

Tiny Baby Parent Handbook

Surrey Memorial Hospital
Neonatal Intensive Care Unit



Image by Jen Stirling.
Used with permission.

A “tiny baby” is either:

- a baby born before the person giving birth is 28 weeks pregnant
- a baby born weighing less than 1000 grams



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Congratulations on your new tiny baby! We understand this might be a stressful time for you and your family. We hope this booklet helps you learn what to expect about your journey in the NICU (say *nick-you*).

We are here to help your baby and you. We are happy to answer your questions. Together, we partner to meet your baby's needs but don't just take our word for it.

What some tiny baby parents said about their journey

We are grateful to the Kandolas, Chands, Shims, and Lieschs for sharing their stories. These are their words.

The Kandolas

Angad Singh Kandola was born at 28 weeks, weighing just 660 grams. He spent 112 days in the Surrey Memorial Hospital and BC Children's Hospital NICUs. He beat all the odds and came home.

I had severe IUGR (intra uterine growth restriction) and went for an emergency C-section. We were not ready for the early arrival of our son.

Our NICU journey was a roller coaster. But you need to be patient throughout the journey. Our patience and positive attitude made us strong and our fighter, Angad, fought this battle and won.

Thank you to the whole NICU family for taking care of our baby and for always standing by our side in this journey.

The Chands

Our twin girls were born at 27 weeks. Baby A weighed 870 grams and Baby B weighed 1020 grams. They were in NICU for 12 weeks. Going through this journey has its ups and downs.

As a parent, you are scared and only want your baby to be safe and healthy. When I first saw our newborn babies in NICU, I remember feeling so helpless. Being present and involved makes a huge difference in your babies' medical progress and development.



The medical professionals were always available to answer all my questions around the clock (24/7) and the specialist would allow us to ask questions during the morning rounds. No question is “stupid” when it comes to the care and health of your baby. Whether it’s regarding a procedure, terminology being used, stats on the monitor, physiotherapy, nutrition, etc. You are your child’s advocate.

Everyone is there to truly help and they become like family over time! The time spent in NICU with your baby will forever be a part of you.



The Shims

After 55 days admitted to antepartum in the Family Birthing Unit, Anja was born at 26 weeks and 5 days. She weighed 820 grams and measured 31.5 cm long. We spent 141 days at the Surrey Memorial Hospital NICU, and between balancing our micropremie daughter, our 3-year-old at home, and a worldwide pandemic, it was truly one of the most difficult few months of our lives.

When we came to the NICU the first time, we had no idea what the road ahead would be, or how hard it would be to navigate. The NICU staff and other micropremie parents were so supportive to us, and walked us through each step of our difficult journey. Every test, every trial, every tear is a challenge, and it's heartbreaking to walk out the doors each day.



We reminded ourselves that we were running a marathon, to take each step one at a time and celebrate every milestone.

We still miss the NICU staff who not only saved Anja's life but cared for her so well, though we are also so happy to be at home as a family of 4.



The Lieschs

Judah (our youngest) was born at 25 weeks and 5 days, on July 15, 2016.

My water broke at 19 weeks after a tough pregnancy, and I spent 3 weeks in the antenatal department before he was born. Judah went on to spend 181 days in both the Surrey Memorial Hospital NICU and BC Children's Hospital NICU before he was able to come home.

Judah is now a happy and healthy, thriving little boy.



How to take part in your tiny baby's care

Babies get the best care when we work together with you. You are the most important people to your baby and an important part of your baby's care team. We can support you to take part in as much of your baby's care as possible.

The NICU can be noisy and busy. Members of your baby's care team can change every day. This can all cause stress for your tiny baby. Parents can help reduce baby's stress. You are baby's consistent people and the best source of love and comfort.

You are welcome in the NICU 24 hours a day, 7 days a week. We hope to see you in the NICU as much as possible. We give your baby the best care possible, but baby knows when you are here. Baby knows how you sound, smell, and feel. A parent's care is special because only you can give it. All of these things help your baby grow and develop:

- your voice
- your scent
- your touch
- your milk
- your love

There are many benefits when parents are present and involved in their baby's care. Benefits include parents and babies building stronger bonds, and babies learning about and feeling the love of their parents. This is why it is best to be present and involved as soon after birth as possible and as much as possible.

