

NBCP Bereavement Care toolkit

Care outside the hospital



national bereavement
care pathway
for pregnancy and baby loss



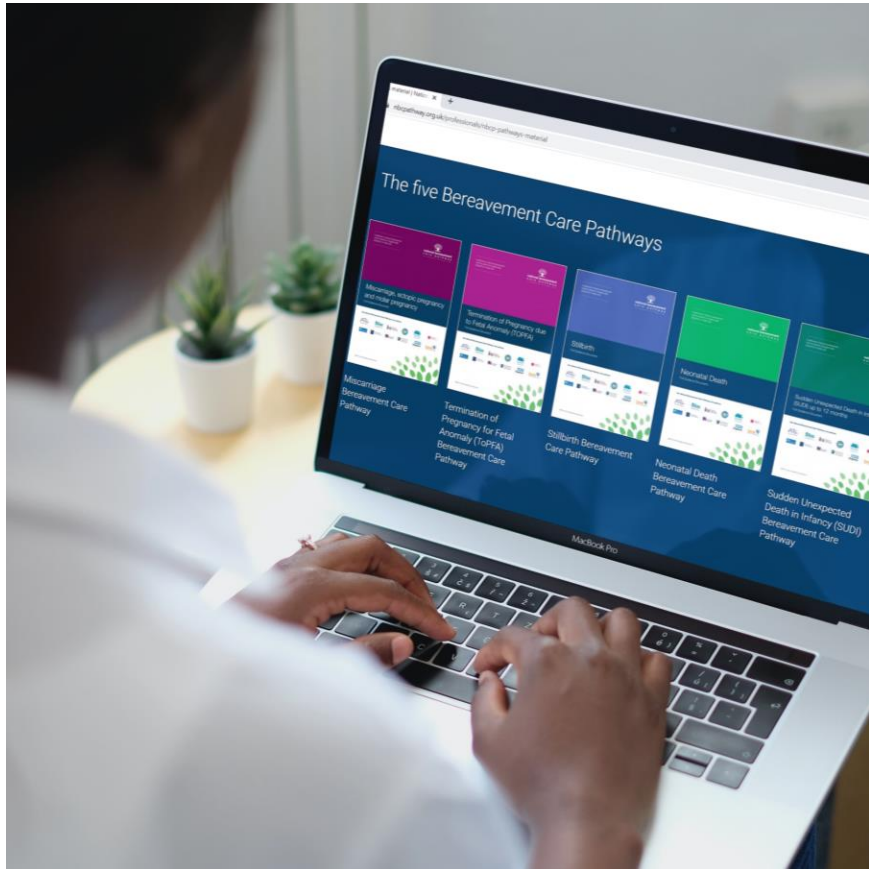
Introduction

If you are a healthcare professional working in any non-hospital setting, providing care for families who have experienced pregnancy loss or the death of a baby, this toolkit is for you.

In this toolkit, we explore how to best provide **high quality bereavement care** outside of the hospital.

Care provided outside of a hospital setting could include a family's home, an ambulance, a GP surgery, or a clinic.

Please note, while throughout this toolkit we use the language of parenthood, we recognise that not everyone who has experienced a perinatal bereavement will identify as a parent. We encourage all staff to follow the lead of the people experiencing the bereavement. Mirror their language, and if you are in doubt about how they would like to be referred to, ask.





