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A guide for parents

**Care around
preterm birth**

February 1997

“Going to hospital after my water broke at only 24 weeks gestation, I was shocked. I never imagined myself going to have a prem baby.”

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The strategic intent of the National Health and Medical Research Council (NHMRC) is to work with others for the health of all Australians, by promoting informed debate on ethics and policy, providing knowledge-based advice, fostering a high quality and internationally recognised research base, and applying research rigour to health issues.

NHMRC documents are prepared by panels of experts drawn from appropriate Australian academic, professional, community and government organisations. NHMRC is grateful to these people for the excellent work they do on its behalf. This work is usually performed on an honorary basis and in addition to their usual work commitments.

Foreword

Care Around Preterm Birth: A Guide For Parents was written for the National Health and Medical Research Council (NHMRC), through its Standing Committee on the Quality of Care and Health Outcomes (QCHOC).

The NHMRC is an independent body, which supports research and projects aimed at improving the quality of care that the Australian public receives so that health outcomes may improve. NHMRC also advises the Australian public, the Commonwealth Government and State/Territory governments on standards of individual and public health and on ways to improve those standards.

This booklet is part of a national program of the NHMRC aimed at developing clinical practice guidelines, which not only assist practitioners to make the best decisions about appropriate health care for specific clinical circumstances, but which also assist the decision-making of those people treated within the health system, by providing them with comprehensive, current information about various health issues and the most effective, appropriate and up-to-date treatment options.

Care Around Preterm Birth: A Guide for Parents is based on a more detailed publication called *Clinical Practice Guidelines for Care Around Preterm Birth*, which has been written more specifically for the health professionals whose job it is to care for women who may give birth preterm, their babies, and families. The aim of the guidelines is to provide doctors, midwives, nurses, obstetricians, paediatricians and neonatologists with information on the best possible care based on up-to-date research evidence.

Both publications are based on the best information available at the time of printing. They can be obtained from Government Info Shops in all capital cities, Tel: 13 24 47.

Richard Smallwood
Chairman
National Health and Medical Research Council

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Introduction

“I was by myself when they told me, ‘We are going to deliver your baby this evening.’ It was such a shock. I had only gone to the doctor with a headache, now I was having a baby tonight.”[†]

Pregnancy can be a difficult and complex time for parents faced with the possibility of a preterm birth. This booklet *Care Around Preterm Birth: A Guide For Parents*, aims to provide clear and easy-to-read information for all expectant parents, though it will be of particular relevance to those either diagnosed ‘at risk’ of having a preterm baby or who know they are going to have a preterm baby.

This booklet deals with issues that are of immediate concern to you and your family. It tries to provide you with background information that will make it easier for you to discuss your concerns with your doctor and other health professionals involved in your care and the care of your preterm baby.

There will be many decisions that you will need to make along the way about the kinds of procedures and care that you and your baby receive during pregnancy and around the birth. Every parent has the right to be fully informed and to make their own choices about the kind of care they receive. It is hoped that the information and explanations provided here will assist you in this decision-making and in discussions with your professional carers.

Preterm birth is a crisis. It is very common for parents to experience a range of emotions such as fear, worry, hurt, grief, and a sense of vulnerability and loss of control. So, it is also hoped that by preparing parents for what they may expect to see, hear, and feel around preterm

[†] The sources for quotes given in in this booklet are given on page 73.

birth, this booklet may go some way toward helping to alleviate such stresses.

Preterm birth is fairly common—every year for the last 20 years just over 6% of pregnancies in Australia have ended in preterm birth. That means that more than 1000 women have experienced a preterm birth each year for that period. Being born too early is the single largest cause of death and illness for newborn babies. Fortunately, though, the more serious very early preterm births are not so common, and major advances in medical treatment have greatly improved babies' outcomes. There have been attempts to reduce the number of preterm births but, disappointingly, the rate has not changed for the past two decades. Exactly what causes preterm birth is still not completely known.

Parents who would like more information than is contained in this booklet, may be able to borrow a copy of the more detailed guidelines, *Clinical Practice Guidelines for Care Around Preterm Birth*, from their local hospital or purchase one from a Government Info Shop in their capital city, Tel: 13 24 47 (see also the last page of this booklet for information on NHMRC publications).

1 What is preterm birth?

Preterm birth is the birth of a baby *before 37 completed weeks of gestation (pregnancy)*. Ideally a baby needs to spend 40 weeks developing in the uterus to be fully ready for life outside, but only babies born more than 3 weeks too early are called preterm.

Not all preterm births are the same. How early a baby is born, why he or she is born preterm and how well the mother is, can all affect the outcome for the baby and the mother.

The first important factor is the number of weeks that the baby has developed in the mother's uterus before birth. Before 24 weeks the chance of survival is extremely small but it improves each week after that. By 28 weeks around 90% of babies survive if they are cared for in a neonatal intensive care unit (NICU). Babies born before 32 weeks are *very preterm*. Within the very preterm group of babies there is a big difference between those born at 28 to 31 weeks (*moderately preterm*) and those born before 28 weeks (*extremely preterm*). Babies born between 32 and 37 weeks are *mildly preterm*.

The second important factor has to do with the reason the baby is born preterm. Sometimes, the need arises for an elective birth before term (by induction of labour or caesarean section) due to illness of either the pregnant woman or the baby, or sometimes both. Usually an obstetrician decides with the mother that the risks of continuing the pregnancy clearly outweigh the benefits. These risks might be to the mother, the baby, or both. Even when they know their baby is to be born electively for a specific reason, parents can still feel in a state of shock when it actually happens.

Other women go into labour spontaneously preterm. As with term births, spontaneous preterm births can start with the onset of contractions or

with the waters breaking (prelabour rupture of the membranes). A spontaneous preterm birth will come as quite a shock to parents expecting a term birth.

However preterm birth happens, many things may be able to be done to help ensure the best outcome for you and your baby.

The type and level of care a preterm baby needs will depend on how early in the pregnancy he or she was born, how big the baby is and whether he or she is sick. For example, twins who are born 10 weeks early (at 30 weeks) who cannot breathe on their own will require a more intensive level of care than a single baby who is born only 4 weeks early and can breathe on her own. A baby born with an illness or abnormality may also need more help, even if the birth was not very early at all. With good care, though, most babies eventually catch up on their growth and development, although some do continue to have problems.

Why does it happen?

Your labour may be induced preterm or your baby may be delivered by caesarean because being born early may offer the best outcome for your baby or it may be the only option to protect your own health. This is called an elective preterm birth (about 25–40% of all preterm births). Elective preterm birth might be recommended if your baby is not growing well in the uterus, something happens to the placenta, the baby is not formed normally or you have a severe illness or disease.

In about 12–15% of preterm births, the baby has died during the pregnancy, or has an abnormality so severe that he or she will not be able to survive after birth.

So, for about half of all preterm births, where the baby is alive at the end of pregnancy and does not have a life-threatening abnormality, it happens because labour starts spontaneously, or the membranes rupture. Sometimes, this happens because of an infection. Sometimes, it is because the woman has a problem with her cervix (the neck of the

4 Preterm birth — a guide for parents

uterus) and the cervix cannot withstand the pressure from the growing baby. Usually, though, there is no explanation for why it happens.

Preterm birth is also very common for women expecting twins, triplets or more (multiple pregnancies). About half of all twins, and nearly all other multiples, are born preterm.

INFORMATION AND RESEARCH ABOUT PRETERM BIRTH

There are always a lot of different opinions about what is best for pregnant women and babies. The NHMRC has made every effort to rely on the best research evidence from around the world in making its recommendations, and preparing this booklet. This includes consideration of what women and families themselves say about the experiences and concerns they have around preterm birth. The NHMRC has also drawn on the experience of health care professionals and maternity consumer advocates in Australia.

The Cochrane Collaboration

Often, the NHMRC was able to use the summaries or reviews of evidence about preterm birth prepared by the Cochrane Collaboration. The Collaboration is an international effort by health care professionals, researchers, and consumers to sift through all the evidence about the effects of health care, and determine what forms of care work best.

This careful and comprehensive process has made it possible to be very confident about the advice offered to you in this booklet.

What if we are asked to take part in research?

Over the last few decades, there has been a great improvement in outcomes for women, babies, and families affected by preterm birth. Research has played a vital role in bringing this about, and in sorting out what health care is helpful. There is still a lot we don't know and new treatments have to be studied carefully before we can be sure they do more good than harm.

continued...

Taking part in research (continued)

It is quite likely that at some time in your pregnancy or when your baby is born, you could be asked to be involved in research (especially at a major teaching hospital). Research projects involving people need to be approved by a hospital or university ethics committee.

You do not have to agree to participate in a research project, and even if you have agreed, you can pull out later if you change your mind. If you want more information about a particular project, you can talk to the people at the hospital, or contact the ethics committee yourself. (That information should be provided to you.) If you would like to know more about research that you could be involved in, feel free to ask the people caring for you what projects are going on.

If health care is to keep improving, and other families are to get better information than is available now, it is important that more research is done. You are not obliged, though, to participate in any research. It is entirely your choice, and your decision one way or the other should not affect the quality of the care you and your baby receive.

2 Will the baby be all right?

What will happen after the baby is born?

When preterm babies are normally formed and have no other health complications, the greatest risk to their health and survival is the immaturity of their lungs, eyes, brain and all other organs and systems of the body. For example, preterm babies can have trouble maintaining their body temperature and difficulty breathing and feeding. The more preterm your baby is, the more dependent she or he will be on specialised care for survival.

So the earlier your baby is born, the more likely it is that the baby will be transferred to a special care nursery (SCN) or neonatal intensive care unit (NICU). For this reason it is strongly recommended that if there is a large risk of preterm birth, a woman should receive specialised care during her pregnancy and plan to give birth in a hospital with an NICU. The less delay there is in getting special or intensive care, the better the baby's outcome is likely to be.

For babies who are mildly preterm—born between 32 and 37 weeks of pregnancy—the stay in hospital can be considerably shorter. About 5 out of every 6 babies born preterm are in the mildly preterm category. These babies are much less likely to need any special or intensive care and a baby born around 35 to 36 weeks gestation is usually mature enough to require little or no assistance. However, the baby may still need some time in special care before everyone can be sure that she or he will be fine.

Will my baby survive?

This is the most important question that you will, naturally, want answered immediately. It may take time, though, until anyone can be sure. Preterm babies do have higher rates of death and illness than babies born at term. This is generally due to the immaturity of the baby's body and organ systems. The earlier in your pregnancy that the baby is born, the greater the risk of illness and death.

Babies born before 24 weeks of gestation have very little chance of survival but after 24 weeks the survival rates improve steadily so that by 28 weeks about 90% of babies survive. Over the last decade new technology and treatments have improved the chances of survival for even the tiniest preterm babies.

