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# Information for Whānau/Family and Friends

Neonatal Services

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## **Congratulations on being an important person in our premature pēpi/baby life!**

Whether it's a boy or a girl, it's a joyous occasion to welcome a new pēpi to the world!

If your relative's or friend's pēpi is in the Neonatal Unit you're probably feeling a mix of emotions. The following information has been written to help you support your relative/friend while their pēpi goes through the neonatal journey.

### **First steps**

*Celebrate!* Even though it's scary, it's okay to share your excitement about a new pēpi. Everyone can be so worried that they forget to share in the joy of the pēpi birth.

*Second*, understand the emotional strain this is causing your relative/friend, and try to put your own needs aside. Many people want to be involved when a pēpi is born, but the Neonatal Service is a whole different experience. Respect your relative/friends' wishes, as hard as this sometimes is.

*Third*, learn about the Neonatal Service and about prematurity. Doing this in your own time can save your relative/friend the strain of having to explain things over and over, which is a burden for many Neonatal Unit parents. You can access information on the Neonatal service website which may be helpful: [Neonatal Service | Te Whatu Ora - Waitaha Canterbury \(cdhb.health.nz\)](https://www.cdhb.health.nz/te-whatu-ora/neonatal-service)

Information on some websites is not always supportive. Avoid sharing scary stories as this will only add to your relative/friend's worry about their pēpi.

### **What are some common emotions that relatives and friends feel?**

You may feel some conflicting emotions. All the feelings listed below are normal and many relatives/friends experience at least some of them. As the pēpi gets stronger, some of the negative feelings may lessen.

- Anxiety and fear over the pēpi medical condition.
- Anger over the difficulties the pēpi and your relative/friend are facing.
- Worry about how your relative/friend is holding up.
- Helplessness over your inability to help the pēpi or ease your relative/friend's distress.

- Pride and joy over the latest addition to the whānau.
- Hope that the pēpi will have the bright future that you and his/her parents want for him/her.

## What to do

There are many awesome things you can do to be a thoughtful and supportive relative/friend. NICU parents are generally so overwhelmed that they often can't say what it is they need, or they are too tired to ask for help. So, when you offer your help, be specific. Give them an exact day you're available, give them a few specific things you could do to help, such as:

- Offer to watch any other children
- Offer to **drive** new mums to the Neonatal Unit
- Offer to **cook meals**.
- Offer to clean the house/do the laundry.
- Keep in touch.
- **Celebrate all the little milestones** the pēpi achieves, eg., transitioning from incubator to cot, coming off the ventilator/oxygen, each weight gain, first feeding attempt.
- Keep an eye out for **changes in mood that may be of concern**, which can affect either parent. Support them to recognise when it's time to get help from a doctor or therapist.

Also remember to:

- **Respect the parents' decisions.** They will have to make many decisions about their pēpi care. Some of these decisions are very difficult, and they may ask your advice. While your advice is important to the parents, they may not always accept it. Even if you don't agree with their decision, accept that the parents are trying to do what they think is best under difficult circumstances.

Keep offering to do these things throughout the Neonatal Unit stay. Many parents find circumstances challenging after the initial excitement wears off. Neonatal stays can span weeks and even months, and they will still appreciate help and support for the entire time. Please don't be discouraged or offended if your relative/friend declines your offers of help – parents all have different ways of coping with the stress of a pēpi in the Neonatal Unit.

## What *not* to do

Having a pēpi in the Neonatal Unit is a very stressful experience for new parents. Most parents experience very intense emotions.

The most important thing to keep in mind is putting the needs of your relative/friend above your own.

Please remember not to:

- **Get upset if you can't visit the pēpi**

The Neonatal Unit has periods of time when only parents are able to visit. Also, many parents want to be the only ones visiting their pēpi. This is normal. So even if you find it frustrating, please respect it.

- **Get upset if you can't hold the pēpi**

As above. Many Neonatal Unit mums in particular are upset that anyone at all is holding their pēpi, and they have to watch nurses and doctors doing things they wish they were doing. One thing they can control is who else gets to hold their pēpi, and sometimes they don't want anyone else to. It's normal, so please respect it.

Also be mindful of the fact that pēpi are admitted to Neonatal Unit for various reasons and there are limits on how long and how often neonatal pēpi can be held by their parents. This can be dependent on when the pēpi was born and the challenges/health concerns they face.