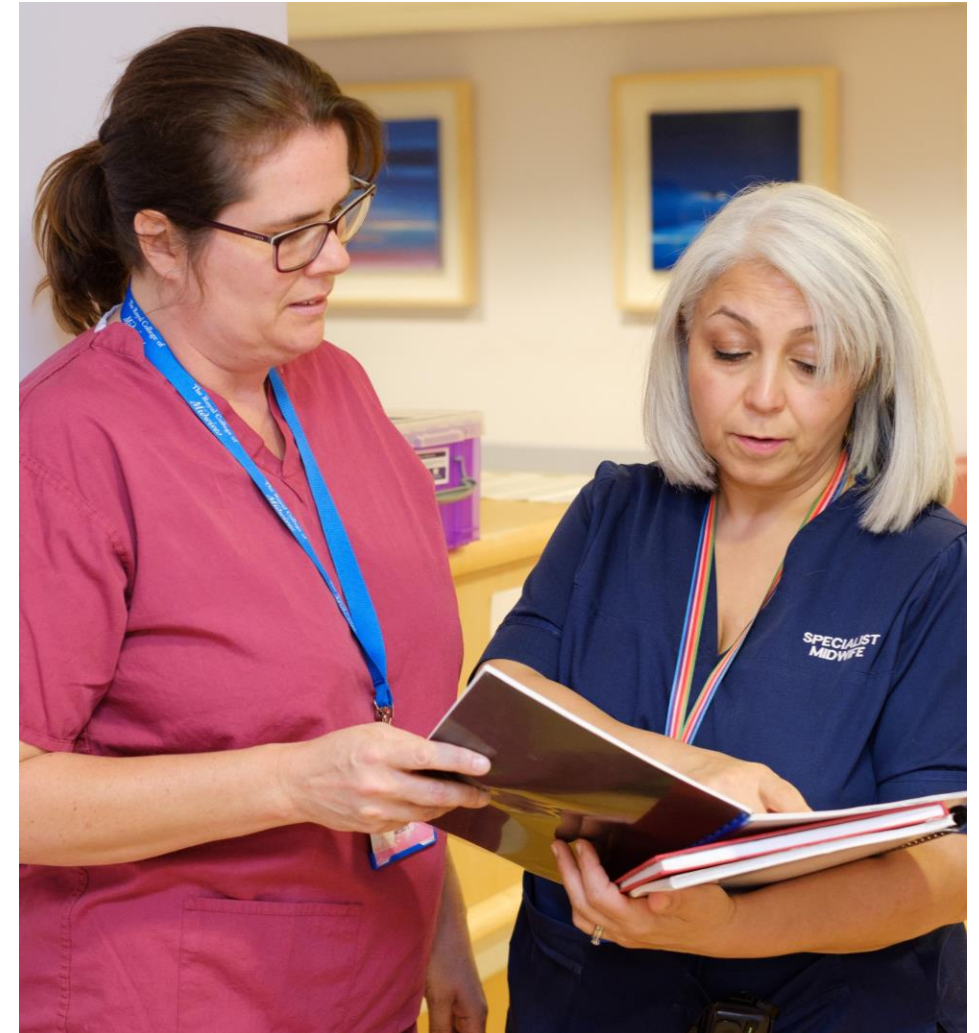
The nine bereavement care standards

The National Bereavement Care Pathway is organised around [nine bereavement care standards](#). These standards can be used to guide the delivery of care in your area.

The standards are organised into three sections:



In this toolkit, we'll take you through each standard to explore how these might be put into practice outside of a hospital setting.



1. Parents



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1. Parents: Personalised care

Bereavement care needs to be tailored to the preferences of bereaved parents and families. When a parent-led approach is taken this can help with the management of transitions between hospital and community settings.

If you work outside of the hospital, it is likely that the family you are caring for will experience a **transition between settings**.

These transitions can mark abrupt changes in the care received, and the handover of care between settings leaves opportunities for parents to fall through the gaps.

A good handover can prevent parents from falling through the gaps.





1. Parents: Personalised care

Take a few minutes to read through the person's notes and understand what the family might have requested. Every bereavement journey is unique and every family is different. Avoid making assumptions about what a parent might want, and how they might grieve.

Activity

- Thinking of your service delivery, can you identify a point when the transition stage could be difficult?
- Can you identify a point when additional time (even a few minutes) could enable you to review a parent's notes?
- [Listen to healthcare professionals discuss providing personalised bereavement care in this NBCP video.](#)
- For further guidance on providing inclusive care to support diverse families, see our [NBCP toolkit](#)





1. Parents: Personalised care



All parents need to be provided with information and support so they can make informed choices about their care and the care of their babies.

Staff in any setting need to have the confidence, knowledge and skills to explain the choices available to parents.