There are, of course, many other factors apart from time of birth that influence each individual preterm baby's chances. For example, the baby's weight at birth is also an important factor for survival. In 1993, the survival up to 28 days of infants born with a weight of 500 to 999 grams was 69% and it was 98% for infants whose birthweight was between 1500 and 1999 grams.

Remember, your doctor will want to speak to you about the details of your own baby's situation, so be sure to ask any questions that you may have. The most critical period will be the first week: most of the preterm babies who die, do so before birth, or in the first week.

What about twins, triplets and quadruplets?

About half of all babies that are one of twins, and most babies who are triplet, quadruplets or other multiples, are born preterm. These babies have less chance of survival than single preterm babies and the risks rise significantly with each extra baby in the one pregnancy. A study that looked at perinatal deaths (before and just after birth) in Australia found that between 1991 and 1993 twins were four times more likely to die

than single babies. If there were more than two babies, the risk was nine times as high as for a single baby.

Individual babies in the one multiple pregnancy can have different growth patterns and experience different health problems, and the outcomes for each can therefore be very different. Even though the level of risk rises quite a lot for multiple births, in general, most twin babies (and many triplet babies) will still survive early birth if they get the care they need. Most of the complications associated with preterm birth occur more often amongst babies from a multiple birth. That is why specialised obstetric care is strongly recommended for all women expecting twins or more.

3 Who is at risk of having a preterm birth?

Am I likely to have my baby early?

It is not easy to know who will give birth preterm. A lot of preterm births happen to women who had no factors showing they were at particular risk at all. There are some lifestyle factors that may affect the risk of preterm birth, and these are discussed in detail later. However, there are some reasons that are definitely associated with a high risk of giving birth preterm, particularly:

- multiple pregnancy (that is, expecting twins or more);
- having had a previous preterm birth; and
- medically-assisted conception (by fertility drugs, or IVF/GIFT or similar techniques).

The major issues associated with each of these factors are discussed below. Women with some medical conditions also have a higher chance of preterm birth (eg diabetes, thyroid disease, epilepsy, heart disease, chronic kidney disease, or high blood pressure). If a woman has pre-eclampsia, which is causing serious concern, an elective birth may be necessary, even if it is early.

Preterm births are also more common in some groups than others. For example, women living on very low incomes have a higher rate of preterm birth, although no one knows exactly why. There are also more preterm births among Aboriginal and Torres Strait Islander women (10% to over 20%, in some regions) than for non-indigenous women.

Multiple pregnancy

Between 40 and 65% in twin and 80 and 95% in triplet pregnancies end in preterm birth. Multiple pregnancies also carry a substantially increased risk of a variety of problems for both the woman and the babies, for example maternal hypertension (high blood pressure) and restricted (poor) fetal growth. Several of these problems can be treated, and this can have important benefits for the woman and babies. Why the risks of preterm birth are so high in multiple pregnancies is not really known.

Previous preterm birth

A good (but not totally accurate) way of predicting the length of a pregnancy is the length of previous pregnancies. If your previous pregnancy ended in a spontaneous preterm birth, then you are at a greater risk of a spontaneous preterm birth in your future pregnancies. The more spontaneous preterm births you have had before your current pregnancy, the greater the risk that your current pregnancy will also end in spontaneous preterm birth. This is especially the case if you had a very preterm birth (before 32 weeks) in a previous pregnancy.

The rates of preterm birth for women who have previously given birth spontaneously before term are about: 15% for one previous preterm birth; 30% for two consecutive preterm births; and more than 50% for several preterm births.

If, on the other hand, you had a preterm birth because of carrying a multiple pregnancy and this time you are having a single baby, you may be less likely to experience another preterm birth than if your previous preterm birth was for an unknown reason.

What if I have had a previous miscarriage?

If you have previously had one or more early miscarriages, there is no evidence that this will increase the likelihood of preterm birth, probably

because early miscarriages are not caused by the same mechanisms as preterm labour and birth.

Sometimes, if you have had several late miscarriages or very preterm births, the problem could be with your cervix. Cervical insufficiency or 'incompetence' just means that the cervix is not able to withstand the pressure from the growing baby. It is very hard to diagnose, but for a few women, if this is the problem, a procedure called 'cervical cerclage' may be suitable. This involves having a stitch (or suture) to support the cervix and keep it closed.

There is not enough evidence to be certain whether or not there is an increased risk of preterm birth if you have had one or more terminations of pregnancy (induced abortions), but terminations early in pregnancy do not increase the risk.

Assisted conception

The use of fertility drugs and assisted conception procedures (eg IVF and GIFT) results in an increased risk of both mildly preterm and very preterm birth. For example, over 20% of mothers on *their vitro* fertilisation (IVF) program or the gamete intrafallopian tube transfer (GIFT) program have a preterm baby. Part, but not all, of this extra risk comes from multiple pregnancies.

It is common practice on IVF and GIFT programs for more than one embryo to be implanted in the belief that this will improve the chances of at least one baby being conceived. However, there is no evidence that implanting more than two embryos does, in fact, increase the chances of getting pregnant. It does, though, increase the chances of a pregnancy being twins or more, which, in turn, greatly increases the chance of losing one or all of the babies. Just over 17% of IVF pregnancies and just over 24% of GIFT ones, are multiple pregnancies.

In over 50% of IVF/GIFT cycles in Australia in 1992–93, three or more embryos were implanted. Because of the increased risk associated with

multiple pregnancies, however, the NHMRC recommends that no more than two embryos be implanted in any one assisted conception cycle.

How will I know if I am ‘at risk’ of having my baby early?

During your pregnancy your health carer will assess your risk of experiencing any major complications, one of which is preterm birth. This assessment is a very important part of maternity care. After the assessment, you will be able to discuss the type of care best suited to the needs of your baby and yourself.

The task of assessing what women are ‘at risk’, and the degree of risk, is not easy because, in most cases, the cause of preterm birth is not known. In many circumstances, a problem that is identified at the beginning of pregnancy may either lessen or get worse as the pregnancy goes on. At other times a problem that was not apparent at the beginning of pregnancy may become important later.

Some doctors use a formal system of ‘risk scoring’, assigning a certain number of points for particular things. None of these systems has been shown to be reliable. They all miss many of the preterm births, and they all result in many women being diagnosed at risk who have completely normal pregnancies. As all these scoring systems are inadequate, the NHMRC strongly recommends that they not be used. The usual process of simply identifying important risk factors is still the best guide.

What will happen if I am at ‘high risk’?

Antenatal (pregnancy) care is available in a variety of different places (for example, different levels of hospitals, doctors’ rooms, birth centres, Aboriginal health services, and home) and from a variety of practitioners (for example, midwives, general practitioners with and without specific obstetric qualifications, hospital medical officers, specialist obstetricians).

Just because you have one, or some, of the so-called 'risk factors' associated with preterm birth, does not necessarily mean you will need highly specialised obstetric care throughout your pregnancy. Primary health care options (eg midwifery services) may still be possible.

However, sometimes specialised obstetric care can make a difference to outcomes, and so becomes vital. This applies to women with a multiple pregnancy and to those with serious illnesses or conditions, such as diabetes, thyroid disease or hypertension.

As well as being appropriate for your health care needs, the care you receive during your pregnancy must also be accessible and acceptable to you. Whether you receive specialised obstetric care or not, the experience of being at risk of preterm birth will be complex and you will be faced with many decisions. Still, while many women at risk of preterm birth require medical care for complications at some point during their pregnancy, a large proportion experience straightforward pregnancy and birth. You should feel free to discuss your individual situation with your doctor and other health carers. If you need an interpreter, that can be arranged. You can also discuss your needs with the social worker or Aboriginal liaison officer at your hospital or health service (see Section 8 for contact telephone numbers).

If you wanted to go to childbirth education classes and you know that you are at high risk of giving birth preterm, it could be a good idea to book in for an earlier series of classes than you intended. If you need to spend time in hospital later in pregnancy, there might also be classes, or individual sessions with an educator, to help you learn more about labour, birth, and the time afterwards.

What other parents have felt about having a high-risk pregnancy

- Finding out your pregnancy is 'high risk' can be a real shock.
- People feel a whole range of emotions — grief over not having the ideal pregnancy, fear, guilt, confusion, disbelief, worry.
- It can be hard to believe anything is wrong if you are feeling well.
- There can be a lot of disappointment if this means a change in plans for care in pregnancy and birth.

“You'd think by the third time, certainly by the fourth, I'd know what to do and who to call. But I always collapsed.”

“I had been so proud of myself for doing everything right. I couldn't believe it was happening to me.”

“When I've compared notes with other women, my pregnancy hasn't seemed so different. I see my doctor more. I've had more tests. But for the most part, it's business as usual.”

“It's hard to explain how your emotions run. One day you think that you're all right and baby is all right, but the next day you feel flooded with all the things that can go wrong.”

*“Fortunately, prematurity is a risk that diminishes with time. We had a good three months of worry spiced with about four false alarms. . . The days dragged by. . . She was, in fact, a week late.”
(a father)*

What can I do to help avoid a preterm birth?

During your pregnancy you will probably receive a lot of advice about how to avoid preterm birth and how to help your baby have the best possible start in life. However, much of that advice, although well-meaning, will not be based on any evidence. Some things that the NHMRC has concluded *may* increase the risk of preterm birth are discussed below. Other factors that *havenot* been shown to influence preterm birth are also discussed. Medical treatments to improve the outcomes for your baby will be discussed in detail later as well.

It is very important to remember that *increase the risk* does not mean the same as *'cause'*. That is to say, if your lifestyle includes one or more of the risk factors listed below, it *doesnot* mean that your actions and/or lack of control over particular life events will *'cause'* your baby to be born preterm. The *'cause'* of preterm birth is usually unknown, so you have no reason to feel guilty or to blame yourself.

If it is, however, at all possible for you to make some changes or to take a course of action that does not cause you any further stress or hardship, then you may be able to improve the chances of your pregnancy going full term.

WHAT YOU CAN DO IN PREGNANCY TO PREVENT PRETERM BIRTH OR IMPROVE THE OUTCOME

Based on all the best current evidence the NHMRC has made the following key recommendations to help prevent you having a preterm birth and, if preterm birth becomes inevitable, improve the outcomes for you and your baby.

- Go to a health care practitioner or health service for care early in pregnancy.
- See a specialist obstetrician if you are at high risk.
- If you're on an IVF/GIFT type program, don't have more than two embryos implanted in one cycle.
- Get help to stop or cut back smoking.
- Avoid very exhausting work or very strenuous exercise if you can.
- Go, or call, for medical advice if you think you are in preterm labour, or your waters break or leak early.
- Get antibiotic treatment if your waters break preterm.
- Plan to give birth at a hospital with a neonatal intensive care unit if you are at very high risk — or move to one if birth before 33 weeks is inevitable.
- If birth before 34 weeks is inevitable, have corticosteroids to mature your baby's lungs.

