the neonatal trust

What to expect

when it wasn't what you expected

The Neonatal Trust

PO Box 9366
Marion Square
Wellington 6141
info@neonataltrust.org.nz

This is a guide to the neonatal experience.

It is full of really useful tips from people who have been on an NICU journey.

Take what you like from this book and leave behind what you don't want.

Feel free to pass it on to someone else.

If you have discovered a survival tip that we have missed, **please pass it on** to us so it can be incorporated into the next edition.

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In this guide the baby is referred to as him, he and his,

and nurses are referred to as her and she.

We hope this doesn't offend anyone.

* Cover photo: Charlotte Rose born 650 grams

Contents

Arrival in the Neonatal Intensive Care Unit (NICU)

Arrival in the Neonatal Intensive Care Unit (NICU)

Meet the people caring for your baby

Who are all the Unit staff?

The consultant neonatologist
A specialist consultant doctor (also called a paediatrician). They are assigned to your baby the day your baby is born, and one will be assigned to your baby for follow–up care once baby is discharged from the hospital. A consultant neonatologist usually wears mufti and doesn't wear a name tag.

Registrar
Registrars are like trainee consultants. They are studying to be consultant paediatricians or neonatologists, and can be identified as they usually wear blue scrubs.

Other medical personnel you may meet who are junior to the registrars, are senior house officers (SHOs) and trainee interns (TIs). They usually wear a name badge. You may see these people more than the consultants.

Charge nurse manager (CNM)
The CNM has overall responsibility and charge of Neonatal Services, and monitors professional standards, education and co–ordination of services both within the NICU (the Unit) and the NICU community team (homecare team). Basically she manages all the staff, resources and environment. She's the boss!

Associate charge nurse manager (ACNM)
An ACNM is a senior neonatal nurse who co-ordinates each shift. If an issue occurs the first port of call is the ACNM. If the issue is unable to be resolved, the CNM is the person to see.

Neonatal nurse specialist (NNS)
An NNS works alongside the doctors attending deliveries, assessing babies and prescribing medications. They are involved in the medical care rather than the nursing care.

Clinical nurse specialist (CNS)
A CNS provides clinical support for both nurses and doctors. They have an educational role and uphold and improve the standards of care within the Unit.

Staff nurse
A staff nurse is a registered nurse. Some staff nurses are also midwives, and some have done additional training in the area of neonates.

Homecare nurse
A homecare nurse is a senior neonatal nurse who co-ordinates discharge planning, parent education and home visits.

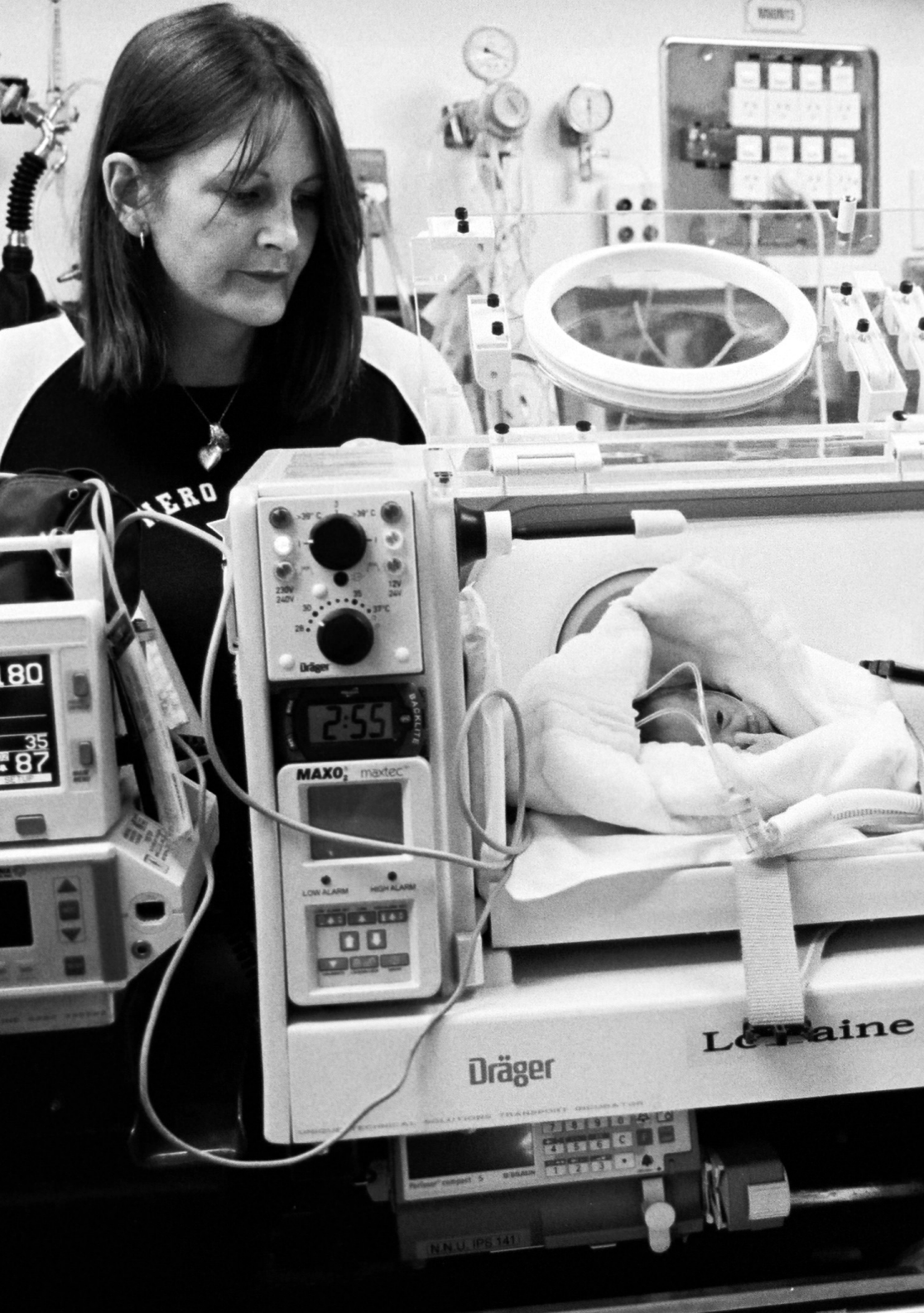
Technician
A technician looks after the equipment that your baby uses.

Lactation consultant
A lactation consultant assists mothers with breast-feeding and expressing.

Ward clerk
The ward clerk carries out the day-to-day paper work of the Unit.

Who are all the additional staff that may visit?

Pharmacologist
A pharmacologist's job is to ensure that your baby is getting the right medication. They also make up a lot of the medications and IV fluids your baby gets while in the Unit.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Physiotherapist

There are several types of physiotherapists that work in the Unit. They are involved right along the journey when they are needed, from the initial assessment of a baby's respiratory problems, advising on appropriate positioning and treatment to help maximise ventilation, through to their neuro-development and speech/feeding. They wear a white top with **Physiotherapist** embroidered on it.

Neuro-developmental physiotherapist

A neuro-developmental physiotherapist works with families to support bonding and attachment with their new baby. They assess and monitor baby's neuromotor development and provide both the parents and nurses with an individualised care plan. They also co-ordinate follow-up care with the child development team, where appropriate.

Speech/feeding physiotherapist

A speech/feeding therapist helps families to safely and efficiently feed their baby. They identify oral motor milestones and work with families to facilitate their child's best efforts.

Radiologist (x-ray)

A radiologist takes x-rays of your baby and wears a white uniform with **Radiology** embroidered on the front.

Radiographer

A radiographer is a radiology specialist that performs ultrasounds on your baby, and interpret the results of the x-rays, scans and ultrasounds.

Social worker

A social worker takes care of the social aspects of the families' well-being.

All of these people work together, with you, as an effective team caring for the well-being of your baby.

At first

This may be a very worrying time for you at the moment. Most people who have had a baby in the NICU (the Unit) never imagined that this could happen to them.

The Unit is especially designed to care for premature or ill newborn babies. The doctors and nursing staff are trained in the care of small babies and understand that you, as a parent, may be frightened of what is happening to you and your family at the moment.

Don't be afraid to ask the staff questions, or to touch and spend time with your baby.

What are the key things to remember in NICU?

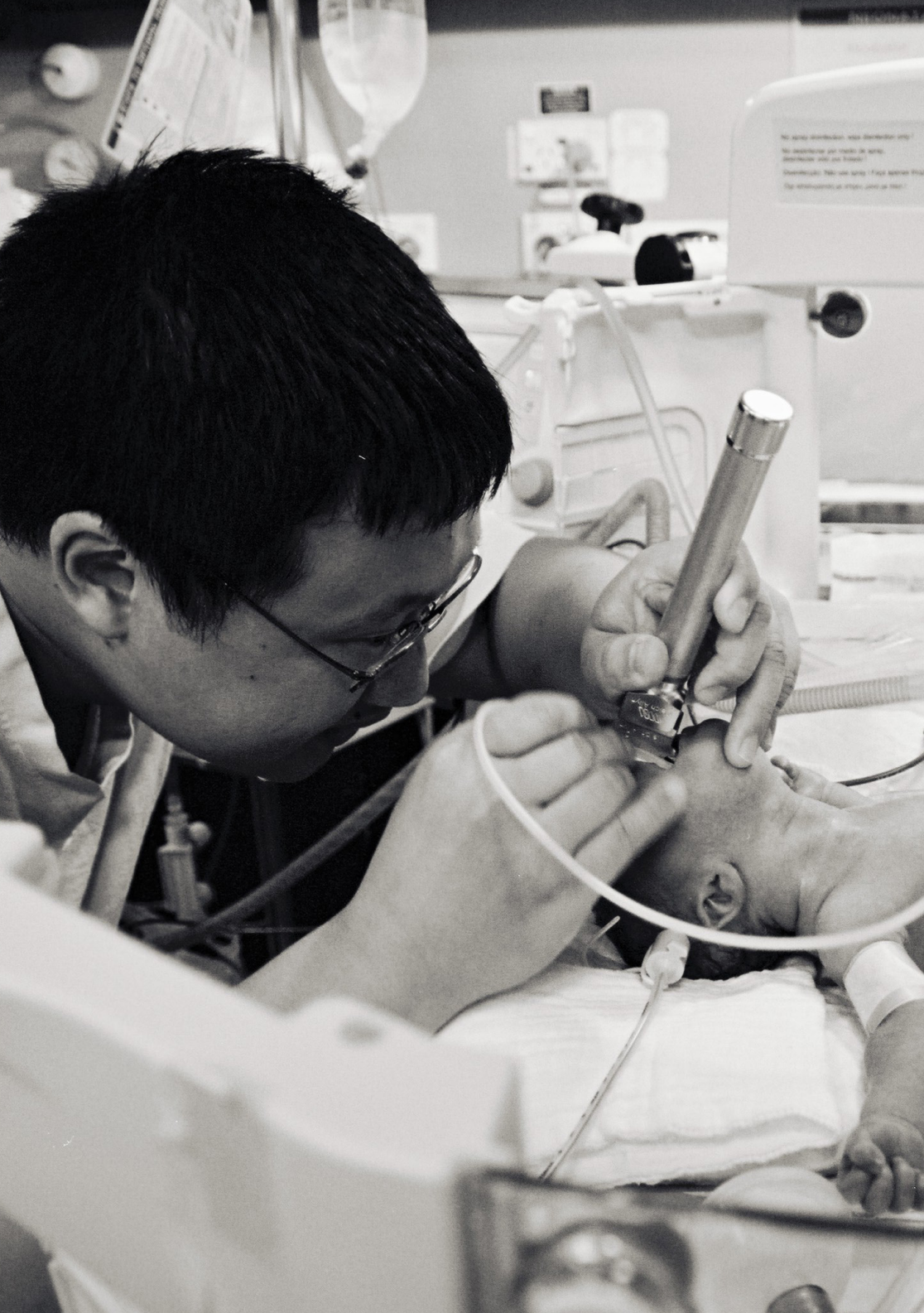
It is very important that you (and your family and visitors) take the time to wash hands and forearms thoroughly each time you come into the Unit. This is to minimize the risk of infections, which small and/or ill babies are susceptible too. Please discourage family and friends from visiting if they have a cold or flu.

Please be mindful of your baby's room mates as it may not be appropriate to ask questions about other babies.

To minimise the risk of spills or burns, staff ask that you do not bring hot drinks into the baby's rooms.

What happens when my baby goes to the Unit?

