PREMATURE BABIES

A GUIDE FOR PARENTS

Dr W H Kitchen M M Ryan A L Rickards J V Lissenden

PREMATURE BABIES

A GUIDE FOR PARENTS

Dr W H Kitchen M M Ryan A L Rickards J V Lissenden

HILL OF CONTENT
Melbourne

First published in Australia 1983
by Hill of Content Publishing Company Pty Ltd
86 Bourke Street Melbourne 3000 Australia

Cover art and design by Csaba Banki

Typeset in Australia by Dovatype, Melbourne
Printed in Australia by
The Dominion Press-Hedges and Bell,
Victoria, Australia

National Library of Australia
Cataloguing-in-Publication data

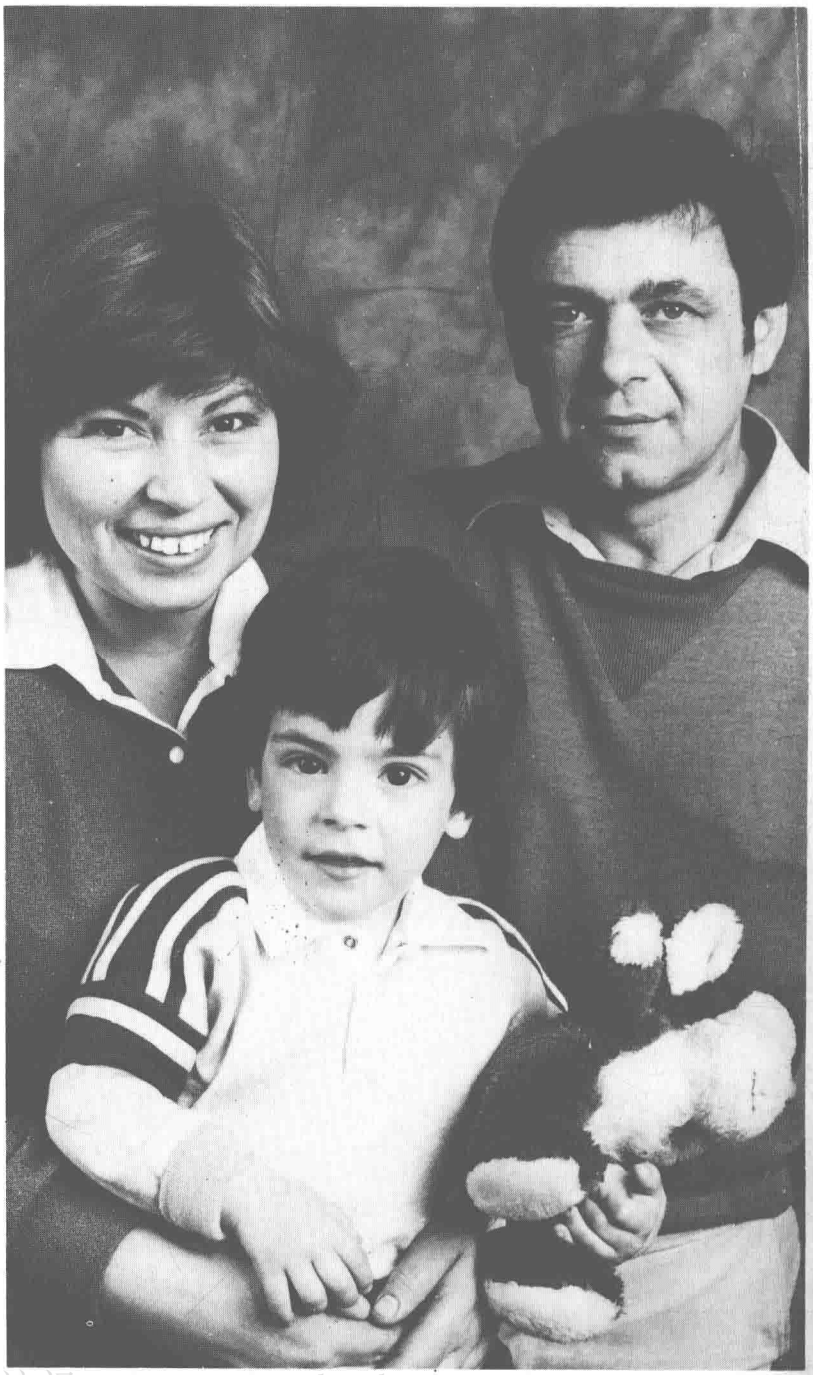
Premature babies.
Bibliography.
Includes index.

