

“THEY’VE WALKED THE WALK”: A SYSTEMATIC REVIEW OF PARENT-TO-PARENT SUPPORT FOR PARENTS OF BABIES IN NEONATAL CARE.

Briefing Paper

September 2019

Parents of babies admitted to neonatal units experience an emotional journey. Feelings of helplessness, fear, sadness, guilt, grief and anger are common, and can lead to ongoing anxiety, depression and post-traumatic stress which may persist long after discharge from the unit. These problems can affect families and society a great deal. Therefore, ensuring these families receive the right support at the right time is key to enabling them to live well and to flourish in the community. In this context, parent-to-parent support is where a parent with first-hand experience of going through neonatal care can empathise with and provide support for the problems and challenges a family may face.



This is a summary of a systematic review that used robust methods to identify, appraise and bring together all the available information on the use and experience of parent-to-parent support for parents of babies in neonatal care.

We wanted to find out:

- * Whether parent-to-parent support is helpful for families experiencing neonatal care;
- * What this support looks like;
- * What factors contribute to the success of parent-to-parent support and,
- * What the experience of those giving and receiving the support is.

We worked with a Parent Advisory Group who played a central role in designing and interpreting the research and who provided important insights on the role of parent-to-parent support within neonatal units as both receivers and deliverers of support.



Please use this QR code to navigate to the project website

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How did we do it?

Finding the literature: We searched 14 research databases, the references of included studies, relevant reviews and websites.

Eligibility criteria: We included any quantitative or qualitative study on the effectiveness or experience of parent-to-parent support for parents with babies in neonatal care. We excluded studies where the support intervention was provided by professionals, where the intervention was for bereaved families or those whose child was receiving palliative care, and where the intervention was more of instruction than support.

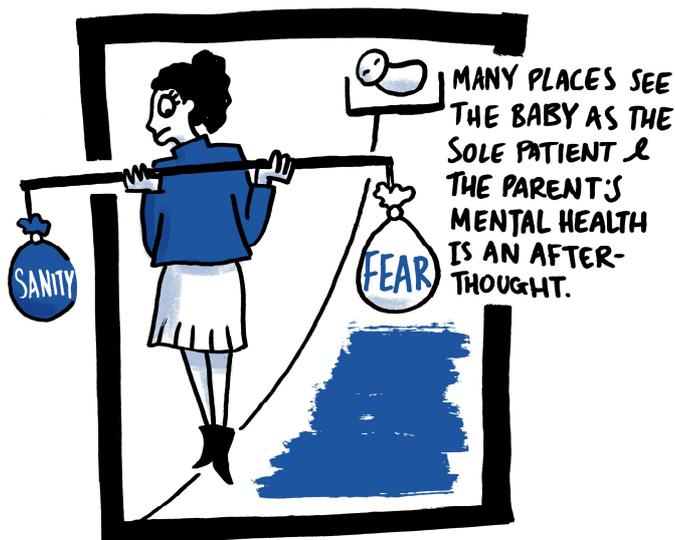
Study selection, data extraction, study quality and synthesis: In line with best practice, all stages were completed independently by two reviewers. Studies of effectiveness of parent-to-parent support were described narratively and presented in tables. Studies with qualitative outcomes were brought together through identified themes and concepts. These reviews were then mapped together in an overarching synthesis.

End user involvement: We integrated end-user involvement throughout the project with a collaborative project team, our Parent Advisory Group and an impact conference event which engaged service providers at a regional level.

Where was the evidence from?

6 quantitative and 8 qualitative studies were included in the review. These studies were not from the UK: 5 from Canada, 8 from USA and 1 from Finland. Only one study included data from fathers in their research.

The quality of the quantitative studies was mixed: only 1 study was rated as strong, 2 as moderate and 3 as weak. This means that we cannot be certain that their findings are reliable or would be replicable. The quality of the qualitative studies was generally good.



What did we learn?