When your baby first enters the Unit, they will have a physical examination and may require blood tests. The treatment your baby receives will be discussed with you by the doctors and nurses caring for them. You may be asked for special consent for certain procedures - if you are unsure of what the tests or words mean, or need reminding, do not be afraid to ask.



For most people the world of the Unit can be a very alien place, and it can take a while to adjust. There is a glossary of commonly used terms at the back of this guide to help you become familiar with all of the new words you will be hearing, and the staff you will be meeting.

What happens when I am discharged from the Postnatal ward?

You may not want to leave the postnatal ward after the birth of your baby. Your body will be experiencing a lot of changes, particularly hormonal, that may make you feel quite sad and weepy at times. This is quite normal and is sometimes called the day three blues.

Home may be a lot quieter than the hospital. On the postnatal ward you can't help but hear and see the other babies crying, which reminds you that your baby is not with you. Being at home could give you time with your family to relax and recover from the birth.

When you leave the hospital for the first time after the birth of your precious baby, you may be anxious for his well-being and care. You can phone the Unit whenever you wish - day or night.

What are all these emotions?

Women may have strong emotional feelings when they give birth. Having a baby in the Unit only intensifies these feelings. Maybe you have feelings of worry, shock and guilt. Questions like "Why my baby?" and "What did I do wrong?" may be racing through your mind. These are totally normal reactions.

Your obstetrician, GP, or midwife may be able to give you some indication as to why your baby came early or needed special care after birth. Some mothers will spend a long time in the antenatal ward expecting and preparing for an early delivery, others will suddenly go into a pre-term labour that cannot be stopped. Often the things that the mother did or didn't do while she was pregnant are unrelated to the baby's early birth.

Fretting over what may have been will not bring back the pregnancy, it will only make you unhappy.

Talking about your worries with your partner, a friend, midwife, social worker, GP, nurse or someone from The Neonatal Trust (a parent support group) can help you put the birth and having a baby in the Unit into perspective. It is often the most insignificant things that will worry you - these are best talked about openly.

Your jumble of thoughts, moods and reactions are perfectly normal to most parents who have babies in the Unit. After your baby has been in the Unit a while you may realise that all the other families who have a baby in the Unit share similar emotions. You are not alone.

How can I look after myself postnatal?

If you are recovering from a caesarean remember to follow the recommendations from the doctors, midwives and physiotherapists and you should be fit and well when baby comes home. If you had a general anaesthetic when you had your caesarean you may feel quite tired for several weeks after the operation. A rest in the day is often a necessary step to ensure a total and rapid recovery. It is important that you make and keep your six week postnatal visit with your doctor. You may want to use this time to talk about the birth.

How can my partner and support people help?

Having a baby in the Unit can be very stressful on a relationship and family. This is particularly the case if your partner has spent days, weeks or even months in the antenatal ward before delivering.

If the baby's mother had a rather traumatic birth experience and is unable to visit your baby, then you, as the baby's other parent, will be the one to spend time with your baby and keep your partner up-to-date with progress.

You may find that you are the one holding the family together. You may need to take on some less familiar roles such as washing, cooking, cleaning, looking after the other children, as well as continuing to work. It is important to remember that you may need to sort things out at home on behalf of your partner.

Families cope in different ways whether it be spending all your time between the Unit and postnatal wards, choosing to spend the time looking after the rest of the family, or choosing to have a bit of time out. These are all ways of coping with this new and unfamiliar situation.

Support each other in caring for your baby. The time spent in the Unit is only a very small part of your lives, and you will need each other when your baby comes home.

If you are a nominated support person who isn't the father of the baby, then you may be allowed access to the baby in the Unit and can relay progress to the mother. Nominated support people can be a grandparent, sister, brother or close friend. If you have been nominated, listen to the needs of the mother.

What do I do with my other children?

You may need babysitters and boredom-busters for your other children while you are visiting the latest addition to your family. Don't be nervous to ask someone to look after your other children. Neighbours, friends, grandparents, aunts and other relatives can be a great help at a time like this.

Childcare can be a good option for older siblings. There are childcare options in the vicinity of the hospital, however childcare centres are not free. If you are already receiving a benefit from Work and Income New Zealand (WINZ), you may be eligible for childcare support. Ask the social worker assigned to you for advice.

Tell your other child or children what to expect before they come into the Unit. Explain what the baby looks like and that he may have a lot of things, like tubes, attached to him. It may help to prepare them if you can show them an incubator (on the internet perhaps) and assure them that the way he looks is perfectly normal for little babies.

Sometimes children get upset by all the things attached to baby. Let them get used to these at their own speed. Many children are more accepting and less fearful of the Unit than adults are.

Sometimes role playing at home, with a play medical kit and a small doll in a suitable or pretend incubator might help your children to understand what is happening to their brother or sister. If there is a setback, don't hide it. Explain simply so they will understand, as they will feel more involved if you tell them about the baby's progress. They may even surprise you and ask "How much milk is baby having today?".

Please ensure your children wash their hands properly before entering the Unit. If they, or any other visitor has a cold, cough, or any other illness please leave them at home as these sorts of bugs can spread rapidly in the Unit.

What are the general visiting rules?

You may need to have a quiet word with your visitors and explain the NICU etiquette before they come into the Unit. Some things you can tell them are that staring at and asking questions about other babies in the Unit can increase the distress other parents are already feeling. It is also an invasion of their privacy and some mothers feel embarrassed and nervous if they are breast-feeding among lots of visitors coming and going. Explaining this to a friend or family member before they visit will be better than to be reminded by a nurse in the Unit, and less embarrassing for all.

You may also wish to show visitors photos and tell them a bit about your baby before they come in. A lot of people have no idea of what to expect and it can be a bit of a shock. They may need some time to adjust.

Each hospital will have its own rules about visitors and who can come in to see your baby or babies, and at what time. Please check what the rules are for your Unit so you can inform your family and friends before they come to visit.

You may not want certain people to visit your baby. It is normal to want to protect your baby from people who are just curious. Parents, and **only parents**, can make a list of people who can visit their baby without them. Staff members will not admit visitors unless they are on the list or come with a parent. Talk to a co-ordinator to arrange this. Staff members will only give information about a baby over the telephone to **parents**. Please do not give the Unit phone number to others.

Sometimes parents-to-be or the family of a baby are shown through the Unit. Some days you may not mind the people looking in, other days it might be the last thing you want. If you are feeling uncomfortable about people looking in on that day, speak to your baby's nurse or the associate charge nurse manager (ACNM).

How can the social workers help me?

There are social workers available to see families who have babies in the Unit. To speak with one of the neonatal social workers you could ask either the nurse looking after your baby, or your midwife while on the postnatal ward about contacting one of Woman's Health or Whanau Care social workers.

Having a baby in the Unit may cause social, emotional, financial, or practical problems in your life. It can often help if there is someone to talk to, or someone to listen to you.

Social workers can provide information and referral to resources available in the community, and offer supportive counselling in a number of areas such as:

- Adjusting to the changes in your life while your baby is in the Unit
- Feelings of loss, grief, anxiety, isolation and depression and how to manage them
- Stress

- Assisting with changed relationships between family and friends
- Accommodation for you and your supporters when you leave the postnatal ward
- Managing at home with other commitments
- Finances
- Work and Income (WINZ) information and referrals e.g. help with buying a breast pump
- Employment
- Family care arrangements
- Any other areas or resources you may need help with during your stay in the Unit.

During your stay

During your stay

Things you can do for your baby

There are many things that you can do for your baby as a parent. If you are unsure of your role in your baby's day-to-day non-medical care, ask the nurse looking after your baby what you can do to help. The nurse will be able to show you and explain how to do these cares, and will answer any other questions you may have regarding your baby's health and wellbeing.

Don't be afraid to touch your baby. At first you may feel nervous touching your baby because he is so small and looks so fragile. He won't break. Handling your baby with confidence will give him a sense of security. Your baby will benefit from gentle stimulation and contact. Ask his nurse for advice about how much stimulation your baby can handle.

Here are some ideas of what you can do for your baby:

- Love your baby and tell him so
- Gently touch him if you are able. The nurse will be able to show you how
- Call him by name (if he has one)
- Give him little pep talks. Tell him how well he is progressing and what you and his family have been doing. At first you may feel a little silly about talking to your baby, but it is a perfectly natural thing to do
- Massage him, gently, if you know how and are able to do so
- Tape small bright pictures, photos, cards or bits of wrapping paper on the outside of the incubator within eye range of your baby, he won't be able to focus yet like most newborn babies but he will be interested in the colours. Change the pictures regularly so that he won't become tired of the same one. Black and white patterns are supposed to be of interest to small babies.


KooGa

As your baby gets a bit older you could try:

- A mobile
- A small nursery music box for your baby to listen to during wakeful times
- A small soft toy left where baby can see it. The nursing staff may need you to put the soft toy in a plastic bag to limit the chance of infection, so please check with them first
- Reading to him.

Remember to ask his nurse before bringing anything in.

How do I go about doing basic cares?

There are basic cares you and your partner can do for your baby. The nurse will be able to show you how to do these. These cares include:

- Eye and mouth cares
- Changing nappies and soiled clothes
- Taking his temperature
- Cleaning the incubator
- Sponge-bathing your baby
- Feeding your baby, even if this means holding the syringe while 1ml of milk drips down the nasogastric tube.

To ensure your baby's safety, **only** nursing and medical staff are allowed to take your baby out of, and return him to, his incubator.

Maybe you feel as though you could never feel comfortable touching, holding or even bathing such a small human being. Set yourself small daily goals such as holding the nasogastric tube when your baby is having some milk, taking his temperature the next day, wiping his bottom the following day, moving gradually through the parent-craft skills until everything comes easily and you are an expert!

Take it slowly, Do one thing (sensory input) at a time. Go at your own pace, your baby's nurse will let you know when he needs time out. With time you will recognise his time out cues yourself.

Premature babies sleep for about 22 hours a day when they are first born, and for some time after. **Try really hard not to disturb him when he is sleeping as this is when his body is growing.** You will remember when you were pregnant that your baby's movements weren't concentrated into a two hour block, but were broken into short bursts of activity over the day. Your premature baby will be like that in the incubator too.

Try to be there when he has his wakeful times. The nursing staff will be able to tell you when this is from his 24 hour chart. Occasionally these wakeful times occur at 3 or 4 am! This isn't the most convenient time for many people!

A premature or special care baby has an immature and extremely sensitive nervous system. Sometimes even the gentlest of things will be too much for him, even a cuddle, gentle rocking, touching or soft talking. Then he may try to give himself some time out.

He may show he is over tired by:

- Screwing up his face
- Spilling (vomiting a little, not related to feeding)
- Hiccoughing
- Stiffening his arms and legs.

You may need to slow down or stop what you were doing. Remember that being very soft and gentle will keep your baby calm. Most full term babies thrive on stimulation, but for a premature or special care baby too much stimulation may be overwhelming. Ask his nurse if you are concerned about how much stimulation your baby can cope with.

What are kangaroo cuddles?

Kangaroo care is a way of cuddling your baby. In past years many paediatricians believed premature babies needed to be isolated to conserve their strength. Now inspiration has been taken from kangaroos and other marsupials that nurture their young in a pouch.

Once babies are well enough, they are taken out of their incubators and placed on their parent's chest, usually under their clothes, so the baby gets skin-to-skin contact and can hear the parent's heartbeat. This closeness provides a warm and soothing environment and helps the parent feel closer to their baby. Some studies suggest that kangarooing may result in physical benefits, fewer breathing problems, less energy-wasting fidgeting, faster weight gain and a more constant body temperature.

A lot of babies seem to improve when they're being held by their parents. They've been listening to these voices in the womb and even the smallest babies recognise their families, and babies who are happier tend to do better. Ask your nurse if your baby is ready for kangaroo cuddles yet.

How can I calm my baby?

Here are a few suggestions:

- Hold his hand and gently talk to him
- Give him your clean little finger to suck
- Stroke the back of his head
- Change his position to side lying or lying on his tummy with a clean nappy rolled up at his feet, it will give him something firm and secure to push or rest against. If you are unsure, ask your baby's nurse to show you good positioning. Again, only one activity at a time.

If your baby is too unwell for kangaroo cuddles or gentle stimulation ask your baby's nurse what you can do for him. Let her know you are interested in doing things for your baby.

Sometimes you may see someone else's baby move from an incubator to a cot, or drink more milk, or come off all the wires and tubes, or be breast-fed or bottle-fed before yours. Don't get too worried or depressed that your baby isn't keeping up with the others.

It is a difficult time for you. Remember that every baby is an individual and will do things at his or her own pace, even if your baby is twice the size of a baby who seems to be having a dream run.

