

# An evaluation of preterm breastfeeding information and support

The Bliss preterm breastfeeding leaflet is currently available to mothers on units in the Shropshire, Staffordshire and Black Country Newborn Network. A study was performed to examine the impact of the leaflet on common problems mothers face in initiating and sustaining milk production and breastfeeding following preterm delivery. In addition, mothers were asked to evaluate local breastfeeding interventions, information and support.

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## Keywords

neonatal; information leaflet; parents;  
preterm infants; premature

## Key points

Jones E., Emmett C., Spencer S.A. An evaluation of preterm breastfeeding information and support. *Infant* 2009; 5(4): 116-20.

1. The majority of mothers read the leaflet and rated it highly.
2. When seeking help for a problem, most participants approached a member of staff first – rather than reading the leaflet.
3. Mothers were positive about the advice they received, irrespective of the source from which it came.
4. The leaflet played a useful role by providing information and reinforcing verbal advice given to mothers by neonatal nurses.

Human breast milk is important for preterm babies to promote the establishment of enteral feeding and to provide immunological protection<sup>1</sup>. Breastfeeding is also beneficial in promoting maternal infant attachment that may be adversely affected by separation in the early post-partum period<sup>2</sup>. The population of a neonatal unit is largely comprised of women who are disadvantaged both socially and economically<sup>3</sup>. Although there is a steep social class gradient in breastfeeding initiation in the UK, many mothers can be persuaded to breastfeed their vulnerable babies provided they are given encouragement and support<sup>4</sup>. Potential barriers that mothers may encounter include: inadequate information regarding the benefits of breast milk and lack of consistent advice and support regarding the initiation of milk expression<sup>5</sup>. Mothers also report having difficulties securing the appropriate equipment and supplies to express milk. Skilled assistance may also be lacking regarding the maintenance of milk expression and the transition to direct breastfeeding<sup>6</sup>. Therefore, it is not surprising that mothers of preterm infants start and sustain breastfeeding at lower rates than mothers of term babies<sup>3</sup>.

Bliss, the special care baby charity based in the UK, offer a Family Support Helpline. Bliss found that some of the most common enquires received were around preterm milk expression and breastfeeding<sup>7</sup>. Consequently they commissioned the production of a preterm breastfeeding information leaflet for parents (FIGURE 1). The leaflet was written by a preterm breastfeeding specialist, a consultant



FIGURE 1 Photograph from the cover of the current Bliss leaflet.

neonatologist with a special interest in nutrition, and the mother of a baby born at 23 weeks' gestation who went on to breastfeed successfully. The completed leaflet was then edited by a freelance medical journalist to ensure the information was presented in a clear and easy-to-read style. Optimal layout and design specifications were adhered to and commercial sponsorship was sought. The leaflet was reviewed by a wide range of specialist health professionals in the field, the Bliss medical and nursing advisory panels, and endorsed by the National Childbirth Trust. The leaflet is one of the most ordered and downloaded of the Bliss Publications<sup>8</sup>. Since the first edition was published in 2002, 68,000 copies have been issued and a further 25,000 leaflets were printed in March 2009.

## Introduction

The Bliss preterm breastfeeding leaflet is currently available to mothers on units in the Shropshire, Staffordshire and Black Country Newborn Network. Since producing, publishing and distributing approximately 100,000 leaflets, (now in the sixth edition), is an extremely time

consuming and costly process for a small charity, it is essential to examine the effect of the leaflet on the common problems mothers face in establishing lactation and breastfeeding following preterm delivery. In addition, it is important that breastfeeding advice is not simply equated with having a breastfeeding information leaflet. Therefore, in order to gain an overall picture of the quality of the advice and support mothers receive regarding preterm breastfeeding across the Network, mothers were asked to evaluate local breastfeeding interventions, information and support.

