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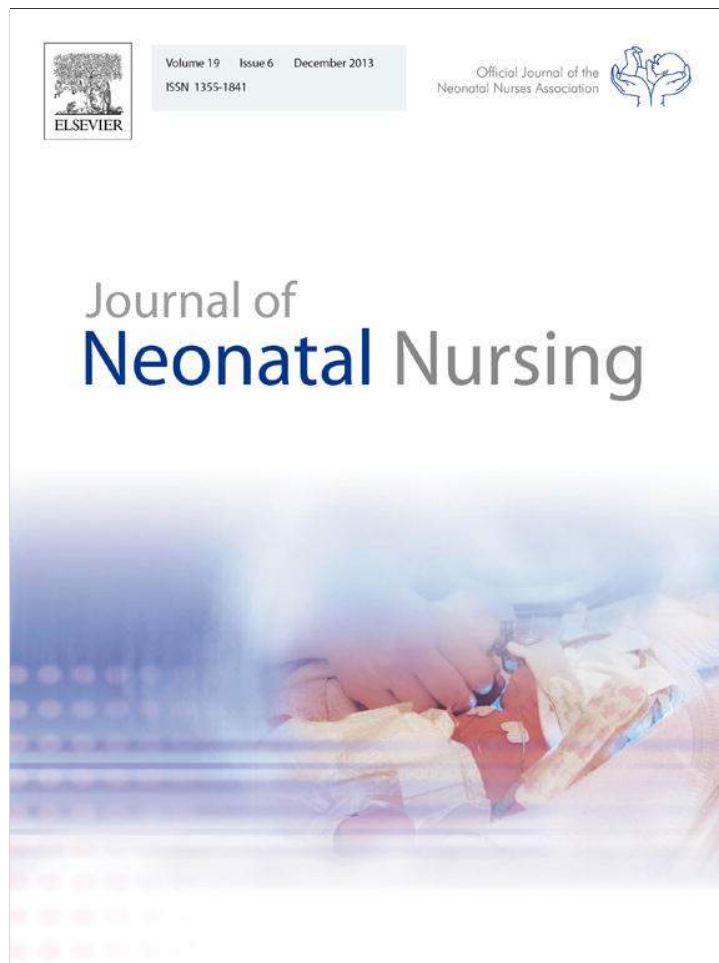


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NEWSPOINT

Supporting parents in the NICU: A new app from the US, 'MyPremie'

A tool to provide parents of premature babies with support, empowerment, education and participation in their infant's care



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KEYWORDS

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Abstract This article describes the new MyPremie app for iPhone and iPad, designed to inform, assist, empower, and support parents of premature babies in the NICU and afterwards. Created by the same team who wrote the book *Preemies: The Essential Guide for Parents of Premature Babies*, the app contains information on medical and developmental issues; suggested questions for parents to ask doctors and nurses to understand their baby's care; a combined baby journal and adult diary with focused prompts to record events and emotions; tools to track growth; and organizing lists for questions to ask, tasks to do, and mementos to collect. The app's pages can be shared by email or Facebook to facilitate communication with family and friends, and printed in PDF and saved. Overall, the app aims to ease parents' distress by providing meaningful parenting activities during a baby's NICU stay and an increased sense of normality, control, and connection. Nurses are encouraged to advise their patients' families about the MyPremie app as a way to help meet their practical and emotional needs and support them through the stressful experience of prematurity. © 2013 Neonatal Nurses Association. Published by Elsevier Ltd. All rights reserved.

Tending to the emotional needs of parents in the neonatal intensive care unit (NICU), in addition to caring for their high-risk infants, is a deeply-felt responsibility for neonatal nurses – one that requires a tailored approach to each family,