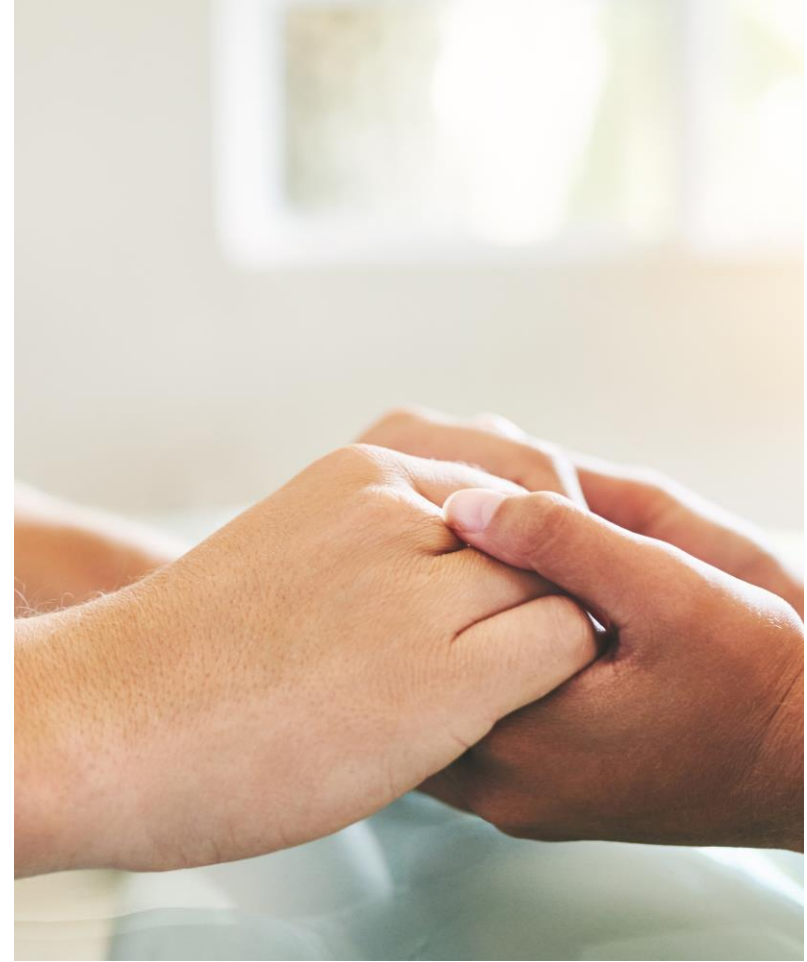
What's important to recognise is that considering choice may be extremely challenging for parents when you're meeting them. **Being able to sensitively and compassionately re-offer choices, or allow room for change, is a learned skill and one to be developed over time and with the support of your bereavement colleagues.**

1. Parents:

Personalised care

Repeating offers and information sensitively at different points in a parent's bereavement journey can be helpful. While some parents might refuse this initially, later down the line they may feel ready for this. **Each family's journey is unique.**

- Are there ways in which you can allow room for parents to make choices that might feel a bit 'outside the box'?





Informed choices: Case study

Here is an example of good practice on providing informed choice around post-mortem.

- In Northern Ireland, the current unavailability of paediatric pathologists means that paediatric post-mortems are carried out at Alder Hey Children's NHS Foundation Trust in Liverpool.
- A multi-professional and multi-site team work together in a 36 hour window for babies to travel between Northern Ireland and Alder Hey, aiming for a 24 hour round trip.
- HSC, bereaved parents and charities have co-produced two short films to support parents in their decision to transfer their baby for post-mortem.





Informed choices: Case study

Activity

- [Watch these two videos on perinatal and paediatric pathology services in Northern Ireland, co-produced by bereaved parents, HSC staff and charities. What learning from this example could be applied to your current service or pathway of care?](#)
- Further information on the videos can be found [here](#).





1. Parents: Bereavement facilities

If you are meeting bereaved parents in any non-hospital setting, it is important that a suitable, sensitive and safe environment is available for the provision of bereavement care.

In your clinical or community space, reflect on how the facilities look from a bereaved family's perspective:

- Is there a lot of signposting geared towards parents and families with living babies?
- Are there pictures or posters on walls that might be insensitive?
- Is the space welcoming?
- Is the space inclusive for families who have had a bereavement?





1. Parents: Bereavement facilities

Activity

- Organise a walk-around to review your surroundings. Ask your local Sands **Hospital Liaison Volunteer (HLV)** or **Sands support group** for support in reviewing your space, including coming on a walk-around with you. You could ask a couple of colleagues in different roles to come with you too.
- Getting the perspective of a bereaved parent and their feedback on your facilities will help ensure the care you provide is family-centred.
- For information on contacting your local HLV, [see here](#)
- For information on contacting your local Sands Support Group, [see here](#)
- If you are unable to find a local Sands group or HLV, please contact bereavementcare@sands.org.uk





1. Parents: Memory making outside the hospital



Making memories of their baby is something parents will have started in pregnancy and will continue to do over the course of their lives. As someone directly involved in their bereavement journey, the words you use and the gestures you make can be impactful and may be moments the family revisit in years to come.