ISBN 0 85572 135 9.

1.Infants (Premature). I. Kitchen, W. H.
(William Henry), 1926- .
618.92'011'0240431

PREMATURE BABIES

Robert, who was tube-fed, is now a fine three year old in this family picture.



Contents

PREFACE

Why a book about premature babies?

Parents are increasingly interested in learning more about their babies, so parent education is now an accepted part of antenatal care. There are a number of excellent books available that explain to parents what they may expect of their baby immediately after birth and in the days, months and years that follow. However, most of this information concerns infants who are born close to the expected time.

Parents of premature infants have great difficulty in finding books that give the information **they** seek. Many of the publications on this subject are written by specialists for specialists and are difficult for parents to understand because of the numerous technical words used. They do not address the issues that are of immediate concern to the parents of a premature baby.

This book has been written to meet the need for more information. The authors have the varied professional backgrounds of nurse-midwife, social worker, psychologist and paediatrician, and in each case experience with their own children has added practical know-how to theoretical knowledge.

The most important people who have helped us with this book are the parents of premature babies. Over the years, fathers, mothers and other members of family have shared with us their fears and worries as well as their satisfactions and successes. They have given generously of their time and shown us many ways in which the care of such families might be improved. In a very real sense these people have asked the questions, given many of the answers and persuaded us that this information should be shared.

Although the doctors and nurses caring for a premature baby make a special effort to keep parents well informed about their baby's progress and problems, some parents still complain of great difficulty in either obtaining or understanding information. This book, then, is designed to give a general guide to parents — and immediate relatives — who are facing the crisis that surrounds the birth of a premature infant. However, a book has one great disadvantage for it 'talks to' rather than 'talks with' parents. So parents are asked to note that **this book is not a substitute for discussions of the details of your own baby with doctor and nurse. They will be expecting to answer your questions and will devote as much time as possible to this**

important part of your baby's welfare. This book provides you with background information and explanations that will help to make your conversations with the medical personnel easier and more meaningful.

Usually, friends and relatives, particularly the infant's grandparents, offer great comfort and support to worried parents, but there are times when lack of knowledge and experience may make their advice either misleading or unhelpful. A chapter titled 'Family and Friends. How can they help?' is included especially and this may be shared with close friends and relatives as well as immediate members of the family.

Throughout the text, the personal pronoun 'he' is used almost exclusively for the premature baby, although the authors are well aware that about half of all babies are female. It was decided to adhere to this established grammatical convention, rather than to lengthen the text and make reading more difficult, by inserting 'he or she' on every occasion.

The authors wish to thank all the parents who have talked to us about their children, who suggested alterations and additions to the text and allowed us to publish their photographs. Dr Rosemary C. Schwarz assisted in the preparation of Chapters 5 and 6 and the Teaching Aids Department of the Royal Women's Hospital, Melbourne, provided illustrations.

Dr W H Kitchen
Paediatrician

M M Ryan
Social Worker

A L Rickards
Clinical and Research Psychologist

J V Lissenden
Nurse-Midwife.

How to use this book

Parents reading this book for the first time soon after the birth of a premature baby may be so shocked and disturbed by their recent experience that the following important messages are all they will want to know for the moment:

- Most babies who weigh over a kilogram (almost 2¼ pounds) will live.
- Premature babies are small, but they are born at a time when the body is fully formed, even in such small details as finger and toe-nails.
- Parents of premature babies are usually very worried and anxious and this is normal. Nurses, doctors and others in the nursery find that many parents are very upset.
- Ask questions. If you don't understand, keep asking your questions; it is your right to know.
- Doctors and nurses will try to be honest with you. If there are special worries with your baby, you will be told.