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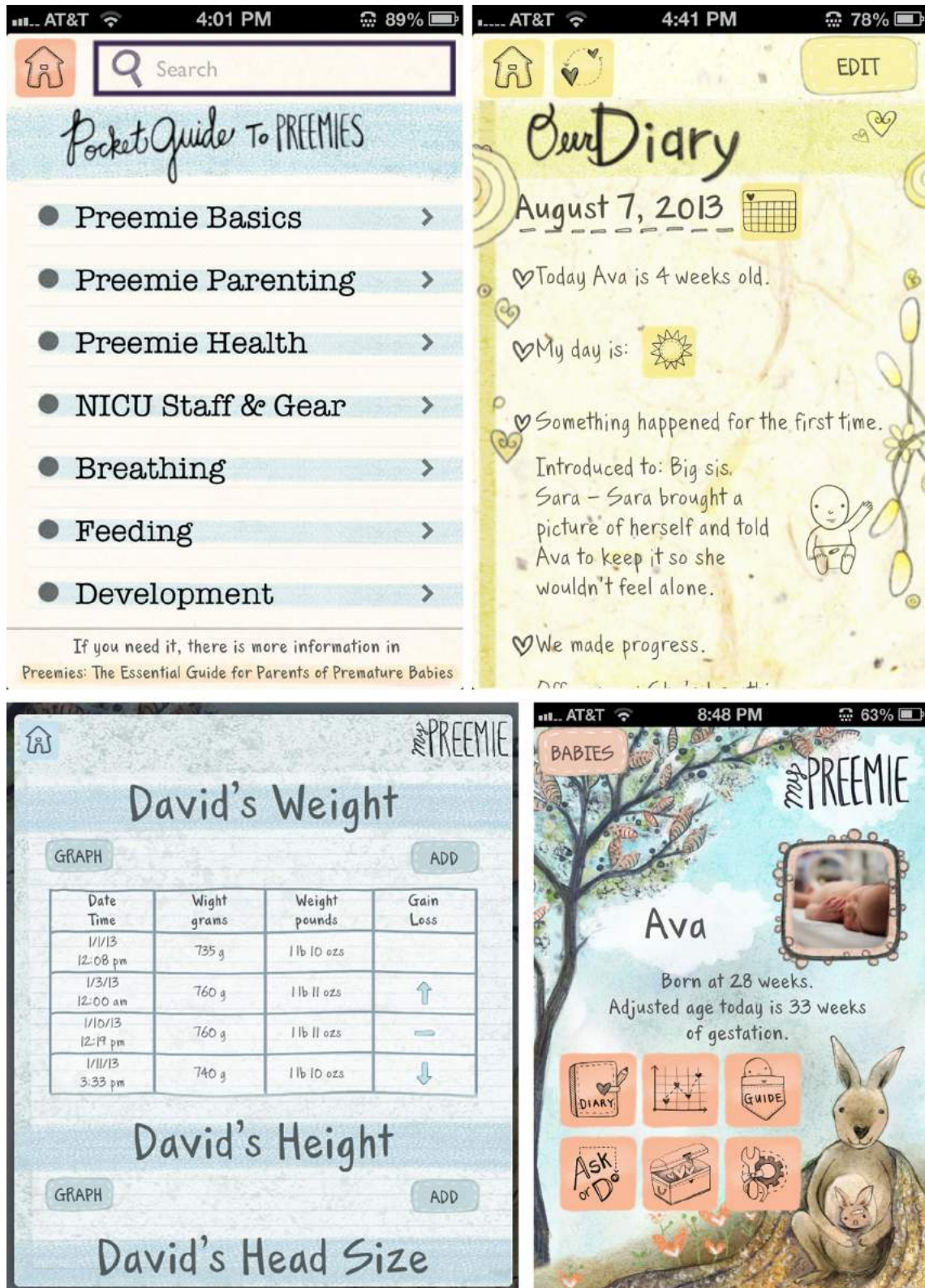


Fig. 1 Some sample screenshots from the MyPremie app.

understanding of psychological issues, good communication skills, and constant patience and adaptability (Cleveland, 2008). As a neonatologist

and two mothers of premies, we know how difficult it is to do well, and how important. To help ease this task, nurses now have another tool: they

can encourage NICU parents to download the new *MyPreemie* app (Palasoftware Inc.) for iPhone and iPad, which we designed to assist, inform, and support parents of premature babies throughout their stressful experience (Fig. 1).

When we wrote our book *Preemies: The Essential Guide for Parents of Premature Babies* (Linden et al., 2000/2010), we aimed to give parents accurate information, realistic hope, and reassurance that they were not alone. We are profoundly gratified by the warm response *Preemies* has received (See <http://www.preemiesthebook.com/reviewsFeedback.html>). But as NICU staff know well, and research confirms, parents of premature babies have other needs that a book is unable to meet: for meaningful parenting activities that make them feel useful and needed at a time when they feel they have handed off parenting to the nurses; for more normality, control, and positive experiences; for a way to express their turbulent emotions and not feel crazy; for staying connected to family and friends while maintaining their privacy (Cleveland, 2008).

Today's young parents rely largely on mobile devices to keep connected and informed: according to market research, in the U.S., 81% of 18–34 year-old mothers carry a smartphone (2013 Social Mom Report). We realized we could respond to these new habits, taking advantage of the interactivity of digital technology to address some of the unmet emotional, logistic, and communication needs of parents of premature babies — helping them regain aspects of the normal, happy, new-parent experience they feel they have lost with their baby's early birth. And so, the *MyPreemie* app was born.

