The National Bereavement Care Pathway

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SANDS
Marc Harder, Project Lead
Presentation to ICCM Convention
September 2017
The need: Postcode Lottery

I felt like a burden on staff - they made me feel they were there to help live babies (mother)

The doctor and midwife had tears in their eyes. The doctor was more practical. They all cared that my heart was broken (mother)

She was asked if she would like to see the baby, it was then brought in on couple of sanitary towels in a bowl, usually used to poo in. A photo was taken and she was then warned the photo would be sent in 3 months’ time in a brown envelope (father)

The doctor was just so horrible to me at the scan … There was another doctor and another doctor after that. I completely freaked out (mother)

The midwife was an angel – so young though (mother)

The post mortem (consent) was with the consultant. I’d had a miscarriage the year before … She was upset. She was really, really good with the results, she had remembered. You could tell she cared (mother)
To overcome inequity in, and increase quality of, bereavement care

**VISION**
To ensure that all bereaved parents are offered equal, high quality, individualised, safe and sensitive care

**OBJECTIVE**

**OUTPUTS**

1. Pathway
2. Guidance
3. Training
4. Evaluation

**OUTCOMES**

1. (Parents): increased choice and increased satisfaction
2. (Professionals): increased confidence and streamlined processes
3. (Commissioners): Improved service delivery, improved Trust data

**PRINCIPLES**

PARENT-CENTRED
ENABLES PARENT CHOICE
EVIDENCE-BASED
HIGH QUALITY
EQUIPS PROFESSIONALS
In scope

England 🇬🇧

Pregnancy loss and death of a baby who dies at any stage of gestation, before, during and after birth. Deaths in a neonatal unit and <12M for sudden and unexpected deaths. All subsequent pregnancies.

Bereavement care in all settings

Out of scope

Wales 🇬🇧  Scotland 🏴 Northern Ireland 🇬🇧

Infants 12M+, or 28 days -12M if not in a neonatal unit and/or if the cause of death is not SIDS.

Clinical Care
Medical Care
Social Care
Developing the Pathway: stakeholder management

**Advisory Group of stakeholders**
- Parents & families
- All Party Parliamentary Group on Baby Loss (APPG)
- Health and social care professionals
- Royal colleges
- Professionals bodies
- Academics
- Faith leaders
- Third sector organisations

**Core Group**

**Project Board**
- Training Sub-Group
- Evaluation Sub-Group
- Parent Advisory Group

**NBCP supported by**
- Department of Health
- appg
What has been achieved so far?

- **2011-2015**
  - AppG (Baby Loss) established

- **Early 2016**
  - NbcP envisaged

- **Summer 2016**
  - Core Group formed

- **Autumn 2016**
  - Stakeholder events

- **Winter 2016**
  - Learning events Scotland & Wales

- **Early 2017**
  - Professional stakeholder events

- **May 2017**
  - Parent workshops

- **Summer 2017**
  - Guidance written
  - Training plan agreed
  - Evaluation & training sub-groups established
  - Independent evaluator commissioned
  - Pilot sites announced

**Sep 2017**
What next?

October 2017
- Wave 1 Pilot launched
- BLAW Baselining

Winter 2017
- Pilot sites live

Early 2018
- Data collection commences, Announce wave 2 sites

April 2018
- Wave 2 pilot commences

Summer 2018
- Guidance & Training iterated & published

Oct 18
- Review; all sites live
Developing the pathway: Parent feedback Spring 2017

What was good about your bereavement care?
What would you like to see improved?

Three over-arching messages:
1. Communication is key
2. There should be continuity and consistency in care
3. Parent-led family involvement is vital
Developing the pathway: Review of current pathways
Spring 2017

Call for evidence – gap analysis
• 28 pathways received
• Scotland, Wales and Northern Ireland reviewed
• Variation in focus, specificity and name
• Assessed against criteria
• Used best practice to inform NBCP content
Developing the pathway: we met with 120 health and social care professionals in Spring 2017:

We asked:

• What content do you want to see?
• What format would work best for you?
• What are your training needs?
• How should this be implemented to be most effective?
Developing the pathway: Professionals said

- Multi-disciplinary focus on bereavement care
- Ability to ‘tailor’ for Trust or Health Board
- Parents at the centre
- Easily accessible
- Training in bereavement care and in the pathway for all professionals - the parents’ voice to feature in the training
- Implemented in pilot ‘waves’

Must be parent-focused and simple to use
Developing the pathway: draft structure

- Content page
- Acknowledgments
- Terminology
- Foreword
- Parent voice page
- How to use this pathway
- Principles of bereavement care
- Intro page for each experience
- Flow chart
- Appendices
- Further reading
- Guidance (detailed)
- (Sands guidelines)

Must be parent-focused and simple to use

Will be evaluated in Wave 1
In our February workshop, one of the bereaved mothers said that when her daughter was passed to the funeral director she had been dead for two weeks so was terrified to see her as she would look worse. The funeral director took a photo of her daughter and showed it to her.

This prepared her and allowed her to spend three days with her daughter. Without this photo she would not have had the courage to do this.

It also left a last positive image which wasn’t the chaos of the night.
Implementing the pathway: wave 1 – October 2017

- 11 pilot sites have been identified across all England regions, with a mix of size, capacity, early adopting of Maternity Transformation Programme, current CQC rating. Some based in neonatal setting, others midwifery led.
- Evaluation work stream to run alongside pilot wave 1
- Link to other initiatives e.g. Perinatal Mortality Review Tool, MBRRACE report, Maternity Bereavement Experience Measure
- Continued dialogue with parents and professionals to shape the pathway
Implementing the pathway: pilot sites
Implementing the pathway: pilot sites
Implementing the pathway: plans for winter 2017/2018

• Further 10-12 sites to be identified for wave 2 pilot launch in April 2018

• Evaluate, feedback, improve and iterate full pathway roll-out in October 2018

• Work to ensure bereavement care is included in commissioning framework
How you can get involved

• Raise awareness of NBCP
• Link with your local Trust / pilot site
• Twitter #nbcp @sandsuk and other partners
• Join our distribution list
• Look out for / prepare for national roll out
• Link into Baby Loss Awareness Week
• Stock bereavement support literature e.g. https://www.sands.org.uk/support/bereavement-support/deciding-about-funeral-your-baby
• Plug the helpline/groups Sands and the other charities run
• Keep up the dialogue
The post mortem (consent) was with the consultant. I’d had a miscarriage the year before ... She was upset. She was really, really good with the results, she had remembered. You could tell she cared (mother)

Thank you!

For further information please contact:

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