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]

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/**

- At the hospital, allocate a lead healthcare professional to the family and keep them fully informed, in an appropriate quiet and private space.
- Where resuscitation is ongoing, it is good practice to allow the parents to remain present if they wish to and ensure they are supported.
- 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.
- 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

- Give families as much opportunity to be with their baby at this stage as possible.
- Provide a quiet, private and comfortable space away from the main clinical area if possible.
- 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.
- Give the family as much time as they need.
- Ensure the family hold their baby if that is possible.
- 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.
- 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.
- 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.

[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.

Initial response

Before the family leave hospital

- 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.
- 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.
- 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.
- 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.
- 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 **www.sudiscotland.org.uk/wp-content/uploads/2015/06/what_happens_next_parent_leaflet.pdf**
- Give the family contact details of support organisations and bereavement counselling (see Useful contacts) and provide the leaflet (above) from the Emergency Department SUDI pack
- Explain the emotional support available via your hospital and primary care colleagues.
- 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.
- Identify the key healthcare contact for any questions the family have.
- 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.
- Inform the hospital medical records department to ensure no clinic appointments are sent.
- Inform the family that any future routine health check or immunisation appointments will be cancelled.

"We were told that our baby would have to go back to [another town] for post-mortem, and I was upset that he couldn't be moved to [a different town], which would have been closer to home. I never got to see my son again. We were interviewed quite quickly by two police - the much younger girl was very efficient, but the older man said nothing. I was told afterwards that he had found it one of the most upsetting experiences of his career."

How will we know we have achieved our aim?

- Families will tell us that they felt cared for and that they were kept informed of what was happening, why it happens and what they could expect next. They will tell us that no judgements on how their baby died were made at this early time by staff and that they felt that staff put their needs first.
- Staff will tell us they feel confident and competent providing information about the early actions and being clear that, at this stage, no one can say why baby died and so legal procedures must be followed. They say their training has provided them with a knowledge of the SUDI Scotland toolkit and local SUDI processes, and they are aware they should not be process driven.

Memories and mementos

Aim to explain sensitively to the family the opportunities for seeing and holding their baby after post-mortem and for any mementos appropriate to the age of the baby.

Families tell us that opportunities for memories and mementos can be missed and at times inappropriate suggestions were made given the age of the baby, which added to their distress.

The steps within this section may span several days and several different scenarios depending on the circumstances and location of baby's death and post-mortem.

What do we need to do?

- Sensitively explain to the family that no mementos can be offered in the Emergency Department due to the legal processes.
- 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.
- Discuss the opportunities to see and hold baby again after the post-mortem has taken place.
- 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.

"We were assured we would get a lock of his hair, footprints etc. but when we asked about these in the following week we were informed we had not signed the correct paperwork at the hospital and could not get these … I am sure the hospital staff would have been devastated this had happened to us if they knew. Our Funeral Director ensured we had his hand and footprint to keep. I would be utterly devastated if I had not got these."

How will we know we have achieved our aim?

- Families will tell us they understood the opportunities to see and hold their baby after post-mortem and to have mementos. They will say their options and the legal limitations were sensitively explained in a way that increased comfort rather than causing added distress.
- Staff will tell us they feel confident and competent to explain the choices families have for seeing and holding the baby and mementos after they leave the Emergency Department.

After death is confirmed

Aim to openly and sensitively talk about what happens after a sudden and unexpected death and the legal processes that will need to take place. Provide information without giving misleading timescales and always offer to refer families to organisations providing long term support.

Families tell us that they can feel abandoned, afraid and often are left alone, not knowing what will happen next. A lot of different staff become involved very quickly from different agencies and this can be overwhelming..

What do we need to do?

Procurator Fiscal and post-mortem examination

- 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.
- 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.
- 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.
- Ensure families are aware they can choose to see, hold and spend time with their child again after the post-mortem examination is complete.
- Support the family to understand that their baby's body will not be released for funeral until certain investigations are complete.
- 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.
- 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.
- 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.
- Take care to ensure the family receives timely, sensitive responses to any questions and are supported with any decisions they need to make.

"The care from the hospital staff. There was none. No one spoke to me, I was left in a room on my own with no one with me. No idea where my other 2 kids (age 3&2) were and then a doctor came in and said "your daughter is dead" that exact phrase. And then I was approached by police and told they were taking her for a post-mortem. They gave me no time with her and I didn't see her again till in the funeral home."