Should parents read the whole book?

When you are ready, we suggest that you read only the sections that interest you and apply to your baby. Many parents will not need to read the book from cover to cover.

Each chapter has the most important information at the beginning. Read the remainder — for more information — when you are ready. You may wish to leave the more detailed sections until another time.

The doctors and nurses looking after your baby will explain about equipment used to help your baby and the difficulties that premature babies may have after birth. You may find it helps to read about these matters in the book and you may like to make a list of questions to ask the doctor or nurse later.

Parents' needs differ in regard to information. Some are happy to have only a general understanding of what is happening and don't wish to know any details or have technical explanations. If this is how **you** feel, it is fine. Other parents may like to know as much as possible. Your needs will be met by talking with the

nursery staff and by reading the parts of this book that concern you; later perhaps, you may wish to look at some of the other published material mentioned at the end of the book.

Very often one parent (usually the mother) will have more opportunities than the other parent to talk with the medical and nursing staff about their baby. However they may find it difficult to pass on the inormation gained to their partner. Appropriate sections of this book may be most helpful in this regard.

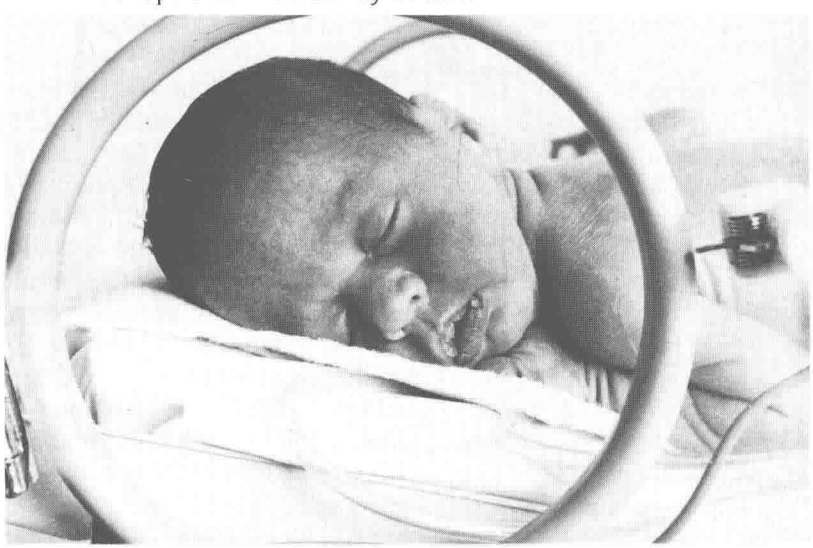
CHAPTER 1 Why is our baby small?

Most newborn babies weigh about 3500 grams, or 7½ pounds. Usually birth takes place about 40 weeks (9 months) from the first day of the last menstrual period. This is often called 'term' or 'the expected date of delivery'. About one baby in every twenty weighs less than 2500 grams (5½ pounds) and most of these infants are cared for in a 'premature' or 'special care' nursery.

All small babies are not the same. The 'true premature' infant is born early and is small just because there has not been enough time for growth to take place. For example, after 28 weeks from the last period, the average baby has grown to 1000 grams (2¼ pounds) and by 36 weeks, the average weight is only 2500 grams (5½ pounds).

Some babies are born close to the expected time but are very small because growth in the womb has been very slow indeed. These poorly grown babies are usually called 'small-for-dates'. Intrauterine growth retardation, dysmature or placental insufficiency are alternative words for the same condition.

It is important to make this separation into true premature infants and small-for-dates infants because they behave differently in some important ways. An example will help to make this clearer. Some completely normal, healthy adults are no larger than an average 14 year old child yet the two are obviously completely different despite their similarity in size.