More than one - multiples

Having more than one baby at a time can be hectic at the best of times, but having both in the Unit can give parents twice the stress.

Most twins are kept in the same room together but every now and then they may have to be separated in different rooms. Sometimes one twin may even be able to go home, or to your local hospital if you are from out-of-town, before his siblings.

It is possible to successfully breast-feed premature twins. You may like to discuss this option with your midwife, your babies' nurse or someone from the Multiple Birth Group who has breast-fed twins.

Call free on 0800 489 467 (0800 4TWINS) to contact your local Multiple Birth Club.

Feeding your baby

How do I go about breast-feeding?

If you have heard a rumour that you won't be able to keep whatever milk you may have because you have had a baby early, forget it. If you know you are going to have your baby early, talk to the midwives to organise the use of a pump and begin expressing breast milk soon after you have had your baby. If you don't have the opportunity to do this, talk to the midwife about breast-feeding and expressing as soon as possible after the birth of your baby.

You will need to express your breasts at least six to eight times a day to build up your milk supply. Colostrum, a yellowish first milk, is produced before regular breast milk. At first you may only get a few drops, and that's ok. A full term baby may only be getting a few drops at this stage too.

This colostrum is very important for your baby as it contains antibodies and is very protein rich. This can be thought of as your baby's first immunisation, it also lines the baby's gut to protect it from infection.

Research has shown that when women have their babies early, their breast milk has higher protein content than if the baby was born at term. This means that your milk is perfect for your baby in helping him grow. Ask your midwife or your baby's nurse for expressing advice. A hand-out on expressing is available in the postnatal pods and the Unit for mothers.

If you have a medical condition for which you are taking medication, discuss this with one of the midwives, nurses or doctors as they will be able to tell you if the drugs pass through to breast milk.

Remember to eat lots and drink plenty. As long as you are expressing at least six to eight times a day you should keep up an adequate supply of milk. Expressing once every two days is not going to keep your milk up in any abundant quantity. Expressing at night time is vital to maintaining supply. The maximum time between expressing should be up to six hours.

Should your milk supply decrease, do not despair and give up hope. With perseverance, determination and by expressing a couple of times during the night, your milk supply will increase. Hand expressing as a change from using a pump may provide your body with the tactile stimulation needed to stimulate the production of breast milk. There are hand-outs available with suggestions to help.

You also don't have to experience the sensation of let down or leaking breast milk to successfully breast-feed your baby.

There are breast-feeding DVDs available to watch in the expressing room and information pamphlets around the Unit. You can talk to a lactation consultant if you are worried about anything or need more information about breast-feeding.

What do I need to know about expressing breast milk?

Hand expressing or hand held pumps

Ask your midwife to show you how to hand express. Some people prefer to hand express and do so successfully for many months. The bonus to hand expressing is that it is cheap, no fancy pumps to buy and the equipment is extremely portable! Remember to wash your hands before expressing.

There are a variety of hand held pumps available, and as everyone is different the choice is really up to you. Some are a vacuum pump style, while others are operated by a trigger mechanism. Have a chat to your midwife, nurse or lactation consultation as to what they think are good brands of breast pumps.

Electrical pumps

Another popular method of expressing is by using an electrical pump. By the time you leave hospital you will have mastered the art of expressing and using the electric pumps located in postnatal pods and in the Unit. Electric pumps are fast and efficient but not everyone likes them. Again, check with your midwife, nurse or lactation consultant.

There are electric breast pumps on each of the postnatal pods, and they can also be hired from pharmacies or baby equipment shops. There is a list available with all of this information. Just ask the nursing or midwifery staff for a copy.

If it is within your budget you could also buy a small electric pump. There are many brands available and they can be purchased from most chemists or baby shops, and the Trust office in the Unit also has a good range.

Check with the Unit how they want you to go about expressing milk for your baby. There is an expressing room in the Unit that provides electric breast pumps and storage for expressing equipment.

How do I increase my milk supply?

To keep your breast milk in good supply you need to express regularly. If your milk is decreasing try expressing two hourly during the day for a couple of days. Don't forget to express at least once overnight, this is

important in maintaining and increasing your supply. Little and often should increase supply. If you are concerned about your milk supply speak to your midwife, lactation consultant or baby's nurse.

More ways to release and increase your breast milk include:

- Placing hot face cloths on your breasts for a few minutes before you express can help to stimulate the release of milk. Expressing after a shower or bath has a similar effect to the hot face cloths
- Drinking a herbal tea called Lactagogue tea may help increase breast milk. It is available from health food shops and chemists
- NaturoPharm Milk Flow tablets can also help, as can Blessed Thistle or Fenugreek
- There is a sheet available with various booster drink recipes in the milk room within the Unit
- Yeast pills or brewer's yeast drinks are good if you aren't allergic to yeast. Avoid all urges to diet excessively after you have had your baby
- Eat well and drink plenty of fluids like water
- Try to rest as rushing around doing non-essential things can reduce the amount of milk you make
- When you take your breast milk to the Unit tell the nurse caring for your baby that you have breast milk for your baby, as it is best to use fresh expressed breast milk (EBM) before frozen.

How do I store my expressed breast milk?

If your baby is able to feed, he will be able to use the milk as you make it and a little bit can be reserved for freezing. If your baby has decided not to eat for a little while (some babies are born too sick or their stomachs are too immature to digest milk straight away), you can store your expressed milk for later use. Please name and date the containers provided for your milk to be stored in.

If expressing at the hospital, **write your name and date on the containers** and freeze in the Unit's freezer straight away. If expressing at home, write your name and date on the container and freeze your breast milk at home. When you next visit the hospital, wrap the frozen milk well in newspaper or place in a chilly bin or a container suitable for transporting frozen goods and transfer to the Unit's freezer as soon as you arrive. Remember to put your milk in your freezer bag with **your name** on it!

You will be given a pamphlet on storage of breast milk both for home and hospital when you are discharged. Make sure you have this information before going home. You will be able to notice the colour change from the heavy cream yellowish colostrum to the thin bluish white of regular breast milk when you first express. Place the most recently expressed milk to the back of your freezer bag as this will ensure the colostrum rich milk is used first.

If your baby's need for milk is greater than your current supply, the Unit staff may discuss with you the need for your baby to be supplemented with an infant milk formula. For the majority of babies, tolerating infant milk formula is not a problem. If you or anyone in your family has an allergy to milk products, talk to your baby's nurse or doctor about this. If you don't want to give your baby formula or have your baby bottle-fed, then talk about this with the staff.

What do I need to know about bottle-feeding?

If breast-feeding doesn't happen for you and your baby, don't worry about it. This is a very stressful time and trying to express or breast-feed under such circumstances can sometimes be just too much. While breast milk is the best food for your baby not all mothers want to, or are able to, breast-feed.

If you or your baby are not happy with breast-feeding, the stress involved with persevering may be too much heartache for both of you. It is your decision whether to breast or bottle-feed. If you have decided to bottle-feed your baby you shouldn't feel guilty that you aren't giving your baby the best. A happy and contented environment is what is best for your baby, and that means a happy mother.

Some people believe bonding only happens with breast-fed babies, but this is untrue. Mothers bond beautifully with bottle-fed babies too.

Infant milk formulas provide all the necessary vitamins, nutrients and minerals that a new baby needs for healthy growth and development, though doesn't contain the protective factors that breast milk contains.

While you still have your baby in the Unit, you can ask for advice about which formula to use and how to make this up. Staff can provide you with a current Ministry of Health pamphlet on the correct way of making the formula. Ask friends, family and nursing staff who have bottle-fed, which equipment they have found to be appropriate for their babies and why, or discuss it with the homecare team.

You may want to discuss bottle-feeding and formulas with your baby's nurses and doctor, especially if there are family allergies with milk products.

To feel confident about feeding your baby it is important to understand the principles of making and storing formula before your baby comes home. There is an excellent video in the Unit on the principles of making and storing infant milk formula.

Keeping a record of your baby

It is a great idea to keep a record of your baby's time in the Unit. The photographs and tiny foot prints will show everyone later how small your baby once was.

If you want a record of your baby's progress through the Unit, try to take lots of photos, your child will be interested to see them when he is older. Take pictures of the whole incubator and its surroundings. Some people hold a pen or a ring next to their baby to show the size difference. Photographs of significant events such as the first hold, first breast or bottle-feed, first bath or first hold without attachments are a testimony to the progress your baby is making.

Remember to note the date on your photos, or note what he was wearing on the day you took that particular photo so you can match them all up later. Photographing with a flash will give you better results.

Some parents find writing down their thoughts, worries and dreams about their baby is very helpful at working through the stress of having a baby in the Unit. Making daily notes of how much your baby weighs and how much milk your baby is drinking can be a nice way of seeing that although the progress may be painfully slow, there is progress. Ask your baby's nurse if they can help you with the nursing and medical notes so you can write them down too.

Providing clothes for your baby

The Unit should have clothes, quilts and blankets for use while your baby is there. If you would like to buy clothes for your baby, ask the Unit staff where the clothing stores are.

Sometimes it is nice for you and your family to see your baby in their own clothes. This helps you to identify your baby as belonging to you and your family, and not as a baby on loan from the hospital who just happens to have your name on the incubator.

It is a good idea to name anything you leave with your baby and tape a notice on the outside of the incubator informing staff that your baby is wearing his own clothes. This may prevent his clothes inadvertently ending up in the Unit's washing, and may deter them from sprouting little legs of their own and wandering off. The Unit cannot take responsibility for lost clothing.

If you become attached to a tiny pair of booties, a wee hat or other clothing that your baby wore but belongs to the Unit, you may like it as a souvenir of how small your baby was. Talk to one of the nurses about exchanging it for some clothing you can provide for the Unit.

Volunteers make the duvet covers, quilts and bed rolls. The work of these people gives your baby, and you, a more comfortable and attractive environment. Please think about the next baby that needs the clothing and blankets. If you find that an item of clothing made it home with your baby inadvertently, you can return the clothing to the Unit.

Where can I get knitting or clothes for small babies?

The Neonatal Trust sells a knitting book called *Knitting for Prems* that contains patterns specifically designed and measured to fit our small bundles.

It is very important that knitted items should be 100% wool as nylon and acrylic can cause sweating and dry skin.

You could try and recycle unused clothing into very cute baby clothes so they need not be an added expense at an already financially and emotionally stressful time.

Thinking ahead to when you go home

Rather than having a set weight at which babies go home, each baby is assessed individually. Your baby must meet the following criteria before he can go home:

- He is breathing on his own
- He is able to feed all meals from either the breast or bottle
- He can maintain his own body temperature
- He is gaining weight regularly
- The consultant is happy for him to go home.

Often, if you are from out of the area, prior to going home your baby is likely to be transferred to the Special Care Baby Unit (SCBU) or children's ward of your local (home town/city) hospital. This is a very good transition from the Unit for your baby and yourself. It allows more parent involvement in your baby's routine and can be helpful to make his transition from hospital to home a little easier.

After the shock of your baby's need for care in the Unit has worn off a little, you may relax a fraction and get into a routine with your baby. Give yourself time, we all know it's really difficult. Think positively, and take each hour as it comes.

Being involved with your baby's life in the Unit may be beneficial for you and your family. You may find it helps you towards accepting the circumstances surrounding your baby's birth and with your future family life.

Having a baby in the Unit may be emotionally draining. Don't forget your needs. You do need some time out as it is hard to be a super parent. It is important for you, your family and partner to spend some time with each other before baby comes home. Going out in the evening or taking the afternoon off just to relax at home can replenish your inner strength.

Are there CPR, safe sleeping and car seat positioning classes?

Most Units run classes in CPR, safe sleeping and car seat positioning. Check when these classes are being held in the Unit (see the notices in the Unit or ask your baby's nurse when these are held). Parents of babies in the Unit are strongly recommended to attend these classes, which cover safety aspects of care for your baby, before they are transferred to their local hospital or before being discharged home. Other people who are going to look after your baby may like to come and learn infant CPR also. If you want to bring family or friends please speak to the homecare team. You may attend the class more than once, again please check with the homecare team.

Are there any books I could read?

Often parents **need** to find out as much information on pre-term babies as possible. This is a really good positive action. The Neonatal Trust has an excellent selection of up-to-date books relating to pre-term and special care babies and associated issues. If you would like to borrow a book, inquire at the Trust office. The public library has a few books on premature and high risk infants, and your local branch librarian can help you find these.

Do I get to spend time in the Unit learning about my baby, before going home?