### The study

#### Aims

To discover whether mothers in the Shropshire, Staffordshire and Black Country Neonatal Network:

- recalled seeing or receiving the Bliss preterm breastfeeding leaflet (without prompting)
- had read or looked at part or all of the leaflet
- perceived the information in the leaflet useful in solving expression and breastfeeding problems
- had accessed other advice and assistance about milk expression problems
- had found other advice and assistance useful in solving breastfeeding problems

#### Study population and setting:

Mothers of preterm infants who wished to express breast milk in units across the Shropshire, Staffordshire and Black Country Newborn Network.

#### Inclusion criteria:

A convenience sample of mothers with preterm babies (ie less than 37 weeks' completed gestation) admitted within the timeframe to neonatal units in the Network who declare an intention of initiating lactation.

#### Exclusion criteria:

- Mothers who stayed on the unit for less than 48 hours
- Mothers of infants who died or were transferred out for surgical or cardiac problems
- Mothers of infants who had oral facial or severe neuro-muscular problems
- Mothers who had an inability to understand written or spoken English

#### Measurement tool

A questionnaire was developed for the purpose of gathering information from

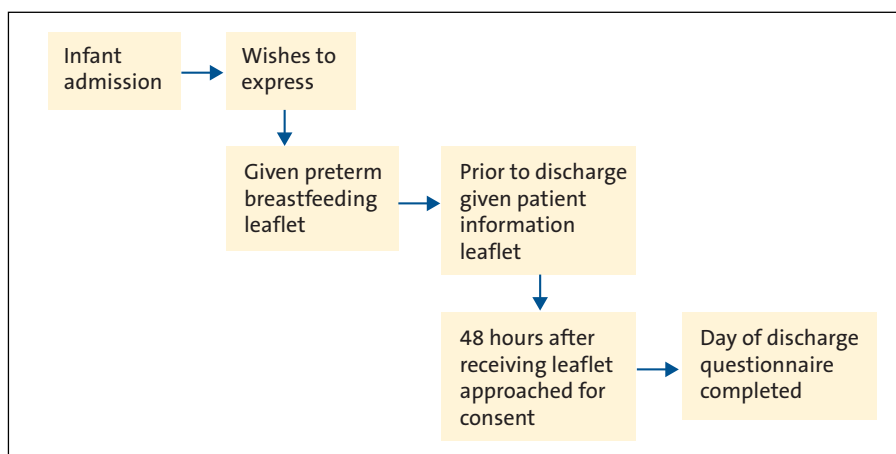


FIGURE 2 Timeline for completion of the questionnaire.

Background variables	Mean	SD	Range
Gestational age (weeks)	30.2	2.8	24-36
Maternal age (years)	30.1	6.4	16-45
	Median	IQR	Range
Birthweight (grams)	1430	160	530-2830
Demographics	Number (percentage)		
Primiparous	57 (63%)		
Multiparous	34 (37%)		
Emergency caesarean section	40 (44%)		
Elective caesarean section	11 (12%)		
Normal delivery	38 (43%)		
Breech delivery	1 ( 1%)		
Breastfed before:			
Yes	21 (23%)		
No	70 (77%)		
Established breastfeeding:			
Yes	51 (56%)		
EBM bottle	21 (23%)		
Breast and bottle	7 (8%)		
No	12 (23%)		

TABLE 1 Demographics of the study population.

respondents. An expert panel consisting of a clinical psychologist, a professor of nursing, a medical statistician, a consultant neonatologist and an advanced neonatal nurse practitioner were consulted in respect to the questionnaire construction. A four-item Likert scale measuring attitudes and experiences of mothers was used. Open-ended questionnaires were also incorporated to encourage mothers to share their experiences. The questionnaire did not mention which sources of information (verbal or written) were being evaluated in order to gain an unbiased appraisal.

The questionnaire was piloted on six mothers for clarity and ability to interpret and answer questions in an appropriate

way, after approval was received from the ethics committee. No further changes were deemed necessary.

