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CHILD & YOUTH HEALTH
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Information for Parents and Prospective Parents of Premature Pēpi/Babies less than 28 Weeks Gestation

Neonatal Service
Christchurch

Outcomes for very premature pēpi cared for in the Neonatal Service, Christchurch

You may be about to deliver a premature pēpi or have recently done so. This booklet has been put together by staff and parents to help you through this very difficult and stressful time. The most important and immediate question parents ask is, “Will our pēpi survive and be healthy?” We will cover this and other similar questions.

The information given here does not replace what the neonatal staff caring for your pēpi will tell you, but we recognise that it is difficult for you to recall all you are told, especially in the first few days after your pēpi is born.

Premature, or preterm, covers any pēpi born before 37 weeks gestation. This booklet will cover issues relating to pēpi born less than 28 weeks gestation. These pēpi are often referred to as extremely preterm.

As a result of major advances in the neonatal intensive care offered to very preterm pēpi in the last 25 years, their survival and outcomes have greatly improved. Our own unit collects information on the survival and progress of the pēpi we care for each year. Since 1995, the neonatal intensive care units in Australia and New Zealand have sent their records to the Australia & New Zealand Neonatal Network (ANZNN) and the figures given in this booklet will be from this data.

Each pēpi is different and depending on the reasons for you having your pēpi early and the specific problems your pēpi faces, a clearer picture will be given to you over the first few days.

Will our pēpi live?

The most important factor that affects survival is how many weeks your pēpi has had in-utero or in the pregnancy. The starting point used to decide this is the first day of your last menstrual period (LMP). This information is usually confirmed by an ultrasound scan. Where there is a difference between dates and scan size of the pēpi, it is important that this is reviewed by you and your Lead Maternity Carer (LMC).

Pēpi very rarely survive if they are born before they reach 23 weeks gestation. Pēpi at 23 and 24 weeks are at the limits of viability, which means they are very fragile throughout their body and have about a 50% to 70% chance of survival respectively, if admitted to the intensive care unit. If the pregnancy is compromised, especially with poor growth, prediction of survival pre-delivery is more like 20-40%.

Survival increases with every extra day your pēpi has in-utero, so the midwives and doctors will usually try and do whatever is possible to continue your pregnancy as long as possible. In particular, they will do this to ensure that steroids given to the māmā (mother) will have the best possible chance of helping your pēpi's lungs and other organs. Forty-eight hours after starting steroids the effect on the pēpi's lungs and other organs is at its best, but we know shorter times can also be helpful.

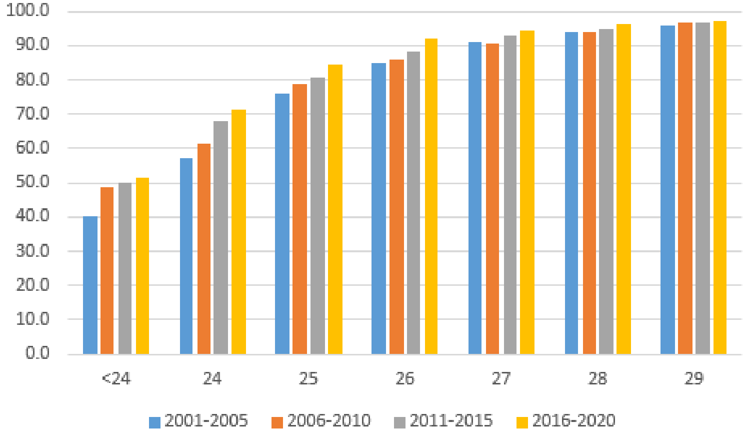
An example of an intensive care area

If your pēpi is about to be born at or before 24 weeks gestation, your views on the care and treatment offered to your pēpi are especially important. Because of the challenges involved in caring for your pēpi and the high risk of long-term complications, your feelings and views will have a bearing on delivery decisions. Sometimes, because decisions have to be made in an emergency, there may seem too little time or information available to you. If your pēpi survives the delivery and is admitted to intensive care, there will be regular opportunities to review the care decisions you and the medical team make for your pēpi. As each day passes, the journey for your pēpi develops and the chance of survival will also change.

Our aim is to work in partnership with you as parents. As well as daily bedside updates the medical team will aim to meet with you in the first two weeks to discuss your pēpi's care and progress.

The following graph shows how the survival of pēpi of different gestations increases dramatically, so that from 26 weeks nine out of ten pēpi survive. Improvements in survival has occurred over the last 20 years especially for pēpi < 25 weeks. The information is collected from pēpi admitted to the neonatal unit rather than all pēpi born so survival can be lower at the lowest gestations.