The Unit has limited facilities for living-in mothers. If your baby has reached the stage where he can breast-feed and the feeds at the breast are being increased, mums may be asked to come and live-in, in the parents rooms. Bed and linen are provided but you will need to provide your own food. There is a fridge for storing food and a microwave for cooking or heating food in. When rooming-in, you will be required to get up and feed your baby each feed. Showers and toilets are also between the rooms.

Going home

Going home

Rooming-in before going home

One or two nights prior to being discharged you may be asked to come and stay in your baby's room. You will be responsible for full care of your baby but a nurse will be allocated to you and staff are available if you need advice. Your baby will be weighed each day to ensure he is gaining weight and when you, the homecare team and the consultant are happy for your baby to be discharged, you will be able to go home.

Survival tips for slightly anxious parents

Taking your baby home from the security and constant monitoring of the Unit may be the hardest thing you have ever done. Here are a few survival tips to help you out at home between discharge and the next paediatrician or specialist out-patient visit:

tip When you have a baby, everyone you know or have ever met before will give you advice on all you ever need to know about babies. This is just something that comes with the territory of becoming a parent. If you have concerns, let your paediatrician, midwife, specialist, GP, Plunket nurse or neonatal homecare nurse know. Don't feel you are being over-anxious about your baby. It is their job to answer your questions.

tip Try to ignore tactless comments about your baby. Some people may not even be aware that they are making hurtful comments when they first see your baby. You can't explain in a second to a stranger the experience you and your family have been through.

Life at home

Once you are home you need to be aware that special care and pre-term babies are very susceptible to any bug that is going around. It is important to turn away visitors who have colds or have recently been ill. If you are breast-feeding your baby will receive some immunity to bugs through the breast milk, but this immunity will stop about four weeks after you stop breast-feeding. Your baby can generally be immunised at the normal ages. Talk to your GP, Plunket nurse or neonatal homecare nurse about this.

Encourage hand washing before touching your baby, especially after doing mucky jobs like gardening and changing nappies. You are probably more aware of germs and hygiene because you have just spent a length of time in the Unit where germ awareness was one of the key issues. Gradually your concern over stringent cleanliness will relax. The same goes for going into a panic if you hear bells and beeps similar to those in the Unit.

Be prepared for a wakeful baby. Remember all your baby has known is 24 hours a day of bustle, sounds and light. In the Unit, as the baby gets closer to going home, the nurses try to differentiate between day and night. This makes the transition between hospital and home easier for the baby.

You may find it useful to keep stimulation at night to a minimum to distinguish between day time and night time. Try talking quietly but only when necessary, and keeping the lights dimmed.

When your baby comes home he may be too unsettled to manage with total silence at first. Soft music or a talk programme on National Radio may provide comfort. Your baby may also feel more secure with a dim lamp on in the room. Your baby can usually be gradually weaned off this over a few weeks.

Life does get easier — just take one day at a time.

Breast-feeding

Taking your baby home from the Unit fully breast-fed is a substantial achievement, as stress can be a major factor in inhibiting lactation. If you have managed to keep your milk flow for the length of time your baby has been in the Unit, well done!

By now you will have realised that it is expressing six to eight times a day that keeps your milk there. For some mothers, keeping up breast-feeding at home is often harder than when baby was in hospital. At home there isn't the same amount of people offering encouragement, your work load has increased, and you will probably have discovered that you have to get up in the middle of the night several times to feed or just check on your baby.

Remember that one of the keys to fully breast-feeding is frequent sucking at the breast by the baby. This stimulates the production of more milk. In other words, the more the baby is put on the breast to feed, the more your milk supply will build up.

Don't be worried if you don't have the feeling of let-down or the sensation is not as strong as it may have been in the past. This doesn't mean there is not enough milk for your baby. You may not experience leaking, but this is not essential to successfully breast-feed your baby.

Babies who were born early are usually successfully feeding by two to six weeks after the time they were supposed to have been born. As your baby gets older and grows larger, the demand for milk will increase. Remember that as your baby sucks longer and more often your milk supply will increase.

How do I increase my breast milk with a breast-fed baby?

When your baby is having growing spurts, you will probably notice an increase in demand for milk (both breast and bottle-fed). These occur some six weeks after the baby's due date and every three months from then on!

Eat for your appetite. Eat healthy foods. Rest.

Try not to over exert yourself, especially in the first few weeks after your baby comes home. Some jobs around the house can be ignored for a time. It is more important to spend time with your baby than to be too house-proud.

Drink plenty of fluids such as water, milk and juice. Drink according to your thirst. Reduce your intake of tea, coffee, coke or fizzy drinks, the caffeine may irritate your baby as it will get through to your milk. This is also true of some compounds found in dairy foods, alcohol, onions, garlic, cauliflower, cabbage and strawberries. You should experiment a little to see if your baby can tolerate these in your milk. It takes 24 hours for whatever food substance you are concerned about to appear in your milk.

Signs of intolerance to substances in your milk include:

- A fussy baby
- A rash on baby's bottom
- A few spots on baby's face.

Smoking cigarettes can decrease the amount of breast milk you produce and the toxins found in cigarettes are found in the breast milk of women who smoke.

If you want to find out more about increasing your breast milk then you can read *The Breastfeeding Mother's Guide to Making More Milk* by Diana West, IBCLC, and Lisa Marasco, M.A., IBCLC.

Is my baby getting enough breast milk?

This is probably the most fretted over question, both in the Unit when you first start to breast-feed, and when you get baby home. You can be sure that your baby is well nourished if he:

- Is content most of the time
- Can last from one to four hours between feeds
- Has about five to six or more wet nappies a day
- Gains an adequate amount of weight over a two week to one month period
- Is alert with good skin and muscle tone.

All babies are different, some will only have four feeds a day and be happy and some babies are hungry babies and like to feed a lot.

The neonatal homecare nurse, Plunket nurse or GP's practice nurse may be able to help you out with breast-feeding problems.

Bottle-feeding

Before your baby comes home you may have decided that you are going to bottle-feed. You probably have bottles and formula ready and are waiting for the big day. Infant milk formulas provide all the necessary vitamins, nutrients and minerals that a new baby needs for healthy growth and development.

Remember that your Plunket nurse or neonatal homecare nurse is able to advise you, should you require any assistance with making formulas, sterilising bottles, and knowing when to increase the amount of formula in the bottle.

There are a few points that must be followed to assure a smooth road. Always wash your hands before handling any of the equipment or milk products to ensure that they are free of germs.

How do I sterilise bottles?

Correct sterilising is really important. There are three methods of sterilising bottles:

1. The first method is boiling the submerged bottle and equipment for 10 minutes in a pot of plain tap water.
2. The second method of sterilising is by using a chemical sterilising solution or tablets. They can be bought at the chemist or supermarket. Make sure that all of baby's bottle equipment is totally submerged under the water. Chemists sell specially designed tanks for keeping bottles in while they are being sterilised. Follow the preparation instructions on the packet of sterilising solution carefully. It is important to use the correct quantity or else the bottles won't be sterile. Once the bottles have been sterilised they can be kept in the fridge until they are ready to use.

3. Thirdly, steamed microwave sterilizing machines can also be purchased.

How do I make up formula?

When making up the formula, **follow the manufacturer's instructions exactly**. This is very important. Never guess at the quantities when mixing up the milk as this could make your baby quite sick. If you overdo quantities it is like feeding baby great thick shakes, if you underdo quantities it is like feeding him thin weak tea.

Always use cooled boiled water to mix the formula, hot water will destroy some of the delicate balances of vitamins and minerals in the formula.

Always store the made-up milk in the fridge, or make up each feed as required by the baby. Don't keep a bottle warm or keep milk to reheat later. If baby goes to sleep half-way through a feed, throw the remaining milk out. Bacteria find warm milk a nice environment to grow in and this could result in your baby getting very sick.

To feed your baby cold or coldish milk is not harmful, but most babies prefer warm milk. After warming the bottle of milk in a container of hot water for a minute or so, test the temperature on the inside of your wrist. It should feel just warm. **It is best not to heat bottles of milk in microwaves, as food and liquids continue to cook for a few minutes after the microwave has been turned off.** What may at first seem just the right temperature for baby soon turns out to be too hot and could burn him.

Milk should drip out of the teat a few drops per second. You can enlarge a small hole with a red hot needle. Throw away a teat with a hole that is too large, as baby won't get the comfort of suckling because the milk will rush out too quickly.

Made-up infant milk formulas have a fridge life of 24 hours. Once the formula milk tin has been opened it has a limited life also. Check the expiry date on the back of the tin, especially if you use the formula milk occasionally. If the milk powder is off, it may give baby a tummy ache and diarrhoea.

Many bottle-feeding mothers worry that they are not going to be able to bond with their baby. Giving plenty of love and cuddles when feeding, just like a breast-fed baby, is a good way to start!

Remember that a bottle-fed baby can be fed by more than one person. Not only does this give you a rest, but your partner and other family members may enjoy feeding the baby.

It is important to stop, sit down and rest while you are feeding and enjoy your baby. This is really important in the first few months of having baby at home and adjusting to life with a full-time child.

Feeding in general

When you take your baby home you may have to feed him more often than you would feed a full term baby, as his stomach is a lot smaller and so can only take little amounts.

It is important that you hold your baby in a comfortable position when you are feeding. Support baby's head and neck with one arm and rest baby's body on your lap - at first you may need a pillow on top of your lap until he grows bigger. This is a good time for eye contact with your baby and for gently talking to him. If your baby is a particularly spilly baby you may have to be quite gentle with him during and after a feed. Sit him up slowly or the last feed may come back at you.

Remember to alternate which hand you hold the bottle in for feeds (just like alternating left and right breasts when breast-feeding) so your baby sees your left and right side.

Your baby may have a bowel motion (poo) after every feed if he is breast-fed. They are usually yellowish and soft. Some breast-fed babies pass a bowel motion 14 times a day and some only pass one in 14 days. Both are normal. If baby is formula fed the bowel motions will be regular, soft, brown, and have a definite shape to them. If your baby passes hard tiny round raisin-like poo or has frequent watery ones, you should go and see your GP or practice nurse as it may be a sign of something else such as a tummy bug or constipation.

Colic

Occasionally you may find your baby is rather fussy. Fussiness generally peaks at three to four months of their adjusted age (the age they would be if they were born on time). This can mean that your baby may have colic.

Colic is most common in the late afternoon until as late as 1 am.

Signs of colic include:

- Grizzling
- Clenched fists
- Legs being drawn up into the stomach
- The need for frequent sucking.

There is no cure for colic and there is no real reason why some babies are colicky and others are not. If you are breast-feeding your baby a possible answer may be in the food that you are eating. Some foods may affect your milk, and in turn, your baby. Some babies don't mind all the interesting foods that mum eats and may never have a problem with colic. Use your own detective work if you think your baby doesn't like some of the food you eat.

Bottle-fed babies can get colic too. There are many potions and remedies available. Before a feed, of either bottle or breast, the recommended dose of an anti-colic formula can help. Ask your GP or homecare team nurse first.

Some people carry their baby in an odd way and find that this can calm the baby and relieve the symptoms of colic. Carry your baby draped over your arm, with his head in the crook of your elbow and one leg on either side of your arm, tummy resting on your arm. Dancing gently and rocking your baby can help too, as can giving baby a warm bath, taking baby for a drive in the car, and rocking baby in the pram.

Crying babies

Babies do not cry without reason. It is their only way of letting you know that something is upsetting them. If this pattern continues even after you have eliminated most of the common causes for baby's grumpiness, seek advice from the neonatal homecare team nurse, your GP's practice nurse or Plunket nurse. Some people think that you will spoil a baby by cuddling them too much. This is nonsense. How can you spoil a baby by comforting them when they are upset?

How do I stop feeling down when my baby cries?

A crying baby makes a very distressing sound, especially if it is your baby. Pre-term babies tend to have a higher pitch cry than full term babies. This high pitch can be distressing to whoever is looking after him. Shouting at the baby to stop crying is guaranteed to make the baby cry even more. Babies respond to the tone of your voice, rather than the words spoken, so speak gently.

Shaking the baby in frustration is an extremely dangerous thing to do. Blindness or brain damage can result. **Never shake a baby**.

Don't be afraid to ask if things are getting you down. Other mothers in a similar situation have used these strategies when baby's crying is getting them down:

- Ensure that your baby is placed safely in the cot, shut the door, go into another room, turn the radio up, take a shower, or sit outside for a few minutes
- Walk baby around the house
- Rock baby backwards and forwards in the pram
- Take baby for a walk or car ride - even if it is midnight
- Ask a friend or relative to come over and give you support or a needed break
- Call the Plunket 24 hour help line toll free on 0800 933 922.