Lifestyle factors that *may* increase the risk of preterm birth

Very heavy work

Certain types of work, involving standing for long hours, lifting heavy weights, excessive noise, and work causing extreme fatigue at the end of the shift are related to an increased risk of having a preterm birth. If you think your workload falls into this kind of category, discuss it with a doctor. If necessary, the doctor could provide you with a letter advising your employer to change your workload, conditions, or duties during pregnancy.

Very vigorous exercise

Regular aerobic exercise can be very good for you and your baby's health in pregnancy, as at other times. Regular exercise that is not very strenuous does not appear to increase the risk of preterm birth, either. However, beginning or maintaining very vigorous exercise in pregnancy is controversial. There is some evidence that it might increase the risk of preterm birth and reduce the baby's birthweight, even when women are trained or well used to a strenuous exercise program. There is not enough evidence, however, to provide an absolute guide as to how much exercise is too much, so you may need to discuss your particular exercise patterns with your doctor or health care worker.

Excessive use of alcohol and other addictive substances

An excessive use of alcohol and narcotics in pregnancy may increase the risk of preterm birth. These, as well as heavy smoking, can also reduce a baby's birthweight. Being smaller can be serious if the baby is born preterm. While cutting back on smoking in pregnancy has not been shown to prevent preterm birth, it can increase the baby's birthweight a little. There are specialised information materials and support programs for pregnant women who want to quit or cut back smoking, and these are helpful to some women. Talk to your doctor or other health worker, or contact your local QUIT program (see Section 8 for telephone helpline number).

Domestic violence

Sometimes, abuse starts, or gets worse, in pregnancy. Blows to the abdomen can sometimes cause harm to the baby (including death and preterm birth), as well as to you. There is also some evidence that being abused in pregnancy may increase the risk of preterm birth in ways that are not yet understood. If you are in a violent or abusive relationship, you may well feel that things are out of your control, and that there is nothing much you can do to improve things for yourself or your baby. However, there may well be services and people in your area that can help you in more ways than you might realise. The social worker at the hospital will know who can help you, and they (and your doctor or other health carer) may be able to offer helpful support and advice as well. Aboriginal health services, community health centres, and women's health centres can also offer advice and support.

Things which have *not* been shown to increase the risk of preterm birth

The following lifestyle factors have *not* been shown to increase the risk of preterm birth:

- paid work
- housework and child care
- stress
- travel and commuting
- sexual activity

Women are commonly advised to reduce or stop these activities in order to reduce their risk of preterm birth. There is no evidence that reducing or stopping any of these activities can prevent preterm birth. Normal sexual activity is safe (as long as your membranes have not ruptured) but, naturally, if you think you are at risk of contracting a sexually transmitted disease you should take the usual precautions.

While very heavy workloads or strenuous exercise, may possibly increase your chances of giving birth preterm (see page 19), there is no

evidence that cutting back on any but the most heavy burdens can make a difference to pregnancy outcomes. Just because something happened, and labour began on that or the next day, does not mean it was the cause of preterm labour.

Women are also sometimes advised that poor nutrition can cause preterm birth or that a particular diet can prevent it. However, while good nutrition is always important, especially in pregnancy, there is no evidence that increasing nutrition or any particular diet can prevent preterm birth.

I've been advised to stay in bed: will that help?

Women at high risk of preterm birth are often advised to stay in bed, sometimes for several weeks on end. 'Bedrest' may also be advised if you are expecting a multiple birth, have a threatened preterm labour or have a serious medical condition such as hypertension (high blood pressure) or antepartum haemorrhage (bleeding in pregnancy).

However, although confining women to bed during pregnancy, either at home or in hospital, has been very common, it has NOT been shown to be effective in reducing the likelihood of a preterm birth. On the contrary, being confined to bed can be a disruptive and stressful experience for the pregnant woman, her partner and/or other carers and family members, without being of any benefit in prolonging pregnancy at all. The NHMRC strongly recommends against confining women to bed just because they are expecting twins, or as an attempt to prevent preterm birth for a healthy woman.

Some complications also can mean that you need to be admitted to hospital for tests or treatments in pregnancy, sometimes more than once. For example, if your blood pressure is very high, or you are bleeding, staying in bed (at home or in hospital) might be necessary.

Having to stay in bed, or go to hospital, can create a lot of practical and emotional hardship, for all the family. It puts a great load on a partner

especially, and you will both need a lot of support from family and friends. If you don't have a partner, getting help will be essential.

If you need to go to hospital, being separated from family and friends can be very distressing, especially if the hospital is a long way from home. You could need help to make sure that everything is taken care of at home, as well as support for yourself in hospital. Don't hesitate to talk to your health carers, or the hospital social worker, Aboriginal liaison officer or health worker. They may be able to help you with any problems and difficulties you might have.

If you do spend some time in bed at home or in hospital, this will probably leave you weak, and less fit than you were before. It can take some time to recover from a stay in bed, even if it was only a few days. You will need to take it slowly afterwards, and should not expect to be back to normal in a hurry.

What other parents felt about being confined to bed or admitted to hospital

- It can be very boring and lonely.
- Everyone can be very worried about the health of both the woman and baby(ies).
- Partners or other family members have to carry a lot of practical and emotional burdens.
- If there are other children, it can be hard on them — this can be another source of worry for parents.
- Sometimes it can be a relief to be in hospital, but it is also often distressing.
- Being separated from family and friends can be very hard to cope with.

“My friends at work thought lying in bed, being waited on hand and foot, sounded heavenly. I couldn't make them understand that it gets old very, very fast.”

“The telephone with a special fifty-foot cord extension was my lifeline, my umbilical cord. I wanted to keep my phone with me everywhere I rested and walked.”

“It's like nursing along a serious illness, but you're not sick.”

“They said I needed to stay in bed and take care of myself, but..... you don't think about yourself. . . you think about those babies.”

“I was very lonely, homesick and cried to go home.”
[Alice Springs]

continued...

What other parents felt (continued)

From fathers —

“I was scared when my wife was hospitalised and didn't really understand what was going on. I felt particularly inadequate in understanding the medical and physiological problems. I felt I had very little control over the situation.”

“When Sharon went into hospital it was her condition I was concerned about, not the baby.”

“I knew I was going to be more important as a parent than ever before. This had both positive and negative feelings.”

“You don't sign a contract and nobody's going to promise you anything. You just do the best you can, and if it works out then all this seems to fade pretty quickly.”

4 What if my baby is going to be born too early?

What is the safest place for my preterm baby to be born?

If you are at high risk of giving birth preterm, you or your baby may well at some time need the specialised obstetric and neonatal care that is only available at a perinatal centre (also called a 'tertiary hospital'). A perinatal centre has a neonatal intensive care unit (NICU) with professionally trained and experienced staff who can provide the best possible care for preterm babies.

Very preterm babies who are born outside such perinatal centres have poorer outcomes. The delay in getting to an NICU when needed can cause problems for some babies, and can increase the chance of the baby dying. It is, therefore, strongly recommended that you organise, if you possibly can, to have your baby in a perinatal centre that has the equipment and expertise to care for both yourself and your baby. The NHMRC strongly recommends that all babies that are coming before 33 weeks should be born in a perinatal centre. If you go into labour as early as this, or need an induction or planned caesarean that early, you need to seek help as soon as possible to give you enough time to get to a perinatal centre.

However, despite the increased risks to your baby, you cannot be forced to go to a perinatal centre. Neither you nor your baby will be transferred against your wishes. Even if you do not want to go to a larger hospital, it is still a good idea to get help quickly, as there are other treatments which may improve your and your baby's outcome.

It is the job of the doctors, nurses, midwives and social workers to look after you and your baby and help you understand the treatments and problems associated with having a preterm baby. The neonatal intensive care unit or special care nursery is designed to imitate, as best as possible, the conditions a baby experiences in his or her mother's uterus.

If you are parents at risk of, or definitely going to have, a preterm baby and if you can get to the hospital during pregnancy, it is a good idea to get a tour of the neonatal intensive care unit and special care nursery. This will help to prepare you in the event that your baby needs to be admitted there.

If you live a long way from your nearest perinatal centre, going there to give birth can cause you and your family a lot of difficulties. If you had made other plans before you knew you were at high risk it can be upsetting to have to reconsider your plans. Transferring to a major hospital may also be unacceptable or impossible for you for other reasons. It is your decision. You need to take into account in making that decision, though, that there is an important drop in safety if you choose to give birth before 33 weeks away from a perinatal centre.

How will I know if I am in labour?

Early recognition of the fact that you are going to give birth preterm is an important factor in improving your baby's outcome. If you were not expecting a preterm birth, the earlier you establish that you actually are going to give birth preterm, the more time you will have to organise to have your baby in a hospital with an NICU. This is especially important if you are less than 33 weeks pregnant. Early recognition also enables the use of other treatments that can help your baby. It is important even if you do not want to move to a perinatal centre.

Research shows that the most accurate diagnosis of preterm labour comes from the pregnant woman herself — if you suspect you are in preterm labour, you probably are.

Therefore, if you think you could be in labour, get in touch with your doctor or hospital as quickly as possible. You should do the same if you are bleeding, or if the membranes rupture.

There are various measurements and tests that can be done, but none of them has been shown to improve a woman's own diagnosis.

If you experience *regular* contractions, the best course of action is to seek professional advice as quickly as possible by telephone, or by going to the hospital or to see your doctor. The *regularity* of the contractions, more than the pain, is the most important indicator that you might be in labour. It is usual to feel some contractions in pregnancy. Actual labour, though, is regular, and it does not go away. It could feel like normal contractions, or just a cramp or ache. Preterm labour may not even be painful at all in the early stages.

What if my membranes rupture?

Other than contractions or bleeding, the other main sign that you could be facing a preterm labour or birth is rupture of the membranes (when the bag of waters around the baby breaks). Sometimes this happens with a real gush that is unmistakable, but sometimes it is just a leak.

If you do experience what is often described by women as a 'watery discharge', and you think the membranes have ruptured or are leaking, you are probably right. *Seek assistance at your doctor's clinic or labour ward as quickly as possible, especially if it occurs before 35 weeks.* The earlier you can get some professional assistance, the better chance you have of improving the outcome of your pregnancy. Again, even if you do not want to move to a perinatal centre, it is very important to get help if your membranes rupture. Research shows that having antibiotics after preterm rupture of the membranes can prolong the pregnancy, and can prevent some of the harm infection can cause to a preterm baby as well. The NHMRC strongly recommends that all women who have preterm rupture of the membranes take antibiotics initially.

Antibiotics can be administered either intravenously, intramuscularly or orally. In order to determine which antibiotics are required, your doctor will need to take a vaginal swab. How long you need to take antibiotics will depend upon your particular set of circumstances; it may be anywhere from six hours up to the entire interval until your baby is born. If you do have ruptured membranes you are likely to be given *corticosteroids* before the birth of your baby. Corticosteroids are drugs that help to enhance the functioning of a preterm baby's lungs (see below).