- If you are with the family in the moments they are with their baby, and you are not in a hospital setting, how might you help parents to have time and contact with their baby?
- Are there toys or clothes that are important for the parents to have with their baby before being transferred to hospital? Are there things that could travel with the baby?



1. Parents: Memory making outside the hospital

Activity

- [Listen to an ambulance team discuss the use of snuggle pods in the care of baby James in our toolkit video.](#)
- What learning could you take from this into a pre-hospital bereavement care pathway?





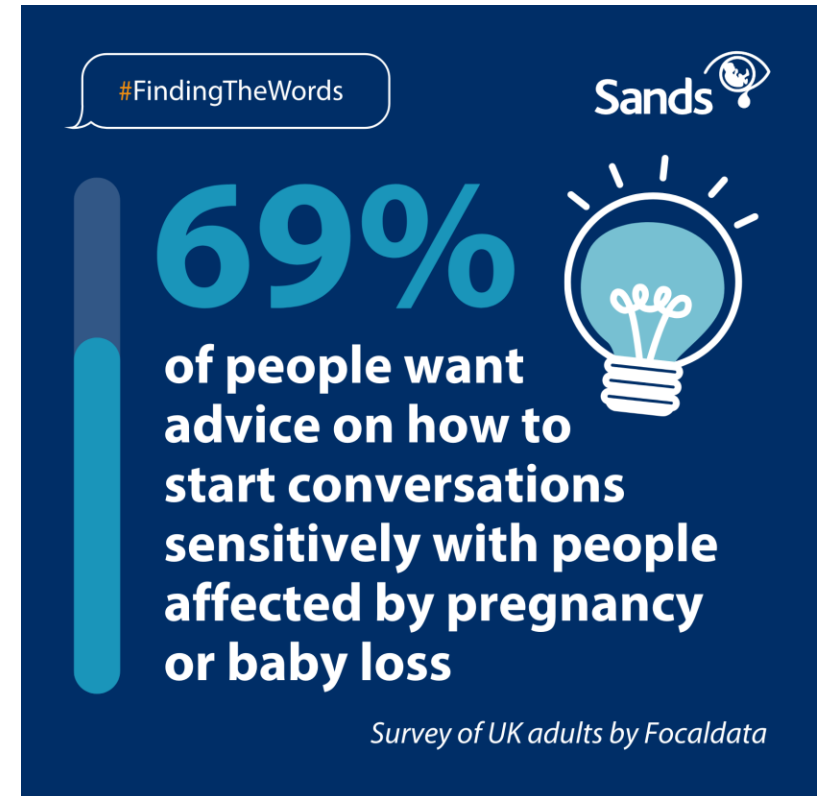
1. Parents: Memory making outside the hospital

If you are meeting a parent at any stage in their bereavement, being able to communicate with them compassionately about their baby is key.

- Worry less about what to say to grieving parents and focus on just listening to what they have to say.
- Express sadness for the parents but avoid telling them you know how they feel.
- Use the name of the child who has died. If the parents have not named the child, be led by how they address the child and mirror their language.
- Avoid phrases like 'moving on'; 'moving forward' is a better alternative.

Activity

- Look at Sands' campaign [Finding the Words](#) for guidance and support to start sensitive conversations about someone's pregnancy loss or baby death.





1. Parents: Memory making outside the hospital

You can help a family continue to make

memories. Families will mark birthdays and special occasions for their baby forever and you can help them to do this.

If you are meeting a family in the community following their bereavement, you can ask them about their baby, ask if they named their baby, and ask to see photos,

At Sands, we know that most parents tell us they don't have enough opportunity to speak about their baby and like being asked. How might you create space and give parents opportunities to speak about their baby with you?



Activity

- [Watch this film from Sands and reflect on what it communicates about grief.](#)



1. Parents: Memory making outside the hospital

Here are some ideas of questions you might ask in conversation.

Tell me about
your baby [use baby's
name if known]?