"I tried to be as open as possible. Even 4 years later the words and lack of sympathy hurt more than I can describe in words. I was 20 years old, my baby was only 5 weeks, I was still recovering from her birth but the sheer coldness of so many 'professionals' was unbelievable."

Registration of death and funeral

- Explain to the family that:
  - 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.
  - once all post-mortem results are available, a final death certificate will be issued which may have an amended cause of death.
  - the Procurator Fiscal investigation and post-mortem tests can take many months.
- 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.
- 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
- Verbal and/or written information should include financial support payment available to families on low income via Social Security Scotland (see useful contacts)

How will we know we have achieved our aim?

- Families will tell us that they were treated with kindness and compassion, had time with their baby and knew what would be happening in the following days and weeks. They will say they were fully informed of lengthy time scales.
- Staff will tell us they feel confident and competent providing bereavement care within the constraints imposed by the early police investigation and legal investigation. They will say they are clear about processes and timescales and fully able to explain these sensitively.

Continuing care

Aim to arrange ongoing contact with the family to keep them informed of what is happening and what will happen next. Ensure families feel well supported in managing this period of waiting, understand what is involved in the review and are offered referral to support organisations.

Families tell us that when they leave the hospital there is sometimes no care offered and if their baby did not go to the emergency department, there can be no central point of contact in the hospital for them to meet with or contact to ask questions.

What do we need to do?

Follow up meetings and contact

- 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
- 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.
- When arranging updates for the family, either about their baby's death or the support and care they have received:
  - give as much notice of meetings as possible, and an indication of what each meeting is about
  - allow plenty of time for families to ask questions and consider how to invite the family to prepare their questions in advance.
  - 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.
  - ensure the family understand the information that is given to them and have access to professionals who can explain each part.
  - offer to liaise with other agencies on the family's behalf.
  - offer information about organisations and services offering emotional and psychological support.
- 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**
- 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].
- 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**

Support in the community

- Know the family's circumstances and the stage of the investigation before you make any contact.
- 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.
- 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 (see Useful contacts).

"Our health visitor kept making visits which was very much welcome and the local doctor made a house visit as well which was appreciated. The one thing I will say though is that when you are been investigated and feel like you are the one to blame for the death of your child, any form of professional makes you worry that they are spying on you and are just waiting for you to slip up so they can take the rest of your life away as well. Everyone I came into contact with was lovely but they came loaded with questions and that made me feel very unsafe."

- 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.
- 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.
- Depending on the previous involvement with the family, and especially if there are other pre-school children, tailor ongoing health visiting care.
- 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.
- 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.

- 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.
- Consider NICE guidance on antenatal/ postnatal mental health **www.nice.org.uk/guidance/qs115** and SIGN guidance on perinatal mood disorders **http://www.sign.ac.uk/our-guidelines/management-of-perinatal-mood-disorders/**

How will we know we have achieved our aim?

- Families will tell us that they knew who to contact to ask questions or for guidance on what was happening, felt well supported in managing this period of waiting and were offered referral to support organisations at an appropriate time. They will say they understood what the review into their baby's death involved.
- Staff will tell us they feel confident and competent to identify and liaise with the key person supporting the family and when referring families to support organisations. They will say they feel fully able to explain the review meeting and sensitively invite families to contribute so that the families experience is fed into the meeting via a professional attending.

SUDI Review

Aim to have knowledge of the SUDI review process and to understand why this takes place, the importance of multi-agency representation and ensuring the family's voice is heard at the meeting.

Families tell us that they were not aware of the meeting taking place and/or that they could choose to express concerns or share their experience so they could better understand what happened to their baby as well as help other bereaved families in the future.

What do we need to do?

The SUDI toolkit sets out the review process **www.sudiscotland.org.uk/sudi-review/**

- 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.
- 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.
- 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

"We were referred to different resources and that's when we were offered genetic counselling about our older autistic boys. We waited 3 months for post-mortem even though we were told it would take 4 weeks."

"Every day we were checking the mail waiting, thinking, there has to be a reason. They retained tissue samples to work out if there was a cause. We haven't been told anything. The boys got sent for heart tests since you can only test hearts that beat. We were told one of the boys had an irregular heart beat and we had to follow that up. They just left us panicking about his irregular heart beat thinking he might drop dead and at any moment. We contacted a support organisation. That helped"

How will we know we have achieved our aim?