Home uterine activity monitoring (HUAM)

If you have already had an episode of preterm labour, you may have heard about the possibility of electronic home uterine activity monitoring. Uterine activity monitors are sensitive, electronic devices that are able to detect some uterine contractions that a woman may be unable to detect herself (just as the ultrasound can detect fetal movements that the mother often cannot feel). However, there is no evidence that the use of home uterine activity monitoring can improve babies' outcomes, while it can lead to over-treatment which itself can cause harm when it is not needed. The NHMRC strongly recommends that home uterine activity monitoring not be used.

What can be done before birth to improve the baby's chances?

There are several kinds of pharmacological (drug) treatments that are used around preterm birth to help improve the outcome for your baby. These treatments will be discussed later in some detail. Drugs can be given:

- to the mother to inhibit labour and delay birth;
- to the mother after preterm prelabour rupture of membranes (PPROM) to delay birth;

- to the mother before the baby is born to improve the baby's outcome; and
- to the baby after birth to improve her or his outcome.

There are some other drugs and treatments that are not discussed below. They have not been shown to work, and the NHMRC does not recommend that they be used.

Trying to stop the contractions in labour

Prolonging pregnancy and delaying labour can be beneficial for the baby, especially for an extremely preterm baby where every extra day or week gained is important.

There are some drugs that can help to stop contractions and labour for women in early preterm labour at least for a short time. These drugs are called 'tocolytic' drugs and include the *betamimetic agents*, which act by causing smooth muscle cells in the uterus to relax.

One such drug, ritodrine, has been shown to delay labour by at least 48 hours — that's an extra 2 days, at least, and possibly more, that the baby may have in the uterus. This gives enough time to change hospitals if you want to, and to use other treatments which can improve your baby's chances of being alive and well. Other betamimetic drugs that may be used for the same purpose as ritodrine include: salbutamol and terbutaline.

When this sort of treatment is used the woman needs to be very carefully monitored, as tocolytic drugs affect other organs in the body apart from the uterus and side effects can be serious, even life-threatening. Possible side effects include: chest pain, tremors, headache, dizziness, nausea and a racing heart.

The use of these drugs is therefore not advisable in women with some medical conditions. For example, betamimetic agents are unsuitable for women with diabetes mellitus as the treatment may lead to loss of

diabetic control. Similarly, the many effects that betamimetic agents have on the heart make this treatment unsuitable for women with cardiac disease, especially those who have cardiomyopathy (a heart muscle disorder).

If it is not possible to use one of these drugs, an alternative that can work is indomethacin.

Corticosteroids to help your baby's lungs mature

Corticosteroids are drugs that help to enhance the functioning of a preterm baby's lungs by stimulating the changes that usually occurs at term. Corticosteroids have been shown to greatly reduce the risk of and death from respiratory distress syndrome (RDS), which is the trouble preterm babies have breathing due to their lungs being underdeveloped.

The use of corticosteroids is one of the most important treatments that can help preterm babies survive and do well. When a baby is born too early the immaturity of her or his body can lead to a number of life-threatening complications. One of the major complications is RDS. A baby with RDS may also experience intraventricular haemorrhage (IVH), which is bleeding within the brain. Corticosteroids also work to protect the baby's immature brain from haemorrhage.

Treatments that are *NOT* recommended

Thyroid hormones have been shown to enhance the effects of corticosteroids on lung function of preterm babies, but they are difficult to administer and do not cross the placenta. Thyrotropin (TRH) has been used to stimulate the unborn baby's own production of thyroid hormones, which theoretically, could enhance the effects of the corticosteroids. However, research has not shown it to be safe and effective, and the NHMRC recommends *against* its use.

Other treatments previously thought to have the potential to protect preterm babies against brain haemorrhage are: vitamin K, phenobarbital and magnesium sulfate. However, studies have not shown conclusively that any of these treatments are effective and as a result they have not been recommended by the NHMRC.

Is preterm labour the same as normal labour?

If you have already had a term baby, then preterm labour may feel quite different. But whether it is your first, second or third pregnancy, perhaps the most important thing to remember is that your own situation, and each pregnancy, is unique.

Perhaps one of the biggest differences in going through labour with a preterm baby rather than a full term one, is that efforts will usually be made to stop the contractions, if that is possible, in an effort to give the baby more time to grow inside you. You may find, though, that more monitoring of the baby's heartbeat is recommended in a preterm labour than otherwise.

It is a common misconception that because a preterm baby is so small, the labour will be less painful. The first stage of labour, when the cervix is dilating, will be the same in preterm labour as it is in labour at term. The second, 'pushing' stage of labour may be a little easier with a smaller, preterm baby, but not necessarily. Each labour is different. You can use the usual forms of pain relief in labour.

Before 32 weeks the rate of caesarean section is higher than it is with mildly preterm and term babies. If you have a caesarean section you may need a general anaesthetic, in which case you will be unconscious when your baby is born. If you have epidural anaesthesia, you will be awake when your baby is born. Most preterm babies, though, are born vaginally. A caesarean may be necessary if the baby needs to be born urgently because of problems with the baby or mother. Otherwise, there is no evidence that a caesarean is better for a preterm baby generally. For

women, caesareans have particular risks and consequences in a uterus earlier in pregnancy, and are best avoided if possible.

In giving birth preterm you are aware that your baby's chances of survival are not as good as those for a term baby and that she or he is likely to need days, sometimes weeks or (rarely) even months in hospital. All this may cause you to feel much more worried and concerned for your baby during labour than you would otherwise be.

People present at the birth

As well as the people who normally attend a birth, such as midwives and obstetricians, a paediatrician and/or a neonatologist and a neonatal nurse will ideally be present at the birth of a preterm baby in a perinatal centre. The NHMRC recommends that these specialists be present for all preterm births before 34 weeks, in order to make sure that babies are safely transferred in the best possible condition to the neonatal nursery.

What will the baby look like?

How early your baby is born will determine how your baby appears. For example, a mildly preterm baby will just be a bit smaller than a term baby, providing there are no other complications. Most parents are shocked by how tiny, thin and frail-looking their very preterm baby is. Because your baby may not have developed body fat yet, the baby's head and tummy will usually look large and out of proportion compared to the skinny chest, arms and legs.

Preterm babies are usually covered in a soft downy hair called 'lanugo'. This is normal for the baby's stage of development in the uterus. This may also come as a shock to parents. The hair is normal, and will gradually disappear.

If you have been told your baby has an abnormality, don't be afraid to ask any question. What parents imagine is often worse than the reality. The midwives and doctor caring for you can also describe how they might expect your baby to look.

If your baby has died before birth, your baby's skin may be darker or perhaps lighter than you may have imagined. The baby's lips may be a deep red colour. The size and appearance of your baby will depend on the length of time the baby continued to grow and any medical condition or abnormality.

What happens when the baby is born?

Preterm babies often need help establishing breathing at birth (resuscitation). This is because their lungs have not yet fully developed. The earlier the baby is born, the greater the need for help.

For most babies, simple methods such as drying, warmth, stimulation and oxygen supplementation by mask are all that is needed. If, however, the baby needs a little more help, then bag and mask ventilation will be used. Some babies may need endotracheal intubation, which involves putting a tube down through the baby's mouth and throat towards the lungs.

Within the first minute after your baby is born your doctor will also establish what is called your baby's Apgar score. The score is based on an assessment that the doctor makes of your baby's heart rate, breathing, colour, muscle tone, and reflexes. Between 0 and 2 points are given for each of these five characteristics, so a total score of between 0 and 10 is possible. The higher the score, the better your baby's health. Preterm babies often have lower scores than term babies because of immaturity. Scores between 4 and 7 are common for preterm birth. A score below 4 is low, and means your baby is having problems. Those problems may resolve quickly, but they could also mean that your baby needs more help. The Apgar score is routinely assessed at 1 and 5 minutes after birth, and subsequently at 5-minute intervals if it is still low at 5 minutes.

Because your baby may need to have resuscitation and receive further close monitoring and/or specialised care, he or she may need to be separated from you very soon after birth. If your baby needs short-term observation and care, she or he will be taken to the special care nursery

(SCN). If, however, your baby needs more intensive longer-term care, she or he will be taken to the NICU. Sometimes the baby needs to be taken away very quickly, and people might not have enough time to explain everything. Your baby should not be taken away without your permission, though. If you need more information, you can 'catch up' with the obstetrician, neonatologist, and neonatal nurses later about how your baby is, and why they recommended your baby needs more care.

In some cases, observation of a preterm baby by the doctor or nurses can in fact occur while the baby is kept with the mother in the birthing unit or on the postnatal ward. Some babies, however, especially those that have been born very preterm will be very unwell and require ongoing intensive care.

Keeping the baby warm

A preterm baby has virtually no fat under her or his skin. As fat is the body's natural insulator, preterm babies can become cold very easily. If a baby gets dangerously cold this is known as 'hypothermia'. One of the major reasons, therefore, that preterm babies are admitted to a special care facility is to provide a controlled, warm environment.

If your baby is only 3 or 4 weeks early, and there are no complications, she or he will be wrapped and put in a warm cot. The cot is usually warmed with a hot water bottle or an electric blanket. The room temperature of the nursery will also be warmed to the appropriate temperature. Keeping your baby wrapped close against you may also be an option.

If your baby is very preterm or has difficulty keeping warm in a warm cot, then she or he may be placed in a closed incubator. This is a plastic-walled, enclosed cot. The temperature is warm enough in the incubator to allow the baby to be unclothed except for a nappy. Having your baby undressed allows easier observation of the baby's skin colour and breathing rate and rhythm.

If your baby is very sick and needs constant attention then she or he may be placed in an open incubator so that your baby's carer has easy access. The

open incubator has a heater positioned above it which self-adjusts the temperature to suit the changing needs of the baby. A sheet of plastic wrap is usually placed over the top of these incubators to assist in keeping the baby warm.

What other parents felt about the birth of their preterm baby

- Giving birth very early can be a real shock, even if you knew it was coming.
- It can be very upsetting and scary to be in labour when you don't want to be, and you know it's too early for your baby.
- If preterm labour or birth is a surprise, it can be hard seeing all your plans go out the window.
- If you move hospitals when you're in labour it can be very upsetting and cause a lot of chaos for the family.
- You could feel numb, very emotional, or anything in between.
- If you've been 'high risk' for preterm birth and you have made it past 32 weeks, it can be a huge relief.
- The reality of your very preterm baby or babies being so tiny and fragile can hit very hard.

"I was by myself when they told me, 'We are going to deliver your baby this evening'. It was such a shock. I had only gone to the doctor with a headache, now I was having a baby tonight. I cried and cried as I called my husband."

"I was upset; it was a shock. I was prepared, but not quite as prepared as I thought. I didn't realise how small she was. I think that's when everything kind of hit me, like, 'Wow, this is what we're dealing with here. Oh my God'."

continued...

What other parents felt (continued)

“When she was first born, I felt a sense of failure. Later, the failure turned to guilt, not only towards her, but also towards the rest of the family.”

