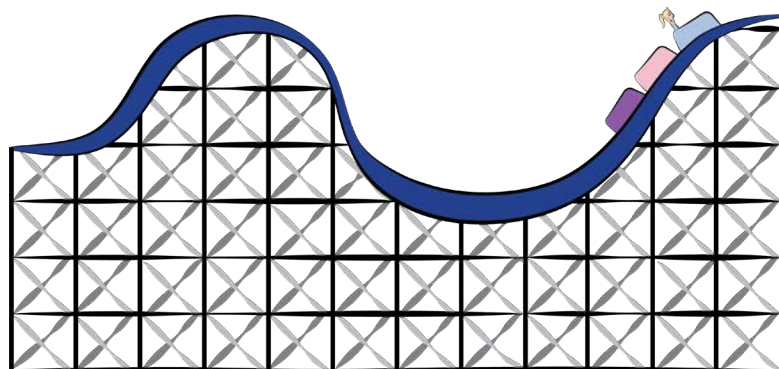


Your Neonatal Journey

This document is a high level guide for your neonatal journey. It's designed to be an easy read of key information and useful tips. These have been created from credible research, the insights of neonatal unit staff and the experiences of people who have been on a neonatal journey. We understand that all journeys are different, so please take what you like from this document and leave behind what you don't want.



With many ups and downs, and twists and turns, a neonatal journey is often described as a rollercoaster. Our best wishes go to families currently on a neonatal journey. We hope the support resources we have created help you to navigate your journey.

Our Support

The information provided in this document is purposely high level. The aim is to provide key information and let you know what is available in more detail. For each section, we have more information available as a standalone resource that be easily downloaded and/or printed. These can be accessed at www.neonataltrust.org.nz/support and include support resources to give an insight into, and/or the benefits of:

- Reading to your Baby
- Kangaroo Cuddles
- Bonding with your Baby
- Sensory Processing
- Leaving the Unit
- and many more

ps, If you have an insight or survival tip that we have missed, please share as we look to make ongoing enhancements to our support resources.

These can be sent to info@neonataltrust.org.nz



SUPPORT RESOURCES

The support we provide for families is delivered in a number of different ways, all aimed at

“MAKING A DIFFICULT START TO LIFE THAT LITTLE BIT EASIER”

This includes the support and education material we've developed with the help of graduate parents of a NICU and/or SCBU journey.

You can find these at:

www.neonataltrust.org.nz/support

THINK REF

If you are on a neonatal journey, think REF!

Rest. Exercise. Food.

A parent's natural instinct is to put all of their focus into looking after their precious new baby. However, this can often come at the detriment of looking after yourself. Rest, Exercise and Nutrition may fall by the wayside. Taking care of yourself is especially important so you can give your baby the best possible care and attention.

We know this intuitively. Numerous studies have also shown babies do better being interacted with, read to and cuddled (etc). These are all things parents are more likely to do if they are feeling good themselves. To learn more about this, and check out our support resources, please head to

www.neonataltrust.org.nz/support



www.neonataltrust.org.nz/support

the
neonatal
trust

READING TO YOUR BABY

Reading to your baby has many benefits.

Talking, reading or even singing quietly to your baby will soothe and reassure them. It also helps them to develop good language and communication skills.

Your baby has heard voices and sounds from inside the womb and continuing this will help both you and your baby. Even the smallest babies recognise the tone of voice and speech patterns of their families. If you can't (yet) hold your baby, reading to them helps provide a connection and bonding as your baby loves to hear your voice as it makes them feel calm and safe. It doesn't matter what you read, just choose a couple of books you feel comfortable with and get started.



Note, please remember to speak softly as loud noises can be scary and the volume has previously been muffled in the womb.

Access this resource and all of our support material, at www.neonataltrust.org.nz/support

/// KANGAROO CUDDLES //////////////////////////////////////



Once babies are well enough, they can be taken out of their incubators and placed on their parent's chest. Inspired by kangaroos and other marsupials that nurture their young in a pouch, this enables the baby to get skin-to-skin contact and hear and feel the parent's heartbeat.

Much more than a way to keep babies warm, babies generally improve when they're being held by their parents. They've been listening to your voices in the womb and even the smallest babies recognise their parents tone of voice and speech patterns.