#### Ethics

The study protocol, questionnaire and information sheet were reviewed and approved by both the Independent Peer Review Committee and the Ethics Committee. Ethics approval was obtained. The ethical committee insisted that parents had written information about the study at least 48 hours before completing the questionnaire. Local Research and Development permission was sought across the Network and clinical governance issues were addressed. All of those involved in the study were made aware of the

	Frequency	Percent
Yes	71	78%
No	6	7%
Didn't answer	12	13%
Can't remember	2	2%

**TABLE 2** Number of mothers given dedicated preterm breastfeeding leaflet.

	Frequency	Percent
Very useful	46	67%
Useful	17	25%
Not very useful	4	6%
Not useful at all	0	0%
Didn't answer	2	3%
Total	69	100%

**TABLE 3** Perception of the leaflet.

policies on research governance and their involvement was approved by the relevant Research and Development Department and the North Staffordshire Ethics Committee.

### Recruitment and enrolment

A local investigator was appointed from each participating unit. All mothers who wished to express breast milk in the Shropshire, Staffordshire and Black Country Network were routinely given a copy of the Bliss Preterm Breastfeeding leaflet on admission to the unit. During the period of preparation for infant discharge, an information leaflet was given to parents about the study. At least 48 hours after receiving the information leaflet parents were asked if they had any questions about the study, and if they still wished to participate, fully informed consent was obtained. A copy of the questionnaire was then issued for completion prior to infant discharge (FIGURE 2).

### Data collection and analysis

Between October 2006 and February 2008, 91 women gave consent to the study, and all who consented completed the questionnaire during the period of preparation of discharge from the unit after a personal meeting with the researcher allocated to the neonatal unit. Data was screened by the medical statistician for inconsistencies which were checked on the spreadsheet prior to analysis. Analysis was descriptive. Categorical variables were summarised using percentages and numerical variables by either the mean and standard deviation,

Where general information was obtained about milk expression	Frequency	Percent	Where specific information was obtained about how to overcome expression problems	Frequency	Percent
Person	28	68%	Person	26	63%
Leaflet	3	7%	Leaflet	2	5%
Both	8	19%	Both	11	27%
Did not obtain leaflet	1	2%	Did not obtain leaflet	2	5%
Did not answer	1	2%			
Total	69	100%	Total	41	100%

**TABLE 4** Information sources regarding milk expression problems.

	Frequency	Valid percent
Leaflet	29	33%
Nurse	48	55%
Doctor	8	9%
Internet	2	2%
CD/DVD/VIDEO	1	1%
Total	88	100%
Missing	3	

**TABLE 5** Information sources regarding establishing breastfeeding.

	Frequency	Valid percent
Very helpful	61	69%
Helpful	24	27%
Not very helpful	3	3%
Not helpful at all	0	0%
Total	88	100%
Not applicable	3	

**TABLE 6** Evaluation of the quality of information received.

or median and inter-quartile range, depending on the shape of the frequency distribution and 95% confidence intervals were calculated for all primary variables. The open-ended questions were evaluated into themes and categories of response, which were numerically coded by the researcher.

### Study results

#### Geographical breakdown of completed questionnaires

The number of questionnaires returned from each participating unit was as follows:

- Russells Hall Hospital 8%
- Stafford District General Hospital 11%
- Royal Shrewsbury Hospital 18%
- University Hospital of North Staffordshire 48%
- Manor Hospital Walsall 9%
- Wolverhampton New Cross Hospital 7%

#### Demographics

The demographics of the study population are shown in TABLE 1. About two thirds of the participants were primiparous and the mean gestational age was 30 weeks (SD 2.8).

#### Main outcome variables

The results of the main outcome variables are shown in TABLES 2-6. In summary, 78% (95% CI 68-86%) of mothers were given

	Frequency	Percent
Private milk expression room	84	92%
Help with first milk expression	81	89%
Good provision of milk expression equipment	86	94%
Experienced problems expressing	42	45%
Overcame problems	35	83%

**TABLE 7** Individual experiences of milk expression.

the information leaflet (TABLE 2). The majority read the leaflet and rated it highly (TABLE 3).