When
did you start to feel like this?

What
other support do you have?

Who
else is in your family?

How
are you feeling now?

Where
was your baby born?

2. Communication & learning



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2. Communication & learning: Referral for emotional support

No matter at what point you are caring for a family on their bereavement journey, specialist psychological or emotional support needs to be available and accessible for families.

As a healthcare professional based in the community, you may be in a unique position to refer a parent to a specialist support service.

Some parents might not be ready to access support the first time you meet them. Have open, curious conversations with parents and let them know about what's available for them.





2. Communication & learning: Referral for emotional support

Activity

- See this free NHSE e-learning module [‘Handling difficult situations with compassion’](#) for guidance on curious conversations about mental health.



2. Communication & learning: A system is in place to signal that there has been a bereavement

If you are a professional working in a community setting, it is likely that the family you are caring for will transition between settings and teams, for example from the care of a hospital-based team to a GP. **These transitions can leave opportunities for information to fall through the gaps and impact care.**

Having a system in place to signal that a bereavement has taken place is really important in building trusting relationships between staff as well as with parents.

It is important that parents are not left to do the distressing work of correcting an administrative mistake, or being asked to repeat their story.

- What do you have in place to check and signal that a bereavement has occurred?
- Is there a system in place that allows for an issue to be raised by a parent once and escalated to all involved?
- Can you avoid sending correspondence out in brown envelopes? While it might seem insignificant, using a different style of envelope when sending letters to bereaved families can be impactful and make services more accessible.



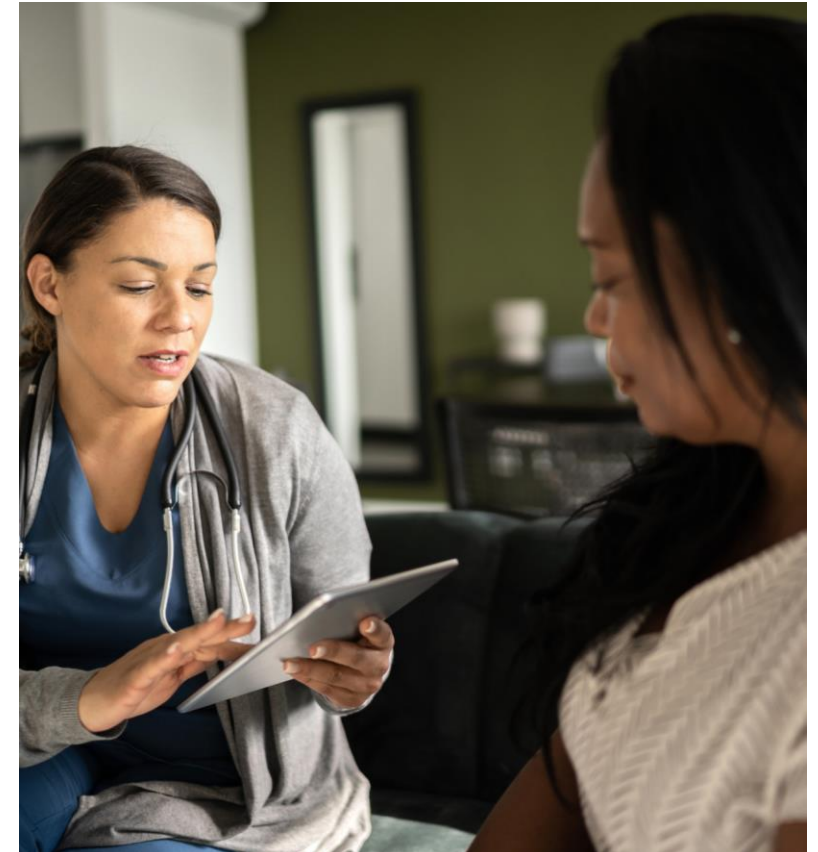
2. Communication & learning: A system is in place to signal that there has been a bereavement

Activity

- [See the RCOG Green-top Guideline on providing care for families in community settings](#)

The RCOG advise the following:

- Ensure that arrangements for routine antenatal care/future appointments for the mother or child are cancelled where relevant.
- Arrange a follow up appointment. Offering an appointment has a beneficial effect, even for those women who choose not to accept it.
- Anyone who has given birth after 24 weeks should be offered a 6-8 week postnatal check regardless of the outcome of the pregnancy.
- Discuss any questions parents have about what has happened and, where possible, explore their fears surrounding any possible future pregnancies.





