

Special babies, special care.

"This is a unique leaflet for parents of a sick baby. It has been written by a mother who herself recognised the need for such a resource. It provides valuable information and a practical guide to help families gain confidence and a greater feeling of control when caring for a sick child. This is so important not only while in hospital, but especially for those parents whose special baby may need additional care once they return home as a family."

Jean Macdonald MBE

Retired Special Care Baby Unit Manager
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The aims of the booklet

It is intended that this booklet will provide a useful practical guide for parents whose own "special baby" may need "special care", whatever the problem may be.

This booklet was written following my experience of caring for our little boy, Ben.

As parents, we needed practical information to help us understand, and to enable us to be actively involved in Ben's care and the decisions which had to be made for him. As this resource did not seem to be available for us, I have used my own experiences, listened to other families, and combined this with my professional nursing experience to produce this booklet. This booklet aims to:

- Explore common feelings for families at this time
- Increase parents' confidence in using a service with which they are likely to feel very unfamiliar
- Provide access to practical information
- Supply contacts for further help, if need

How do you feel?

This may be your first baby, or an addition to your family, but if you have been told that your baby has a life-long condition or deformity, you may be feeling very alienated from your previous expectation of the happy image portrayed by the media, and one which most new parents in truth experience. You may be feeling:

- shocked, bewildered or even numb
- fearful
- guilty
- angry
- confused
- worried for the future

Being on a ward, surrounded by healthy, crying babies and happy parents can be very hard to deal with: you may feel isolated; you may be wanting to ask a lot of questions, but be apprehensive about the answers; you may be worried about feeling judged. All these emotions are natural. Many are a part of grieving, a process of coming to terms with the news of your baby's problems.

If you think back to your pregnancy and labour, it is common to wonder if any thing you did, or if anything about your care, may have affected your baby. It is important that you are able to ask the questions you need to, and talk about your fears and feelings.

Your Family and Friends

This will be a difficult time for your family and friends who will feel unsure what to do or say. Grandparents, friends, and other children you have, may be affected in different ways. If you have a husband, or partner, try to make time for each other. If you can, talk, listen, and try to understand what each other has to say. You may of course each have very different feelings. If you have other children, try hard to give them some quality time.

...and, finally, remember to take time to care or yourself.

Shattered Dreams

This poem was the first of a series I wrote, and expresses *my* feelings at a time when our son Ben was only a few weeks old and still on a Special Care Baby Unit. I found writing *how* I felt helped me.

*Dreams shattered and feelings scattered
A precious baby was what most mattered
A symbol of two people's love-
A love that's grown and grown
Our love - a love that's truly meant to last forever*

*Dreams for the future
Planning to care and planning to share
A new life began
A new life so precious from the start
Precious and protected from the world*

*Dreams shattered
Protection from the world was gone
Tears shed and hopes gone
Never have we felt such emotion
More emotions than in any, any song*

*Lying there so innocent
Looking oh so sweet
What has happened to shatter such precious dreams
Life is so fragile
BJ so sweet
CP so awful- oh what a feat*

*Meeting life's challenges
Crossing life's hurdles
This must be the highest one they could find*

*Now looking for happiness
Searching for strength
To rebuild our dreams, and rise to the challenge which
Someone has sent*

Rachel Hawley, January 1992

Note: BJ: Benjamin Joseph CP: Cerebral Palsy

Special Care Baby Unit

What to expect

The Special Care Baby Unit or SCBU is a special ward where your baby may need to stay for a period of time particularly if your baby needs continuous observation and care, or is unwell and requiring closer monitoring than can be given on the postnatal ward.

- On the unit are nurses who have been trained to be able to give this special care.
- The unit area is always quite warm to suit the babies' needs.
- Babies will be nursed as necessary in an intensive care cot or an incubator, or in a small cot as on the postnatal ward.
- Even if your baby is on a ventilator, or in an incubator, you can still be fully involved.
- The nurses will teach you how you can help to care for your baby
- You may notice extra monitors and equipment here - this is very normal and necessary in this area, although you may find it alarming. The staff will explain what their functions are to you. Always ask questions and express any fears, as the staff will be able to offer you answers and advice which will reassure you.

Staff - who are they, and what do they do?

Midwife - A midwife will have monitored and advised you throughout your pregnancy, and a midwife (from hospital or community) will have assisted you throughout the labour. Contact with a midwife will continue following the birth of your baby for up to 28 days.

Obstetrician - Is the doctor responsible for the care of you and your baby throughout your pregnancy and during your labour. You may be seen by the Obstetrician after your delivery and for a postnatal check at 6 weeks.

Nursing Staff On Special Care Baby Unit - These are nurses who are trained and qualified to give your baby specialised care after the birth. In some areas, there are nurses who are able to divide their time and care between the unit and your family home after you take your baby home.

Paediatrician - Is the doctor who will look after your baby for as long as follow-up care is needed, or throughout childhood.

Health visitor - Your Health Visitor is linked to your GP practice, and will see you when you return home. She normally monitors children 0 - 5 years of age, assessing their development, giving immunisations and vaccinations, and offering general advice about childcare including monitoring growth.