Most parents who have experienced a crying baby will tell you that it is a nightmare at the time, but the baby does grow out of it.

Growth and development

When you leave the Unit with your baby you can ask the homecare team for a growth chart which is especially designed for premature babies. You can fill it in as you get updates on your baby's weight, length and head circumference. This can be stapled into the back of your Plunket book. Ask your Plunket nurse to continue filling it in for you.

A premature baby will not reach developmental milestones at the same time full-term babies do. Remember to always look at your own baby as an individual. Try not to compare him to other babies of the same age, either full-term or premature. No two people are the same. Even premature twins can develop at different rates.

Generally, babies must complete the 40 week gestation period and then after this time they will smile, sit, and crawl, usually in the same time frame as a full term baby. In other words, parents with a baby born at 30 weeks will have a wait of 10 weeks until the baby has reached his 40 weeks and then they can begin to watch for a smile after another four to six weeks.

Some people cannot understand the normal delays that premature babies have. You may have to remind your friends and relatives that your baby arrived before his due date and so he is still catching up. Often a lot of other things click with a baby at his due date, such as breast-feeding. Your baby's weight gains and growth on the Plunket chart look much better when you remember to count back the number of weeks your baby was early. This usually puts the growth in the blue band instead of way below it.

Your baby's paediatrician, the neonatal homecare nurse and the neuro-developmental therapist are the experts in the growth and development of a pre-term baby. Don't be shy to ask questions at your next appointment.

Stimulating your baby or introducing new activities has to be done slowly, one thing at a time, just as when baby was in the Unit. Watch for the distress signals like looking away, fussing, crying, arching his back, hiccupping, non-feeding related vomiting, or stiffening arms and legs.

If your baby shows any of these signs, slow down the pace of one activity when stimulating your baby and stop all others. You may, for example, rock more slowly, stop talking and break eye contact. This gives baby a chance to relax and to slowly build up the coping skills that are important for his healthy growth and development.

A happy, relaxed baby may show some of the following signs:

- Good skin colour
- Bright and alert eyes
- Can make and hold good eye contact
- Arms and legs are relaxed and move smoothly.

Try not to handle your baby too much. This helps to avoid over-stimulation. Over-stimulated babies can be tired and cranky. More importantly, know your baby and his moods and patterns, remembering that they change as he grows. This is where all that time sitting with him in the Unit pays off. If any of the signs of a cranky baby persist and you would like reassurance talk with the neonatal homecare nurse, Plunket nurse, or your GP's practice nurse.

What is the long-term outlook for my baby? Is he really ok?

These are some of the **big** questions parents ask. Most premature babies develop normally, and only a small percentage have long-term problems. If you are concerned about your baby, the paediatrician will be able to talk with you about this.

Premature babies aren't always little - there have been some quite famous pre-term babies: American writer Mark Twain, scientists Albert Einstein and Sir Isaac Newton, British politician Sir Winston Churchill and Russian ballet dancer Anna Pavlova.

Being told again and again by your baby's doctor that everything is ok sometimes is just not enough. There always is the haunting question or doubt in your mind that is only answered when he says his first word, crawls or walks.

When he is a loud and active toddler, or a teenager or adult, you will find it hard to believe he was once so fragile, and vulnerable, unable to live on his own.

Some parents can become too protective with their premature baby, even when they have been assured that everything is alright by the doctor. This can interfere with the baby's normal development. It can even alienate the child from the rest of the immediate and extended family if they are protectively swaddled against siblings and their peers.

Set realistic progress goals and skills for your child. Use the advice and recommendations from your paediatrician, neuro-developmental therapist and other health professionals you may see. They will be able to give some indication as to how well (and realistically) you are working with your child in encouraging him in his progress.

Experts believe that the single most important factor in the development of premature infants is their home environment. It is your attention and caring that will help your child develop his potential.

Clothing and nappies

One of the most important things for any new baby is warmth. This is even more so for a premature or small for-gestational-age baby.

Your baby will have been helped to keep warm by incubators and being well wrapped up in cots, and although he is more mature when he goes home, he may still have minimal fat reserves beneath his skin. This means that he is prone to losing heat very quickly. Be aware that overheating is dangerous also!

What is the best way to dress my baby?

It is best to use natural materials such as cotton and wool. These materials let a baby's skin breathe i.e. absorb slight dampness from crying or nappies, helping the skin to stay dry. It is recommended that pure wool be used for hats, booties and singlets, as well as cardigans and jackets.

A baby going home in winter may need a cotton singlet and then a woollen one on top, plus a gown or stretch-and-grow suit and a cardigan and booties. Booties are best worn on the inside of the feet of the stretch-and-grow suit. If wearing a gown in winter a baby may need two pairs of booties on for extra warmth.

Hats are very, very important for any baby, as a lot of heat is lost from the head. A baby that is quite small when ready to go home in winter may still need a hat on most of the time he's awake, until he adjusts to home temperatures and gets a bit bigger.

When you go out with your baby to begin with, it may be wise to put another hat on if he wears one all the time at home. Otherwise it can be like taking him out without one on at all. Alternatively, a cuddly wrapped around him will add another layer. Summer babies will probably need a woollen hat on at first too, at least outside for a while; it can always be taken off if baby gets too hot. SIDS recommends no hats in bed or when he is asleep.

This may sound like a lot of clothing, but remember that babies cool down quickly. If you feel your baby is getting too warm you can always remove a layer, which is quicker than trying to warm up a baby that has become cold.

Summer babies still need careful attention as they too cool down more quickly than their full term and bigger friends. A woollen singlet and a long sleeved and legged stretch-and-grow and booties will probably still be necessary at first. Don't be concerned if your baby appears overdressed compared to everyone elses baby. Remember how important his warmth is to his health and growth.

Ensure that his clothing has room to spare for all his limbs to move freely. Remember not to jam his wee feet into bootees or crawlers that have become too small.

As your child grows older it is still wise to keep him in woollen singlets during cold times, including nights in the cot, as this will help to guard against colds.

What do I need to know about cloth nappies vs disposable nappies?

Nappies are not a particularly cute aspect of your baby's wardrobe but they are an essential part. When you take baby home and if he is still rather small, you may like to consider making some small nappies. Cut down a cloth nappy to size and hem so that it doesn't unravel in the wash. This makes a nice prem size nappy. If you don't really want to do this, see if you can find some old nappies that are a bit thin. These will be nice and soft on baby's skin and can fold down without being too stiff and bulky.

Washing nappies will be something you will have missed out on so far. It is preferable to soak the nappies first in water, a nappy rinse solution or good old-fashioned bleach, which whitens and disinfects like the nappy rinses. Getting nappies ready for the nappy bucket requires you to scrape off the poo (an old knife is good for this) and then give the soiled nappy a quick scrub with an old dish brush.

If you are using a rinsing solution you won't have to add soap powder during the washing process, as this counteracts the soaking solution. If you do use washing powders ensure that the nappies are well rinsed.

Nappy rash can be a bit of a problem for some babies. Zinc and castor oil cream, bought from the chemist or supermarket, is a very good preparation for red bottoms. Often it will prevent or fix a nappy rash. Curash powder is also very good. Changing your baby's nappy when wet or dirty is another way of avoiding rashes. Sometimes a stubborn nappy rash may be thrush (Candida). It is best to show this rash or any rash with broken skin to your GP or Plunket nurse and they will be able to tell you the next step.

Disposable nappies are available in a range of sizes and some are specifically designed for girls or boys. They have the advantage of easy fitting, no laundering and are ideal for travelling. They can work out more expensive than cloth nappies but they can be more convenient for many parents.

Health information

Don't feel you are being over-anxious about your baby's health and well-being by asking lots of questions. Remember, you know your baby, and if he isn't his usual self, or you think he doesn't look right, then trust your feelings. It usually takes a phone call to either the practice nurse at your GP's rooms or the Plunket nurse to set your mind at ease or confirm your suspicions.

Can I smoke around my baby?

Do not smoke in the same house or car as your baby. Very low birth weight babies are extremely susceptible to respiratory problems and passive smoking is harmful to the health of your baby. Do not allow anyone else to smoke in the same house as your baby. Remember that no one's smoke is more important than your baby's lungs. A discreet sign on the outside door saying "Thank you for Not Smoking" usually does the trick, and then the question doesn't arise. However, some visitors can be insensitive to your baby's precious lungs and may need reminding. All babies and children need fresh air. When you come to the Unit you will be given the opportunity to be part of a smoking cessation programme. If you wish to quit smoking, ask to speak to the smoking cessation coordinator in your hospital, they can provide you with smoke-free signs along with information and help on giving up smoking.

How do I manage medication for my baby?

If your baby comes home on any medication (including vitamins, iron, supplemental oxygen) **do not stop, change, or alter** anything without instructions from the paediatrician who prescribed the medication. The neonatal homecare nurse will be able to discuss your concerns about the medications your baby is on. If you are at all concerned about your baby, contact his paediatrician or family GP. Usually a phone call can ease a worry.

tip If you get some of the iron supplement on some of the baby's clothes, try getting rid of it by squeezing fresh lemon juice and a sprinkling of table salt on the stained piece of clothing, then wash as usual.

Why does my baby need an apnoea monitor?

Some babies will go home from the Unit with an apnoea monitor because they have not become expert at remembering to breath. An apnoea monitor is a small box which is attached to the baby's tummy by a lead. This monitors the rate of the baby's breathing. When the baby's breathing drops below a certain rate (number of breaths per minute), or stops altogether, the baby has had an apnoea and an alarm goes off. This alarm tells you, or the caregiver, to hurry up and lift baby out of his bed, pram or car seat and have a look at him. Lifting the baby up is often enough to restart or stimulate breathing.

You and your family will soon learn to live with the apnoea monitor. The apnoea monitor picks up the movement of baby's breathing, so make sure that you can hear it at all times. It is important that you know how to perform CPR. See previous information about CPR classes.

Some people buy or borrow an intercom system. This can make going out to the clothes line less stressful, as you will still be able to hear the alarm clicking away. There is a large range of intercoms available. Some run on 9 volt batteries and others run on mains power. You can purchase intercoms from electronic equipment shops or baby equipment shops. It seems that intercoms that are in the higher price range have a better signal receiving range than the cheaper models.

You must be able to hear the apnoea alarm if it goes off. This may mean that you won't be able to be in another room with the TV up loud. Some household tasks like hanging out the washing, using a sewing machine and vacuuming are almost impossible to accomplish while still being able to hear an apnoea monitor alarm. Fortunately, those tasks can all wait until your partner or a friend is around to help or listen!

The neonatal homecare nurse or paediatric district nurse is available to answer any questions about the monitor and to revise your resuscitation procedures.

Getting a babysitter may be difficult. Not too many people are willing to babysit an infant with an apnoea monitor. It is important that whoever you choose is comfortable with the apnoea monitor and knows infant resuscitation.

Anyone can go to the Plunket or Karitane family unit in their area and receive instruction on how to resuscitate an infant. Ask your Plunket nurse for further details.

Knowing when to stop putting the apnoea monitor on the baby may be difficult for some families. The familiar reassuring sounds of the clicks can be hard to part with. Some families go cold turkey from the apnoea monitor, others need to wean themselves off it gradually.

Follow-up clinics and the health professional team

When you have an appointment with any of the health professionals mentioned below, it is practical to have a list of questions, problems, or worries to ask them. Nothing is worse than getting home and remembering that you forgot to ask about a little problem that has been niggling you for weeks.

Who are the neonatal community nurses or homecare team?

The neonatal homecare team provides expert follow-up home visits by a nurse experienced in the care of pre-term and special care infants for up to three months after discharge from the Unit, depending on your baby's requirements. Ask at the Unit how this works in your region.

When does Plunket get involved?

Visiting the Plunket nurse is voluntary. Your areas Plunket nurse usually comes and does one home visit once you are discharged from the homecare team. After that you will normally visit the Plunket nurse at your local Plunket clinic. For some people these visits may not seem as serious as the check-ups at the hospital, but Plunket is a good regular weight, height and advice station. Plunket nurses have a wealth of knowledge and practical advice regarding the health and well-being of babies and children.

Plunket can be especially useful for first-time mums as they organise play groups for babies born around the same time. These groups can be good for you too, especially if this is your first baby. At first these groups may seem a bit harrowing, especially when you have such a small older baby compared to the others in the group. But, remember that your baby isn't going to be two kilos forever, and if you strike a good group you may continue to meet when baby becomes a toddler, school age or older!