Approximately half of the study population (45%) experienced problems with milk expression. Although the majority gained information about their difficulty in a conversation with an individual (TABLE 4), 27% obtained information about how to overcome their problem from both a person and a leaflet (TABLE 4).

Approximately half of mothers reported difficulties establishing breastfeeding (45%), although not always the same mothers who had problems expressing. The majority, (83%), overcame any problems they were experiencing. Again

the mothers who had a problem in this area did not use the leaflet on its own when sourcing a solution.

When asked if they found ‘other advice and assistance useful in solving breastfeeding problems’, the majority circled ‘leaflet’ and one other source (TABLE 5).

In general mothers were positive about the advice they received, irrespective of the source where it came from (TABLE 6).

### Individual experiences of milk expression

A summary of the experience mothers had with milk expression can be found in TABLE 7. The problems experienced were: engorgement (2%), too little milk (10%), mastitis (5%) and a variable milk supply (9%). Other comments included: needing to persevere with expressing before their milk supply increased (24%), having to re-lactate (re-stimulation of lactation after lactation has ceased) (3%), and being advised to take domperidone (4%). Only 19% of mothers taking part in the study had previous experience with milk expression.

### Breastfeeding problems and perceptions

Establishing breastfeeding was very important to 76% of mothers. However, only 8% found it easy to establish preterm breastfeeding and 45% encountered difficulties during the process of establishing breastfeeding:

- 31% felt that a poor milk supply contributed to their problems
- 10% mentioned having to persevere until their supply improved
- 13% stated that their baby was too small to latch onto the breast
- 1% found neonatal jaundice contributed to lack of interest during feeding
- 19% stated that their baby had to learn to feed
- 3% experienced sore nipples.

When asked to describe the overall experience, the specific answers given were:

- it was a good experience (37%)
- it was good to contribute to care (20%)
- breastfeeding helped to bond with baby (19%)

### Leaflet evaluation

When asked specifically for open-ended comments about “what was the most useful about the leaflet”, a break down of the answers can be found in TABLE 8. When asked about the quality of the leaflet, 30% described the leaflet as “well written”, 35% found it “easy to understand”, 22% stated

	Frequency	Percent
Could still breastfeed despite preterm	12	13%
Benefits of breast milk and breastfeeding	15	16%
Everything in the leaflet was ‘useful’	28	31%
Importance of breast milk	4	4%
How to attach and position a baby at the breast	9	10%
Found the leaflet reassuring	10	11%
Loved the photographs	10	11%
Learned a lot about ‘how to express’	11	12%
Learned how to ‘establish breastfeeding’	9	10%

TABLE 8 Most useful feature of the leaflet?

	Frequency	Percent
No information on milk suppression	2	2%
Needs trouble shooting page	4	4%
No information on using one or both breasts per feed	2	2%
No information on increasing milk supply	1	1%
More information required on the transition to direct breastfeeding	3	3%
Needs more information on milk banks	1	1%

TABLE 9 Shortcomings of the leaflet.

*‘I found expressing gave me a sense of doing something for my baby, it was the only thing I could do for him while he was incubated and ventilated. I felt helpless and terrified for weeks.’*

*‘Although expressing was one of the hardest things I’ve encountered due to the mental and physical demands, it was worth it because my baby was thriving.’*

*‘I never would have breastfed if my baby had been born healthy, but now I want to give him the best I can to help him to get better. I feel so close to him when I am breastfeeding’.*

*‘I found it frustrating trying to breastfeed my son. He was sleepy and wouldn’t suck. But I plan to carry on expressing my milk as long as I can and he can have it in a bottle. It is my way of being in control, but still giving him my milk. I still feel that in some way it is my fault that he was born so early’.*

*‘I read the leaflet from cover to cover again and again. I found it encouraged me to persevere, even when my baby’s condition took a nose dive. The parents’ story made me keep going’.*

TABLE 10 Examples of the comments made by the mothers in the study.

that the information was “clear”, and 5% found the parents’ story “empowering”.