The memories you make in the NICU stay with you forever. We look forward to taking part in this journey with baby and you.

Getting medical care in the NICU can be stressful for your baby. We can support your baby but baby knows we are not you. Your baby needs and wants you to bring them comfort.

We can show you how to give hand hugs safely so you can comfort your baby while they get medical care. Medical care can include any of these activities:

- Handling times when your baby's nurse gives care, such as feeding or changing diapers.
- Changing the breathing mask or breathing prongs of baby's breathing machine.
- Suctioning with a thin tube to remove mucus from baby's mouth or lungs.
- Placing a feeding tube to deliver nutrition to your baby.
- Placing an intravenous (say *in-tra-vee-nuss*, also called "IV") tube to deliver fluids, medicines, or nutrition to your baby.
- Taking blood from your baby's heel for blood tests.
- Looking at your baby's brain or heart with an ultrasound machine.

It is normal to have many questions. Ask us questions and tell us when you need help.

More members of your tiny baby's care team

Many people work together as part of your tiny baby's care team in the NICU. Read this list to learn how we help your tiny baby.

We partner with you to meet your baby's needs. We cannot do this without you.

I'm so thankful I got to be there for rounds every day. My baby's condition was so up and down. It was so nice to be part of rounds every day so I could ask questions as they came up.

Mom of tiny baby born at 26 weeks

Here are some members of your tiny baby's care team:

Clinical Associate (also called "CA")

This is a pediatrician (say *pee-dee-a-trish-shun*, also called "children's doctor"). They work with the neonatologist to care for your baby.

Lactation Consultant (also called "LC")

This is a healthcare provider with special training in breastfeeding or chestfeeding. They can talk to you about how to increase your milk supply and how to use a breast pump.

Music Therapist

This care team member is an expert at using music to lower baby's heart rate and stress. In the NICU, your baby and you can work with the music therapist when baby is ready.

Music therapy is a great way for your baby and you to bond. Humming and singing your favourite nursery rhymes or songs can help your baby and you.

Neonatologist (say *nee-oh-nay-tall-oh-gist*, also called "Neo")

This is your baby's main doctor. They are a pediatrician (say *pee-dee-a-trish-shun*, also called "children's doctor").

They have the extra training needed to care for the babies in our NICU.

NICU Aide

This care team member helps us work safely. They clean equipment and check that we have the supplies we need.

Occupational (say *awk-you-pay-shun-null*) Therapist (also called "OT")

This is a therapist with special training in how babies grow and develop. In the NICU, they teach you different ways to help your baby develop. As part of the feeding team, they support your baby and you to learn different ways to be successful with feeding.

Parent Mentors

These care team members are volunteers. Their babies were once in the NICU. Parent mentors support parents like you by sharing their story and listening to yours.

Patient Care Coordinator (also called “PCC” or “charge nurse”)

This is a registered nurse. They coordinate care in the NICU. They help the members of your baby’s care team get the information they need to care for your baby. We invite you to talk with the PCC. Ask your questions and share any concerns about your baby’s care.

Physiotherapist (say *fizzy-oh-thair-a-pist*, also called “PT”)

This is a therapist with special training in the brain and body. In the NICU, they teach you how to help your baby’s brain, muscles, joints, and lungs grow and develop. They also help you get ready to take baby home.

Registered Dietitian (say *di-yet-tish-shun*)

This is a healthcare provider with special training in choosing the right foods and fluids for each baby’s health needs. They check that babies get the nutrients they need to help them grow as well as possible.

Registered Nurse (also called “RN”)

This nurse has extra training to give the special care your baby needs in the NICU. They care for 1 to 3 babies each day.

Registered Pharmacist

This healthcare provider is an expert in medicines and health. They can answer questions about the medicines you or your baby are getting. They can answer these questions and more:

- What are the medicines for?
- Are there any side effects?
- Is it okay to breastfeed or chestfeed while taking medicines?