It is good for your baby to spend time with other babies his age, even if they aren't the same size - yet! Ask your Plunket nurse about facilities like Karitane Units and new mothers groups.

What is a neuro-developmental therapist?

The visiting neuro-developmental therapist (the lady with the toys and exercises) will routinely visit most babies born under 1250gms of weight or those born before 30 weeks gestation. She may also visit other babies who are heavier in weight but have had problems that may affect their development.

Visits will be at your home and the therapist will advise you on what developmental milestones to look for. She will also give you suggestions and ideas on how to stimulate your baby's progress in all areas of development. This is an early intervention service for you and your baby which is available up to the age of five years.

The visiting neuro-developmental therapist is referred to you by the Unit or from regular follow-up paediatric clinics.

Why is it important to have medical follow-ups?

Attending follow-up appointments with the paediatrician, surgeon, audiology clinic, ophthalmology clinic and any other specialist your child may have collected along the way, is very important. During these check-ups the health professional can assess your baby and answer any questions you may have about his progress. The benefit to your child of these seemingly never-ending appointments is that the professionals can detect and identify any specific problems your baby may have developed, and they can begin the appropriate treatment as soon as possible (or set your mind at ease by giving you the all clear). Early intervention is best.

What happens after we get discharged?

After you have been totally discharged from the regular follow-up care of your child by the paediatrician (this may take anywhere from a few weeks to a few years), your family GP can refer you back to any of the health professionals you have seen within the hospital, should the need arise.

Postnatal depression (PND)

It is hard to know if you have PND. True PND can be present by six weeks after the birth of your baby. When you visit your obstetrician, GP or midwife for your six week check-up, you may want to discuss how you are feeling. Worry and anxiety, especially at first, is common for parents when they finally take baby home from hospital. Both men and women can become depressed over the stress of having a baby in hospital or the responsibility of having to care totally for a baby on their own.

Signs of PND and general depression are:

- Extreme anxiety, especially over the baby
- Constant irritability particularly towards your partner and your other children
- Profound guilt over your reactions
- Loss of appetite
- Poor concentration
- Insomnia and waking early
- Loss of interest in sex
- Extreme tiredness
- Inability to make decisions
- Tearfulness
- Inability to enjoy day-to-day living.

Please note that many of these symptoms can occur after a woman has had a baby and may not be postnatal depression.

PND is quite common and nothing to be ashamed of. If you think you have any of these symptoms, talk about them with a health professional.

PND is not a permanent illness.
You do get better and you get better faster if you get help.

There is research that suggests some women may be at higher risk of PND than others. These risk factors include:

- Difficult and long labour or birth
- Caesarean section
- Multiple birth
- Having a baby that needs intensive care treatment.

Sudden Infant Death Syndrome (SIDS)

Many parents are concerned about SIDS. The sleeping position of a baby seems to play a large part in the prevention of SIDS. Lying baby on his **back only** is recommended.

The following actions are precautionary measures recommended to help prevent SIDS:

- Do not smoke in the same house as the baby
- Place baby to sleep on his back in his own bed
- Breast-feed, if possible, for at least six months.

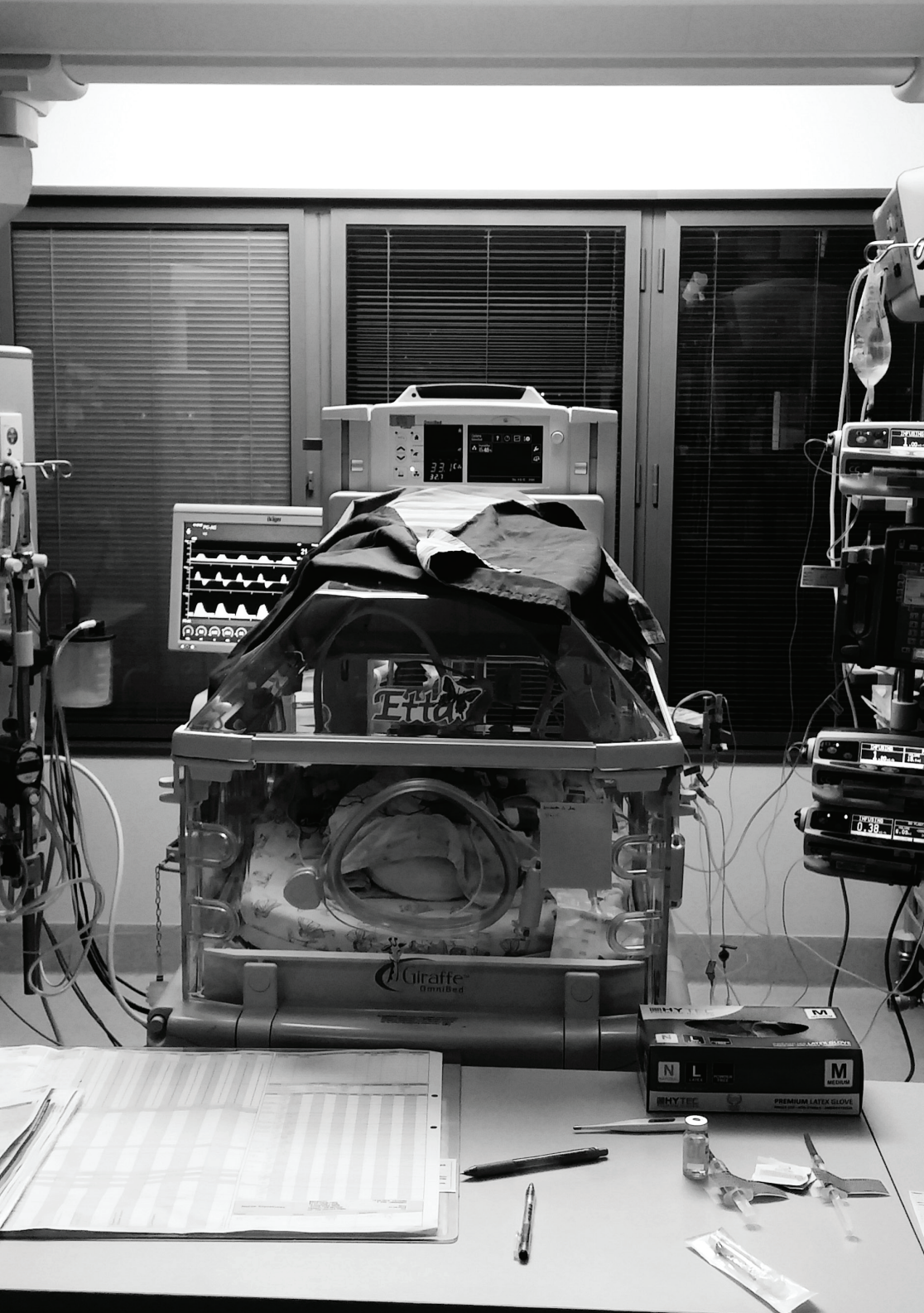
Some premature babies who have been in an incubator for a long time don't like the closed-in feeling of a bassinet. You could put your baby straight into a cot but do not use bumper pads or loose duvets. Make baby's bed up at the bottom of the cot, this reduces the risk of him moving underneath the blankets. Keep the head clear at all times. Bring the blankets up to his armpits only and tuck them in well.

You can check quite easily whether your baby is warm enough. If baby's back and chest feel comfortably warm to your hand, he will be warm enough. Babies often have cool hands and feet even with booties on and after being snuggled up in bed. Hands and feet are the last parts of the body to be warmed.

Room temperature

Babies who have been in the Unit have been used to warm room temperatures. A heater with a thermostat on it can be left on all the time initially to keep the chill off, if you are feeling cold yourself. The thermostat ensures that the room remains at a constant temperature.

If baby is going to be sleeping by a window make sure there are no draughts. A rolled-up towel placed along cracks in the joinery will usually stop draughts. Sun can be a problem too. If baby is sleeping in the sunlight during the day, a curtain or blind should be pulled down to keep the sun off his body. Babies can overheat quite quickly and this can result in dehydration.


Ethan
Giraffe
OmniBed
M
MEDIUM
PREMIUM LATEX GLOVE

Car seats

It is a legal requirement that all passengers travelling in a car be safely belted in. This goes for babies too.

To ensure the safety of your baby when travelling by car it is important that you securely fasten your baby in a standards approved car seat. A baby cocoon in the back seat of the car is not a safe way for a baby to travel.

Baby car seats can be hired from the Plunket Society, and some baby shops, like The Baby Factory, for reasonable rates. Friends may have a car seat that you can borrow. If you plan to have more children it can be cheaper to buy a car seat. If you are hiring a car seat from Plunket, they need to be ordered when baby reaches 1600 grams and confirmed a week before discharge.

When putting baby in a car seat his body needs to be kept straight (not slumped over) so breathing is easy and he gets plenty of oxygen. The closer your baby is to lying down, the better off he is.

When you attend the CPR, safe sleeping and car seat positioning class you will be shown how to correctly position your baby in the car seat, as most car seats are designed for the larger term baby.

Further pregnancies

Some families decide not to have any more babies after having a baby in the Unit. If you decide to have another baby there is always the thought that the current pregnancy may end with another baby in the Unit.

If you have a medical problem that dictates that you will have a child in the Unit again, it is really important to visit the Unit again during your pregnancy to re-familiarise yourself with the surroundings. You can forget just how small prems are.

It is important to remind yourself that all children are individuals and it may be different this time. Try to have no expectations from past experiences placed upon the new pregnancy.

Some women find themselves counting the weeks of the next pregnancy. If you find yourself doing this with your next pregnancy, you will understand that it is a very normal thing for someone who has had a pre-term baby to do.

Depending upon the circumstances, having a second or third child in the Unit may not be as stressful as the first time. Second time around, you are aware of how the Unit functions. Things do change, so you cannot expect the same staff to be there or looking after your baby.

Next time you may be more assertive with your role as a parent in an intensive-care environment. You may know more and want to do more for your baby. You will have some knowledge of the types of treatments and cares a pre-term or special care baby will receive.

Speak to the staff about your previous experience. Let them know how you feel and what your hopes and expectations are for this new baby.

You may be able to do things that you were unable to do last time. Things such as taking more photos, being there more, perhaps breast-feeding for longer. With the next pregnancy you will have learnt from the first, and hopefully things will be better for you and your family.

Reference information

Reference information

The Neonatal Trust

The Neonatal Trust (the Trust) is made up of parents, like you, who established the Trust in 1986 as a way of saying thank-you to the staff for the care of their children. The staff in the Unit work in partnership with the Trust to provide a better environment for the babies.

What does The Neonatal Trust do for the Unit?

The Trust aims to provide the Units with things that make life a little easier for the babies, parents and staff, such as:

- Equipment, e.g. syringes
- Breast pumps
- Breast-feeding chairs
- Books for both the staff and parents so we all may learn more about our amazing babies.

What does The Neonatal Trust do for parents?

From the Trust came a support group that provides support in a variety of ways for parents who have a baby in the Unit, such as:

- A weekly lunch
- Small size clothes and knitting patterns
- Breast pumps
- Parents rooming-in rooms (provision of home comforts)

- Parent support group and playgroup for graduates
- Ward visits.

The Trust produces a number of publications for parents, including this guidebook.

Because all of the Trust members have been there, done that, we do understand all that you are feeling and what is ahead of you. We are always available for a chat, and to offer tips on how to get through what is a very difficult and personal time.

Our phone numbers are available from the Trust office or Unit staff. **Please don't hesitate to call**, as often it is reassuring to talk to someone who has lived through it.

How can I help?

Anyone can help with the work of the Trust and the Trust accepts all offers of help and support. Often people think "I have to give a donation". While a donation would be wonderful, the Trust is about people and would like to extend an invitation to you to become involved with the Trust's work.

You can help in many ways, such as:

- Helping with fundraising or giving a donation
- Coming to meetings
- Knitting and sewing, remember all knitting needs to be 100% wool.

The Neonatal Trust office

There are Neonatal Trust offices located onsite at Wellington and Auckland Neonatal Intensive Care Units, and offsite at the other centres. Parents can access the following services through the Trust offices:

- A parent library of neonatal-relevant books and articles
- Pre-term-sized knitting patterns and pre-term-sized clothing for sale at a reasonable cost
- Hire of electric breast pumps (these are hospital grade Medela electric pumps)
- Sale of hand and electric pumps at competitive prices. The Neonatal Trust has an excellent range of manual and electric pumps for sale at very competitive prices. We stock the Avent, Medela and Ameda ranges of pumps and can generally order items within 24 hours if not in stock.

How can I get in touch with The Neonatal Trust?

