

# An infusaport education package - addressing the needs of parents



Janine Furmedge<sup>1</sup> Professor Paul Monagle<sup>1,2,3</sup> Dr Chris Barnes<sup>1</sup> Professor Fiona Newall<sup>1,2,3</sup>

1 The Royal Children's Hospital Melbourne.

2 Murdoch Children's Research Institute at The Royal Children's Hospital, Melbourne.

3 Department of Paediatrics, The University of Melbourne at The Royal Children's Hospital, Melbourne.



## Introduction

Hemophilia is a potentially life threatening bleeding disorder for which treatment is administered intravenously. Infusaports are commonly used to establish reliable intravenous access in young children and most families learn to access their child's infusaport to give treatment at home. Provision of education is critical to ensure families can safely carry out infusaport care. However, few studies have explored how best to teach parents to perform this complex and often confronting procedure on their child.

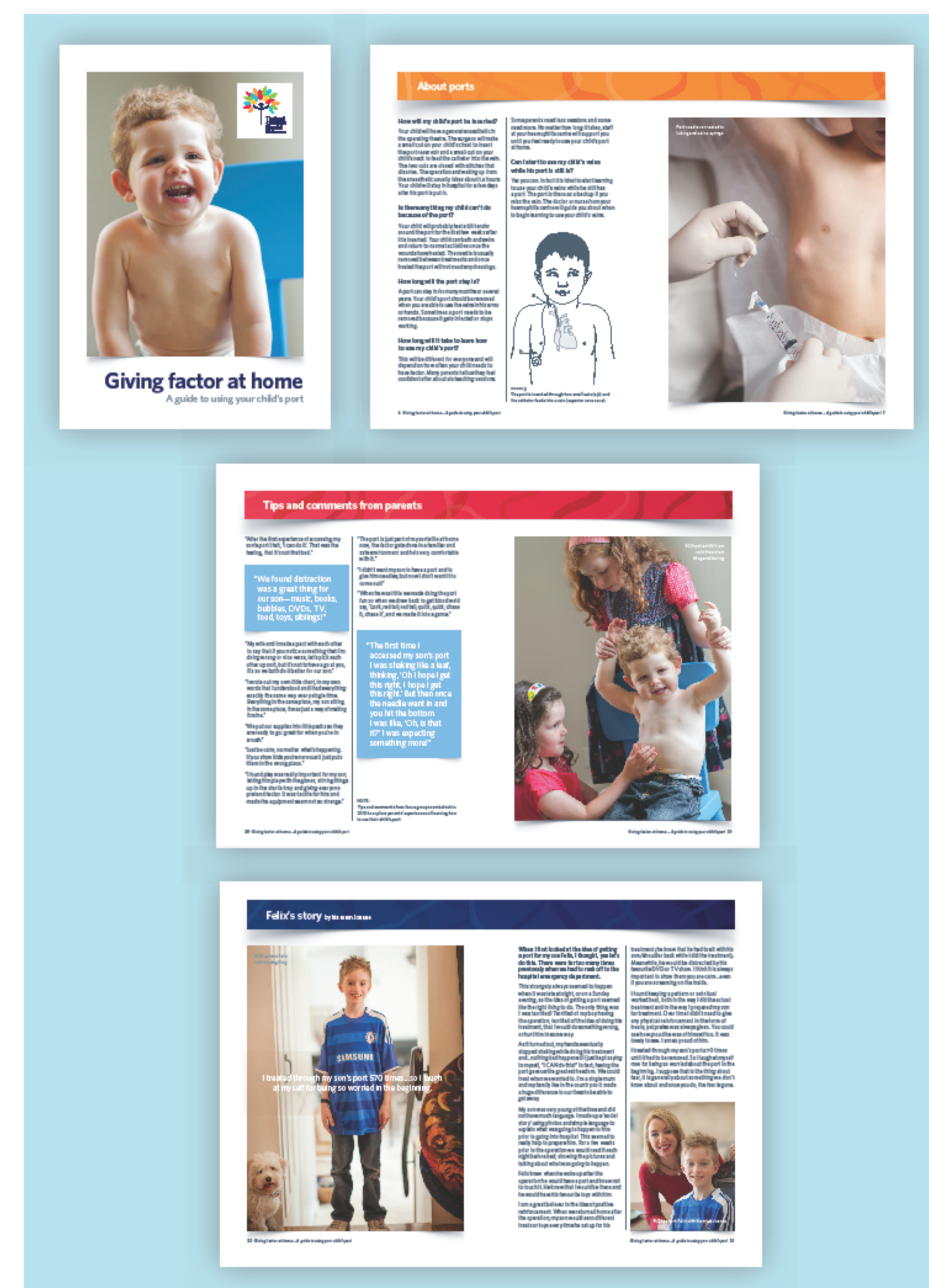
## Aim

The purpose of this project was to develop and evaluate an infusaport education package based on the experiences and education needs of parents as identified by a previous study at our centre.

## Methods

A written teaching package was developed incorporating strategies parents had identified as likely to assist their learning. As a result the package incorporated photos, checklists and 'step by step' instructions. Parents had expressed the desire to hear the voices and experiences of other families, leading to the inclusion of stories, anecdotes and tips from other parents. In addition, consistency of teaching was identified as very important and so a checklist and information directed to nurse teachers was included as a mechanism to address this issue.

The draft package was evaluated by four 'expert' parents who had previously learnt how to administer clotting factor to their child via infusaport. Suggestions from expert parents were incorporated and the package was then piloted and evaluated by four 'novice' parents undertaking infusaport education for the first time. Evaluation was via questionnaire. As an adjunct to written information, novice parents were offered the opportunity to have an individualized DVD produced of them performing infusaport access on a model.



## Results

All eight parents agreed or strongly agreed the written package was easy to read and understand (5 level likert scale; strongly disagree, disagree, undecided, agree, strongly agree). Overall package content was rated as extremely useful and length of the package was considered 'about right' (5 level likert scale; too long, a bit long, about right, a bit short, too short) by all eight parents. Suggestions from expert parents for changes to the package included adding an estimate of the time it usually takes parents to learn the procedure and stating the importance of creating a positive environment for the child. There were no suggestions for changes from the novice parent reviewers. As depicted in Figures 1 and 2, most of the content of the port education package was rated as very useful or extremely useful by both expert and novice parents.

Figure 1: Evaluation by expert parents



Figure 2: Evaluation by novice parents



General comments were invited and were very positive:

"Really terrific booklet, wish we had access to it"

"This is fantastic! Not just for new families beginning, but for 'older ones' to brush up on and re-iterate the basics."

Interestingly all four novice parents declined production of an individualized DVD describing that they learnt best by 'doing' rather than watching a DVD. In one parent's words;

"I learn best through going through the procedure - actually doing it myself. Watching myself doing it on a DVD would not have registered as well. This is probably why I made so many trips to the hospital before feeling confident enough to do it myself at home!"

## Conclusion

The exploration of parents' learning needs and the involvement of parents in the development and evaluation stages has led to the production of an infusaport education guide we believe will meet the needs of families learning to access their child's infusaport to administer clotting factor at home. That all novice parents declined the production of an instructional DVD was somewhat surprising but highlights the importance of not making assumptions about how patients or parents should learn and to develop educational tools according to the needs and requirements of the learner.

## Acknowledgements

The production of "Giving factor at home. A guide to using your child's port" was funded by a Bayer Hemophilia Caregiver Award.

A special thank you to the families who generously gave their time to share their experiences of learning how to use their child's port, to write their stories, to be photographed and to review and pilot this guide.

Note: Families have provided written consent for the use of photographs.