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



national bereavement
c a r e p a t h w a y
for pregnancy and baby loss

Progress Report

June 2020



Background


The loss of a baby at any gestation is devastating for parents. Poor bereavement care, from the moment of first diagnosis and breaking bad news, only exacerbates the profound pain felt by parents. While approaches to bereavement care in the UK have improved in recent years, inconsistency remains, resulting in a postcode lottery for parents.

To tackle this the National Bereavement Care Pathway (NBCP) for pregnancy loss and the death of a baby was developed in 2017. It covers five experiences of pregnancy and baby loss; Miscarriage (including molar and ectopic pregnancy), Termination of Pregnancy for Foetal Anomaly (TOPFA), Stillbirth, Neonatal Death and Sudden Unexpected Death of an Infant (SUDI) up to 12 months. Initially funded by the Department of Health and Social Care, and with the backing of the All Party Parliamentary Group on Baby Loss, pathway development was led by Sands, working closely with a Core Group of partners consisting of baby loss charities and professional organisations.

Following a 'call for evidence', draft pathways were created on the basis of good practice across the country.

The NBCP includes nine standards and provides the framework and tools to ensure that all health professionals are adequately equipped to provide excellent bereavement care during the immediate aftermath of pregnancy or baby loss. It was initially piloted in two waves of 11 and 21 sites across England, then, following a positive evaluation, rolled out with the aim that all Trusts should adopt it.





“Overall, the care we received cannot be faulted, and we are so grateful to have had this level of care. I truly hope this becomes a national standard that all bereaved parents will benefit from, as I cannot express how much it has helped us navigate through this most difficult time.”

Parent of a stillborn baby, Spring 2019

NBCP core standards



A parent-led bereavement care plan is in place for all families, providing continuity between settings and into any subsequent pregnancies.



Bereavement care training is offered to staff who come into contact with bereaved parents, and staff are supported 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 bereavement lead in every healthcare setting where a pregnancy or baby loss may occur.



Bereavement rooms are available and accessible in all hospitals.



The preferences of all bereaved families are sought and all bereaved parents are offered informed choices about decisions relating to their care and the care of their babies.



All bereaved parents are offered opportunities to make memories.



A system is in place to clearly signal to all health care professionals and staff that a parent has experienced a bereavement to enable continuity.



Healthcare staff are provided with, and can access, support and resources to deliver high quality bereavement care.

How does the NBCP work?



The NBCP project supports NHS Trusts by providing a central collaboration point to access the most up-to-date guidance, share good practice, resolve issues, and access supporting tools and resources.

This is achieved by:

- regularly co-creating with parents and healthcare professionals pathway guidance materials
- creating training and learning materials for staff, initially via a work pack and now via two well used e-learning modules¹
- publishing the nine bereavement care standards and ensuring that the NBCP is embedded in relevant national guidance and frameworks
- facilitating regular workshops for professionals who are leading or involved in the local delivery of the NBCP
- creating a network of NBCP professionals and providing these with regular updates on progress and recent practice examples
- facilitating a parent advisory group who continue to support us to develop all stages of the NBCP.

The project is dynamic and flexible, innovative and adaptable, responding to (and indeed influencing) national policy. An example of this is how the NBCP has created resources for families and healthcare professionals during the current COVID-19 pandemic.

¹ <http://www.e-lfh.org.uk/programmes/national-bereavement-care-pathway>



The difference the NBCP makes

The following two sections are taken from the independent Evaluation of the National Bereavement Care Pathway (NBCP) Final report (Wave two), May 2019². Insight was gathered through survey and interview responses from parents and professionals in 21 of the second wave pilot sites for the NBCP. The evaluation aimed to measure the impact and effectiveness of the pathway and to identify key learning to inform its subsequent development.

What parents say

In 2014 the Listening to Parents after stillbirth or the death of their baby after birth report³ found that only half of women whose baby died before labour felt involved in decision-making and confident about decisions made at the time they found out that their baby had died. These findings show the difference the NBCP has made.

“The hospital was amazing at comforting me and my partner during the birth of our son... they were also very gentle with him once he was born which was a main concern of mine, we both felt our son was well taken care of and so was I. We cannot thank all the staff that dealt with us enough.”

“We were given the opportunity to reflect on the situation calmly and offered the right support to make the decisions that we were most comfortable with. We felt that someone would always be available to listen and discuss any of our concerns.”

² <https://nbcpathway.org.uk/about-nbcpathway/nbcpathway-evaluation>

³ <https://www.npeu.ox.ac.uk/downloads/files/listeningtoparents/report/Listening%20to%20Parents%20Report%20-%20March%202014%20-%20FINAL%20-%20PROTECTED.pdf>



What parents say

84% agree the hospital was a caring and supportive environment

92% agree they were treated with respect

89% feel the decisions they made in hospital were the right ones at the time

89% feel they were communicated with sensitively

75% feel that all staff could provide a consistently high level of care

87% were offered access to ongoing emotional support after they left hospital

89% were given information about relevant support organisations they could access in the community

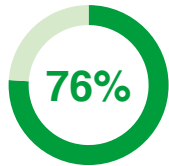
What professionals say



“Different departments are working together more closely – they are more aware of what each other is doing, before we may not have come together. We are communicating better. We have a lady who had a pregnancy loss at term last year and she has found out she is pregnant again, she’s just nine weeks, I’ve been able to contact the early pregnancy unit for a reassurance scan, they are now a lot more open to doing that as they realise it’s important.”