ANZNN survival to discharge after admission to NICU (3 blocks of 5 years)



Years 2001 through to 2020

Why do some pēpi die?

The main problems that affect your pēpi's survival in the first week of life are lung or breathing difficulties, bleeding and blood flow in the brain and infection. We will talk with you about the particular problems your pēpi has and more detailed information will also be available.

Once your pēpi is born, with the placenta no longer there, the pēpi's lungs need to work to supply oxygen for the body's tissues to function properly.

Most pēpi under 28 weeks will need a ventilator immediately after birth and if so will usually receive extra surfactant into the lungs. This makes breathing easier until pēpi produce it themselves. Surfactant is a lubricant that helps keep the airways open and reduces the work of breathing. Often pēpi improve quickly after this and are ventilated until they are strong enough to breathe on their own. We then use CPAP (continuous positive airway pressure) or NIPPV (nasal intermittent positive pressure ventilation – similar to full ventilation, but into the nose) to reduce the work they do breathing. When breathing improves they usually move on to a time on HiFLow (high flow nasal cannula).

A pēpi on CPAP – small mask or soft prongs sit just on, or inside nose

CPAP machine

Unfortunately, sometimes the lungs are so fragile that bleeding or air leaks occur. This can lead to a collapsed lung or cysts developing. When these occur the ventilator needs to do more work to keep the oxygen levels up and more lung damage can occur.

Fortunately the lungs can recover from those initial problems, and while ventilation, CPAP or extra oxygen may be needed for many weeks, the lungs continue to heal and grow into childhood. The doctors may say your pēpi has chronic lung disease (CLD) but with time and sometimes, extra treatment, recovery can occur.

Bleeding

Bleeding into or around the brain occurs more frequently under 30 weeks gestation and causes more problems the earlier your pēpi is born. Bleeding can be easily seen with ultrasound scans of your pēpi's head. These scans are done routinely after birth starting around day 3. The bleeding may be small and in areas that don't affect brain development, such as in the ventricles (four connected fluid-filled cavities in the middle of the brain). These usually resolve without causing injury to the brain. Occasionally bleeding is large and occurs in the brain tissue. If this happens the doctor caring for your infant will discuss with you how this might affect your pēpi in the long-term. Large bleeds may make your pēpi's condition unstable, and a discussion about what is best for your pēpi, including withdrawing intensive care, may take place. Sometimes the scan doesn't show up problems until 4-6 weeks of age, so a scan is always repeated then so that more details of any effects can be given to you.

Infections

Infections can cause your pēpi to become very sick. Very premature pēpi are more prone to infection because their skin is thin, their body's defence or immune system is not fully developed, and we need to put lines in the veins to feed them and give medications, especially in the first 2 to 3 weeks. Most infections can be treated with antibiotics, however occasionally the body reacts so badly to the infection that recovery is not possible.

Apnoea and Bradycardia

All pēpi born under 28 weeks gestation have an underdeveloped breathing control centre in the brain. There are times when your pēpi will forget to breathe or have events where the heart slows and/or your pēpi’s oxygen levels fall. Because of this, your pēpi is monitored continuously and alarms sound if the measurements fall below the levels we set. These are safety limits and do not mean your pēpi will come to harm. We start them on caffeine soon after birth, which is known to reduce these events.

Your pēpi will also often have heart scans as part of their care.

If our pēpi survives will there be problems with how they develop and learn?

By the time your pēpi goes home the team of people caring for your pēpi will have had time to discuss with you the overall progress your pēpi has made. With the help of the nurses your pēpi will learn to feed and respond to you in increasing ways. Our physiotherapist will assess your pēpi’s body movements and reflexes, which progress as your pēpi matures. We will know the results of the early and later head ultrasound scans. Also the staff regularly examine your pēpi. All this information is used to predict the possibility of ***movement, hearing, eyesight, learning and social problems***. Some of these problems will be mild, others will cause delays in development (either alone or in combination), and some will leave lifelong disabilities such as deafness, blindness and cerebral palsy (stiff or weak muscles, tremors affecting movement).

Pēpi bigger than 1800g progress from incubators to cots

Again, your pēpi gestation at birth can be used to predict the likelihood of these problems developing before your pēpi individual life story is known. For example, at 24-25 weeks 20% of pēpi will have a lifelong disability, and 50% have problems affecting their learning. At 28 weeks the chance of a lifelong disability is between 5% and 10%, and learning problems around 15%. Even pēpi born at term have a 3% and 10% chance of these difficulties respectively.

