

# Sands briefing on the National Bereavement Care Pathway (NBCP)

# Introduction to the National Bereavement Care Pathway Standards

The <u>National Bereavement Care Pathway (NBCP)</u>, seeks to improve the quality and consistency of bereavement care received by parents from the NHS after pregnancy or baby loss. The NBCP is led by Sands in collaboration with bereaved families, other charities and Royal Colleges and is backed by the government. It provides health care professionals with frameworks, tools and educational resources to support excellent care.

Launched as a government-funded pilot in 2018, the NBCP is based around nine standards of bereavement care and includes five pathways for different experiences of pregnancy loss or the death of a baby (miscarriage, termination of pregnancy for foetal anomaly, stillbirth, neonatal death and sudden unexpected death of an infant up to 12 months).

To meet the standards every NHS Trust should ensure the following:

- 1. All bereaved parents and families are provided with personalised care.
- 2. All bereaved parents and families have the opportunity to use an appropriate, available and accessible bereavement room.
- **3.** All bereaved parents and families are offered opportunities to make memories.
- **4.** All bereaved parents and families are informed about and, where needed, referred for emotional support and for specialist psychological support.
- **5.** A system is in place to clearly signal to all health care professionals and staff that a parent has experienced a bereavement.
- **6.** Bereaved parents and families are confident that learning from their baby's death will take place and are fully informed throughout.
- **7.** Bereaved parents and families receive their care from an appropriately staffed team.
- **8.** All staff involved in the care of bereaved parents and families receive the training and resources they need to provide high-quality bereavement care.
- **9.** Healthcare staff are effectively supported to care for bereaved parents and families.

<u>Evaluation undertaken during pilot phases in 2019</u> found that the majority of professionals surveyed agreed that bereavement care improved and became more consistent in their hospitals over the period of the NBCP pilot.

All 128 NHS Trusts in England have now agreed to adopt the NBCP and implement the pathways. However, it remains voluntary, so Trusts are not required to fully implement the standards and compliance against the is not fully monitored. We have concerns that whilst Trusts may agree to adopt the NBCP, there will be significant variations in implementation of the pathways leading to inconsistencies in care across different areas unless the NBCP is made mandatory

# The impact of high-quality bereavement care

#### Bereavement Rooms

Bereaved families experiencing pregnancy loss or the death of their baby tell us that this extremely difficult experience is made even more challenging when they are forced to spend time in clinics or on wards surrounded by pregnant women/ birthing people and/or their babies.

<u>In their recent report into maternity services</u>, published in 2024, the CQC noted that, 'To reduce the potential for bereaved families encountering or overhearing new and expectant parents, national guidance is clear that families should have a private and comfortable space to grieve their loss.'

Despite being one of the nine standards of bereavement care, we know that not all hospitals are currently able to provide a properly equipped or suitable bereavement room.

We have heard of instances where bereavement rooms are located on units/ wards with pregnant women or birthing people and babies. We are also aware that not all bereavement rooms have separate entrances or exits, requiring bereaved parents to walk through birthing units or labour wards where they may encounter babies.

If it is not clear that a room is being used by a bereaved family, such as a standalone bereavement room, this increases the likelihood of staff being unaware that a bereavement has occurred which in turn can lead to inappropriate and upsetting questions or comments.

The importance of bereavement spaces in hospitals cannot be overstated. In many circumstances the time spent in a bereavement room may be the only opportunity for the family to make memories with their baby. If a separate room is not available, or it is not properly equipped, bereaved parents may not get this opportunity.

In their 2024 report, the CQC recalled instances where bereavement rooms were not in line with national guidance, lacking sound proofing or located within antenatal/ early pregnancy units. After speaking with bereaved parents, they heard, 'how the negative psychosocial impact of antenatal environments made their experience worse.' Shockingly, the CQC also noted that where bereavement rooms were good, 'refurbishment was often funded by hospital charities or community fundraising.'