Neonatal team encourage skin-to-skin contact with the pēpi parents, as this is important for many things including bonding and establishing breastfeeding. This bonding time is important for both pēpi and parents. While it may be difficult not being able to have a cuddle, it can be incredibly difficult for your relative/friend when the time they spend with their pēpi is limited. They will let you know when their pēpi is ready for cuddles from extended family/whānau and friends.

- **Ask lots of questions about the pēpi condition or prognosis**

You will want to show your concern, but keep in mind that neonatal parents are worried all the time. Your worries about the pēpi need to come second to theirs.

## What to say

More important than saying anything at all is listening. Asking, “How are you holding up?” and then listening will be incredibly supportive. Celebrate every success the pēpi has, whether it’s breathing for themselves, gaining weight or moving from an incubator to a cot.

Also, these things are great:

- "Congratulations!"
- "Look how sweet s/he is!"
- "S/he looks so strong!"
- "S/he looks like mum/dad/grandma/grandad ..."
- "How are you holding up?"
- "Is there anything I can do to help?"
- “Would you like me to update all our whānau/friends? What would you like them to know?”

## What *not* to say

So many people inadvertently say things that are upsetting to new parents of premature pēpi. If you’re trying to be sensitive and thoughtful, don’t worry about exactly what to say. But here are some classic comments that parents of premature pēpi dislike:

- **"S/He’s so tiny."** Parents are aware of how tiny their pēpi is, and it's a source of great worry. Try to focus on strengths and positives.
- **"Will s/he be ok?"** Parents wonder the same thing and don’t have an answer. Making them remember the worry and the uncertainty is a huge strain. Time will tell. Focus on the now and on the positives.
- **"What did you do wrong? / What caused this prematurity?"** They wonder the same thing and are probably feeling terrible guilt about it – which is misguided. There is nothing that modern medicine can truly do to prevent prematurity and most often it happens despite a mother doing everything ‘right’. So, don’t add to her guilt by implying that she could have prevented it. Even if you thought the mother could have done a ‘better’ job when pregnant, now is not the time to add that burden to a worried whānau.
- **"At least the baby is with great ‘babysitters’."** Sure, Neonatal Unit nurses and doctors are highly trained, but nobody wants their own pēpi to be cared for by someone else.

- **"I don't know how you're doing it! / I wouldn't be strong enough to handle this"** They wish they weren't, and it makes them feel more alone because everyone else thinks they're holding up well when in fact they may be feeling like they're falling apart.
- **"At least you didn't have to gain all that weight."** Nearly all mothers would rather gain all the weight than watch their pēpi face challenges.
- **"When will s/he be in a cot?" / "When will s/he be able to feed for themselves?"** Parents want to know the same thing! It is important to focus on all the small milestones their pēpi achieves as they grow, as they are very exciting steps in their pēpi journey! Shifting their focus to questions they can't answer increases their anxiety levels. Celebrate with them when each milestone happens.
- **"When will s/he come home?"** It seems innocent enough, and it's something you will be curious about. But parents are 100 times more curious about it than you are, and the doctors and nurses simply can't tell them when their pēpi will be ready to go home. Parents of premature pēpi almost always hate this question, so just avoid it if you can.

## **Bring a gift?**

Absolutely!

Premature pēpi deserve gifts too! Many people worry they'll get the 'wrong' thing. Here are some gifts that almost always bring much-needed joy:

- Premature clothes (but not too many – they grow quickly!)
- Stuffed animals (but these often can't go to Neonatal Unit for infection control reasons)
- Gift cards for the hospital cafeteria
- Gift cards for petrol, groceries, restaurants
- Books to read aloud to pēpi
- Care packages filled with snacks, a journal, hand lotion, and other goodies
- A massage or day at the spa, or any treat you know your relative/friend will love

## **Remember!**

Once the pēpi goes home from the Neonatal Unit, s/he can still be medically fragile. They may have left the Neonatal Unit, but they often require special care and attention to help them succeed at home. Your relative or friend will have been given a lot of information from the Neonatal Unit team on how to best care for their pēpi. Your relative/friend will be the best guides for you in how to hold/feed/care for this pēpi, so make sure you ask them if there are any special considerations you need to keep in mind when helping them to care for their pēpi.

**Congratulations** on being an important person in this premature pēpi life! The kindness and support you give his/her parents will be extremely important over the next few weeks and can make a huge difference in all their lives

**Te Whatu Ora**  
Health New Zealand  
Waitaha Canterbury