2. Communication & learning: A system is in place to signal that there has been a bereavement

Sensitive, compassionate communication extends to written communication, for example, 'routine' appointment letters.

Activity

- Compare the two routine emails on these next slides. Here's the **first example**. It's factual and direct, but not particularly compassionate.

Dear X

I understand that you need to book an appointment with us following the loss of your baby.

Please contact me on

If you have any questions, please let me know.

With kind regards,



2. Communication & learning: System to signal

Here's the **second example**. In this example, we're demonstrating compassion before moving on to the business of the email.

- Even in a routine written communication, we can demonstrate that we care, and the person is more likely to be able to take in the rest of the email after reading the first sentence.
- While writing this may take a little more time, the impact on the parents and their outcomes shouldn't be underestimated.
- Can you review a routine piece of correspondence and identify a couple of small changes that could make it more compassionate?

Dear X

I am sorry to hear of the loss of your baby boy. I understand that you will be going through a very difficult time right now.

I am contacting you because I am aware you will need to book an appointment with us. Everything may seem quite overwhelming for you at the moment, so if you would like me to explain anything to you please let me know.

Please give me a call on xx to make a date for your appointment, or if you'd rather I call you, just respond to this email.

With kind regards,



2. Communication & learning: Learning from reviews

Bereaved parents and families are confident that learning from their baby's death will take place and are fully informed throughout.

- The families you care for may be involved in an ongoing review or investigation into the death of their baby.
- It is likely that parents will receive communication and results of any investigations while in a community setting.
- For support in understanding these processes please see the [Sands webinar on supporting parents and PMRT review](#)



3. Staffing



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3. Staffing: The bereavement team

If you are meeting a family in the community following their loss, they should have a bereavement lead who is coordinating their care. Often, this is the bereavement midwife. The lead will have excellent knowledge of the bereavement service and links to other professionals involved in the care of the family.

- Who is the bereavement lead in your Trust or Health Board?
- Building trusting relationships with other bereavement staff in and out of the hospital will help build a high quality bereavement service.
- Building trust takes time and attention. Frequent contact together with good quality conversations are critical in building trust between individuals, and they help people understand each other.



- For support on multidisciplinary team working, please see our toolkit [Working Together](#).



3. Staffing: Training and resources



All staff need training in order to develop the knowledge, confidence and skills to provide bereavement care to the families they meet.

Sands has a range of **training resources** available for anyone to access, no matter their professional role or workplace. Visit the [Sands Training microsite](#)

- Free webinars, including [Providing pregnancy and baby loss support for people who work in a community setting](#)
- Specialist full day, half day or 2 hour bereavement care workshops for those working in multi-disciplinary teams, community services or for GPs, Health Visitors or student midwives. See more [here](#).



3. Staffing: Training and resources



There are two short [NBCP e-learning modules on NHS England's e-learning for healthcare site](#). These are free to access and available for anyone to enrol on—you don't need to have an NHS email address.

Introduction to Bereavement Care: a 10 minute module for anyone coming into contact with a bereaved family in their role

Principles of Bereavement Care: a 30 minute module for healthcare professionals



3. Staffing: Training and resources

Feeling apprehensive or nervous about caring for a bereaved family is normal, no matter at what point you are meeting them in their bereavement.

Many healthcare professionals feel unsure about what they should say or do.

It's really important to acknowledge these feelings and recognise they are normal. Accessing the support and training you need to address your fears will mean you are better equipped and able to support the families you meet.

Activity

- [Listen to healthcare professionals discuss seeking support in this NBCP video.](#)





3. Staffing: Training and resources

Many healthcare professionals go into their work because they want to help others. One of the most difficult parts of caring for a bereaved family is that you can't fix their bereavement. It can be difficult to sit with someone's pain.

Activity

- [Listen to healthcare professionals discuss 'being present' with bereaved families in this NBCP video.](#)
- [Watch this video by psychotherapist Megan Devine on helping someone who is grieving.](#)
- Reflect on both videos. How might communicating with a bereaved parent look for you professionally when you are not trying to 'fix' something?





3. Staffing: Training and resources

It is important that staff have access to the support and resources they need to deliver high quality bereavement care.