- Families will tell us they understood what the review into their baby's death involved, were invited to contribute in a way they felt was appropriate and understood the value of doing so.
- Staff will tell us they feel confident about what a SUDI review is, when it takes place and the importance of attending this meeting. They will say they feel confident and competent encouraging families to give feedback and contributing successfully to SUDI reviews.

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 the baby who died had a condition which could be an increased risk for future babies, and genetic counselling would be appropriate, make a referral.
- Make the family aware of the reassurance and support available through the Next Infant Support Programme **www.scottishcotdeathtrust.org/nisp**

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

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)

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 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**
- Check maternity record and/or clinical system for any flagged actions.
- Please be aware there may be families that do not wish to discuss the death at all and that the family may still not know why their baby died or may have a been given a cause which could have a bearing on this pregnancy.
- At an appropriate stage, sensitively discuss safe sleep for babies.
- If parents have chosen to have an apnoea monitor, check this has been received before 36 weeks.
- Make the family aware of the reassurance and support available through the Next Infant Support Programme **www.scottishcotdeathtrust.org/nisp**

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.
- Make sure the family feel confident using an apnoea monitor if they have one before they leave hospital.

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**
- Aim to offer a referral to paediatric services for reassurance appointments.

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.

Families 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?

See the SUDI toolkit for guidance on supporting staff **www.sudiscotland.org.uk/staff-support/**

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, 'burn-out' or mental health difficulties for example:
  - feeling 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 **https://www.sad.scot.nhs.uk/wellbeing/**

"The staff themselves were amazing. I could tell they were also visibly upset by what we were going through. Their support was overwhelming - we were not rushed to do anything and were very well looked after. The hospital itself was a small country hospital. I would say they rarely dealt with this type of situation and were a little unsure of protocols etc."

"The SUDI pathway covers such a massive spectrum that acknowledging engagement from nurses, doctors, A&E, ICU and children's ward is crucial. Our son was involved in an accident and was put in the SUDI bracket. It is imperative that the pathway is used in all these areas. Our experience was that the staff were not used to handling such traumatic situations, in small children, and as parents we were very aware of this."

How will we know we have achieved our aim?

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

Outcome measures

Aim to ensure the Board, units and services regularly assess the quality and consistency of their bereavement care and act to improve all families' experience.

Families 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 families to give feedback on each stage of their bereavement care for example via conversations at discharge and follow up appointments, contact with the service's or Board's feedback service and external channels such as Care Opinion **www.careopinion.org.uk**.
- Check feedback is actively sought, for example by prompting families to think about points they want to raise before they attend follow up appointments and reviews. Ensure feedback is recorded, shared and responded to.
- Ensure all staff who come into contact with families who experience SUDI are aware of and understand their role in the National Bereavement Care Pathway.
- Enable and support staff to give feedback on providing bereavement care for example via team meetings and debriefs.
- Ensure key staff, in particular the SUDI paediatrician, Emergency Department staff, health visitor/midwife, have undertaken communication training.

Outcome 2
Improvement measures are in place

What do we need to do?

- Carry out a baseline assessment of quality and consistency at each stage of bereavement care in your unit, service or Board.
- Review evidence from all channels for listening to feedback from women, 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 offering mementos
  - services attending SUDI reviews.
- 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 timeframe within which the aim should be achieved

How will we know we have achieved our aim?

- All units, services and Boards have named senior staff with responsibility for the quality and consistency of bereavement care following SUDI, are listening to all families and staff, and are implementing improvement plans.

Useful contacts

Key support organisations

Scottish Cot Death Trust

Scotland's only charity dedicated to sudden and unexpected deaths of babies. Dedicated one to one bereavement support, counselling and befriending for parents and grandparents. Sibling support and play therapy offered. Online group peer support and family days offered.

www.scottishcotdeathtrust.org/our-support-services

The Trust also provides a next infant support programme helping families during a next pregnancy and after the birth of the baby.

www.scottishcotdeathtrust.org/nisp

They work with bereaved and distressed families as well as offering bereavement support services to staff involved when a baby has died.

www.scottishcotdeathtrust.org/professionals

Held In Our Hearts (formerly Sands Lothians)