The pharmacist is available daily in the NICU. They work with your baby's care team to be sure your baby gets the medicines and nutrients they need.

Respiratory (say *resp-pra-tow-ree*) Therapist (also called "RT")

This is a therapist with special training in the breathing system and treating breathing problems. In the NICU, they help babies with their breathing and breathing machines.

Social Worker

This is a healthcare provider with special training to support you and your family during challenging times. In the NICU, they meet with families who have a tiny baby. They can teach you different ways to cope with stress. Ask them about different services that help families of tiny babies.

Speech Language Pathologist (say *path-thaw-low-gist*, also called “SLP”)

This is a therapist with special training in how the muscles of the mouth, throat, and breathing work. In the NICU, they are part of the feeding team. They help your baby feed and swallow safely, and help you learn about how your baby communicates.

Unit Clerk

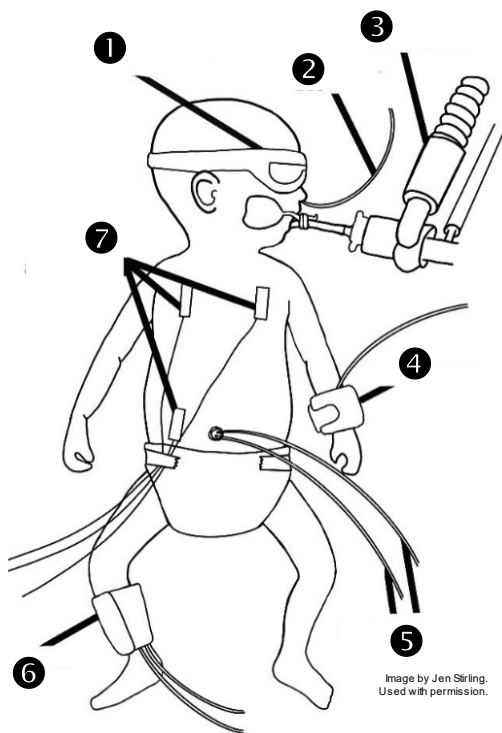
This is usually the first person to greet and welcome you when you enter the NICU.

Your tiny baby's tubes and wires

It can be scary to see your tiny baby connected to tubes and wires. They help keep your baby safe. If you have questions about the tubes and wires, please ask your baby's nurse.

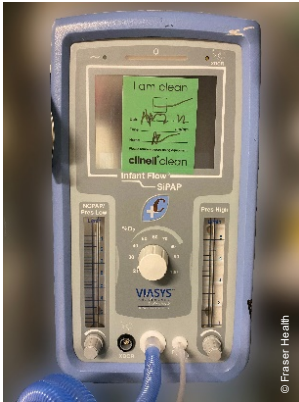
Baby with breathing tube

Some babies need extra help to breathe. These babies use a breathing tube, also called endotracheal (say *end-doh-tray-key-yul*) tube, that connects their lungs to a machine like the one in this photo. This machine, called a ventilator, helps them breathe.



- ① Eye shield
- ② NG (nasogastric) feeding tube
- ③ Endotracheal breathing tubing
- ④ Oxygen sat probe (shows level of oxygen in the blood)
- ⑤ Umbilical lines
- ⑥ BP (blood pressure) cuff
- ⑦ ECG leads (monitor wires)

Image by Jen Stirling.
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Baby with CPAP (say *see-pap*, continuous positive airway pressure)
Some babies can breathe on their own but need help to keep their airways open. These babies wear a mask over their nose. A CPAP machine, like the one in this photo, delivers extra air and oxygen through the mask to help babies breathe better.

A CPAP cap helps keep baby comfortable and keeps CPAP tubing in the right place.