Regular checks at clinic with a paediatrician and from a development follow-up monitoring or early intervention service will be offered to you and your pēpi, depending on the predictions we make.

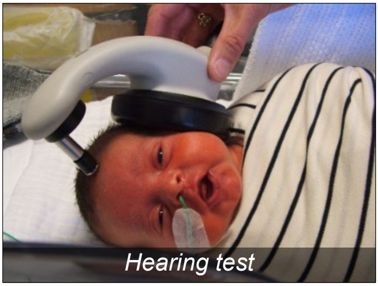
What are the common developmental problems our pēpi may have?

Movement

Pēpi born before 32 weeks can have problems with low muscle tone (floppiness) or high muscle tone (stiffness). Both types of muscle tone can lengthen the time it takes for your pēpi to roll over, sit up by themselves, crawl and walk. Often the level of floppiness and stiffness reduces as the pēpi gets older and the delays are less obvious by the time they are 2 years old. When problems appear to be from a permanent muscle tone problem, your doctor may refer to the particular problem such as cerebral palsy. Even if this diagnosis is made, with help from a physiotherapist and developmental therapists, most children improve and are able to walk. A few (about 3 in every 100 pēpi) are affected more severely and need aids to help them or even a wheelchair.

Fine hand movements are also important for moving small objects, writing, drawing and feeding yourself. Again physiotherapy and occupational therapy can help children learn these skills.

Hearing



Hearing test

The hearing can be affected more so in pēpi less than 30 weeks gestation. About three pēpi in every 100 will need to wear hearing aids. If picked up early there is better chance of having understandable speaking skills. We test the hearing of all pēpi admitted to the neonatal service with an Automated Auditory Brain Stem Response (AABR) before discharge as part of the National Newborn Hearing Screening program.

Pēpi who do not pass this test will be referred to the Audiology Department at Christchurch Hospital. Some will have a further test in the first 2 years even if they passed the AABR screening. All children have their hearing checked again when turning 4. If concerns develop between these checks let your GP or paediatrician know.

Eyesight

About 15% of our pēpi under 30 weeks' gestation show signs of immaturity in the development of their eyes, which is called Retinopathy of Prematurity (ROP). Of these, one or two pēpi per year will need laser treatment or an injection to prevent the retina pulling off from the back of the eye, which can result in blindness. We check your pēpi's eyes every fortnight from 4-6 weeks after birth until the blood vessels have reached the edge of the eye. When problems develop and treatment is given promptly, serious problems can often be avoided. We usually see the problems when your pēpi reaches 33-38 weeks gestation. The main risk for ROP relates to how premature your pēpi was at birth, but also how sick your pēpi has been, and sometimes the effects of high oxygen levels in the blood. Most problems, such as short and long sightedness and squints, are detected over the first few years of life and can be treated with glasses or surgery.

Learning problems

It is difficult to predict long term learning problems from brain scans alone. Learning problems are more common the earlier your pēpi is born. They are more common, about 50% in the extremely preterm (< 28 weeks), than the very preterm (28-31 weeks (20-30%)), older preterm (32-36 weeks (15%)) and term infants (10%). The majority of the problems are mild. They may not be picked up until your child is at preschool or kindergarten, and sometimes not until school when problems with concentration, behaviour and skills such as reading, spelling and doing sums are needed. The range of problems can vary and not all areas are affected in one child.

With education and support most children do well and attend the local school or school of your choice. Some children do need special help in the form of teacher aides and some attend special classes in special schools.

Social development

From birth your pēpi will recognise your voice, smell and touch. Interacting with your pēpi in a gentle, calm way will help them feel safe and secure in their environment. At first they communicate socially in small ways, exploring their surroundings. You may see some of your own characteristics in your pēpi, as you get to know their individual personality. How you interact with them and encourage them to learn impacts their development in many ways. Seek help if you need assistance with getting to know your pēpi. Our support team includes social workers and a Māori Health worker.

How can we as parents care for our pēpi when he/she is so sick?

This is an important question that all parents wonder about. The intensive care unit can seem very high-tech and at first you may feel quite uncomfortable while visiting your pēpi, as well as wondering where you actually fit in with regard to parenting. Remember, no one can replace or challenge your role as parents. Māmā and papa/fathers often have different opportunities and needs.

It is important you discuss any concerns with the nurses caring for your pēpi. Ask as many questions as you can think of so that you can become more informed. This may also help to reduce some of your anxieties. We offer support from our social

Pēpi feel safe being swaddled for bath workers, Māori Kaimahi worker and unit psychologists.

