



# **Evaluation of the National Bereavement Care Pathway (NBCP) Scotland**

**Final report**

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## **1. Executive Summary**

### **1.1. The National Bereavement Care Pathway (Scotland)**

The National Bereavement Care Pathway (NBCP) Scotland Project is funded by Scottish Government and delivered in partnership with Sands – the stillbirth and neonatal death charity.

The project provides dedicated, evidence-based care pathways designed for all healthcare professionals and staff who are involved in the care of women, partners and families at all stages of pregnancy and baby loss.

The vision of the NBCP is to increase the quality of bereavement care and reduce local and national inconsistencies so all bereaved women, partners and families in Scotland receive compassionate, person-centred care.

Nine health boards signed up to the NBCP in Scotland before 2024 and participated in this evaluation.

### **1.2. Evaluating the NBCP project**

The evaluation of the NBCP Scotland project aimed to measure the impact and effectiveness of the pathway and to identify key learning to inform its subsequent development. Specifically, the evaluation focussed on answering the following overarching questions:

- What are parents' experiences of bereavement care in boards that implement the pathway?
- What aspects of bereavement care do parents feel could be improved?
- What are health professionals' experience of implementing and working with the pathway?
- How has the pathway made a difference to bereavement care within boards?
- What aspects of bereavement care do health professionals feel could be improved?

To answer these questions, the following research was conducted.

- Baseline and follow up surveys amongst health professionals in the participating boards. 569 responses were received to the baseline survey and 418 to the follow up. The profile of "all respondents" to the baseline and follow up samples varied; however we were able to match 63 respondents from the baseline survey to the follow up survey to create an identical "matched" comparison group.
- 9 in-depth interviews with health professionals who had used the pathway, recruited from the follow up survey.
- An online survey amongst bereaved parents who would have experienced bereavement care when the NBCP was established within the participating boards. 58 responses were received.

8 in-depth interviews with bereaved parents recruited from the survey.

### 1.3. The parent perspective

The online survey provides a snapshot of 58 parents' experiences of bereavement care in 8 of the 9 participating boards. All the respondents were mothers or those who had the physical loss. It reveals high levels of satisfaction with the bereavement care received.<sup>1</sup>

- 84% of respondents agreed the hospital was a caring and supportive environment (10% disagreed)
- 86% agreed they were treated with respect (8% disagreed)
- 84% agreed that the decisions they made in hospital were the right ones at the time (10% disagreed)
- 89% feel they were communicated with sensitively (5% disagreed)
- 80% agreed that all staff could provide a consistently high level of care (4% disagreed)
- 83% were offered access to ongoing emotional support after they left hospital (13% disagreed)

The qualitative feedback supports these findings, giving a compelling picture of the impact that receiving good bereavement care can make, as well as providing a more nuanced understanding of the parents' perspective.

#### 1.3.1. Care in hospital

The compassion and respect shown by staff, the time and information parents receive to make informed decisions, and the opportunities parents have to create memories of their babies are all strong influences on parents' overall impression of the care they received in hospital. Most parents report these aspects of care are delivered well.

*"The care we received across the time we were in hospital was just incredible, I don't think we would have been able to handle everything had the staff not been so amazing. They were so amazing that we are confident that when we have another baby we will go back to [that hospital] because we could feel how much they care. The best staff to have with you during the hardest time." – Colette<sup>2</sup>; Early loss*

*"The care from the midwife throughout the whole process was amazing. She was very supportive and sympathetic throughout the whole experience. She made my husband feel comfortable throughout the whole experience and made us feel welcome in the lovely room we had for the period we were in hospital. Nothing was a bother and if there was anything we needed she was there for us." – Yvette; Early loss*

*"Every single person was aware of the situation. Although they are all different, each member of staff we spoke to had our care at the front of their minds, not once did I feel under pressure or unsure. In such a difficult time the staff made it that little bit easier and took all the extra worries or stress away." – Olivia; Early loss*

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<sup>1</sup> Survey questions included options to respond "neither agree nor disagree" or "I don't know" to certain statements. Therefore if, say 85% of respondents agreed it does not follow that the remainder (15%) disagreed. Across all these statements the level of disagreement was low.