MyPreemie has six sections, each designed to empower parents with information, easy-to-use tools, support, and a sense of normalization (acknowledging that certain obstacles are common and expected):

- The *Pocket Guide to Preemies* is essentially a mini book inside the app with clear and concise information on over 115 topics that can be searched or browsed. This section of the app puts information at the fingertips of parents when they need it in the NICU. To encourage communication with the medical staff and aid parents' understanding, each topic comes with several related Suggested Questions that they can ask the doctor or nurse about their baby.
- Parents are able to select a Suggested Question and with one tap transfer it to their *Remember to Ask* list, where it is easily accessible when a nurse or a doctor is available for a conversation.
- A parallel *Remember to Do* list helps keep personal tasks organized. Both lists are particularly

useful at a time when parents typically have trouble focusing and remembering.

- The Trackers section provides a tool for parents to actively participate in their baby's daily care by tracking his or her growth, one of the most important parameters and a key to progress. Parents can log their baby's weight, length, and head circumference measurements and immediately see them plotted on premature infant growth charts, viewing the trend over time and whether their baby is growing as expected. The Trackers feature empowers parents to participate in decision making regarding their baby's development and decreases their feelings of exclusion, as demonstrated in this quote from a parent-blogger: "This evening her calories went from 22 to 24 in her breast milk.... I am charting her growth with my preemie app (yes, there is an app for that) and she is below the 10th percentile, so I agree with the move to add more calories to boost growth." (<http://tinytandan.wordpress.com/2013/07/16/day-58-july-16-cannula-countdown/>)
- *Our Diary* is a combined baby journal and adult diary eliciting facts, photos, feelings, and thoughts that parents fill in every day, as a fun and meaningful activity, and as a useful pastime in the long hours spent at the baby's bedside. Each Diary page has an easy-to-complete series of prompts specifically focused on the experience of premature babies. Parents can select from multiple-choice lists of special events (such as a first feeding or coming off oxygen) and emotions (such as proud, afraid, or numb), or they can write their own. Two prompts are specially designed to elevate mood: "I am looking forward to..." and "I am grateful for...". Every day parents are asked to record the names of the nurses taking care of the baby, enhancing bonding. Nurses can promote a sense of collaboration and mutual understanding by flagging events for parents, talking with them about how the day's page might be filled out, and comparing perspectives. *MyPreemie's* Diary normalizes parents' experiences, and it empowers them by helping them identify and remember special events, express their emotions, and feel included in their baby's care. Keeping a journal such as this has been shown to decrease stress in the NICU (Macnab and et al., 1998).
- Another section of *MyPreemie* called *Treasured Mementos* offers a checklist of meaningful items from a preemie's early days — such as the hospital bracelet and isolette name card — that parents are encouraged to gather as keepsakes of their child's early start in life. They can add other cherished

items to the list. This feature of the app, like others, helps normalize and organize parents' experience.

In designing the *MyPreemie* app, we struggled with how to acknowledge the loss of a preemie's life and offer support to the parents going through this tragic experience without creating unnecessary anxiety and fear in all other parents. Our solution is a Loss Pathway embedded in the Diary that is triggered only by specific prompts. When a preemie has died, the app offers condolences, suggested readings, and the option for parents to create a special Memory Page to memorialize their baby. Parents can continue to use the Diary and record their feelings after their baby's death if they want, on pages with different prompts now focused on supporting them through their grief. The Loss Pathway is a good example of how a digital app with its interactivity can adapt itself to each preemie's path and is an ideal tool to provide personalized information and support.

Finally, *MyPreemie* can ease the stress of keeping friends and relatives updated with news of the hospitalized baby. On the one hand, parents want to involve their loved ones and stay connected to them; on the other, they often crave privacy and wish to avoid emotionally charged or lengthy conversations. *MyPreemie's* solution allows all pages of the app to be easily shared by email or Facebook – edited for different recipients if desired – with just a couple of taps. NICU staff may appreciate this feature as well, when it helps avoid having to repeat the same information to multiple family members. Pages of the app can also be printed in PDF and saved, preserving all the work parents put into them and creating a beautiful baby book to cherish forever.

Our goal for *MyPreemie* is that it not just be useful but also a source of pleasure at a time when too many parents are overwhelmed with negative feelings. We worked with an artist to give it the gently whimsical look of a hand-illustrated baby-book, making it a haven of warmth and calm in the midst of the high-tech environment of the NICU. Parents can even choose the color and design of their Diary pages – one of the small delights we aimed for throughout the app.