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

www.heldinourhearts.org.uk

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

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

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 Benefit Office

Parents can contact the Child Benefit Office at HM Revenues and Customs for information about eligibility, claiming and stopping Child Benefit.

www.gov.uk/government/organisations/ hm-revenue-customs/contact/child-benefit

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

Funeral Assistance

Funeral support payment available to families on low income via Social Security Scotland

www.socialsecurity.gov.scot

Jobcentre Plus – Bereavement Services Helpline

Provides information about benefits claims.
Telephone: 0345 608 8601

www.gov.uk/contact-jobcentre-plus

Lullaby Trust

Resources for professionals
(intended for England & Wales)

www.lullabytrust.org.uk/professionals

Milk Bank Scotland
Provides screened donor milk to babies who have no or limited access to their own mother's milk, often to babies born prematurely.

www.nhsggc.org.uk/your-health/health-services/milk-bank-scotland/

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

www.moneyadviceservice.org.uk

Multiple Births Foundation (MBF)
Provides support and information for multiple birth families (including bereavement support) and information for professionals.

www.multiplebirths.org.uk

National Association of Funeral Directors
Provide support and guidance for funeral firms and bereaved families using their services.

www.nafd.org.uk

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

www.naturaldeath.org.uk

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

www.ourmissingpeace.org

Registry Office
National Records for Scotland

www.nrscotland.gov.uk/registration

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

Society of Allied and Independent Funeral Directors (SAIF)

Independent funeral directors' national organisation.

www.saif.org.uk

Working Families
Provides information about parents' rights at work and to benefits after they experience miscarriage, stillbirth and neonatal death.

www.workingfamilies.org.uk/articles/miscarriage-stillbirth-and-neonatal-death-your-rights-at-work/

Their Family Friendly Working Scotland website offers free help and advice for working parents and carers

www.familyfriendlyworkingscotland.org.uk/employees/

Training and support resources

Resource	Type	Link
Perinatal Mental Health Resources	downloads	**www.inspiringscotland.org.uk/perinatal-mental-health-services/**
Bereavement following Pregnancy Loss and the Death of a Baby	e-learning	**www.knowledge.scot.nhs.uk/mater-nalhealth/learning/bereavement-following-pregnancy.aspx**
One chance to get it right: bereavement care	e-learning	**www.ilearn.rcm.org.uk/enrol/index.php?id=583**
NES nursing & AHP clinical supervision 1 - includes supportive resilience	e-learning	**learn.nes.nhs.scot/3653/clinical-supervision/clinical-supervision-unit-1-fundamentals-of-supervision**
NES Supporting Families around the Resuscitation of a Baby or Child	video	**Supporting Families around the Resuscitation of a Baby or Child**
NES Talking to children who are bereaved	video	**Talking to children who are bereaved**
NES Understanding the processes following a sudden or unexplained death	video	**Understanding the processes following a sudden or unexplained death**
Helping parents with mental health issues	webpage	**www.bestbeginnings.org.uk/helping-parents-with-mental-health-issues**
SUDI Professional Guidance	webpage	**www.sudiscotland.org.uk/professional-guidance/**
SUDI Review	webpage	**www.sudiscotland.org.uk/sudi-review/**
SUDI Timeline	webpage	**www.sudiscotland.org.uk/process-overview/**

SUDI staff support	webpage	**www.sudiscotland.org.uk/staff-support/**
Staff resilience	webpage	**www.sad.scot.nhs.uk/resilience/**
Teach Back Method	webpage	**www.healthliteracyplace.org.uk/toolkit/techniques/teach-back/**
Scottish Cot Death Trust advice for professionals	webpage	**www.scottishcotdeathtrust.org/professionals**
Held In our Hearts advice for professionals	webpage	**www.heldinourhearts.org.uk/hospital-support**
Lullaby Trust advice for professionals	webpage	**www.lullabytrust.org.uk/professionals**
SUDI Toolkit	webpages	**www.sudiscotland.org.uk**
Values based reflective practice	webpages	**www.knowledge.scot.nhs.uk/vbrp.aspx**
NICE guidance ante natal and postnatal mental health	webpages	**www.nice.org.uk/guidance/qs115**
SIGN guidance on perinatal mood disorders	webpage	**www.sign.ac.uk/sign-127-management-of-perinatal--mood-disorders.html**

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