

National Bereavement Care Pathway helps improve care received by parents

Friday 10 May, 2019

A project to improve the quality of care that bereaved families receive when their baby dies has been found to be making a big difference, and should be rolled out nationally, a new study has found.

To ensure bereaved parents and their families are supported in the best way possible, the National Bereavement Care Pathway (NBCP) was launched in 2017 and has been piloted in 32 NHS Trusts in England. The NBCP helps professionals to provide families with a greater consistency and quality of bereavement care after pregnancy or baby loss.

Independent research by Fiveways previously highlighted improvements made in the 11 Wave one sites when it reported its findings in October 2018. The final report relating to 21 Wave two sites published today analyses the experiences of bereavement care from parents and healthcare professionals.

The results have revealed high levels of satisfaction with the bereavement care they received when their baby died. Parents also said the hospital was a caring and supportive environment, they were treated with respect and many feel the decisions they made in the hospital were the right ones at the time.

Collaborators in the project including baby loss charities and Royal Colleges are calling on NHS Trusts to adopt the National Bereavement Care Pathway and adhere to nine specific bereavement care standards.

Minister for Mental Health, Jackie Doyle-Price MP, said: "Every stillbirth or baby loss is a tragedy and we remain absolutely committed to supporting parents through this difficult time.

"This independent evaluation shows that NBCP has already helped to strengthen the support for many bereaved families across the country, but there is more to do and I would urge all NHS Trusts to adopt this approach to ensure all care surrounding baby loss meets these consistent standards.

Through our Long Term Plan for the NHS we are also accelerating action to halve the number of stillbirths and neonatal deaths over the next five years and improving access to perinatal mental health care for mothers and their partners."

Surveys completed by 1,268 health care professionals and a further 494 in the follow up, revealed the Pathway has improved staff capability and bereavement care practice amongst teams working at the 21 Wave two Trusts.

Since the Pathway was introduced, more health care professionals feel they now have consistent and clear guidelines which support them to provide good quality care for bereaved parents. The Pathway has improved the dialogue between hospital departments which has helped professionals to deliver care more consistently.

The experience of bereavement care were gathered from 63 parents accorded in an online survey. 84 per cent agreed the hospital is a caring and supportive environment with 92 per cent agreeing they were treated with respect.

Clea Harmer, Chief Executive at Sands (stillbirth and neonatal death charity) which leads on the NBCP and Chair of the NBCP Core Group, said: "Parents who receive poor care can exacerbate the grief they feel, but good care can and does help them on their painful journey. That's why the NBCP is so important because every parent equally deserves excellent bereavement care. It's the very least we can do for them.

"Sands is delighted that the independent evaluation of the NBCP has highlighted the impact excellent bereavement care can have for bereaved parents and on enhancing collaborative working amongst healthcare professionals, which has met the initial objectives that Sands and our partner organisations set out to achieve.

"The NBCP has made a huge difference to the lives of bereaved parents and healthcare professionals, and has improved the care they receive. We would like to see the Pathway rolled out nationally, so that all bereaved parents receive the quality care they deserve."

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Jane Fisher, Director, Antenatal Results and Choices (ARC), said: “For us at ARC, it is very gratifying to read bereaved women commending the sensitivity of care they received through the painful experience of ending a pregnancy after a prenatal diagnosis. It is also really positive that health care professionals are able to use the NBCP to change local policy and protocols to provide more parent-centred bereavement care.”

Helen Korrane, Campaigns and Policy Manager at Bliss, the premature and sick baby charity said: “Nothing will ever be able to take away the grief parents suffer when they lose a baby but ensuring the right care and support is in place can help them come to terms with their tragic loss. The results from this survey show that the NBCP is already making a difference to the experience of bereaved parents at pilot sites. We urge all NHS Trusts and health boards to adopt the pathway and ensure healthcare professionals feel properly equipped to care for bereaved parents.”

Jenny Ward, acting CEO of The Lullaby Trust said: “We are delighted to see the positive outcomes of the evaluation. It proves just how vitally important proper care is in the journey of bereaved parents. We hope that this encourages other areas to provide a consistent level of support to families going through the trauma of a child death.”

Ruth Bender-Atik, Chief Executive of the Miscarriage Association, said: “The Miscarriage Association is delighted that the independent evaluation has demonstrated that implementing the NBCP has led to improvements in bereavement care for those affected by loss. We are particularly pleased that there is positive feedback regarding the care provided for those bereaved through early losses and we join our partners in calling for a national roll-out of the NBCP.”

NHS Trusts are being encouraged to take up the NBCP as part of the collaboration’s roll out plans. A number have already taken part in local workshops to identify gaps in local practice and to develop plans to improve bereavement care, based on the 9 bereavement care standards promoted by the group.