Good provision of support and resources will equip staff to provide sensitive bereavement care, create safe maternity and neonatal systems, and build compassionate, responsive organisations that welcome learning.

Sands have compiled resources for professionals, including:

- [Guidance on involving parents in review](#)
- [Information on the data on baby deaths in the UK](#), links to national reports and enquiries, and the work of the Sands & Tommy's Joint Policy Unit
- [Key statistics on pregnancy loss and baby death in the UK](#), including guidance on understanding the numbers

For monthly updates on relevant research, education and policy information, sign up to the [Sands Professionals Bulletin](#)

Sands helped to develop NHS England's Saving Babies' Lives Care Bundle, which provides guidance on evidence-based best practice to reduce perinatal mortality. [Version 3 can be viewed here.](#)



3. Staffing: Staff support

- **Supporting staff wellbeing is integral to a high quality bereavement care service.** No matter what role you hold outside of a hospital setting, supporting families who have experienced a bereavement can be immensely challenging.
- You may have had your own experiences of pregnancy loss or the death of a baby and may need support.
- Building an organisational culture in which the wellbeing of staff is prioritised, and regular opportunities to debrief and reflect are built into practice, is paramount to providing compassionate care.

Activity

- Watch our [NBCP film on supporting staff wellbeing.](#)

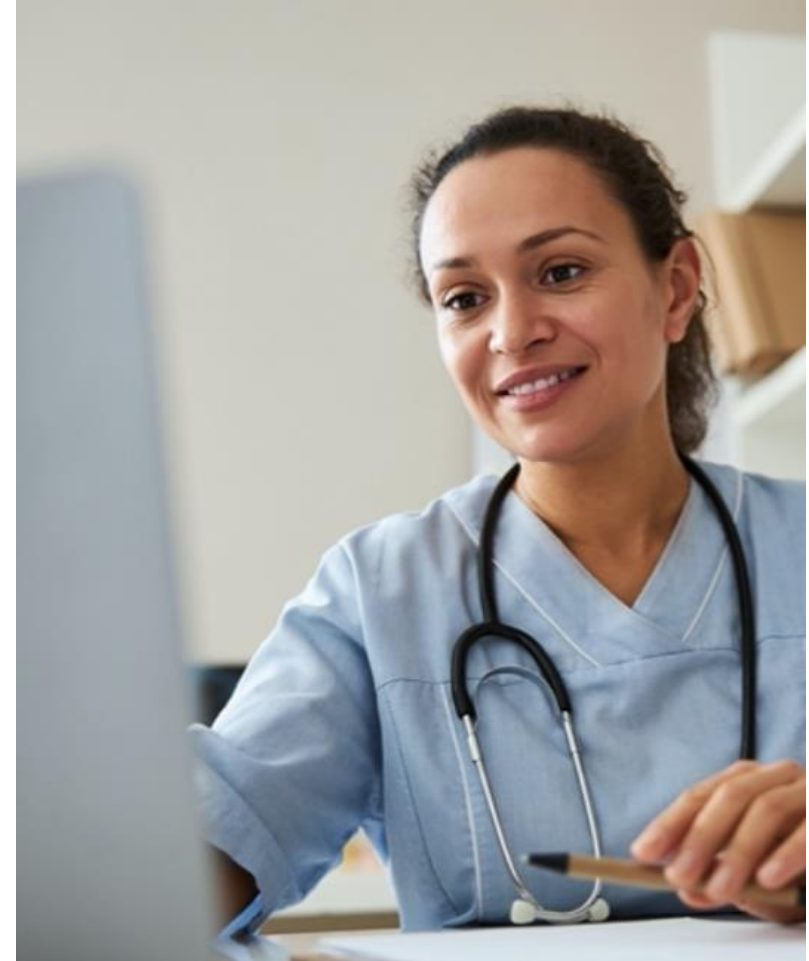


Professionals

Staff support

See our [Staff Wellbeing NBCP toolkit](#) for further resources and guidance on supporting the mental and emotional health of staff in your service.

Sands support is available for anyone affected by pregnancy loss or the death of a baby, including professionals working with baby loss. If you would like to speak to one of our Bereavement Support Services Officers over the phone or over email, please [follow this link for contact information](#).



Thank you



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NBCP is led by



Saving babies' lives. Supporting bereaved families.

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