<sup>2</sup> Names have been changed

*"Staff spent a lot of time explaining things well and discussing our options. No time pressure was put on us to make decisions. Some of my initial gut reactions were discussed with me and no pressure was put on me to change my mind. I'm so glad to have had those discussions and made the decisions we made. Things would have been a lot worse if I hadn't had staff with time and patience to talk and support me through these decisions." – Lorraine; Ended after prenatal diagnosis*

*"The midwives gave us as much time as we wanted to spend with our daughter, we never felt rushed to leave and were offered extra time to stay with her." – Jeannie; Ended after prenatal diagnosis*

The physical surroundings in the hospital can have a strong influence on how people feel about how they have been treated.

*"The room was beautiful. This is unfortunately not our first miscarriage and we have always been stuck on a ward bed in the early pregnancy unit listening to newborn babies cry and mums with kids or bumps walking past, and it's soul destroying to see what you are meant to be having but not. To have a room where we can cuddle on the same bed and not see anything like that was beautiful and so incredibly needed. My partner was able to lay in bed and hold me as I went through everything, miscarriages are horrible at the best of times but to have a place that feels homey and comfortable was lifechanging." – Alex; Early loss*

*"My only criticism is the position of the clinic; it isn't the nicest thing to see expectant mothers with baby bumps when you're going to discuss miscarrying yours." – Bex; Early loss*

Some parents had examples of inconsistent or insensitive bereavement care in hospital that the NBCP aims to address. In these cases, the aspects of care considered important to parents' are:

- Being cared for by staff that acknowledge the baby and the loss, providing compassion and a "human touch"
- Providing dedicated, comforting areas for giving birth or being cared for during experiences of loss
- Allowing partners to be present to provide emotional support during medical procedures
- Being able to spend time with their baby
- Ensuring supportive, sensitive, and informative communication throughout the care process, in particular paying attention to patients' concerns and symptoms
- Having the information, opportunity to discuss, and time to make their own informed decisions
- Ensuring hospital notes are correct and read by staff.

### **1.3.2. Care after hospital**

The scope of the pathway includes the signposting and referring of parents to support, and to mental health services where these are needed, but not the provision of these services.

Most parents were satisfied with the information and support they were given for when they had returned home. Several respondents mentioned valuing the ongoing support of their bereavement midwife.

*"From finding out about our baby's condition till the moment she passed and then leaving the hospital six days later and even now four months later we are still in close contact with the bereavement midwife and she has been amazing at helping us in this hard time." – Deborah; Stillbirth*

A minority felt follow-up care post-discharge was absent, or that there was a lack of continuity and quality in bereavement care after leaving the hospital. These respondents expressed feeling confused and emotionally raw after leaving hospital.

*"I have had no contact since leaving the hospital and no support. I was really struggling and it was my funeral director who shared where I could get support. He was so shocked that we hadn't heard anything from the hospital." – Esther; Early loss*

In these cases, the aspects of follow up care considered important to parents' are:

- Proactivity – not relying on the bereaved person to make contact
- Flexibility – being offered at a time that best suits the bereaved person, not everyone will be ready for support at the same time
- That it involves local support groups and charities who can provide ongoing support.

*"The aftercare has been very helpful, Held in our Hearts are an amazing charity and I am very grateful they are there for us whenever we need them. Without this support it would be a lot harder to get through." – Jeannie; Ended after prenatal diagnosis*

#### **1.4. The health professional perspective**

The baseline and follow up surveys and qualitative interviews with professionals allow us to report on how the NBCP has been used and the changes associated with its introduction. Overall, there is evidence that the pathways have improved bereavement care within participating boards, although there is still work to be done.

##### **1.4.1. Overall improvements in bereavement care**

- 61% of all respondents to the follow up survey felt that bereavement care had improved since the start of the NBCP project<sup>3</sup>. Only 5% felt it had got worse. Agreement rose to 82% amongst those respondents who were aware of changes brought about by the project<sup>4</sup>.
- 36% of all respondents to the follow up survey agreed that fewer mistakes had been made when delivering bereavement care since the time of the NBCP's introduction (12% disagreed).
- 61% of respondents who were aware of the pathway agreed that the consistency of bereavement care had improved since its introduction (5% disagreed).