George, viewed through the porthole of his incubator, he weighed 1760 grams at birth and was 7 weeks premature. He has sucking blisters on his lips, a common occurrence in young babies.

Gestation and gestational age

Doctors and nurses often use the term 'gestation' to indicate the number of weeks that the baby has developed in the uterus (womb) before birth. A 9 month or 'term baby' has a gestational age of 40 weeks; a baby who is born 3 months prematurely has a gestation (gestational age) of 28 weeks.

Why did my baby come early?

Most parents ask themselves why they had a premature baby and wonder whether either of them is to blame in any way. Premature labour is seldom anybody's fault and particularly not that of the parents.

The unborn baby in the uterus

What causes premature labour?

Often the cause for premature labour is unknown; sometimes there is a definite medical reason:

(a) **Twins and triplets** are very often born early.

(b) **'The waters' may break early** (premature rupture of the membranes). Normally the sac of fluid (liquor) surrounding the developing baby does not break until shortly before the baby is born when labour starts at about the expected date (term). Sometimes, the 'waters' break many weeks earlier than the expected time and the mother usually comes into labour hours or days later.

(c) **Neck of womb opens** (cervical incompetence)
Normally the neck of the womb (cervix) remains tightly closed until labour starts at term. Sometimes the neck of the womb begins to open up many weeks before the due date. The 'waters' may break and labour start. This is an important cause of premature delivery that can often be prevented next pregnancy by a 'cervical stitch'. In suitable cases, the obstetrician ties a piece of thread around the neck of the womb, quite early in the pregnancy; this helps that pregnancy to go to term.

(d) **Bleeding of the 'after-birth'** (placenta) Sometimes the

premature labour is caused by a small amount of bleeding which separates the after-birth from the wall of the womb.
This is called an 'accidental haemorrhage' and, as the name implies, cannot be prevented and is nobody's fault.

(e) **Baby brought on early** (deliberate action because of some illness in the mother that makes it unwise for the pregnancy to continue.) Occasionally, labour is brought on (induced) because the unborn baby is becoming increasingly sick, for example in the case of severe Rh disease, or when special tests show the baby is not growing and it is therefore safer for him to be born, even if premature.

(f) **Abnormalities of the womb are occasionally the cause of premature labour.** Your obstetrician would know about any such abnormality and should explain it to you in detail.

It should be repeated that sometimes no cause for premature labour can be found. In this situation many mothers continue to worry that something they or their partner has done has caused the premature birth. If you have any special worry of this kind, no matter how illogical it may seem, ask about it. There are many 'old wives tales' that have caused some mothers of premature babies a great deal of unnecessary worry.

Why is a baby small-for-dates?

(a) The baby may be very small but born close to the expected date if the mother has high blood pressure (essential hypertension) or 'kidney-trouble' (pre-eclampsia) during pregnancy. Normally the mother would be well aware that she had these conditions.

(b) Small mothers fortunately often have small babies; usually they are taller than their mother when they grow up.

(c) Occasionally a baby is small-for-dates because of a virus infection that started long before birth, such as German measles (rubella).

(d) Sometimes small-for-dates babies have a serious malformation. This is usually very obvious as soon as the baby is

born and your doctor will have discussed this with you.

(e) Heavy cigarette smoking, excessive alcohol during pregnancy and narcotic addiction sometimes result in a small baby.

(f) Sometimes the placenta (after-birth) is not transferring enough 'food' from mother to developing baby to allow normal growth to continue.

Sometimes there is a combination of several of these conditions. As you read these lists of causes, it is obvious that the birth of a very small infant is seldom the parents' fault. If you are worried that smoking, alcohol or drugs were to blame, this should be discussed with your doctor.