“The pathway helps to ensure parity of esteem with the clinical guidelines... I think it is brilliant – and something we can’t do without”

What professionals say



of professionals who were aware of the pathway agree that, overall, bereavement care has improved in their trust during the period of the pilot.

This high level of agreement was also found amongst midwives, a group who may have been the most aware of where quality of bereavement care needed to improve with their hospital.



of professionals who were aware of the pathway agree that the consistency of bereavement care has improved in the period of the pilot, 7% disagreed



of professionals who were aware of the pathway, agree that there have been fewer mistakes in bereavement care since its introduction



The proportion of professionals feeling prepared to communicate with bereaved parents has increased from **88% to 92%**



The proportion of professionals feeling capable to discuss bad news with bereaved parents has increased from **66% to 72%**



The proportion of professionals feeling supported to deliver good quality bereavement care has increased from **66% to 79%**
As part of this, the proportion of professionals who feel they have the opportunity to debrief after difficult conversations with bereaved parents has increased by 7%.



of professionals who were aware of the pathway agree that it is easy to use and that it was easy to follow.



What improvements were identified?

The need to ensure a combination of written and verbal communication of information to parents and to address issues outside of the scope of the NBCP, particularly ongoing psychological and emotional support services in the community, and the sensitive handling of subsequent appointments and meetings at the hospital were all identified as areas which need to be improved.

The CQC inspect the quality of bereavement care

The Care Quality Commission (CQC) inspection framework for maternity services now covers the quality of bereavement care for parents following pregnancy loss or the death of a baby, and is closely linked to the standards in the NBCP. Many trusts that have implemented the NBCP therefore see this reflected positively in their inspection reports.

However, more needs to be done to ensure bereavement care standards are reflected in inspection frameworks which examine care in the case of earlier and later losses.

Why adopt the NBCP?

With around half of hospital trusts in England adopting the NBCP, momentum is building and soon a tipping point will be reached where more trusts have adopted the NBCP than those which haven't. Trusts already adopting the NBCP have reported tangible improvements and positive feedback from staff, parents and families. It is crucial that parents receive consistent high quality bereavement care appropriate to their needs, and that they feel supported to navigate their bereavement journey:

- The independent evaluation⁴ highlighted that 92% felt they were treated with respect (4% disagreeing) , 89% felt the decisions they made in hospital were the right ones at the time (2% disagreeing) and 89% felt they were communicated with sensitively (5% disagreeing). Respect, decision-making and sensitive communication are foundational to high quality bereavement care and the NBCP clearly helps to make the difference.
- The NBCP enables trained staff to feel confident and supported (recognised) in the provision of specialised care.
- The NBCP also helps trusts to meet inspection criteria regarding the delivery of maternity care, and to be confident in their staff's ability to provide bereavement care and to maintain a positive reputation.

⁴ <https://nbcpathway.org.uk/about-nbc/nbc-evaluation>

The picture as of June 2020

67 (49%) sites in England, including all
32 pilot sites have fully committed to the NBCP

Overall **136 (99%) sites** have engaged with the NBCP in some way

58 (43%)

have expressed a formal interest

11 sites (7%)

are engaged but have yet to
express an interest formally

only a handful (1%)

have not engaged at all.

NBCP e-learning modules⁵ were rolled out last year and have been well received. When asked their opinion of the modules, 92% said that they could immediately apply what they had learned to their work and 75% felt they were appropriately challenged by the material. 85% said that they felt more confident when talking to bereaved parents.

⁵ These are freely available at <https://www.e-lfh.org.uk/programmes/national-bereavement-care-pathway/>



Next Steps

In order to support the roll out, Sands and its partners will continue to support NHS Trusts by providing:

- a central point of co-ordination,
- access to free workshops and networking opportunities
- learning resources
- updated guidance materials
- further training modules
- opportunities to share best practice

Trusts will be supported to take up the NBCP further by:

- providing a welcome pack including a guide to adopting the NBCP and a self-assessment tool (enabling trusts to audit their current practice against elements of the nine bereavement care standards.)
- supporting the action planning process so that trusts know the level of care they are providing and what they need to do to improve
- establishing a network of local NBCP leads - this will be further developed during 2020/2021
- providing regularly updated guidance based on latest best practice and input from parent advisors
- embedding the NBCP into national frameworks and guidance
- expanding the training and learning offer, for example 'leading high-performing multi-disciplinary teams in bereavement care'.

For more information visit:
nbcpathway.org.uk



Additional Information

Sands is leading the NBCP project, and the core group of organisations involved includes:

Sands

ARC (Antenatal Results and Choices)

Bliss

Lullaby Trust

Miscarriage Association

Neonatal Nurses Association

Royal College of Midwives

Royal College of Nurses

Royal College of Obstetricians and Gynaecologists

Royal College of General Practitioners

Institute of Health Visiting

NHS England

A representative of the health research community

Evaluation of the project was enabled by a kind donation from
Teddy's Wish - a charity founded by bereaved parents.

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Charity Registration Number: 299679
Scottish Charity Registration Number: SC042789