Liaison SCBU sister or health visitor - You may meet the Liaison SCBU Sister or Health Visitor while your baby is on the Special Care Unit. She will be in contact with your own GP practice and Health Visitor before you both go home.

Social worker - A Social Worker may be able to offer you advice and information about benefits, childcare and support services in your local area.

Hospital chaplain - Whether you are religious or not, the Hospital Chaplain can be a great source of comfort at this time, providing a shoulder to lean on, cry on, and a non-judgmental ear allowing you to share your feelings.

Practical tips while your baby is in hospital:

- Talk to the nurses and doctors about your fears and worries
- Keep a record about your baby day to day - in a notebook or a diary
- Write your questions down as you think of them to help you remember
- Take photos (these will be precious)
- Plan your family and friends' visits to the hospital

- Catch up with your sleep
- Eat healthily
- Remember to find time for your postnatal exercises
- Accept encouragement to get involved in your baby's care - you will soon overcome the strangeness of the incubator and machinery or tubes.
- If you are breast-feeding, express milk regularly and bring it to the unit.
- Rest as much as you can - this experience can be very exhausting.

If you have the opportunity to have a short break as parents this can be very beneficial, even if it seems strange or hard now. It can give you the chance to have privacy as a couple and time to talk together - to recharge your batteries.

Practical tips if your baby needs "special care" after leaving hospital:

If your baby is needing additional care, and perhaps regular medication and ongoing clinic appointments, planning and advice regarding practical things will help you keep in control and manage your new routine.

- Keep a written record: this can be brief and flexible, perhaps in a diary, highlighting relevant aspects concerning vomiting, bowel opened, drug changes made in clinic etc.
- Cool bags: a small insulated bag may be useful when out and about if you are regularly having to carry medicine - which may need to be kept away from extremes of temperature
- Tablet cutter: this small gadget will ensure speedy and accurate splitting of tablets if division of tablets is required.
- Write down questions before appointments: it may help you when you attend clinic appointments to prepare by writing down a list of questions in advance. It is so easy to be distracted if you don't, and it may seem a long time until you have a chance to ask again.
- Giving medicines when out: if out visiting, it may be possible to pre-fill a syringe with medicine and to store it safely in a children's cutlery container until the required time
- Be honest about what you feel, and have confidence in your own beliefs. You will be relying on the skills of health care professionals for their expert medical advice, but, as parents, you will benefit by the privileges made by observations only possible by 24 hour contact, rather than brief encounters at appointments.
- Telephone for advice or support - whenever you feel a need to between clinic appointments. You will be given contact numbers to use - keep them in a safe place, with you at all times - even if away from home.

Personal experiences

The experience of having a sick baby is unique to you. There are many reasons why a baby may need "special care", and your own experience may feel very traumatic at this time, whatever the reason. No doubt you will experience a wide range of emotions which may span from the highest hope to the depths of despair.

Many babies will only spend a short time in hospital, but sadly for a few babies problems do not go away. Any stay in hospital is difficult because most parents are not prepared for this experience.

It is not unusual for parents to write about their experiences of caring for a child. Some of these stories are published; as a book, in magazines and newspapers, or in booklets like this. Some of these stories are happy, some inspiring, and some sad.

You may find it helpful to read, as you can learn and gain understanding from those to which you can relate - you may feel less alone.

The following are some quotes from families' own experiences:

In hospital:

"I felt awkward and different from the other women on the ward who were all busy with their babies, chatting about the births and getting ready to go home."

"I was very keen to breast feed Sophie and Ella but at first they were unable to suck properly. The nurses encouraged me to use the breast pump to express milk which was then fed to them through the feeding tubes. I felt delighted to be doing something for them."

"Having the use of a room within SCBD was very important. It enabled me to be close to Ross and care for him as much as I could and also gave me privacy when the family came to visit."

"I remember being frightened of the technology, the uncertainty of the prognosis."

"Although the staff kept us informed about what was happening we felt very isolated and alone."

"A nurse came over and put her arm around me and explained that I was grieving and my feelings were perfectly natural. This helped me a great deal to put things into perspective."

Going home before your baby:

"After two weeks on SCBD, I was well enough to go home. This too was a particularly emotional time and I needed the support of the staff to get me back into the real world again."

Going home with your baby:

"Having home visits from a SCBD nurse was a life line. So was the fact that I could contact the unit at any time and not feel a nuisance - and that applies even now."

"I shall always be grateful to a lady on SCBD who gave me her telephone number, as she lived close by me, and assured me I could phone her day or night if there was a problem. I never phoned her, but knowing I had her support made things a lot easier."

Support groups

It may be helpful to contact a relevant support group who may offer you support, and/or be able to provide useful information, advice or contact points which may be helpful now or for you or your baby in the future, e.g. research, finance, schooling, information leaflets, specialist centres, childcare, respite etc.

Many thanks to the parents of Sophie and Ella Chisholme, Stefania Cinelli, James Robson and Ross Summer, for contributing to this booklet 'There were three in the bed and the little one said...'

Written by Rachel Hawley - A tribute to Ben