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Improving bereavement care for those affected by pregnancy loss or the death of a baby

Two recent news stories have highlighted the importance of high quality bereavement care in the UK. First is the recent Office of National Statistics announcement illustrating that the number of babies dying from stillbirth and neonatal death in the UK has fallen from 15 a day to 14. This was a welcome revelation and confirmation that things are heading in the right direction, with 350 fewer babies dying in 2018 than in 2017. However, it's clear that more needs to be done to continue these improvements, and sadly it means that around 5,000 families will need bereavement care in 2020 after the loss of a baby through stillbirth or neonatal death.

Second is the recent report into Shrewsbury and Telford Hospital NHS Trust's care of families after the death of their babies – a powerful reminder of the need for high quality, consistent and parent-centred care after loss.

The National Bereavement Care Pathway (NBCP) for Pregnancy and Baby Loss seeks to raise standards in bereavement care to a high level of quality and a high level of consistency. Along with our partners, we've worked with 32 pilot sites in England over the past 18 months to develop a set of pathways not only for stillbirth

and neonatal death but also for the many thousands affected by miscarriage, termination of pregnancy for fetal anomaly and sudden unexpected death in infancy.

The evaluation of the pilot phase was published in May 2019 (**FIGURE 1**)¹ and highlighted that in the pilot sites, the NBCP:

- improved the bereavement care received by parents after the loss of a baby
- increased confidence and empowered staff to provide consistently good bereavement care
- enabled hospital teams and departments to work together to ensure consistency of care regardless of the nature, gestation or circumstance of the loss
- supported effective coordination and collaboration at a national level, enabling the project to succeed at a local level.

To that end, the NBCP in England is currently being rolled out, with trusts encouraged firstly to express their interest and then to formally commit to adopting the pathway. Tools to aid making the commitment to adopt the NBCP standards are provided along with a self-evaluation tool and an action plan template.

Since May 2019, 82 sites have expressed their

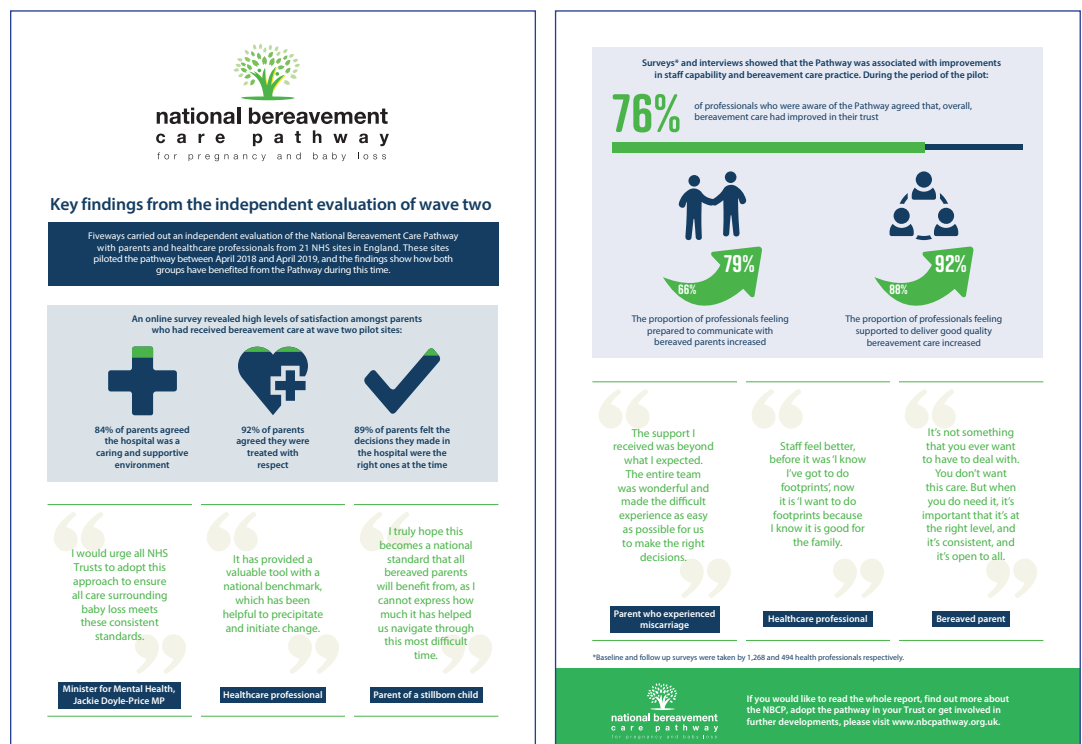


FIGURE 1 The NBCP evaluation.

