

National Bereavement Care Pathway



**national bereavement
care pathway**
for pregnancy and baby loss

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Background: The care that parents receive following a miscarriage, or the death of a baby in or out of hospital can vary significantly regionally, between local hospitals and even within the same unit. We know this directly from parents (1.) as well as from the MBRRACE-UK confidential enquiries (2.). Follow-up in the community when families go home following a miscarriage or baby death can be equally variable and inadequate. Issues around care can also arise for parents whose baby dies in the community where a coroner or the police become involved. These inconsistencies can lead to distress for parents and families, impacting their emotional and physical well-being and leading to seeking help from their GP. This distress can also have an adverse effect on future pregnancies, for example, and stretching limited NHS resources.

Aim: The aim of the National Bereavement Care Pathway (NBCP) is to overcome inequalities in the provision and experience of bereavement care in England, to ensure that all bereaved parents are offered high quality, individualised, safe and sensitive care. The NBCP project will provide evidence-based, best practice guidance around the non-clinical aspects of bereavement care for professionals working alongside parents and families experiencing the loss of a baby at any stage, from miscarriage to the death of a child up to 12 months. The NBCP project is supported by England's Department of Health (DH).

Methods: A Core Group of principal stakeholders was established in September 2016 with representatives from baby-loss charities and relevant professional bodies (3.). The project is also working with a wider Advisory Group, including parents, professionals, researchers and the All Party Parliamentary Group (APPG) on Baby Loss, to ensure all views are heard (4.). Two sub-groups are focusing on evaluation and training. The work is led by a project lead, funded by Sands, and reporting to DHSC in England.

In February 2017, three parent stakeholder groups were held in Manchester and London, with 33 parents from differing experiences sharing their views. Workshops with 120 healthcare professionals in attendance were then held in May 2017. These views were triangulated with the benchmarking of around 30 bereavement care pathways currently in use across the UK. A pathway was then drafted by a number of stakeholders from the groups above. These pathway documents have been updated regularly as a result of feedback from the 11 pilot sites.

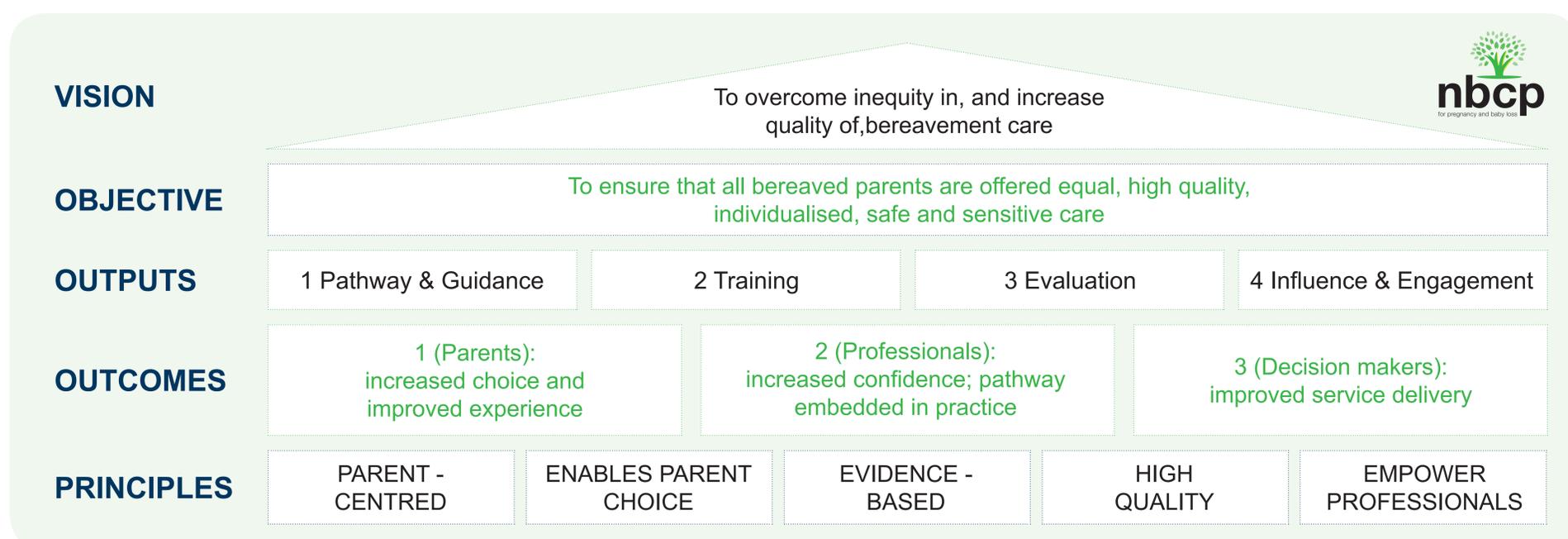
Training: A training pack has been provided to pilot sites which contains information for professionals and scenario-based examples to enable implementation of the pathway. Sands is also working with Child Bereavement UK and the RCGP to develop an online learning module around bereavement care, the initial draft for which has been drafted by a GP.

Results so far: Work with parent focus groups highlighted three key areas to develop within the pathway: communication, continuity and consistency, and parent-centred care. The interim evaluation report conducted by independent reviewers Fiveways was published in April 2018 and highlighted that: the need is ever-present; those healthcare professionals of a more senior grade are more comfortable in delivering bereavement care; parents' experience of bereavement care is likely to be more inconsistent where there is no Bereavement Lead in post.

Next steps: A further 21 sites were launched in wave 2 in April 2018, making 32 in total. The full evaluation report, due to be published in the autumn of 2018, will help determine the process of rolling out the NBCP across the country.

“I am proud to be involved in such a worthwhile project. I hope that we can transform the immediate and long term aftercare that parents receive after pregnancy loss or death of a child.”

Dr Natasha Hulson GP, co-lead for Leeds NBCP Wave 2 site



NBCP Core Partners



References

1. Listening to Parents, Maggie Redshaw, Rachel Rowe and Jane Henderson, NPEU, 2015
2. MBRRACE-UK, confidential enquiries into antepartum, singleton, stillbirths at term, 2015
3. Sands, ARC, Bliss, Lullaby Trust, Miscarriage Association, Neonatal Nurses Association, Royal College of Midwives, Royal College of Nurses, Royal College of Obstetricians and Gynaecologists, NHS England, Institute of Health Visiting, University of Bristol
4. All-party parliamentary group on baby loss: <https://www.lullabytrust.org.uk/about-us/who-we-are/appg/>