Further information regarding these standards, how to register with the pathway and other details can be found at www.nbcpathway.org.uk

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Notes to editors

For further information, please contact Lee Armit, Press and PR Officer on 020 3897 3449/07587 925411 or media@sands.org.uk

The NBCP project works in collaboration with other charities and with the support of the Department of Health and the All Party Parliamentary Group on Baby Loss, to improve the care receive when a baby dies unexpectedly.

The five experiences of pregnancy or baby loss in the Pathway are miscarriage, termination of pregnancy for foetal anomaly, stillbirth, neonatal death and the sudden unexpected death of an infant up to 12 months.

Case studies who can describe their experience of care and their involvement in the NBCP are available for interview upon request. Interviews with healthcare professionals are also available.

The 63 responses received (20 per cent of which were followed up by a qualitative interview) from bereaved parents in the online independent survey conducted by Fiveways reveal high levels of satisfaction with the care they received when their baby died:

- 84% agree the hospital was a caring and supportive environment
- 92% agree they were treated with respect
- 89% feel the decisions they made at the hospital were the right ones at the time

Further surveys were completed by 1,268 and 494 health professionals (which included interviews), shows the Pathway has improved staff capability and bereavement care practice:

- 76% of professionals who were aware of the pathway agree that, overall, bereavement care has improved in their trust during the period of the pilot
- The proportion of professionals feeling prepared to communicate with bereaved parents has increased from 88% to 92%
- The proportion of professionals feeling supported to deliver good quality bereavement care has increased from 66% to 79%.

The 32 NBCP sites are:

Wave 1

- Ipswich Hospital NHS Trust
- Barking, Havering & Redbridge University Trust - Queens Hospital, Romford
- Chelsea & Westminster NHS Foundation Trust including West Middlesex Hospital
- Medway (Maritime) NHS Foundation Trust
- Northern Devon Healthcare NHS Trust (Barnstaple Hospital)
 - Walsall Healthcare NHS Trust
 - Heart of England NHS Foundation Trust
 - Hull & East Yorkshire NHS Trust
 - York Teaching Hospital NHS Trust
 - Liverpool Women's Hospital Trust
 - Wirral University Teaching Hospital

Wave 2

- Alder Hey Children's NHS Foundation Hospital,
- Pennine Acute Hospitals NHS Trust (Oldham Hospital)
- Southport and Ormskirk Hospital NHS Trust
- University Hospitals of Morecambe Bay NHS Foundation Trust
- Leeds Teaching Hospitals NHS Trust
- Harrogate and District NHS Foundation Trust (Health Visiting Team)
- County Durham and Darlington NHS Foundation Trust
- The Newcastle on Tyne Hospitals NHS Foundation Trust
- North Lincolnshire and Goole NHS Foundation Trust (based at Scunthorpe General)
- Norfolk & Norwich University Hospitals NHS Foundation Trust
- University Hospitals Coventry & Warwickshire NHS Trust
- Derby Teaching Hospitals NHS Foundation Trust
- Kettering General Hospital NHS Foundation Trust
- University Hospitals of Leicester NHS Trust
- Nottingham University Hospitals NHS Trust
- Western Sussex Hospitals NHS Foundation Trust
- Frimley Park Hospital NHS Foundation Trust
- University Hospital Southampton NHS Foundation Trust
- Royal United Hospitals Bath NHS Foundation Trust
- Royal Cornwall Hospitals NHS Trust
- North Middlesex University Hospital NHS Trust

The National Bereavement Care Pathway is being led by: Sands (Stillbirth and neonatal death charity), Bliss, The Lullaby Trust, The Miscarriage Association, ARC (Antenatal Results & Choices), Royal College

of Obstetricians and Gynaecologists, Royal College of Midwives, Royal College of Nursing, Royal College of General Practitioners, Neonatal Nurses Association, Institute of Health Visiting, NHS England.

About Sands

Every day in the UK, 15 babies are stillborn or die shortly after birth.

Sands is the leading stillbirth and neonatal death charity, which exists to support anyone affected by the death of a baby.

Sands provides bereavement support services both nationally through its Freephone helpline, mobile app, online community and resources, and locally through a network of around 100 regional support groups based across the UK and run by trained befrienders.

Sands works in partnership with health care professionals, trusts and health boards and offers a range of training programmes and bereavement care resources to ensure that every bereaved parent and family receives the best possible care wherever they are in the UK.

Sands promotes and funds research to better understand the causes of baby deaths and save babies' lives. The charity also raises awareness of baby loss and works with governments, key influencers and other stakeholders to make reducing the number of babies dying a priority nationally and locally.

Over the past 40 years, Sands has grown into a national charity with a powerful vision, to create a world where fewer babies die, shared by dedicated volunteers, fundraisers, members, donors, healthcare professionals, partners, staff and bereaved parents and families.

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