It may not feel possible, but there are many things you can do for your pēpi even though they are so small and fragile. Even if your pēpi is extremely preterm or sick you will generally be able to touch him/her as soon as you see them. Placing your hand on your pēpi’s head or where your pēpi can grasp your finger may seem like small acts but are very important for you as parents and for your pēpi.

Talking and reading to your pēpi is good for later language development. Remember, they have been listening to you talk during the pregnancy and are likely to recognise you both. We have books available for you to use.

Expressing and providing breastmilk

Providing breastmilk is important for the care and health of your infant. Only a māmā’s own milk provides the building blocks required for a healthy infant, and even more so for an infant in the Neonatal Unit. Even if you are unsure of your long-term feeding goals we encourage you to provide colostrum (small amounts of milk in the first week) for your pēpi.

The hospital is set up to help you express for your infant and you will be given a colostrum pack to help you with hand and pump use.

- Early expressing – within the first hour after birth. Birthing Suite staff will help you express.
- Frequent – 8 times in 24 hours. Not by the clock but as often as you can, including once at night.
- Efficient – hand expressing or double pumping, using the electric pumps in Birthing Suite, Maternity or the Neonatal Unit. The pumps have a setting to reflect how a premature pēpi suckles. It is called the initiate programme and has been very successful helping māmā in those first days when everything is overwhelming.

- Pumping log – it is hard to remember a lot of things in those first days so a pumping log will help you keep track of your expressing. Remember, in those first days it’s not about how much you make but how often you express, getting those messages to the brain to make a milk supply. Even 0.2 mL is enough to boost your pēpi’s immunity to cope with life in the Neonatal Unit.

If you are unsure whether or not to breastfeed your pēpi, you need to discuss this with a doctor or nurse on the unit. We have lactation consultants and infant feeding specialists to help you.

The Christchurch Neonatal Unit has the Human Milk Bank, a service to provide screened and pasteurised donor breastmilk in the first week, if you consent. Pasteurised Donor Milk (PDM) is considered safer than formula for pēpi in the Neonatal Unit but cannot replace your own milk for quality, health and safety for your infant.

Providing cares for your pēpi

Cares is a term used to describe such things as changing nappies, taking your pēpi’s temperature, and generally carrying out an assessment of your pēpi. At first, they may seem very small and fragile and you may be too scared to touch pēpi.

We have introduced a concept called Family Integrated Care (FICare) so parents can be involved in a range of cares. There are often opportunities to learn different skills and to become independent and confident caring for your pēpi before discharge.

Kiri ki te kiri /Skin-to-skin care is a lovely way for you as parents to have close contact with your pēpi. Your pēpi is placed on your chest so that Kiri ki te kiri contact occurs. The only thing your pēpi will be wearing is a nappy. Warmth is maintained by placing a blanket over your pēpi, but more importantly by your own body temperature. Kiri ki te kiri care enhances bonding and is an important process in the progress of your pēpi’s physical and emotional wellbeing. It may improve your pēpi’s stability and growth (with less pauses in breathing and a more even heart rate).

The nurse caring for your pēpi will discuss with you whether your pēpi is stable enough to manage a Kiri ki te kiri cuddle.

Skin-to-skin cuddles

Quiet time between 1.00pm and 3.00pm is a special time for parents only to spend with their new pēpi. We try and keep procedures and tests to a minimum during this time as well and keep the unit noise levels down to a minimum.

Visiting times for other close family and siblings can vary so please check with your nurse. Visiting time is usually 3.00 to 8.00pm unless we are overcrowded or dealing with high infection risks. Please ensure visitors are well – no coughs, colds, etc.

How long will our pēpi stay in hospital?

The progress of each preterm pēpi is very individual and time needed in hospital largely depends on how premature your pēpi is. Discharge timing is determined by how well they are going with their feeding and growing, how well they keep warm in a cot and when their breathing problems have resolved. If your pēpi delivers at 23-25 weeks, they will most likely be discharged home a little after their due date. If your pēpi delivers at 25-27 weeks, they will most likely be discharged around their due date, and if your pēpi delivers at 27-32 weeks they will most likely be discharged a few weeks prior to their due date. It is important to remember that these are guidelines only and that some pēpi will be discharged earlier and some later than the above estimates.

Pēpi who are transferred to our neonatal unit from outlying hospitals will be transported to these hospitals as soon as their level of care can be given at the referring unit close to home.

It is our philosophy that parents should be welcomed and encouraged to be with their pēpi at any time, even when their pēpi is very sick or receiving lifesaving treatment. You should be confident that your wishes would be respected in this matter. However, keep in mind that both you and your pēpi will need periods of rest.

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Health New Zealand
Te Whatu Ora