“I was moved back to the ward and put on a drip. How I prayed that the drip would stay, as I did not want to go and see my baby. I was afraid of what I would see.”

“Seeing him in the incubator soon after the birth, I felt he wasn't mine and that I hadn't just given birth to him.”

“It seemed that I had been emotionally braced for a crisis for so long that I could not believe that everything was finally okay.”

“The twins were so scrawny, not at all like the babies you see in ads.”

“I remember telling myself that I wouldn't let myself get too attached, but the moment I touched his tiny hand, I felt this surge of love.”

“I'm a mother but I don't feel like a mother because he's not with me.”

5 What happens after my baby is born ?

What if we are at a hospital without an NICU?

Not all preterm births can be predicted, and some happen too quickly to consider moving the mother to a perinatal centre. Sometimes, women decide to stay locally in the hope that it will work out. So inevitably, quite a lot of babies need emergency transport to NICUs. Babies will not be transferred against their parents' wishes, but again, things can move very quickly without much time for discussions and explanations if a baby is born having trouble, or starts to get sick later.

Having your baby transferred to another hospital is distressing. The added burden of longer travelling time and separation from family and friends, together with fears for a baby's welfare, are very difficult to cope with. It all puts an immense amount of strain on yourself and your partner/husband and family. For some families, it just is not possible to visit the hospital at all and this can be emotionally devastating.

It is hard to be prepared for an emergency with your baby. If your baby is to be moved, he or she might go in an ambulance, or be picked up by aeroplane, or sometimes by helicopter. The perinatal centre or Flying Doctor Service will send out a 'retrieval team' of doctors and nurses to take care of the baby during the move— and the mother as well, if she is able to travel.

It may be possible for you to get information to help prepare yourself for the transfer, but it could also happen very quickly. It is hard to be prepared for the sight of the high-tech cot that the baby will be placed in. It is like a mini-intensive care unit, and some parents have described it as

a 'space ship'. Sometimes, parents just feel numb when all this is going on, but more often, it is enormously hard to have your newborn baby taken away, even if it is the best thing to do.

Sometimes the mother is not well enough to go with the baby. Sometimes there may be no one else from the family to travel with the baby. It can be a very distressing prospect to think of your tiny new baby being without family so soon after birth. Sometimes one or both of the parents need to make their own way to the perinatal centre. Make sure you get enough information about how to get there, where to go and park if you are driving, and the names and contact details of who to talk to when you get there. Ideally, there will be someone who can answer all your questions, and help you make any decisions that need to be made. The doctors and nurses will usually be able to be of great help and support, but sometimes, medical emergencies with the baby and/or mother mean they cannot help immediately.

Sometimes there may be someone you know who lives near the perinatal centre who could visit your baby if you can't be there. If you don't know anyone, you could also contact the social worker or Aboriginal liaison officer at the perinatal centre and talk to them as well as the doctors and nurses looking after your baby.

If you are unable to go with the baby, but your partner or others can, it can be very hard to cope with being left alone while trying to handle your feelings about separation from your baby and your own recovery. It is often difficult for partners/husbands/family members to decide to either stay and support the mother, or travel with the baby. Most often, parents decide that it is more important for someone to go with the newborn baby.

For partners/fathers, the stresses and strains of the transfer can be enormous. Worrying about their partner as well as the baby, particularly if both are very ill, and feeling torn between going with both, as well as possibly other children, can be an ordeal. A lot of decisions and arrangements may need to be made quickly, with little time to cope with their own feelings and emotions.

If you know there is a big chance of your baby being born preterm or ill, it is a good idea to try your best to arrange as much support as possible ahead of time to help you through this difficult time.

While it can help to know that the only reason your baby has been transferred to another hospital is so that she or he can receive the best care possible, that does not make it easy. It is important to know, though, that those who are looking after your baby are aiming to transfer your baby back as soon as possible!

Travel allowance

If you live in a rural or remote area you may be able to get financial help from the Isolated Patients Travel Assistance and Accommodation Scheme (IPTAAS). It can be hard to work the system out, though, so contact the social worker or Aboriginal liaison officer at your hospital or health service. They can also help you with all sorts of other issues. You can also contact the social worker and Aboriginal services at the perinatal centre: it doesn't matter if you are not there. If your baby is there, or on the way, they will help you, too.

How can we keep in touch and get information?

Having a very preterm baby can mean quite a lot of separations: it is not always possible for the mother and baby or babies to be in the same hospital at all times. Even if they are in the same hospital, they could be in different wards while the mother recovers from the birth and any illness. Every effort will be made to keep you and your baby or babies as close to each other as possible, though.

If you cannot get to the nursery, you can speak directly to the people looking after your baby at the NICU. Your phone call will be most welcome. The NICU will allow photos and videos of the baby to be taken and most nurseries will have polaroid cameras available. The NICU staff can arrange photos for you, if you can't get to the NICU yourself. If you would like a photo, feel free to ask for it, to make sure it happens. If you live a long way from the hospital, there may be hospital or hostel

accommodation close by that you could use. Sometimes, the baby's father or other family members can also use this accommodation. In some places, there are units where the whole family can stay for a while. Ask the staff at the NICU, the social worker, or the Aboriginal liaison officer or health worker.

If you can visit the NICU, you should find that the doctors and nurses are very happy to answer lots of questions, and help you as much as they can. If you cannot visit the NICU often (or at all), you can still get in touch as often as you need. The staff will understand that not everyone can get there, no matter how much they want to.

There are a few different ways you can keep in touch— particularly by telephoning the doctors, nurses, Aboriginal liaison officer, and/or social worker. Make sure you get a list of all the names and phone numbers of the people responsible for looking after your baby. The NICU staff may also know of a parents' support group so you could contact people who have been there before. The social worker, Aboriginal liaison officer, or someone from the support group may also visit your baby and report back to you.

Some doctors are willing to have consultations and advice taped, or to write down information specifically about your baby to send along. Even if you can be there for a consultation, it can be useful to have a tape or written information because it can be hard to take in everything at once.

The NICU will also have leaflets and booklets that might help you. If you have had twins, triplets, or more babies, there may also be a multiple birth club or association near you, which can offer the support of other parents, as well as written information. If your baby has an abnormality or illness, there might also be a support group of other families in the same situation. If your baby dies, or is going to, a stillbirth and neonatal death parents group (SANDS) might be a big help. Ask the staff at the NICU. (See Section 8 for some contact details.)

Getting over the birth and your own complications

If you have had a caesarean, have been (or are) ill, or have been in bed for a week or more, it could take a while for you to be well enough to move around. This can be very distressing if you want to be able to be with your baby, but you should not underestimate your own problems in your concern for your baby. After a preterm birth, it is not unusual to feel depressed either, and you should not hesitate to ask for support for yourself from the people around you.

If you were confined to bed for any length of time before the birth, you should not expect to be able to bounce right back, even if you have no complications now. Your body will have weakened while you were in bed, and you will need to take it very easy for a while until you are stronger again.

What other parents felt like when they were separated from their baby

- Having your baby or babies taken away attached to machines with lots of wires and tubes can be terrifying, even if it is also reassuring.
- It is very hard to accept being pregnant one day, and without your baby the next.
- You can be on a rollercoaster of all sorts of emotions, or just feel numb or scared. You could be too sick yourself to feel much at all.
- If you live a long way from the hospital, the travel and coping with a strange place can be frightening and lonely.
- If you can't visit, it can be devastating.
- Getting news and pictures of your baby can make you very emotional, or it could all feel very unreal.

“It was like they were taking part of me away.”

“I remember being afraid to call for several reasons. One is the obvious one that I was afraid to hear bad news. Secondly, I just couldn't concentrate on what was explained to me. . . I just couldn't comprehend it.”

“I felt very torn—I wanted to be at the hospital all the time but I also needed to be at home with my two other children, aged four and two, as they needed extra comfort at this time.”

“The first week after her birth was the worst because I was too sick to see her. I was so worried about her.”

“[It was] a long time . . . before I actually got to hold her . . . I had felt so cheated.”

continued...

What other parents felt (continued)

“Expressing milk became my emotional support—it proved that I had a baby who existed, and it gave me a routine and a feeling that I was doing all I could.”

From fathers —

“Most men hold their feelings back, but when that head came out, I just melted . . . started crying . . . it was one of the magic moments in life. And then all of a sudden the baby’s gone, and it’s like you’re falling off a cliff, and you’re stuck in slow motion.”

“It was a lot of running back and forth and it was very tiring.”

“I was instinctively trying not to care too much, then I would catch myself and feel bad.”

“The experience was so terrifying for Elizabeth that even though I had feelings and they were quite legitimate, I could only deal with them at certain times.”

Who will look after my baby?

In addition to your normal health carers (family doctor, community nurse) and those who you will have met during your antenatal care and in labour (midwife, obstetrician), at the NICU or SCN a number of professionals with expertise in the care of newborn infants will be looking after your baby. These will include:

neonatologists — specialist doctors who care for newborn infants; and

neonatal nurses — nurses who specialise in the care of newborn infants.

Other health professionals who might be involved in the care of your baby include radiographers, physiotherapists and ophthalmologists (eye specialists). In addition you may need to discuss your situation with a social

worker and a follow-up coordinator will help to ensure that a suitable program of follow-up is organised for your baby.

Can I breastfeed my baby?

This will depend on both your, and your baby or babies' situation. Usually, though, there is no reason why you cannot breastfeed your baby or babies, even if they need to be in the NICU. If your baby is only mildly preterm and otherwise fine, then the situation will be much the same as if you had the baby at term.

If your baby is very preterm, though, it may not be possible for you to breast or bottle feed her or him immediately. It is important to remember that a preterm baby should really still be growing inside his or her mother's uterus in which case it would not be getting any kind of milk at all. It is only natural, therefore, that your baby is not ready to suck and digest milk. Your baby may need to be fed intravenously (via a drip) for a while.

If you want to breastfeed, you will need to help your body establish milk production soon after the birth, whether or not the baby is ready to take the milk. The midwives, nurses, and/or lactation consultants at the hospital will help you with this, and show you how to express your milk and store it so that it can be given to your baby then or later. You have to start expressing immediately because it is not possible to start breastfeeding when the baby is old enough to suck. You can change your mind and stop breastfeeding but you can not start it later on.

Even before you can start trying to feed your baby directly by breast, or your own milk in a bottle for when you are not there, your baby might be able to have your milk given through a mouth or nose tube (called gavage feeding). If you are at a different hospital to your baby, your expressed milk can be sent to your baby.

Breastmilk is ideal for babies, and it can be very important to women, too, to be able to care for their babies in this way. When a baby is very

preterm or ill, it takes a huge commitment to establish and continue breastfeeding, but many women are able to establish very good breastfeeding. If you are unable to breastfeed, decide not to, or change your mind, this should be understood and respected. Feeding your baby formula will also provide him or her with good nutrition.