In qualitative feedback, professionals cite several positive changes in care provision brought about by the NBCP including improved access to psychological support for families and staff, and efforts to improve facilities to care for bereaved parents.

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<sup>3</sup> Each board implemented the pathway at different times.

<sup>4</sup> 63% of all respondents to the follow up survey had heard of the NBCP, 37% had not but they were still asked for their perspective on whether care had improved or not in the period following the pathway's introduction.

#### 1.4.2. Raising the profile of bereavement care

In the follow up survey, 82% of those aware of the pathway agreed it has helped to raise the profile of effective bereavement care in their board (5% disagreed). In qualitative feedback several professionals mention the pathway being valuable in lending credibility and providing supporting evidence for the need to change working practices in bereavement care.

*"Bereavement care is often, in my experience, what gets pushed aside. There is not much time allocated to it. Strategically, it's probably not really thought about. We can see that in the resources that we've got. So this [the NBCP] has been great for me because, actually, it's given a real voice and a language to keep bereavement on the agenda, to make people to take it seriously. It's no longer just my voice, but it's a national voice and an initiative that's really important." – Participant 164, Bereavement Counsellor*

*"Other midwives have said when they took the pathways to their management and said, 'this is the expectation', they were able to secure funding to improve things." - Respondent 132, Hospital based midwife*

#### 1.4.3. Investing in dedicated staff

The introduction of dedicated staff with responsibility for bereavement was the factor cited most often as an example of an improvement prompted by the NBCP in the follow-up survey's qualitative responses. These roles increase people's confidence in the information and support being offered to both parents and staff.

*"Families have a bereavement lead who they have access to and regular contact with for as long as they require it. Staff have support from the bereavement lead which has helped me to feel more confident in the role I have in caring for families." - Respondent 23, Hospital based midwife*

#### 1.4.4. Training

Comparing the baseline and follow up surveys, there has been a clear increase in the proportion of respondents who have received bereavement care training, especially within the matched group where the proportion of those trained rose from 50% to 72%. In qualitative feedback, several respondents mentioning increased provision of bereavement care study days and training, available to a wide range of staff.

*"The team here put on a bereavement study day which incorporated the pathway and all the different aspects of it, which was opened up to not just midwifery staff, but neonatal staff, FMP, health visiting, obstetrics. So that helped a lot, and it was very well attended, so it highlights that everybody wants to get it right." - Respondent 169, Hospital based midwife*

*"We've done some training with early pregnancy about whether people seem taken aback or not, everyone has to be offered the same memory making, regardless of gestation. So staff are now more comfortable in providing very small memory boxes, ensuring that parents are offered a scan photo." - Respondent 132, Hospital based midwife*

As a result of the training, several respondents felt that staff had a better understanding of what quality bereavement care involved.

*"Staff have a deeper understanding of what is expected of them in their role in caring for these women." – Respondent 108, Hospital based midwife*

In addition, 43% of all respondents to the follow up survey agreed that their skill in communicating with bereaved parents had improved since the time of the NBCP's introduction (only 2% disagreed).

#### **1.4.5. Staff feeling supported**

The proportion of professionals feeling supported to deliver good quality bereavement care increased from 55% to 66%.

This support can encompass several things including training, information provision, new guidelines, and streamlined paperwork, systems, and processes. In addition, the proportion of professionals who feel they have the opportunity to debrief after difficult conversations with bereaved parents has increased from 46% to 56%.

*"People feel more supported within the workplace and that time to debrief and discuss cases has improved, and standardising paperwork has just made it easier for staff - which improves their confidence in carrying out bereavement care." - Respondent 73, Hospital based midwife*

*"We now have a clear pathway with defined contact points and actions, including when and who to communicate with." - Respondent 123, Consultant*

#### **1.4.6. Collaboration between departments**

It is also clear that the pathway has prompted increased collaboration between departments. The proportion of matched respondents who agreed with the statement "There is a smooth handover of bereavement care when women and partners move between departments in the hospital" increased from 35% to 49% between baseline and follow up.