If you'd like to get in touch with a local branch, contact details are at the back of this guide.

Is The Neonatal Trust on Facebook?

We have a fantastic community of support on our National Facebook page, The Neonatal Trust - New Zealand. Please join our page so we can keep you up-to-date with upcoming events and the wonderful work our Trust is doing. Our page has information on playgroups, useful articles and discussions started by parents who have also had a NICU/SCBU journey. Many families have shared their amazing journeys and we'd love to hear your story, see your pictures and answer your questions when you're ready.

Glossary

Glossary

Below is a list of terms commonly used in the Unit. If you come across additional terms used in relation to your baby, you may like to make a note of them in the parent space pages.

A

Absorb: The body's ability to take in, or incorporate back into the body, fluid, or food.

Adjusted age: The term used to describe the age your baby would have been if he was born full term. For example, for a baby born nine weeks early at 31 weeks gestation; at nine months after his birth, his adjusted age is seven months.

Alveoli: Tiny sacs in the lungs where oxygen and carbon dioxide are exchanged with the bloodstream.

Anaesthetic: A drug for bringing on loss of sensation (and hence pain) in many medical and surgical procedures. General anaesthetic (GA) produces unconsciousness and is administered by a specially trained doctor called an anaesthetist.

Antibiotics: Drugs used to fight off bacterial infection. They have names like vancomycin and gentamicin.

Anaemia: The reduction to below normal levels of haemoglobin (red blood cells) in the blood.

Aorta: The artery leading from the heart that supplies oxygenated blood to the body.

Arterial blood gas (arterial sample): A sample of blood taken from an artery to measure its oxygen, carbon dioxide, and acid content.

Arterial catheter (indwelling arterial catheter): A thin plastic tube placed in an artery to withdraw blood for testing and to measure blood pressure.

Artery: Any blood vessel leading away from the heart. Arteries carry oxygenated blood to the body tissues (with the exception of the pulmonary artery which carries non-oxygenated blood to the lungs from the heart).

Apgars: A numerical scoring system, usually applied at one and five minutes after the birth of all newborn babies. This is to evaluate the condition of the baby based on heart rate, respiration, muscle tone and colour. Scores are on a scale of one to 10, with 10 being the best score. Baby's condition can alter either way after the first five minutes and therefore your baby can have two Apgar scores that are usually of different values.

Apnoea: The temporary stopping of breathing by the baby.

Apnoea monitor: A monitor connected to the baby with a sensor, to specifically detect apnoea.

Apnoea mattress: A monitor that uses a sensitive flat pad or mattress to detect apnoea.

Aspiration: Breathing of material into the windpipe (trachea) or lungs, or the removal of material from the windpipe, lungs or stomach by suction.

Asphyxia: A lack of oxygen and high carbon dioxide level in the blood and tissues.

B

Bagging: A slang word to describe the procedure of applying a mask connected to a squeezable bag over the baby's mouth and nose to achieve ventilation of the lungs.

Bilirubin: The name of the breakdown product of red blood cells. Excess amounts cause jaundice, a yellowing of the skin. Bilirubin is excreted in faeces.

Blood gas test: A test performed on a sample of arterial blood to be sure that the amounts of oxygen and carbon dioxide in the bloodstream are normal.

Blood count: A test of a sample of blood to tell the numbers of red and white blood cells. Also known as a FBC.

Blood pressure (BP): The pressure or force that the blood exerts against the walls of the arteries in circulation. It is described by two numbers; systolic (the top or high number) and diastolic (the low or bottom number).

Blood transfusion: A procedure for replenishing (topping up) the baby's blood with adult donor blood.

Bonding: Establishing a close relationship between a parent and child.

Bronchial tubes: The tubes that lead from the windpipe (trachea) to the lungs.

Bronchopulmonary Dysplasia (BPD): BPD is a lung disease that affects newborn babies. In most cases BPD occurs in babies who are born prematurely and have required extra oxygen and/or a ventilator, up to and after 28 days of life, to treat their original lung problem. In many cases, the symptoms of BPD disappear quite rapidly. Some babies with BPD may have breathing difficulties for many months or years.

Bradycardia: An abnormally slow heart rate measured by beats per minute. A foetal or neonate heart beat rate of less than 100 beats per minute is abnormally slow. Normal foetal heart rate is 120 - 160. Neonate's heart rate averages 140 beats per minute.

Breast pump: A device either hand or electrically operated to extract breast milk.

C

Caffeine: A medication given to babies that helps them to remember to breathe.

Candida: See Thrush.

Capillaries: Very small blood vessels which remove waste from, and provide oxygen and nutrients to, body cells.

Carbon dioxide (CO_2): Gaseous bodily waste product transported via the bloodstream and exhaled by the lungs.

CAT scanner or CT scanner (computerised axial tomography): A computer-controlled x-ray machine capable of capturing cross-section images of body tissues.

Catheter: A tube used to put fluid into the baby's body, or to drain the excessive fluids from the body.

Cerebral: Applying to the structure and functions of the brain.

Chest tube (CT): A tube that has been surgically inserted in the chest wall to suction away air and allow a collapsed lung to re-expand.

Chromosomes: Each human body cell has 46 chromosomes, 23 pairs. Chromosomes are the genetic blueprint containing all the information that makes each human unique.

Colostomy: An opening, created through surgery, to allow the colon (lower part of the large intestine) to empty its contents directly through the wall of the abdomen.

Colostrum: The first breast milk produced after the birth of the baby. It is thick and yellowish in colour, and high in protein and antibodies.

Complementary feed (Comp): An additional feed of either expressed breast milk or formula milk, after the baby has had a feed from the breast.

Congestive heart failure (CHF): Failure of the heart to act and perform efficiently because of circulatory imbalance.

Culture: A biological term for a specially prepared substance to grow microbes (germs) on, in order to identify which disease-producing organism is responsible for an illness.

D

Dehydration: Loss of body fluids. Due to vomiting and/or sweating caused by overheating or diarrhoea.

Dextrose: A solution of sugar given intravenously (through an IV) to maintain or raise the level of sugar in the blood.

Drip: A common name for an intravenous infusion. The fluid from the IV bag travels through tubing and through a pump which measures and gives the exact volume required to the baby.

CPAP (continuous positive airways pressure): Keeps the air sacs in the lungs inflated when baby breathes out, this eases the work of breathing.

E

EBM: Expressed breast milk.

Echo cardiograph or echo (ECG): The use of ultrasound to examine the structure of the heart. The ultrasound waves are directed at the heart through the chest, with the findings recorded graphically on an echo cardiogram.

Electrode, sensor, or probe: Plastic strip or wire taped to the baby's arm or leg, or a disk taped on a baby's chest to relay signals from the heart, lungs and skin to monitors.

Electrolytes: Essential substances found in everyone's body which are electrically charged and give solutions such as blood or plasma the ability to conduct electric current. A balance of electrolytes is important. Dehydration causes an imbalance and needs treatment with electrolytes.

Endotracheal tube (ET tube): A plastic tube that is passed through the baby's nose or mouth into the windpipe (trachea) and is connected to a ventilator (respirator).

Engorgement: The process of the breasts becoming uncomfortably large and tight feeling. Either felt initially as the milk comes in several days after the birth, or due to too low a frequency of milk expressing or breast-feeding.

Extended posture: A position in which baby lies with straight arms and legs.

Extubate: Removal of a tube from the trachea (airway) which is attached to a ventilator.

F

Fontanelle: The large soft spot on the top, and the smaller one on the back of the baby's head. They will close within 12 and 18 months.

Formula milk: Special preparations of cow's milk or soya bean, modified to closely resemble the chemical composition in human breast milk.

G

Gavage feedings: Feedings through a tube inserted through the mouth or nose that goes straight to the stomach.

Gastrostomy: An opening in the abdominal wall, created through surgery, to provide nutrition straight to the stomach when the oesophagus is injured or blocked, or to provide proper drainage after abdominal surgery is performed to maximize nutrition.

Gestational age: The time (in weeks) from the last menstrual period. A full term pregnancy is 40 weeks.

Glucose: A natural sugar which is a main source of energy for the body.

H

Head circumference: Measurement of the maximum distance around the baby's head.

Head scan: See Ultrasound.

Hernia: (1) Umbilical - At the naval or umbilicus, a lump under the skin caused by a part of the intestine that protrudes through a fragile area in the abdominal wall. (2) Inguinal - A lump under the skin in the groin area caused by a part of the intestine protruding through a fragile part of the abdominal wall.

Heredity: Characteristics transmitted from one generation to another in genes on the chromosomes.

Haemoglobin (HB): The colouring of red blood cells, carrying oxygen from the lungs to body tissues.

Haemorrhage: A medical term to describe bleeding, either inside or outside the body.

Heel prick: A small prick in the baby's heel, made so that a blood sample can be obtained for testing, usually for blood gases or blood glucose levels.

Hind milk: Breast milk of a much higher fat content that follows the let-down reflex once baby has been suckling for a few moments.

Hypoglycemia: The condition of having a low level of sugar in the blood.

I

Incubator: Special enclosed bed for a newborn in which temperature, oxygen, and humidity can be controlled.

Infection: The invasion of a person's body either internally or externally and the rapid multiplying growth of micro-organisms, in other words bugs. A bacterial infection is usually fought with an antibiotic. Viral infections cannot be treated with an antibiotic.

Intravenous (IV): The administration of fluids, or drugs through a hollow needle inserted into a vein.

Intubation: The passing of a small plastic tube through the mouth into the baby's trachea as part of the ventilation process.

Isolation: The name for the area where babies are nursed on their own, in case they pass on their contagious infections to the other babies or need protecting because they are more fragile.

IUGR: Intra uterine growth retardation (see SGA).

IV (intravenous): Into the vein.

J

Jaundice: The yellow colour of a baby's skin caused by raised bilirubin in the blood.

L

Lactation: The body's process of making breast milk.

Lanugo: The soft downy hair all over the body that a lot of premature babies are born with. This falls out after a short while.

Lipids (a white fluid): Fats that are needed to promote growth. Used in conjunction with TPN as a total food for baby when baby is not able to feed by mouth. Normally administered via a long line.

Liquor: Amniotic fluid.

Long Line: An IV that generally lasts for a long time. It is positioned in a central vein. It has less likelihood of being infected.

Lumbar puncture: A procedure for investigating diseased cerebrospinal fluid. This is done by inserting a needle between the vertebrae at the bottom of the spine (waist height), in order to tap cerebrospinal fluid and occasionally to inject drugs in to the cerebrospinal fluid.

M

Meconium: A greenish-black, mucus-like substance present in the intestines of newborn babies. This is usually the first bowel motion after birth.

Meconium aspiration: Inhalation or breathing in by a foetus of amniotic fluid that has meconium in it. Caused when a foetus becomes stressed prior to delivery. The sticky material irritates and partially blocks the airways causing breathing difficulties in the newborn period.

Monitor: A machine used to observe and record such functions as breathing, temperature, and heart rate. The electrodes and sensors are connected to this machine.

MRI (magnetic resonance imaging): MRI is a painless test used to view the inside of the body without using x-rays. It uses a large magnet, safe low energy radio waves and a computer, to produce two or three-dimensional pictures.

Mucus: Slimy substance found in the nose and windpipe.

Multiple: One or more, usually referring to the number of babies born at the same time to the one mother.

Murmur: Sound of turbulent blood flow in heart or blood vessel.

N

NAD: No abnormalities detected. Often seen in babies notes after tests.

Nasogastric tube: A very thin flexible tube that can be passed through a nostril or by the mouth to the stomach via the throat. Babies can be either tube-fed or have the contents of their stomach checked by aspirating.

Neonatal: Newborn, describing the first 28 days of life (although many babies are in the Unit for longer than 28 days).

NEC (Necrotizing Enterocolitis): An inflammation of the gut wall and lining that affects some premature babies.

Neonatologist: A doctor who is specially trained in the care of sick and premature newborns.

NG Tube (nasogastric tube): Used for feeding babies too young to feed by sucking milk from the breast or a bottle.

O

O/G tube: A tube passed through the mouth, via the oesophagus into the baby's stomach for feeding or suction purposes.

Open incubator: An incubator that is an open bed with an overhead warmer (heater) to keep baby's body temperature constant.

Oxygen: A gas that makes up about 21% of the air we breathe. Some babies who have breathing difficulties may need more oxygen than that supplied in the air. It is measured in percentages and in litres per minute.

P

Patent ductus arterlosus (PDA): A typical situation in preemies where the fetal blood vessel which links the aorta and the pulmonary artery does not close following birth.