Parents' thoughts on the reasons for premature birth

In the days and weeks after the baby's birth, many parents spend much time trying to think of the cause. It seems to be in our nature to try to find a cause. Some parents place the blame on doctor or nurse-midwife, usually unjustly; many mothers blame themselves, almost always incorrectly. To the outsider the 'cause' they settle on may seem trivial and illogical, for example, failure to take medicine as prescribed or eating unusual food. On other occasions, the father may be blamed, again, often unjustly.

The question of 'cause of prematurity' is one that you must discuss with your doctor or nurse so that, as parents, you are not assuming blame that is unjust and illogical. Some parents are embarrassed to mention their ideas about possible causes of premature labour because they fear that they will appear foolish. Medical and nursing attendants expect to be asked these questions; they will take them seriously and will give you an answer if it is known. However, there are some controversial areas; these include the influence, if any, of sexual intercourse during pregnancy and of a previous termination of pregnancy. If you are concerned, we can only repeat our earlier advice to discuss the matter with your doctor.

CHAPTER 2 Will my baby live?

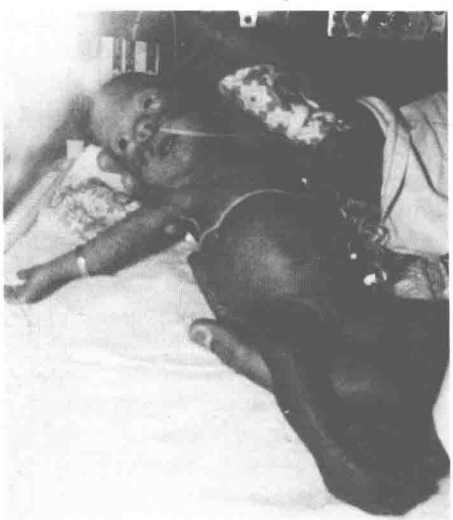
This is likely to be your first and most important question and only time will answer it for you. Your paediatrician is the one to give you information on your baby's chances.

The majority of babies entering a neonatal intensive care unit eventually go home. In recent years, the care of very small infants has made tremendous advances. Admittedly, very few babies who are more than 14 weeks premature survive, but at each week after that the chances improve with increasing gestational age. Most babies who are less than eight weeks premature will live.

The weight and degree of prematurity of your baby are not the only factors used by the doctor to assess chances of survival. Some infants have severe difficulty with breathing, or are suffering from the effects of oxygen lack during labour or have a serious malformation. Your doctor will know if your baby has any of these conditions. On the other hand, some infants are unusually free of trouble and there is room for greater optimism.

When will the 'danger' or critical period be over?

Parents often ask this question and the paediatrician may find it a hard one to answer. The first day of life is by far the most dangerous time and most of the deaths occur before two weeks. If your infant reaches this age you would be most unfortunate not to take him home eventually. There is an important exception. Infants needing ventilator support are not really 'out of the woods' until they are breathing entirely without help and the lungs have returned to normal. Even so, about 70 per cent of infants who are sick enough to need ventilator treatment recover fully.



This is Carlie who weighed 860 grams at birth. She is shown here in her father's hands with his wedding ring around her wrist.

Do not hesitate to ask your doctor for his estimate of the baby's chance of living. A few doctors will not mention this unless you ask. It is also important to remember that the first day is the most dangerous time, and thereafter the outlook usually gets steadily better. Admittedly, unexpected complications may sometimes turn up later, but you and your doctor will then talk about their importance.

CHAPTER 3 Difficulties premature babies may have

This chapter gives more technical information on the difficulties mentioned in the previous chapter. It is suggested that you read the sections that apply to your own baby rather than read about all the problems, most of which you may not meet at all.

Early development

When a baby is born prematurely, basic functions such as sucking, swallowing, and digestion of milk are poorly developed. A baby who is born early does not speed up his development; on the contrary he matures at about the same rate as in the uterus and he will not behave like a term baby until he reaches the expected time of birth. For example, a baby who is born ten weeks early (at thirty weeks) usually will not learn to suck vigorously and behave like a healthy newborn infant until he is eight to ten weeks old.