Is parent-to-parent support helpful for families experiencing neonatal care?

There is some evidence that mothers receiving parent-to-parent support report reduced feelings of maternal anxiety and perceived stress and improved feelings of self-esteem. Some evidence also suggests that mothers receiving parent-to-parent support report better overall satisfaction with their care whilst in hospital and better levels of confidence in being able to care for their child after discharge and in the first few months at home.

However, no research was identified that specifically measured how useful or helpful parents found parent-to-parent support in different settings (in hospital, during transition to home or at home).

What does parent-to-parent support look like?

- * In 11 of the 14 studies parent-to-parent support involved some form of one-to-one contact, largely face-to-face in hospital or at home but contact was also provided via telephone and email in some of the studies.
- * In 3 studies parent-to-parent support was provided as an online group intervention; one study involved face-face group support sessions.
- * Peer supporters were mainly mothers who had experience of going through neonatal care with their baby, however not all peer supporters were trained in delivering support. None of the studies described support or mentoring for the peer supporters.
- * The views and roles of fathers were underrepresented or missing in the included studies.
- * Frequency and duration of support was variable and flexible according to the needs of the parents.
- * None of the studies reported using a mixed approach to providing support i.e. one-to-one *and* group, face-to-face *and* online support. The reasons for this are unclear, although only 3 studies were published since 2013 when social media may be more pertinent.



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How does it feel to give and receive parent-to-parent support?

Our review identified 4 main themes:

Trust

Peer supporters were seen as friends with whom parents could be honest and 'real' with, who understood their experience and recognised the value of timing of support.

Hope

Peer supporters were felt to give parents confidence in their caring skills and helped to 'normalise' their experiences.

Information and help

Peer supporters were able to translate technical terms and point out key information.

Connecting

Peer support helped to reduce feelings of isolation and was often part of a two-way relationship benefitting hospital staff as well as parents.

What factors contribute to the success of parent-to-parent support programmes?

Discussion with healthcare professionals and commissioners identified 4 shared practice points:

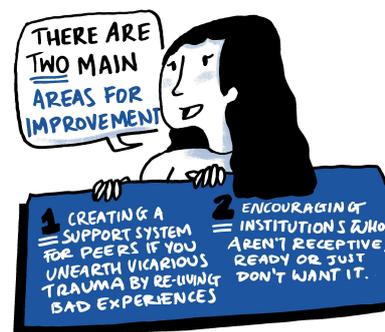
- * Local knowledge is invaluable: what may work in some units may not work in others.
- * Parent-to-parent support can help by providing emotional support, reducing feelings of isolation and providing a valuable source of information and help within hospital and beyond.
- * Hospital staff can learn from those providing parent-to-parent support.
- * Support needs to be individualised.

What happens now?

Our review of the research has shown that parent-to-parent support appears to have a positive impact on families, their experience of neonatal care and caring for their baby at home. Further research is needed to improve our understanding of the role of parent-to-parent support in neonatal units and to inform the implementation of robust and sustainable services.

Specifically, further research is needed to understand:

- * the most effective content and configuration of a parent-to-parent support service; including the role of and impact on fathers,
- * the potential negative impacts for givers and receivers of support and,
- * the barriers to implementing this type of support service in hospital and at home and how to overcome them.



The project was conducted by Harriet Hunt, Rebecca Abbott, Kate Boddy, Rebecca Whear, Alison Bethel, Christopher Morris, and Jo Thompson Coon from the University of Exeter, Leanna Wakely from Devon-based charity SNUG (Supporting Neonatal Users and Graduates), Susan Prosser Lead Nurse for Children from the Royal Devon and Exeter Hospital, Andrew Collinson Consultant Paediatrician from Royal Cornwall Hospitals Trust, and Jennifer Kurinczuk Director of the National Perinatal Epidemiology Unit. With thanks to our dedicated Parent Advisory Group who contributed to all stages of the project. With thanks to Rae Goddard/Scriberia for illustrations.

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