### Leaflet limitations

When asked about what they found was “least helpful” about the leaflet, 56% of participants had no criticisms and reported that “all was useful”. Others raised topics that they would like to be included in the next revised edition (TABLE 9). These topics have been incorporated into the current revised issue of the Bliss preterm breastfeeding leaflet<sup>7</sup>.

### Open-ended comments

Mothers used the open-ended section at the end of the questionnaire, to describe their experience of having a baby on a neonatal intensive care unit. TABLE 10 lists a selection of the poignant responses received.

### Study limitations

Due to the fact that only one local investigator was appointed to each unit, data could only be collected when the investigator was on duty and the questionnaire could be handed out to the mother following fully informed consent, under the time frame stipulated by the Ethics Committee. (Parents were only approached for consent 48 hours after receiving the Patient Information Sheet). This meant that it proved very difficult to approach all the mothers who were eligible for study inclusion and gain a consecutive sample. This may have created a sampling bias in which those who were unsuccessful in establishing breastfeeding may have been under represented.

The Shropshire, Staffordshire and Black Country Newborn Network has a dedicated breastfeeding group which is

very proactive in promoting and facilitating breastfeeding training. In addition, two units from the study population are in accredited Baby Friendly Hospitals and two units have successfully received their UNICEF Certificate of Commitment, which indicates that they are working towards Baby Friendly. Therefore, mothers have access to highly skilled neonatal staff for breastfeeding information. This level of expertise may not be typical of all neonatal units in the UK.

## Discussion

There is strong evidence to suggest that leaflets alone may be ineffective or harmful for enhancing breastfeeding initiation and duration<sup>9</sup>. However, a Swedish study that utilised a three-staged approach to breastfeeding, using advice, leaflets and intensive staff training, found evidence to suggest that leaflets had a significant effect on breastfeeding initiation rates<sup>10</sup>. There may be some difficulties in generalising the intervention to the UK but, in principle, the combined approach looks promising.

In this study mothers found the leaflet to be a useful source of information and support. Mothers evaluated it as well written, easy to read and understand. They liked the lay out, the photographs (FIGURES 3 and 4) and found the parents' story inspirational. Although there is no definitive evidence that the leaflet had an effect on breastfeeding outcome, many mothers stated that the leaflet encouraged them to carry on with the relentless task of frequent milk expression. Furthermore, it is encouraging to note that on discharge, 56% of the study participants were breastfeeding exclusively, 23% were giving expressed breast milk (EBM) in a bottle, and 8% were both bottle feeding (EBM) and breastfeeding. How this compares to national statistics is unclear. Currently there is no outcome data available on preterm breastfeeding rates on discharge in the UK. Locally a proforma is being developed to audit milk expression and breastfeeding rates across the Network.

A multi-faceted approach to breastfeeding training is the current model for breastfeeding training across the Shropshire, Staffordshire and Black Country Newborn Network. Leaflets are handed out to parents in the early period following infant admission, after a brief discussion about the value of its contents. However, the leaflet is not intended to be the sole source of breastfeeding



FIGURE 3 Parents touching their newborn baby.



FIGURE 4 An example of preterm breastfeeding.

information and support for mothers. Mothers are also supported by a well trained and highly motivated multi-disciplinary work force. This study demonstrates that leaflets are an essential tool to reinforce and remind mothers of the key points discussed with a skilled support person.

## Conclusion

In this study the vast majority of patients remembered looking at the Bliss leaflet and it was deemed to be helpful by most of these. Whilst this study was not able to determine whether the leaflet improved breastfeeding outcome it does lend support to the continued use of this material from a patient perception perspective. However the importance of well trained neonatal staff in helping mothers to prevent and overcome difficulty cannot be over-emphasised. The leaflet appears to help but has to be used in conjunction with excellent staff training and support for breastfeeding if good results are to be obtained.

## Acknowledgements

We would like to thank the Shropshire, Staffordshire and Black Country Newborn Network for funding this project.

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