Feeding behaviour

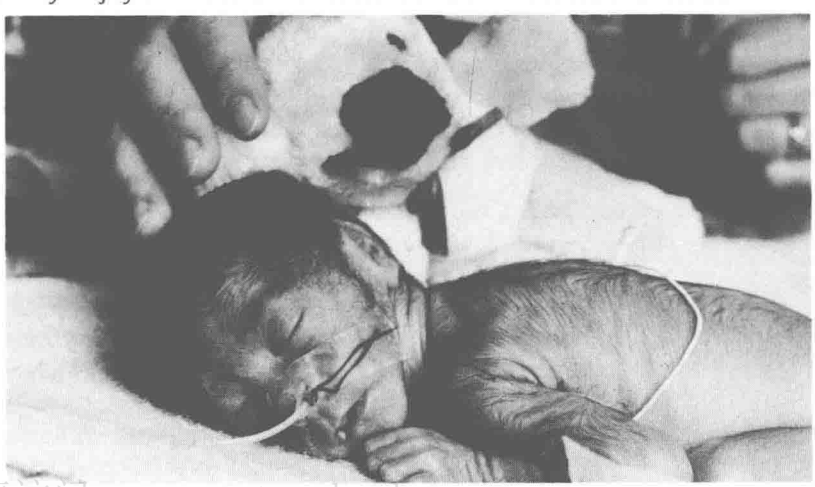
If your baby was born three or four weeks early, usually there will be only minor difficulties. He could be a little sleepy and not very interested in taking the breast or bottle; or you may find his sucking less vigorous. With extra help from nursing staff and persistence and understanding on the mother's part, these temporary minor troubles should be overcome so that full breast or bottle feeding is possible; usually, your baby spends just a little extra time in hospital. With this slight degree of prematurity, it is sometimes worth spending a week or so in a mothercraft hospital if you are not fully confident when ready to leave the maternity hospital.

If the baby is more than four weeks premature, greater temporary difficulties may be expected. Infants between four and eight weeks early usually manage to suck some of their feeds from a bottle in the first two or three days of life. At this stage, the baby only requires small amounts of food. Gradually, as his feeds are increased in line with his bodily needs, he will tire and be unable to take his full quota. The baby who is too tired to suck is 'tube-fed'. This is also called 'gavage feeding'. You will be able to watch this type of feeding in the nursery. Tube feeding is performed by a specially trained nurse who gently passes a fine

plastic tube through the baby's mouth into his stomach. Then a funnel or syringe is connected to this plastic tube and the milk slowly runs into the infant's stomach. The feeding (gavage) tube is then gently removed. Tube feeding does not upset the baby or damage the gullet; it makes sure that the baby gets enough milk to thrive. When the mother of a tube fed baby feels comfortable with the idea, she may like to help with the tube feeding.

Tube feeding does not teach or encourage a baby to be 'lazy'. About two weeks before the 'expected date of birth', most infants begin 'to fight gavage'. They are restless, suck on the tube and toss their heads around during the tube feed. This is the signal for which the nurse has been waiting. For a few days, the nurse gives the first part of the feed by gavage and then encourages the baby to suck the remainder from a bottle. Sometimes 'alternate gavage and bottle' is given, allowing the baby to suck one feed and then to be tube fed next time. As soon as a baby begins to suck from the bottle the mother usually will be able to help with some bottle feeds.

If the baby is more than four weeks premature he is unlikely to do well at the breast and will be best managed by skilled nurses with tube feeding. Sometimes babies who are not ready to suckle are put to the breast to help mother and baby get to know each other. The infant often does not suck, or only poorly, but gradually breast feeds will improve. This practice of having baby at mother's breast is often called 'skin contact'. Both mother and baby enjoy the skin contact even if little or no milk is taken.



Joseph weighs 1020 grams, he is 2 weeks old in the picture and has a fine covering of hair (lanugo), normal for premature babies. He is not able to suck yet so the tube in his nose goes to his stomach. He needs some milk every hour.