What else can parents do to help?

Stroking your baby, or singing and talking can be very soothing for you and the baby (your voices are already familiar to your baby). Even though the doctors and nurses will be gentle, and provide comfort and pain relief for procedures, some of the care and treatment your baby needs may be very uncomfortable. As parents, your touch and care can always be reassuring and pleasurable for your baby.

Many parents are scared to touch their baby because she or he is so small and sick and has so many wires attaching her or him to so much equipment. The NICU staff will gladly share their knowledge and experience with you. They will also tell you if your baby is too sick to be touched. As your baby becomes stronger you will be able to feed and bathe her or him and become even more involved in your baby's care.

If it is at all possible, visiting the NICU can be important for the whole family. Visiting their new little baby brother or sister can be good for your other children, and strengthen their future relationship. As long as they aren't sick themselves, family members will be encouraged to visit the NICU. Remember too, that those looking after your baby want to inform and involve you as much as possible in the care of your baby.

Many parents find it hard to know what to ask or to know what words to use. This is understandable because it is a new and often frightening and traumatic situation. Most parents find, however, that they gain confidence the more they start to talk with their carers and share information and experiences.

Having a baby in the NICU — what other parents have said it is like

- The machines, noise, and lack of privacy in an NICU can be hard to get used to.
- It is very hard, or next to impossible sometimes, to understand exactly what is going on at first.
- The support of the NICU staff can be a great help, especially once you get to know some of the doctors and nurses.
- You could feel very detached from your baby or babies, your emotions could go up and down, or you could feel very confused. You might be shocked at some of your thoughts and feelings.
- If you can't be with your baby, you could be desperate for news, or afraid to keep in touch.
- You could be scared to touch your baby, wish you could hold him or her all the time, or anything in between.

“You are mourning the child you DIDN'T have, and are becoming accustomed to this pathetic bundle of problems. So I howled—and talked to anyone who would listen.”

“Initially the machinery etc was frightening but the staff reassured us what the normal readings were and in the end the sight of drips, alarms etc. became a way of life.”

“I was frightened to love her too much in case she died.”

“She opened her eyes and seemed to look right at me, she was so still and small and I felt these great waves of love and pity wash over me.”

“As she grew stronger I supposed my feelings did too.”

“I was like a seesaw. You become weak from so much emotion, then wake up and start it all over the next day.”

continued...

Having a baby in the NICU (continued)

“Feelings of inadequacy surface when you cannot give each baby the attention you would like to... I often envied parents who could concentrate wholly on their one baby.”

“I often felt torn between wanting to spend time with Paul as he was very sick..... Sam was easier to visit as he was happier and healthier.”

“My first impression of the baby was that she was smaller than the pictures really showed and that she was beautiful.”

“The nursery is good. The staff give you a little report on how she is. They tell the truth — they don't hide anything from you. They are patient and dedicated, but I still resent having to be there.”

From fathers —

“I always felt kind of lonesome walking out of the hospital by myself.”

“There were times when I was very happy not to see people because I really was tired of answering questions and reexplaining the whole goddamn thing.”

Getting support

The support that parents get either from formal support groups or from family members and friends can be very important. However, the kind of support that parents of a preterm baby feel they need is a very personal thing. Most hospitals can put you in contact with formal support groups and programs if you are interested. Sometimes it is comforting and helpful to speak to other parents who have been through the same thing and know first hand what the trauma of preterm birth and having a sick baby in a neonatal intensive care unit is like.

However, not everyone likes the idea of formal support groups and programs. Some people prefer to get as much support as possible from their family and friends, from whom they can receive physical, emotional and financial support.

RECOMMENDED

6 What treatments will my baby need?

The major complications that most preterm babies experience are caused by the fact that they are born before their bodies are ready for life outside the uterus. Some babies may also have other complications not necessarily associated with being preterm (for example, congenital abnormalities such as heart defects).

The NHMRC Clinical Practice Guidelines do not attempt to cover all the problems that can occur with preterm babies but concentrate on conditions that have the most implications for their survival and long-term health. These are: respiratory distress syndrome (breathing problems), infections and retinopathy of prematurity (a condition affecting the retina of the eye).

Breathing problems

In the uterus a baby's lungs are filled with a fluid, which goes once they are born. However, because preterm babies are born early, their lungs still have that fluid in them and are not mature enough to get rid of it efficiently. Because some fluid remains in your baby's lungs, the lungs don't work as well and so your baby is unable to get enough oxygen. Not being able to get enough oxygen will cause your baby to breathe quickly and this problem is called 'wet lung' or 'transient tachypnoea'. Once it clears, the baby's breathing settles down to the normal rate of about 40 breaths per minute.

Surfactant treatment

The lungs of preterm babies may be immature and do not have enough of a substance called 'surfactant' in the air spaces. This, together with the immaturity of the tissues of the lung, leads to increased stiffness, making it more difficult for the baby to inflate and maintain expansion of the air

spaces of her or his lungs. A special preparation of surfactant can be given at birth or within 12 hours after birth under the direction of a neonatologist in the NICU, and has been shown to be very good at reducing the breathing problems known as *respiratory distress syndrome* (RDS) in preterm babies. RDS is one of the most important causes of death and illness in preterm babies. Babies that have to have a tube inserted into their windpipe to help them breathe (see below) will also receive surfactant treatment.

As well as immature lungs, a preterm baby's breathing centre in the brain may also be immature. This may result in brief breathing pauses called *apnoea* (meaning 'not breathing'). If your baby has these problems she or he may appear bluish in colour when an apnoea occurs and the heart rate often falls transiently (called bradycardia). Your baby will be closely monitored and an alarm will sound if the baby forgets to resume breathing on his or her own so. Babies are routinely monitored and treated successfully for this condition.

Assisted ventilation

If your baby is unable to breathe well enough on his or her own, several different methods are available to ensure that he or she gets enough oxygen. These methods have greatly increased the survival of preterm babies with RDS. The equipment used may include a special tube inserted into the windpipe via the nose or mouth (endotracheal intubation) connected to a mechanical ventilator. The ventilator is a machine that will take over the breathing for your baby. Babies who need the assistance of a ventilator may take quite a while before they are able to breathe on their own without the use of a machine. It could be days or weeks.

Infections

A preterm baby's defence mechanisms against infection are not fully developed and so they are at an increased risk of infections. The more preterm a baby is born, the greater the risk of infection. A preterm baby is at risk of infection immediately after birth, and in subsequent weeks due to acquired infection from care givers or the hospital environment.

The risk of infection is increased in intensive care nurseries because of the use of procedures such as tubes into blood vessels and endotracheal intubation, which whilst life-sustaining, are invasive and can allow infections to enter the baby's body.

To protect the baby from infection at birth, women with preterm ruptured membranes are treated with antibiotics (see pages 27–28). If there is a risk that the baby may have been infected before or during birth, he or she will probably be treated with antibiotics. A vaginal swab will need to be taken from the mother to identify the infecting agent.

To prevent against infection occurring in the hospital, all those who enter the SCN or NICU (staff and family) must adhere to strict hygiene guidelines. Usually this involves washing hands and lower arms to the elbow with a broad spectrum antimicrobial preparation on entry. Staff are required to adhere to this procedure before and after handling individual babies or performing procedures. If a staff or family member is unwell they may not be able to enter the NICU/SCN until they regain their health (especially with infections such as skin lesions, gastroenteritis, cold sores, or hand infections).

Damage to the eye

About 1 to 2% of the babies born at less than 30 weeks gestation lose their eyesight permanently. This is caused by a disease called *retinopathy of prematurity* (ROP). The main cause of ROP is prematurity itself, so the earlier the birth, the greater the risk of ROP occurring. It can be treated and visual impairment sometimes prevented. Preterm babies therefore need to have their eyes examined by an eye specialist (ophthalmologist). Significant problems with this condition almost never occur in babies born after 32 weeks of pregnancy.

What is ROP?

ROP affects the developing blood vessels of the retina, which line the inside of the back of the eye. The tips of these blood vessels grow abnormally and in severe cases they enter the cavity of the eye and form scar tissue. At first this scar tissue is at the very edge of the retina and so does not affect vision. If the

scarring extends into the middle of the retina, however, it may distort the tissues inside the eye and cause reduced vision. Mild degrees of ROP (stages 1 and 2) are very common and, in these babies, recovery is complete.

Severe ROP (stage 3) is less common and occurs almost only in babies born extremely preterm (before 28 weeks). If your baby has severe ROP, then your doctors will discuss with you exactly what this means.

The amount of oxygen treatment needed to help your baby's breathing and the baby's general condition may also influence whether ROP develops or becomes severe. However, some preterm babies who have no serious illnesses still develop ROP, while others who have been very unwell do not. Your doctor will want to inform you as much as possible, so ask your doctor to discuss ROP in reference to your own baby's particular circumstances. The NHMRC has also produced more detailed information about ROP for parents. This is included in Appendix D of the *Clinical Practice Guidelines on Care Around Preterm Birth*.

Screening for ROP

Screening for ROP does not need to start until several weeks after birth and is carried out by an ophthalmologist. Screening is usually completed before your baby is discharged to home but sometimes an examination may be necessary after you have taken your baby home. Most hospitals will arrange to see your baby as an outpatient. It is very important that you keep this appointment.

Treatment of ROP

ROP can be treated and often visual impairment can be prevented. Treatment of severe ROP is by either 'cryotherapy' or 'laser therapy' to the retina. Cryotherapy freezes the affected parts of the retina by applying a small probe against the outer surface of the eye. Laser treatment involves shining a laser light through the pupil of the eye onto the affected retina. Both forms of treatment aim to prevent the retinal scarring and damage from spreading.

Your baby will need analgesia (pain relief) and sedation for this operation and it will take her or him several days to recover from it.

Follow-up

Regardless of ROP, all preterm babies need to have their eyesight checked during their childhood. All babies who have required treatment for ROP will need to be examined from time to time over a period of a few years. Some, particularly very preterm babies with ROP, may become short-sighted and need glasses, and some children may develop squints.

If your baby has very severe ROP and her or his vision is seriously impaired there are special support groups in each State of Australia that may be able to help you cope.

Other conditions

There are many other conditions that your preterm baby may need to be treated for, including some that are only usually seen in very preterm infants, such as:

- *intraventricular haemorrhage* (IVH) — bleeding in or around the cavities (ventricles) of the brain caused by lack of oxygen, rises or falls in blood pressure or alterations in blood flow. This is very rare in babies born after 30 weeks of gestation but it occurs in 20% of babies born earlier than that; and
- *necrotising enterocolitis* (NEC) — inflammation of the bowel wall causing a very swollen stomach and sometimes bile (green-coloured fluid) in the stomach fluid, or blood in the stools.

Other conditions affect preterm babies that also sometimes affect term babies such as: *jaundice* (yellow colour of the skin, that is more common among preterm babies because of the immaturity of the preterm baby's liver); or *anaemia* (lack of red blood cells or haemoglobin in the blood to carry oxygen). Both these conditions can be treated.