It is unacceptable that charities and community fundraising is being relied upon to deliver hospital rooms in line with national guidance. The maternity leadership within each Trust must consider how they can provide bereavement rooms, whilst the Department of Health and Social Care must reflect on how they can support individual Trusts to deliver these.

#### Staff Training

Another important element of the NBCP, is ensuring that all staff involved in the care of bereaved parents and families receive the training and resources they need to provide high-quality bereavement care. This includes being able to support bereaved families to make memories in bereavement rooms.

In June 2022, <u>Sands released a report</u> on access to bereavement care training for healthcare professionals.

We found that just over half (51%) of NHS trusts and boards make bereavement care training available to healthcare professionals caring for parents following pregnancy loss or the death of a baby, and only 12% are given time during working hours to attend. In most, training is offered once a year and only for one hour.

This is far too short to cover the breadth and depth needed to equip healthcare professionals with the skills, knowledge and confidence they need to provide excellent care for families whilst also looking after their own wellbeing. This includes staff needing to be trained to take consent for post-mortems and tests.

We are calling for all NHS maternity staff to be provided with and given the time by their employers to complete bereavement training, as well as any medical professionals who meet parents experiencing pregnancy and baby loss. This may include staff working in Accident & Emergency, gynaecology wards, sonographers, ambulance services and GPs.

## Our call for a fully mandated and monitored NBCP

Although we are pleased that all NHS Trusts in England have now adopted the NBCP Standards, we believe now is the time to be ambitious and to push for a fully mandated NBCP in England to ensure that all parents receive the bereavement care they need.

We know that many hospitals face challenges in fully implementing the NBCP, which requires both leadership support and additional funding. This ranges from estate challenges, such as finding suitable locations for bereavement rooms or creating separate entrances, through to staff shortages creating barriers to releasing staff from schedules to undertake training. We are also aware that there are significant variations in the number of bereavement midwives employed by different NHS Trusts, the amount of time they are allocated to provide bereavement support and their ability to provide cover to all families. In hospitals where there is only one bereavement midwife employed to provide support, this leads to gaps and a loss of provision during holidays or sickness.

However, with support from NHS England, Trust Leadership and the government none of these issues are insurmountable. All hospitals must be supported to properly implement the NBCP Standards. This will require NHS England and trust leadership to support maternity staff in implementation and for the government to provide the necessary funding to enable them to do so.

Furthermore, the Department of Health and Social Care must consider how they can monitor compliance with the standards to ensure the quality and consistency of bereavement care received by parents, no matter where they live in England.

### How you can help

#### Written Parliamentary Questions to table:

- To ask the Secretary of State for Health and Social Care, with reference to the CQC National review of maternity services in England 2022 to 2024, published September 2024, what discussions his department have had about implementing the recommendation that the Department of Health and Social Care provide additional capital investment in maternity services to ensure that women receive safe, timely care in an environment that protects their dignity and promotes recovery.
- 2. To ask the Secretary of State for Health and Social Care for (a) a timetable for publication of NHS England's National Health Service maternity and neonatal estates survey and (b) whether the survey examined compliance against national guidance that families should have a private and comfortable space to grieve their loss following pregnancy loss or the death of a baby.

- 3. To ask the Secretary of State for Health and Social Care what discussions his Department have had with NHS England on ensuring that all NHS staff caring for bereaved parents receive bereavement care training.
- 4. To ask the Secretary of State for Health and Social Care if his Department have had discussions with their counterparts in Scotland on the mandating of the National Bereavement Care Pathway.

#### **About Sands**

At Sands, we work to save babies' lives and ensure that anyone affected by pregnancy or baby loss gets the care and support they need. We provide trauma informed bereavement support as well as providing a safe, understanding and caring community for anyone who needs us. We support and promote research to better understand the causes of baby deaths and save babies' lives. We equip healthcare professionals with the skills and knowledge they need to deliver compassionate care to parents in their time of need. We raise awareness of baby loss and work with governments, the NHS and healthcare professionals to make saving babies' lives and improving bereavement care a priority. We are the voice of bereaved parents at a national level.

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