interest, of which 19 have gone on to formally commit, making 51 in total including the pilot sites, or around one third of NHS England trusts. Naturally we are delighted with the response from trusts to adopt the NBCP and their commitment to work towards the nine bereavement care standards (FIGURE 2) as follows:

1. A parent-led bereavement care plan is in place for all families, providing continuity between settings and into any subsequent pregnancies.
2. Bereavement care training is offered to staff that come into contact with bereaved parents, and staff are supported to access this training.
3. All bereaved parents are informed about and, if requested, referred for emotional support and for specialist mental health support when needed.
4. There is a bereavement lead in every healthcare setting where a pregnancy or baby loss may occur.
5. Bereavement rooms are available and accessible in all hospitals.
6. 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.
7. All bereaved parents are offered opportunities to make memories.
8. A system is in place to clearly signal to all healthcare professionals and staff that a parent has experienced a bereavement in order to enable continuity of care.
9. Healthcare staff are provided with, and can access, support and resources to deliver high quality bereavement care.

In order to help the implementation of the pathway, a series of workshops were held across England in November and December 2019. More than 250 professionals attended the workshops run by representatives of the NBCP core group. Delegates were shown the new e-Learning For Healthcare modules (www.e-lfh.org.uk); the first of these is a short introduction to bereavement care. This module is not just for healthcare professionals but also for anyone who is in contact with families bereaved of a baby – a school-teacher, social worker, hospital receptionist or barista in the hospital atrium café, perhaps. The second module is more detailed and geared towards healthcare professionals who work directly with bereaved families.

Following the trial the of the training resources during the pilot programme, the NBCP training sub-group created these e-modules with input from the NBCP Parent Advisory Group and with the help of a grant from Health Education England. Many of the charities involved in the NBCP collaboration provide more

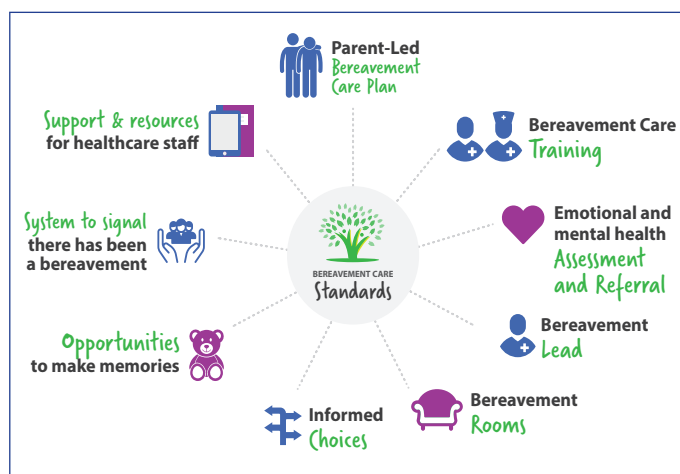


FIGURE 2 The NBCP bereavement care standards, which should be adhered to by trusts regardless of the type, time or circumstances surrounding loss.

in-depth training sessions and are often able to deliver one-day multidisciplinary workshops. The e-modules are a stepping stone to (rather than a replacement for) these sessions. Hundreds of e-learners have completed the modules since the launch in September 2019 and excellent feedback has been received so far.

In Scotland the project has been gaining momentum over the last few months, with five early adopter sites about to go live to test Scottish-specific pathways under the NBCP, with an evaluation and further roll out due to take place later in 2020.

We are hugely indebted to the many parents and families who have shared their stories with us, helped to create documents, spoken at events, advised us on wording and helped in so many other ways to develop the NBCP over the past two or three years. We continue to ensure that bereaved parents are at the heart of all we do.

Reference

1. **National Bereavement Care Pathway for Pregnancy and Baby Loss.** NBCP Evaluation. 2019 online at: <https://nbcpathway.org.uk/about-nbcpathway/evaluation>.

Further information and the most recent developments regarding the pathways can be found at:

www.nbcpathway.org.uk

Twitter #nbcpathway

7th Neonatal Nutrition Network Study Day

June 18th, 2020



The UCH Education Centre, 1st Floor West, 250 Euston Road, London, NW1 2PG

N3- The Neonatal Nutrition Network

University College London Hospitals



NHS Foundation Trust