Multiple studies have proven that it has a number of benefits for parents and for babies including:

- Fewer breathing problems
- Faster weight gain
- Less energy-wasting fidgeting
- A more constant body temperature

Access this resource and all of our support material, at www.neonataltrust.org.nz/support

GLOSSARY

The world of neonatal care most definitely has a language all of its own. While on your neonatal journey, you'll hear many words and medical terms which can seem a little overwhelming at first. We have created a glossary of the most commonly used medical and clinical terms, plus abbreviations you may encounter.

If you hear a term used that you don't understand, please ask your baby's nurse or doctor to explain it or write it down for you. Being able to understand neonatal language will help you feel more informed about the care your baby receives and is another step towards making a difficult start to life a little easier.

You can download the glossary as a PDF from:
www.neonataltrust.org.nz/glossary

B

Baby wearing

The practice of "wearing" or carrying baby in a baby wrap on the chest. This can help develop security, bonding and deeper sleep for baby. Can help increase breast milk production.

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

One of the breakdown product of red blood cells.

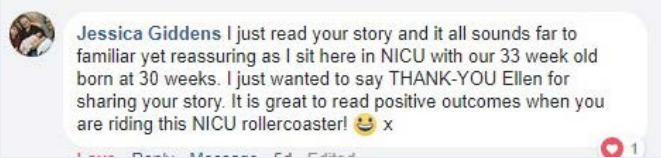


PERSONAL STORIES

We receive a lot of positive feedback from families in a neonatal unit who read the personal stories shared by others. They talk of feeling strength, hope and positivity knowing that they are not alone going through these experiences and feeling certain emotions.

We've aggregated a number of personal stories covering a range of different journeys – from very early babies through to full term babies with health complications, plus an example of the early arrival of twins, and more.

Seek these out at
www.neonataltrust.org.nz/personal-stories



MILESTONE CARDS

Neonatal journeys can be like riding a roller coaster - with ups and downs and twists and turns. To help with the celebration of key events our resources include Milestone cards to use in your special photos. They cover a range of achievements such as reaching weight milestones, special firsts such as bathing, kangaroo cuddles, and more.

To borrow the cards to use in your photos ask the team in your NICU or SCBU, as we've provided a set to all neonatal units across New Zealand. To see a list of the cards available, head to www.neonataltrust.org.nz/milestones



GRADUATION CERTIFICATES

Going home for the first time after a neonatal journey is a very special moment. No matter how long your stay in a Neonatal Intensive Care Unit (NICU) and/or Special Care Baby Unit (SCBU) was, the journeys are different to what you expected. To help you celebrate this milestone, we have prepared Graduation Certificates for you – one for every neonatal unit in New Zealand.

Head to www.neonataltrust.org.nz/graduation-certificates where you will find links for your NICU and SCBU. Simply click on the link to open the PDF which you can print and/or download.



GOING HOME

You may have been in hospital for quite some time and now the big day has arrived. Heading home can often bring mixed emotions and be rather overwhelming, especially if your baby is coming home tube feeding, on oxygen or with medical issues. Working with parents who have been there and reflected on what helped them, we've developed a resource with a few things to consider and questions to ask.

Access this resource and all of our support material, at www.neonataltrust.org.nz/support



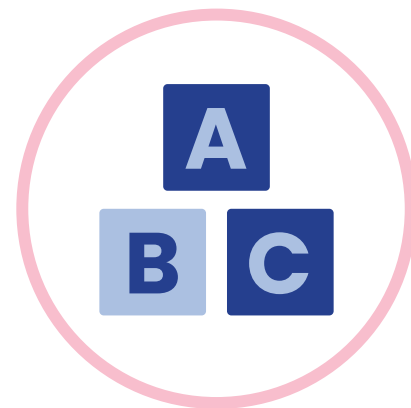
EARLY INTERVENTION

SOME OF THE QUESTIONS PARENTS ASK WHEN LEAVING THE UNIT ARE

'Will my baby's development be normal?'

'What's corrected age?'

'Will they have learning difficulties?'



'What can I do to help encourage their development?'

It's reassuring to know that most premature babies have normal development. Extremely premature, or low birth weight and sick babies have a higher risk of development problems – but even in these cases, many babies develop normally.