What are the long-term complications a preterm baby may experience?

More than 90% of extremely preterm babies who survive and go home to their parents will be free of any major problems. However, some babies have longer-term problems. These usually affect babies weighing less than 1000 grams at birth, although, occasionally, heavier babies can be affected. The most common complications affect vision (which has already been discussed above), hearing, coordination and mental development. Behavioural problems and difficulties with learning and concentration can also occur.

For this reason, most hospitals with neonatal intensive care units also have a follow-up program where the smallest babies attend regular check-ups in the first years of their lives in order to monitor growth and development. Follow-up appointments also provide an opportunity for parents to discuss any concerns they may have about how their baby is developing. Early intervention programs especially tailored for your baby's needs will help to maximise her or his development.

What if my baby has died or will die?

Knowing that your baby has died, or will die, can cause a turmoil of feelings. Feelings such as sadness, shock, anger and confusion are experienced by many parents. These can be difficult to deal with, particularly at a time when you need to make a number of decisions.

It is important to remember that in most circumstances, decisions do not need to be rushed and that you can take time to make decisions which are right for you. It can be helpful to talk things over with your family, close friends, doctor, hospital social worker, or Aboriginal liaison officer.

Your baby may already have died before birth. The staff caring for you during your labour will be able to answer questions about the progress of labour and provide emotional support for you and your partner. They

will also be able to discuss and plan with you the moments following your baby's birth and your first contact with your baby.

Sometimes, there may be little warning that your baby has become critically ill or is dying, because the medical condition of preterm babies can change very quickly. Staff will try to notify you if your baby has become critically ill and you or your partner are not at the hospital. Hospital staff, social workers and Aboriginal liaison officers can help you to notify other members of your family or friends, and help with other arrangements.

Social workers, Aboriginal liaison officers or health workers, and hospital chaplains may also be able to visit your baby and make the arrangements you would like if you are unable to get there yourself.

If you have twins or more, while one baby may die, another baby may be well, or still have a chance of survival. It can be difficult to deal with so many conflicting emotions and demands.

What if my doctor has suggested removing life supporting treatment?

You may be asked to consider removing life supporting equipment if it is believed that treatment cannot help your baby. This is often a very difficult decision for parents. Some parents may feel that everyone around them is giving up hope for their baby's survival, while for others, the removal of life supporting treatment brings a sad relief. It can be valuable for you to spend time discussing the withdrawal of life supporting treatment with your family, your doctor and the hospital social worker or Aboriginal liaison officer.

If you choose to withdraw treatment, it may be important for you to have your baby blessed or baptised before this happens. This can be performed by yourself, a close family member, a member of the hospital staff or a celebrant of the family's faith.

As no one can be exactly sure how long your baby will live without life supporting treatment, it is important for some parents that they are with

their baby when treatment is withdrawn. Some parents, after being advised that their baby would live for a number of minutes, hours, or even days without treatment, have been distressed when their baby died immediately following the removal of life supporting treatment. Families can often be together with their baby in a private area or room organised by the hospital staff.

Sometimes, babies live for a number of weeks or months following the removal of life supporting treatment, and parents have been able to have their dying baby with them in the familiar surroundings of their home.

Being with your baby

The time you have spent with your baby in the labour ward, special care nursery or neonatal intensive care unit may have been the only time that you have been able to be together as a family. Usually when a family member or close friend dies there are many memories of time spent together, which serve as a comfort for those who grieve them. After your baby has died, spending some time with your baby may give you the opportunity to do some of the things you might have done if your baby had lived.

During the time you spend with your baby, you might choose to bathe or sponge your baby. You could dress your baby in specially made clothes knitted or sewn for small babies, which are often provided by the hospital. Many parents choose to take photographs and videos, and to have ink and clay prints made of their baby's hands and feet. Parents have also spent time talking to their baby, saying things that would otherwise have been left unsaid.

What decisions will I need to make?

Postmortem examination

It is of great importance to many parents to find out the cause of their baby's death. After your baby has died, you may be asked to consent to a postmortem examination of your baby's body.

During a postmortem the baby's body is examined to reveal a possible cause of death and to exclude other suspected causes of death. A postmortem examination can also provide important information about genetic disorders. Sometimes, a postmortem examination will provide no additional information for parents about their baby's cause of death, but even knowing that can be important in a future pregnancy.

A full postmortem includes a surgical procedure performed by a specialist doctor trained in pathology. Sometimes, parents have chosen an alternative to a full postmortem, such as a limited postmortem or an external examination only. When considering a postmortem, many parents have found it valuable to spend time discussing the examination with their doctor and hospital social worker. Parents are able to see and hold their baby following a postmortem.

If your baby has a postmortem examination, a verbal report of preliminary findings is usually available from your doctor within twenty-four hours of the examination. The final results from tissue sample investigations may take from two to four months.

Funeral, memorial service and burial

It is a legal requirement that all stillborn babies and babies who die in the newborn period be buried, placed in a mausoleum or a permanent resting place, or cremated. Before this occurs, many families choose to arrange a ceremony for their baby.

This funeral or memorial service can provide parents with the opportunity to acknowledge their baby's life and death, and to say goodbye to their baby. Many parents arrange a service through a funeral director, and some parents arrange a ceremony themselves. Some families plan very small, private funerals attended only by immediate family members. Others choose to involve extended family and friends.

Some parents choose to wait a week or more before arranging the funeral, memorial service or ceremony. This allows time to recover from a caesarean operation or other medical treatment, and gives yourself and your partner some extra days to rest after days or weeks spent in a

neonatal intensive care unit with your baby. Waiting to hold the funeral may also provide an opportunity for other family members and friends to be with you and your family. The hospital social worker will be able to help with information and suggestions for your baby's funeral.

Afterwards

After you return home, it can be hard to meet people who may be expecting good news about your baby or who ask about your baby. Going shopping, meeting neighbours in the street, taking other children to school or returning to work may all seem overwhelming. You may feel isolated and lonely.

Give yourself time to recover both emotionally and physically. Medications often prevent the expression of emotions and are usually unnecessary. Future events such as your expected date of delivery, the anniversary of your baby's birth and death, another pregnancy or significant family occasions may be difficult for you. It is important to have someone you can share your thoughts and feelings with over the weeks and months following your baby's death.

7 When can my baby come home?

Although it depends on a lot of things, the rule of thumb is that babies usually go home at, or slightly before, the date that they were originally 'due'. So, if your baby was born eight weeks early, it could be eight weeks till they are home. In between, they may move from NICU, to an SCN closer to home when they no longer need specialist care.

If you have twins, triplets or more, they will usually need to be in the nursery for longer than other babies born at the same time in pregnancy. Sometimes there will be quite a large difference between how long it takes each to be ready to leave the NICU, and then leave the SCN. If it is only a bit of a difference, it might be possible to have one stay in the SCN a bit longer, so that you do not have to try and divide your time between two different places. Sometimes, though, it is inevitable that one baby might come home before the other(s).

Being discharged from hospital before the baby is ready to come home too can be very distressing. Even though you can still visit your baby, it can leave you feeling very 'empty handed', with a lot of emotions. You're a mother but you don't have your baby to care for. This may be heightened by how other people behave towards you, especially if they behave awkwardly and are not comfortable in asking about how you are feeling or how your baby is doing, especially if she or he is very sick.

If you live a long way from the hospital, it may be possible for you to get accommodation from the hospital close by. You can ask the staff at the NICU, or the social worker or Aboriginal liaison officer.

Do preterm babies grow and develop like a baby born at term?

When you think about the sort of things that your baby should be doing such as sitting up, crawling, walking or talking, it is important that your expectations are realistic and that they are based on your baby's 'corrected age', or true developmental age. In order to work out your baby's 'corrected age' you need to subtract the number of weeks that your baby was born early, from your baby's birthday age. Twelve months after your baby is born will be her or his first birthday. But remember, if your baby was born 12 weeks preterm (at 28 weeks gestation) her or his corrected age will really only be 9 months. This means that even though 12 months have passed since your baby was born, your baby will be doing things that a 9 month old baby born at term would be doing.

Follow-up

As the majority of babies who have been in special care nurseries are neither extremely preterm nor extremely unwell, they may not need a special follow-up. For many preterm babies, the medical services already in existence in the community, for example, the family doctor, local paediatrician, maternal and child health nurse and/or the community early childhood nurse, can best provide support and follow-up (see Section 8 for further information).

All babies who have been in intensive care require follow-up after they leave the hospital for medical reasons. If your baby is extremely preterm, or is or has been extremely unwell, then she or he will require specialised follow-up services from a multidisciplinary team experienced in the type of problems that are encountered after a baby is discharged from hospital. Problems may involve neurodevelopmental problems, specific learning difficulties and behavioural and family relationship problems.

Research has shown that coordinated family support programs and follow-ups have significant benefit for both children and parents. The extra care and support can improve children's mental development, and lessen emotional, family and school problems.

Risk of preterm birth in future pregnancies

As was discussed earlier in Section 3 of this booklet, the risk of preterm birth in your next pregnancy increases if you have already had a preterm birth. Before you leave hospital, an obstetrician should talk to you about your personal risks and answer any questions you may have about the future.

What other parents felt like about taking their baby home

- Sometimes parents can't wait for their baby or babies to come home, and sometimes they dread going it alone without the nursery.
- If you have more than one baby, they may not come home at the same time. It can be hard to cope with the different feelings and practical difficulties you could have.
- If your baby has feeding or sleeping difficulties, it is physically and emotionally exhausting, and you could under-estimate how much support and help you need.

“The day the three of us came home, I cried. It was a fantastic day.”

“Those first few months after Michael came home were difficult ones. He required so much attention.”

“After Zachary came home, I thought I would have a terminal case of the happies. Instead, the loneliness of isolation and the constant demands of this not-so-new-any more baby started to affect my moods. I was sad, I was happy, I was tired, I was lonely.”

continued...

What other parents felt (continued)

“It took some time to develop a sense that this is a healthy baby and things were going to be okay. I would get up in the middle of the night and poke her to see if she was still breathing.” (a father)

“That was a very good time for us. I remember enjoying those weeks enormously — sort of the payoff for all we had gone through.” (a father)

“Some day you finally quit having to explain. When someone says, ‘She’s so small’, you reply, ‘Yes, she is’, and you don’t feel the need to continue.”

8 Where can we go for more information about preterm birth?

Your carers will want to share as much information with you as they can. Even once you and your baby are home, you can always get advice from the NICU. Your carers know and understand how difficult a time preterm birth is for parents. Do not hesitate to phone them or drop in, they will be only too pleased to help. As one parent expresses, being able to get answers to questions is very important:

“Answers are really needed during this rough time. It’s a big part of recovery.”