Phototherapy: Treatment for jaundice that involves the use of ultra-violet or halogen light directed at the baby in the incubator. Treatment usually lasts for several days.

Pneumothorax: A leak of air out of a baby's lungs, but still within the chest cavity. This can press on the lungs and will usually require draining away outside the body through a tube.

Pulse: The rhythmic expansion and contraction of an artery with blood flow which may be felt with the finger.

Pulse oximeter: A monitor which measures the amount of oxygen in the baby's blood stream. It is usually fixed to the foot or the hand. It has a red light.

Plasma: The fluid component of blood in which the blood cells are suspended.

Prone: Describes the position of the baby, when lying on his stomach.

R

Respirator: A machine (also known as a ventilator) that regularly pumps air in and out of the lungs when a baby cannot breathe for himself.

Retinopathy of prematurity (ROP): The abnormal growth of the blood vessels of the eye, seen in many premature infants. This happens because the blood vessels are not finished developing at the time of a premature infant's birth. They have to finish developing outside the protected environment of the womb.

RDS (Respiratory Distress Syndrome - also known as Hyaline Membrane Disease): Usually baby's lungs are kept open by a chemical, called surfactant that everyone has in their lungs. Some babies have less surfactant and the alveoli (small air sacs in the lung) start to close up, making it really hard for baby to breathe. The baby develops RDS, that is, has increasing difficulty in breathing. Babies are ventilated and may be given artificial surfactant.

Retina: The back of the eye where blood vessels supplying the light-sensitive cells are located.

Room air: The air that we normally breathe (contains 21% oxygen).

Rooming in: The time when you stay overnight at the hospital and have total care of your baby just prior to coming home.

S

Sedation: The use of a drug which will quieten the baby down, promoting less movement and a placid state of being. This is sometimes done to babies who are being ventilated, so they don't fight the ventilator and become more stressed.

Septicaemia: An infection in the bloodstream affecting the whole body.

Shunt: A passage made artificially, between two areas of the body, usually placed to drain liquid.

SGA (small for gestation age or small for dates): Babies born weighing a lot less than other babies of the same gestation at birth.

Squint or Strabismus: A condition in which the eye muscles can't hold both eyes to look in the same direction. This gives a cross-eyed look which is more noticeable when the person is tired.

Sterile: Free from contamination by living microbes (bugs).

Steroids: (1) A large group of chemically related compounds of diverse origin and function. Those related to cortisol from the adrenal gland can help to mature the lungs of a foetus before birth. (2) Used to reduce lung swelling in BPD.

Stimulation: (1) Developmental encouragement given to a baby, either by talking, singing, reading or having things to look at. (2) Physical encouragement to continue breathing, such as tickling or a gentle prod when an apnoea occurs.

Supplementary: In addition to. Usually refers to adding vitamins and minerals to the baby's diet, or complementing breast with milk formula feeding.

Suture: (1) Stitches for holding together surgical incisions. (2) Lines in a baby's skull.

Suction: Aspiration of gas or fluid, usually from the lungs by mechanical means.

Surfactant: Compounds which line the air sacs (alveoli) of the lungs reducing surface tension and thereby preventing lung collapse on breathing out (expiration). Artificial or synthetic surfactant is now available for those infants who have difficulty producing their own shortly after birth. It is given to babies through the ventilator. Surfactants have names like Curosurf.

Syringe: An apparatus for injecting into, or withdrawing fluids from, the body.

T

Tachycardia: Rapid heart rate, above 170 beats per minute.

Tachypnoea: Rapid breathing rate, over 60 breaths per minute.

Thrush: A fungal infection.

Thermacot: A bed that has a warmed gel mattress to help babies maintain their temperature. Babies also have bedding as they would in a cot.

TPN (total parenteral nutrition): A mixture of sugar, minerals, vitamins and proteins given via IV.

Trachea: The windpipe, which extends from the throat to the bronchial tubes.

U

UTI: Urinary tract infection.

V

Vein: A blood vessel which carries non-oxygenated blood to the heart.

Ventricle: (1) A tiny chamber, as in those of the heart. (2) Tiny chambers in the middle of the brain where cerebrospinal fluid is created.

Virus: A small infectious organism that thrives in the cells of the body.

Conversion scale

How much does my baby weigh?

grams	pounds/oz	grams	pounds/oz	grams	pounds/oz
304	10 ¾	610	1 lb. 5 ½	1063	2 lb. 5 ½
312	11	624	1 lb. 6	1077	2 lb. 6
319	11 ¼	638	1 lb. 6 ½	1091	2 lb. 6 ½
326	11 ½	652	1 lb. 7	1105	2 lb. 7
333	11 ¾	666	1 lb. 7 ½	1119	2 lb. 7 ½
340	12	681	1 lb. 8	1134	2 lb. 8
347	12 ¼	695	1 lb. 8 ½	1148	2 lb. 8 ½
354	12 ½	709	1 lb. 9	1162	2 lb. 9
361	12 ¾	723	1 lb. 9 ½	1176	2 lb. 9 ½
368	13	727	1 lb. 10	1190	2 lb. 10
375	13 ¼	751	1 lb. 10 ½	1201	2 lb. 10 ½
382	13 ½	766	1 lb. 11	1219	2 lb. 11
389	13 ¾	780	1 lb. 11 ½	1233	2 lb. 11 ½
397	14	794	1 lb. 12	1247	2 lb. 12
404	14 ¼	808	1 lb. 12 ½	1261	2 lb. 12 ½
411	14 ½	822	1 lb. 13	1275	2 lb. 13
418	14 ¾	836	1 lb. 13 ½	1289	2 lb. 13 ½
425	15	851	1 lb. 14	1304	2 lb. 14
432	15 ¼	865	1 lb. 14 ½	1318	2 lb. 14 ½
439	15 ½	879	1 lb. 15	1332	2 lb. 15
446	15 ¾	893	1 lb. 15 ½	1346	2 lb. 15 ½
454	1 lb	907	2 lb	1361	3 lb
468	1 lb. 0 ½	921	2 lb. 0 ½	1375	3 lb. 0 ½
482	1 lb. 1	935	2 lb. 1	1389	3 lb. 1
496	1 lb. 1 ½	949	2 lb. 1 ½	1403	3 lb. 1 ½
511	1 lb. 2	964	2 lb. 2	1418	3 lb. 2
525	1 lb. 2 ½	978	2 lb. 2 ½	1432	3 lb. 2 ½
539	1 lb. 3	992	2 lb. 3	1446	3 lb. 3
553	1 lb. 3 ½	1006	2 lb. 3 ½	1460	3 lb. 3 ½
567	1 lb. 4	1020	2 lb. 4	1474	3 lb. 4
581	1 lb. 4 ½	1034	2 lb. 4 ½	1488	3 lb. 4 ½
596	1 lb. 5	1049	2 lb. 5	1503	3 lb. 5

grams	pounds/oz
1517	3 lb. 5 ½
1531	3 lb. 6
1545	3 lb. 6 ½
1559	3 lb. 7
1573	3 lb. 7 ½
1588	3 lb. 8
1602	3 lb. 8 ½
1616	3 lb. 9
1630	3 lb. 9 ½
1644	3 lb. 10
1658	3 lb. 10 ½
1673	3 lb. 11
1687	3 lb. 11 ½
1701	3 lb. 12
1715	3 lb. 12 ½
1729	3 lb. 13
1749	3 lb. 13 ½
1758	3 lb. 14
1772	3 lb. 14 ½
1786	3 lb. 15
1800	3 lb. 15 ½
1814	4 lb
1828	4 lb. 0 ½
1842	4 lb. 1
1856	4 lb. 1 ½
1877	4 lb. 2
1885	4 lb. 2 ½
1899	4 lb. 3
1913	4 lb. 3 ½
1927	4 lb. 4
1941	4 lb. 4 ½
1956	4 lb. 5
1970	4 lb. 5 ½
1981	4 lb. 6
1998	4 lb. 6 ½
2012	4 lb. 7

grams	pounds/oz
2026	4 lb. 7 ½
2041	4 lb. 8
2055	4 lb. 8 ½
2069	4 lb. 9
2083	4 lb. 9 ½
2097	4 lb. 10
2111	4 lb. 10 ½
2126	4 lb. 11
2140	4 lb. 11 ½
2154	4 lb. 12
2168	4 lb. 12 ½
2182	4 lb. 13
2196	4 lb. 13 ½
2211	4 lb. 14
2225	4 lb. 14 ½
2239	4 lb. 15
2252	4 lb. 15 ½
2268	5 lb
2282	5 lb. 0 ½
2296	5 lb. 1
2310	5 lb. 1 ½
2325	5 lb. 2
2339	5 lb. 2 ½
2253	5 lb. 3
2367	5 lb. 3 ½
2381	5 lb. 4
2395	5 lb. 4 ½
2410	5 lb. 5
2424	5 lb. 5 ½
2438	5 lb. 6
2452	5 lb. 6 ½
2466	5 lb. 7
2480	5 lb. 7 ½
2495	5 lb. 8
2509	5 lb. 8 ½
2523	5 lb. 9

grams	pounds/oz
2537	5 lb. 9 ½
2551	5 lb. 10
2565	5 lb. 10 ½
2580	5 lb. 11
2594	5 lb. 11 ½
2608	5 lb. 12
2622	5 lb. 12 ½
2636	5 lb. 13
2650	5 lb. 13 ½
2665	5 lb. 14
2679	5 lb. 14 ½
2693	5 lb. 15
2707	5 lb. 15 ½
2721	6 lb
2735	6 lb. 0 ½
2749	6 lb. 1
2763	6 lb. 1 ½
2778	6 lb. 2
2792	6 lb. 2 ½
2806	6 lb. 3
2820	6 lb. 3 ½
2834	6 lb. 4
2848	6 lb. 4 ½
2863	6 lb. 5
2877	6 lb. 5 ½
2891	6 lb. 6
2905	6 lb. 6 ½
2919	6 lb. 7
2933	6 lb. 7 ½
2948	6 lb. 8
2962	6 lb. 8 ½
2976	6 lb. 9
2990	6 lb. 9 ½
3004	6 lb. 10
3018	6 lb. 10 ½
3033	6 lb. 11

grams	pounds/oz
3047	6 lb. 11 ½
3061	6 lb. 12
3075	6 lb. 12 ½
3089	6 lb. 13
3103	6 lb. 13 ½
3118	6 lb. 14
3132	6 lb. 14 ½
3146	6 lb. 15
3160	6 lb. 15 ½
3175	7 lb
3189	7 lb. 0 ½
3203	7 lb. 1
3217	7 lb. 1 ½
3232	7 lb. 2
3246	7 lb. 2 ½
3260	7 lb. 3
3274	7 lb. 3 ½
3288	7 lb. 4
3302	7 lb. 4 ½
3317	7 lb. 5
3331	7 lb. 5 ½
3345	7 lb. 6
3359	7 lb. 6 ½
3373	7 lb. 7
3387	7 lb. 7 ½
3402	7 lb. 8
3416	7 lb. 8 ½
3430	7 lb. 9
3444	7 lb. 9 ½
3458	7 lb. 10
3472	7 lb. 10 ½
3487	7 lb. 11
3401	7 lb. 11 ½
3515	7 lb. 12
3529	7 lb. 12 ½
3543	7 lb. 13

grams	pounds/oz
3557	7 lb. 13 ½
3572	7 lb. 14
3586	7 lb. 14 ½
3600	7 lb. 15
3614	7 lb. 15 ½
3628	8 lb
3642	8 lb. 0 ½
3656	8 lb. 1
3670	8 lb. 1 ½
3685	8 lb. 2
3699	8 lb. 2 ½
3713	8 lb. 3
3727	8 lb. 3 ½
3741	8 lb. 4
3755	8 lb. 4 ½
3770	8 lb. 5
3784	8 lb. 5 ½
3798	8 lb. 6
3812	8 lb. 6 ½
3826	8 lb. 7
3840	8 lb. 7 ½
3855	8 lb. 8
3869	8 lb. 8 ½
3883	8 lb. 9
3897	8 lb. 9 ½
3911	8 lb. 10
3925	8 lb. 10 ½
3940	8 lb. 11
3954	8 lb. 11 ½
3968	8 lb. 12

Parent space

The following pages are for you. Use this space to write down your thoughts and feelings.

We provide support to families of premature or sick full term babies as they make their journey through Neonatal Intensive Care, the transition home, and onwards.

We are committed to supporting these courageous families, the people who care for them, and partnering with organisations and people who want to support us.

We are dedicated to making a difficult start to life that little bit easier.

the neonatal trust

www.neonataltrust.org.nz