Early intervention can be used to describe a number of ways that professionals can support children and whanau to have the best outcome for their child. It's used to help families whose children have special needs, developmental delays or behavioural issues to help minimise these and to allow them to reach developmental milestones and grow in all areas of their life.

Research shows that early is the key to supporting children and making progress with their learning and development, the idea is to lessen the effect of the disability or delay. These areas can include, physical, cognitive, communication, social, emotional and adaptive.

To learn more, and access all of the support resources available, head to:

www.neonataltrust.org.nz/support

KEEP INFORMED

To keep in touch with 'all things neonatal' you can:



Head to our website

From support documents to shared personal stories, our website is a good place to start for those wanting to learn more about neonatal journeys

www.neonataltrust.org.nz



Sign up for our monthly email newsletter

This shares our latest news and provides links to key information. To receive this, you can quickly and securely add your details at:

www.neonataltrust.org.nz/connecting



Like us on Facebook

Here you can be kept in touch with stories and information to support you through your neonatal journey

www.facebook.com/neonataltrustnz



Follow us on Twitter

Twitter is a great way to keep up to date on a range of updates from The Neonatal Trust

www.twitter.com/neonatalnz



Follow us on Instagram

Instagram is where we share updates and images on all things neonatal

[@the_neonatal_trust](https://www.instagram.com/the_neonatal_trust)

www.neonataltrust.org.nz/support

FAMOUS PREMS

Prematurity isn't a new thing. In fact many high achievers had an early entrance. Some of these were born centuries ago and battled incredible odds to survive in the first place given the conditions and knowledge at the time. They then went on to achieve incredible things in the creative, academic, science and leadership fields. While every journey is different, and the outcomes cannot be pre-determined, we've received a lot of positive feedback that it's great to hear of high achievers, including:

Wayde van Niekerk

Born at 29 weeks and weighing just over 1kg, Wayde van Niekerk's parents never thought he would survive, let alone become a successful athlete. At the Rio 2016 Olympic Games he made history winning South Africa's first gold medal since readmission. He won the men's 400m event in 43.03 seconds, smashing the world record at the same time.



Albert Einstein

Physicist and Nobel Prize Winner in 1921, he was born early in Ulm, Germany in March 1879. Albert Einstein contributed more than any other scientist to the 20th-century vision of physical reality. At his birth, Albert's mother was reputedly frightened that her infant's head was so large and oddly shaped. His parents also worried about his intellectual development as a child due to his initial language delay and his lack of fluency until the age of nine, though he was one of the top students in his elementary school and then progressed rapidly from there.

Anna Pavlova

Born prematurely in 1885, Anna Pavlova became one of the world's most famous ballerinas. Her small size and stature, likely a result of her premature birth, set her apart from other ballerinas of the time.



Other 'famous prems' include:



Character images on this page created by the talented Tania of [Drawer Full of Giants](https://www.instagram.com/drawerfullofgiants).

For printing and sharing, get the PDF of 'famous prems' at www.neonataltrust.org.nz/famous-prems

SUPPORT RESOURCES

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Learn more at www.neonataltrust.org.nz/think-ref

Reading to your Baby

A resource to encourage a practise that helps both parents and the baby



Kangaroo Cuddles

Learn about this practice that is great for both bonding and development



Bonding with your Baby

Thoughts on, and tips for, connecting with your neonatal baby



Your Emotions

A resource to help with the emotions you're feeling



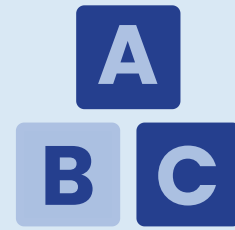
Tips for Dads

Written by Dads who have been there, a resource to help neonatal fathers



Supporting Development*

Learn how to best stimulate your baby with tips to help your baby learn and develop



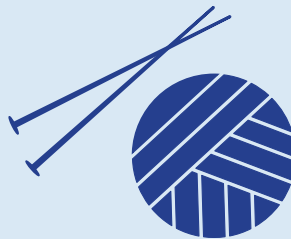
Sensory Processing*

A resource to help your baby deal with the barrage of sensory input in the world



Benefits of Knitting

Wool is a 100% natural fibre. Learn about the many benefits of knitting



Leaving the Unit

Tips and things to think about as you prepare to take your precious baby home



*Produced in partnership with, and using the research based material of, *Baby Sensory*



www.neonataltrust.org.nz/support