Hospitals also know of any support groups and will be only too happy to put you in contact with someone. The aim of such groups is usually to provide emotional and practical support to parents and families of preterm babies. Quite often these groups are set up by other parents who have had a preterm baby and are willing to share their first-hand knowledge and experience with others.

Other support services you may need to use or just feel more comfortable using are listed below with contact telephone numbers where possible.

- Australian Multiple Birth Association (and local multiple birth clubs): National Office, Tel: (02) 9386 9443
- Interpreter services, Tel: 13 14 50
- Nursing Mothers’ Association
National Office, Tel: (03)9877 5011
- National Association for Loss and Grief:, Tel: (06) 239 7011

- Stillbirth And Neonatal Death Support Group (SANDS)
National Office, Tel: (02) 9906 7004
- QUIT helpline, Tel: 13 18 48

For the following services check under government services in your local telephone directory for telephone numbers:

- Aboriginal health workers and liaison officers
- domestic violence/centres against sexual abuse (hospital social worker will advise)
- lactation consultants
- ministers/priests/hospital chaplains
- preterm support groups (most hospitals with an NICU have a parent support group)
- social workers

NOTE: The Australian Association for the Welfare of Child Health (AAWCH) maintains a Paediatric Support Link Database that documents every health-related group in Australia.

Explanation of technical terms

“[I need] someone to interpret or explain what is going on. These doctors use big words . . . and you’re sittin’ there goin’, ‘In English now, please’.”

The health professionals (doctors, nurses, midwives) who are caring for you and your preterm baby, will use a lot of terms that you may not be at all familiar with. The information most parents-to-be have learnt about pregnancy and birth does not include knowledge about being at risk of preterm birth or what to expect when having a preterm baby.

Parents at risk of preterm birth have a lot of important decisions to make and new information to learn to help them make the best choices. Not being able to understand the language used in relation to yourself and your preterm baby may make an already difficult and often stressful time, even more so.

Therefore, in order to help parents and those who support them become familiar with the language health professionals frequently use when discussing care around preterm birth, **aglossary** of the most commonly used terms is provided over the next few pages. This glossary is also where you will find the definitions of any terms you may not be familiar with that are in this booklet.

If, however, you want clarification of any of the terms, be sure to ask your doctor, nurse, midwife.

Glossary of terms commonly used around preterm birth

Antepartum	During pregnancy (literally before birth). (<i>see also</i> Intrapartum, Post-partum)
Antepartum haemorrhage	Significant blood loss before the baby is born.
Apgar score	Apgar scores are clinical indicators of the baby's condition shortly after birth. The score is based on an assessment that the doctor or midwife makes of the baby's heart rate, breathing, colour, muscle tone, and reflex irritability. Between 0 and 2 points are given for each of these five characteristics, so a total score of between 0 and 10 is possible. The higher the score the better. The Apgar score is routinely assessed at 1 and 5 minutes after birth, and subsequently at 5-minute intervals if it is still low at 5 minutes. Preterm babies often have lower scores than term babies because of immaturity.
Apnoea	Absence of breathing for short periods.
Assisted conception	Infertility treatment, including IVF, GIFT and fertility drugs, used to aid conception. (<i>see also</i> <i>In vitro</i> fertilisation, Gamete intrafallopian tube transfer)
Auscultation	Act of listening for sounds in the body with a stethoscope; used in pregnancy for detection and counting of the fetal heart beat.
Betamimetic drugs	Drugs that cause relaxation of the uterus, that is stop contractions. (<i>see also</i> Tocolysis)
Birthweight	The first weight of the baby (stillborn or liveborn) obtained after birth (usually measured to the nearest 5 grams and obtained within one hour of birth). (<i>see also</i> Extremely low birthweight, Low birthweight, Very low birthweight)

Caesarean section	Birth of a baby involving an operation through the abdomen. Performed either before the onset of labour (elective caesarean section) or after the onset of labour (emergency caesarean section).
Cervical cerclage	An obstetric procedure where a suture is used for holding the cervix closed to try and prevent miscarriage and spontaneous preterm birth
Corticosteroids	Drugs that mimic the action of the natural steroid hormones (hydrocortisone and corticosterone). These drugs can help the lungs of a fetus to develop more quickly while in the uterus.
Elective delivery	Birth by either caesarean section or induced labour, before labour spontaneously begins.
Endotracheal intubation	Insertion of a tube through the baby's trachea (windpipe) to assist breathing.
Extremely low birthweight	Birthweight of less than 1000 grams. (<i>see also</i> Birthweight)
Extremely preterm	Baby born after less than 28 completed weeks of pregnancy. (<i>see also</i> Preterm)
<i>Ex utero</i> retrieval	<i>see</i> Neonatal retrieval
<i>Ex utero</i> transfer	<i>see</i> Neonatal transfer
Fetal death	Fetus dying before birth. (<i>see</i> Stillbirth)
Fetal congenital malformations	Physical abnormalities (also sometimes called 'birth defects') that are present at birth, usually because of abnormal development in the first three months of pregnancy.
Fetus	Word used to refer to the baby before he or she is born.
Forceps	A metal obstetric instrument shaped like two spoons that can be used for pulling the baby through the vagina.

Functional maturity	How well a baby is functioning physically for their gestational age.
Gamete intrafallopian tube transfer (GIFT)	A human fertilisation technique in which male and female gametes (sperm and ova) are injected through a laparoscope into the ends of the woman's fallopian tubes.
Gestational age	The duration of pregnancy in completed weeks as calculated from the date of the first day of a woman's last menstrual period.
Gestation	Another word for pregnancy.
Home uterine activity monitoring	Use of an electronic device at home for monitoring contractions before childbirth.
Hormone	A complex chemical substance produced in one part or organ of the body that initiates or regulates the activity of an organ or group of cells in another part of the body.
Hyaline membrane disease	A breathing disorder (respiratory distress syndrome) of preterm babies caused primarily by a lack of surfactant in the baby's lungs.
Hypertension	High blood pressure
Hyperglycaemia/hypoglycaemia	When the glucose (sugar) level in the blood is too high (hyper-) or low (hypo-).
<i>In utero</i> transfer	<i>see</i> Maternal transfer
<i>In vitro</i> fertilisation (IVF)	A method of assisted conception sometimes called a 'test-tube pregnancy'. <i>In vitro</i> literally means 'in glass' because the fertilisation of the ovum with sperm occurs outside the woman's body and the fertilised egg is then implanted into the uterus.
Induced birth	A birth that is 'brought on' intentionally by the doctor, by rupturing the membranes (breaking the bag of waters around the baby) or by giving hormones by a drip, orally or as suppositories.

Intermittent positive pressure ventilation (IPPV)	A form of assisted or controlled breathing using a ventilator.
Intrapartum	Occurring during childbirth. (<i>see also</i> Antepartum, Post-partum)
Intrauterine growth restriction	When fetal growth is estimated to be less than adequate (formerly known as intrauterine growth retardation).
Intraventricular haemorrhage	A type of bleeding in the brain.
Low birthweight	Birthweight of less than 2500 grams. (<i>see also</i> Birthweight)
Maternal transfer	Transfer of mother and baby <i>before</i> birth (sometimes called ' <i>in utero</i> transfer'). (<i>see also</i> Neonatal transfer)
Mildly preterm	Baby born after more than 32 but less than 37 completed weeks of pregnancy. (<i>see also</i> Preterm)
Moderately preterm	Baby born after more than 28 but less than 32 completed weeks of pregnancy. (<i>see also</i> Preterm)
Multipara	A woman who has given birth at least once. (<i>see also</i> Parity)
Multiple birth	When two or more babies are born from one pregnancy.
Neonatal	Newborn: 'neo' means new and 'nate' means birth. The neonatal period lasts until 28 days after birth.
Neonatal death	The death of a liveborn baby within 28 days of birth.
Neonatal morbidity	Any condition or disease of the baby diagnosed after birth and before separation from care.
Neonatal intensive care unit (NICU)	An intensive care unit in a hospital, equipped especially for newborn babies.

Neonatal retrieval	Baby collected and transferred to a neonatal intensive care unit by a specialist neonatal transport retrieval team (sometimes called <i>ex utero</i> retrieval’).
Neonatal transfer	Baby transferred to another hospital after birth(sometimes called <i>ex utero</i> transfer’). (<i>see also</i> Maternal transfer)
Nullipara	A woman who has never given birth. (<i>see also</i> Parity)
Obstetrics	Specialised care for pregnancy and childbirth.
Parity	Number of previous pregnancies resulting in livebirths or stillbirths. (<i>see also</i> Nullipara, Multipara, Primipara)
Perinatal	The time around (‘peri’) birth. The perinatal period begins at 20 weeks in pregnancy and ends at 28 days after the birth.
Perinatal death	A fetal or neonatal death.
Placenta praevia	Literally meaning that the placenta is ‘before the baby’ — a condition where the placenta is positioned low in the uterus (close to the cervix, or even closing it off), which can result in bleeding and separation of the placenta.
Placental abruption	When the placenta comes away from the uterus wall before birth. This can cause haemorrhage or even death.
Post-partum	After birth — the post-partum period is the month after giving birth. (<i>see also</i> Antepartum, Intrapartum)
Post-term birth	A baby born after 42 weeks gestation.
Pre-eclampsia	A typical disease of pregnancy that is characterised by high blood pressure and a loss of protein from the urine.
Prelabour rupture of membranes	The rupture of membranes (waters break) before the onset of significant uterine contractions (previously

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(PROM)	known as 'premature rupture of membranes' (also PPROM: preterm prelabour rupture of membranes).
Preterm	A baby that is born before 37 completed weeks of pregnancy. (<i>see also</i> Extremely preterm, Mildly preterm, Moderately preterm, Very preterm)
Preterm labour	Labour that starts before 37 completed weeks of pregnancy.
Primipara	A woman who has given birth only once (to a live or stillborn infant). (<i>see also</i> Parity)
Respiratory distress syndrome	A breathing disorder of preterm infants. (<i>see also</i> Hyaline membrane disease)
Resuscitation of baby	Active measures taken to assist the baby's breathing and heart beat; or to treat depressed breathing effort or other problems.
Retinopathy of prematurity (ROP)	An eye disorder affecting the retina of preterm babies.
Singleton birth	Birth of a single baby.
Small for gestational age	A baby that has not grown to the size expected for his or her gestational age.
Small-for-dates	<i>see</i> Small for gestational age
Special care nursery (SCN)	Nursery for babies needing observation or treatment but not intensive care.
Stillbirth	Birth of a baby with no signs of life at birth; it means that the baby has died before before birth.
Tocolysis	The attempt to stop or limit uterine contractions in preterm labour using drugs.
Very low birthweight	Birthweight of less than 1500 grams. (<i>see also</i> Birthweight)
Very preterm	Gestational age of less than 32 completed weeks of pregnancy. (<i>see also</i> Preterm)

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Questions and notes

You may like to use this space to jot down any questions you have for your doctor/nurses or make notes from the conversations you have, etc.

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