Although *MyPreemie* is geared to the period of a premature baby's birth through the first few months at home after hospital discharge, the app can be used much longer if a parent wishes. Most of the topics in the Pocket Guide cover information through the toddler years, and the Tracker tables (but not graphs) and Diary can be continued indefinitely.

In sum, we designed the *MyPreemie* app to be a one-stop shop for the multiple needs of NICU

parents, and those who have seen it attest to the support and benefits it can provide ([Stroll/Carry/Love, June 15, 2013](#); [TechMom Tuesday, June 4, 2013](#); [Urbanflowerpot, July 10, 2013](#); [Twinstuff Community, May 7, 2013](#)). Most parents of preemies, however, are not aware that such a tool exists for them, and may not think to ask for one unless neonatal nurses, as their most trusted advisors, draw their attention to it and recommend it. One former NICU parent wrote: "The new app, *MyPreemie*, should be mandatory for any family with a premature baby.... [It] is so beautiful and amazingly functional, that it can bring peace of mind and structure to a time when families often feel like they are free falling without a net." ([Stroll/Carry/Love, June 15, 2013](#)) By making families aware of this new resource, perhaps demonstrating it to them so they can see it for themselves, and collaborating with parents in its use, nurses can stay at the forefront of family care, reinforcing their relationship with parents and adding to the many tremendous services they provide to the families of their tiny patients.

Conflict of interest statement

The authors, with developer Paul Schmitt of Palasoft Inc., are the creators of the *MyPreemie* app. *MyPreemie* is for sale in the Apple iTunes store; proceeds go to Palasoft and Apple. The authors made out-of-pocket investments in the app that may at a future date be partially reimbursed from proceeds.

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References

- Cleveland, L.M., 2008. Parenting in the neonatal intensive care unit. *JOGNN* 37 (6), 666–691.
<http://www.preemiethethebook.com/reviewsFeedback.html>.
- <http://tinytandan.wordpress.com/2013/07/16/day-58-july-16-cannula-countdown/>.

- Linden, D.W., Trenti-Paroli, E., Doron, M.W., 2000/2010. *Preemies: the Essential Guide for Parents of Premature Babies*, second ed. Gallery Books, New York.
- Macnab, N., et al., 1998. Journal writing as a social support strategy for parents of premature infants: a pilot study. *Patient Educ. Couns.* 33, 149–159.
- Palasoftware, Inc. MyPremie. <https://itunes.apple.com/us/app/mypreemie/id620128292?mt=8>.
- 2013 Social Mom Report. A 21st Century MOM Insight Series by Babycenter. http://www.babycentersolutions.com/docs/BabyCenter_2013_Social_Media_Marketers_Handbook_US.pdf.
- Stroll/Carry/Love, June 15, 2013. A Beautiful App for Parents of Preemies. <http://strollcarrylove.com/index.php/a-beautiful-app-for-parents-of-preemies/>.
- TechMom Tuesday, June 4, 2013. Reasons I Love MyPremie App/Review. <http://alliosnews.com/2013/06/techmom-tuesday-reasons-i-love-my-preemie-an-app-review/>.
- Twinstuff Community, May 7, 2013. A Review of the MyPremie App. <http://www.twinstuff.com/a-review-of-the-mypremie-app/>.
- Urbanflowerpot, July 10, 2013. Review and Giveaway: MyPremie App. <http://urbanflowerpot.com/?s=MyPremie+App>.

Bliss nurse update

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Available online 29 August 2013

In 2011 Bliss launched its Bliss Nurse programme with the first nurses appointed at St Georges Hospital in London. Since then we have recruited to Norfolk and Norwich University Hospital and we are thrilled to announce that in the Autumn we appointed the next two nurses to the James Cook University Hospital, Middlesbrough and Birmingham Womens Hospital and Heartlands Hospital covering SW Midlands network.

The Bliss Nurses will ensure that the unit they work on provides consistent, high quality family-

centred care, including promoting breastfeeding, kangaroo care and ensuring the right facilities and help are available. With no clinical duties Bliss Nurses will have time to focus on the needs of the whole family and work with colleagues to ensure the standard of family-centred care is raised throughout their regions.

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You said...we did

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Mothers and fathers of babies in neonatal care are on a difficult journey, often with limited control or involvement in their baby's care. They are in a

stressful position – not only are they the anxious family members, but they are also the 'proxy patient', having to speak for their baby. However,