*"In our organisation the NBCP has enabled a greater awareness and cross specialty/departmental communication regarding bereavement care. Common difficulties/wins can be shared and, with the NBCP lead's support, there is the sense that positive change is far more likely than if we are working in individual silos." - Respondent 159, Consultant Neonatologist*

*"We have more of a 'one team' approach to everyone's involvement and responsibilities." – Respondent 123, Sonographer*

*"We can now go to our sonography team and say, 'Here's the work that's been done nationally. Parents and families are saying there is definitely an issue with the way that difficult news has been broken, and there is a problem with follow-up appointment times as families are having to wait too long'. So the lead sonographer has been made aware that it is an expectation nationally that sonographers undertake extra training. So that is something that's underway that would never have happened if it hadn't been for the pathways." - Respondent 132, Hospital based midwife*

#### 1.4.7. Room for improvement

The surveys asked whether professionals felt there was “a lot we need to do to improve the delivery of bereavement care in our board”. For this statement, disagreement is seen as positive. Disagreement increased in the matched group from 17% to 24% between baseline and follow up.

In qualitative feedback, it is clear that many of the calls for improvements in bereavement care involve increased and continued delivery of the positive changes described above. For example, respondents called for more bereavement care training, dedicated staff, improved paperwork, better facilities, more visibility of specialist bereavement staff, more awareness of the pathway amongst all staff, and better communication. These are all aspects that the NBCP seeks to address.

*“Facilities and resource constraints impact on how positive changes can be made. Colleagues are keen to provide better care but are not supported by the working environment and feel even more under pressure knowing that we need to improve the care we give.” - Respondent 64, Midwife Sonographer*

*“I feel that communication between staff is poor when women attend early pregnancy with miscarriage. Midwives often don't know that a woman's pregnancy has terminated. This makes it very difficult for everyone.” - Respondent 157, Community-based midwife*

An additional barrier to change mentioned by several respondents was the issue of staffing - being short staffed, losing experienced staff and workloads not allowing for time for training. This was seen by some to be negatively affecting the quality of bereavement care.

*“Although there is work on improving the pathway, I think families have inevitably been negatively impacted by the chronic short staffing levels within the unit as well as the loss of a lot of experienced midwives.” - Respondent 143, Hospital-based midwife*

In addition, a few respondents questioned whether the resources to make significant improvements in bereavement care (e.g. for more staff or improved facilities) would be made available.

*“The self-assessment is helpful but actually how do you make improvements with low staffing and little to no resources?” – Respondent 33, Nurse*

#### 1.4.8. Using the NBCP

Overall, professionals’ experience of using the pathway is very positive. Of those respondents to the follow up survey who were aware of the pathway:

- 73% agreed that it was easy to use (only 3% disagreed).
- 74% agreed the content was simple to follow (with 2% disagreeing).
- 64% agreed that the pathway “linked well with other pathways used within our board” (with 5% disagreeing).

#### 1.5. Conclusion

In conclusion, this evaluation reflects the positive impact of the National Bereavement Care Pathway (NBCP) Scotland.



It is evident from parents' responses that many aspects of the NBCP are being effectively implemented within the participating boards. Parents who experienced bereavement care after the NBCP was introduced overwhelmingly agree that the hospital was a caring and supportive environment and that they were treated with respect, communicated with sensitively, and offered ongoing emotional support after they left hospital.

The majority of professionals surveyed agree that bereavement care has improved and become more consistent in their hospitals over the period of the NBCP pilot. This is due to the appointment of dedicated bereavement care staff, increased staff training and more collaborative working across departments. As a result, staff feel more skilled and supported to deliver good quality bereavement care.

The NBCP has proved it is an effective catalyst for positive change – raising the profile of bereavement care amongst staff and decision makers within boards. However, adapting working practices and building staff capacity can take time, especially when teams are short staffed and under pressure. Going forward, the challenge is to increase the awareness and reach of the NBCP to more staff and ensure new collaborative ways of working are embedded and evaluated.