- ① CPAP breathing tubing
- ② Eye shield
- ③ CPAP cap
- ④ ECG leads (monitor wires)
- ⑤ BP (blood pressure) cuff
- ⑥ Umbilical lines
- ⑦ Oxygen sat probe (shows level of oxygen in the blood)
- ⑧ OG (orogastric) feeding tube

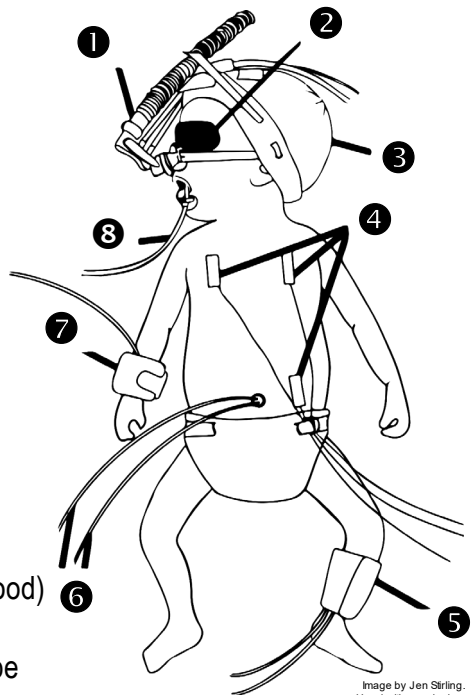


Image by Jen Stirling.
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Equipment in your tiny baby's room

Your tiny baby can look even smaller next to all the equipment in their room. All of it helps keep your baby safe.



The equipment is very sensitive. Please do not touch any of the buttons on the equipment. Their alarms are not there to scare you. They help keep your baby safe. If you have any questions about the equipment, please ask your baby's nurse or respiratory therapist.

Monitor

The monitor shows information about your baby's health. Baby wears monitor wires that send information to the monitor, such as:

- how fast baby's heart is beating, called heart rate
- how fast baby is breathing, called respiratory rate
- how much oxygen is in baby's blood, called blood oxygen level (or "oxygen saturation" or "oxygen sat")

The most common sounds in the NICU are alarms that come from the monitors. These are some of the alarms:

- brady (say *brad-dee*) when baby's heart rate is lower than their usual heart rate
- desaturation (also called "desat") when baby's blood oxygen level is lower than their usual level
- apnea (say *app-nee-ah*) when baby is holding their breath

Your baby's monitor might alarm but not every alarm is for your baby. Your baby's monitor can also show information for other babies. We invite you to ask your baby's nurse for more information about the alarms.

Isolette (say eye-so-let, also called “incubator”)



The isolette helps keep your baby warm and safe. Ask about how to have skin-to-skin contact when baby is inside the isolette.

Intravenous (say in-tra-vee-nuss, also called “IV”) Pump



IV pumps control some of the fluids, medicines, and nutrition your baby needs.

Whiteboard

UNDERSTANDING MY STAY		
My Name:	Preferred Language:	My Family:
Today's Date:	My Nurse Today is:	My Doctor Today is:
I'm Hoping To Go Home On:	Today's Plan/Goals:	What does your baby's important for your baby:
I Can Do Home When:	Messages From My Family:	

A whiteboard is on the wall in your baby's room. Any member of your baby's care team can write on it, including you. Tell us if you cannot find the whiteboard pen.

Use the whiteboard for all of these reasons:

- To tell us about you and your family.
- To write your questions and comments.
- To remember our names and the plan for the day.

A day in the NICU for your tiny baby

Life in the NICU can be unexpected and challenging. You are learning about your new baby, your role as a parent of a tiny baby, and the many activities in the NICU.

Finding a routine that works for you and your baby can help you cope. Help us help you. Talk to us about what you hope and expect for your journey in the NICU.

Here are some activities you can expect every day in the NICU.

Rounds

Rounds are when the care team meets to review the needs of each baby. We meet every day outside each baby's room. Most days, rounds start in the morning and can last several hours.

You are an important part of your baby's care team. We invite you to take part in rounds and ask questions. This is the best time to connect with most members of the care team.

Nurses and a doctor meet for a short time during the night shift. If you miss morning rounds, ask your baby's nurse about taking part in this meeting.

Skin-to-Skin

Skin-to-skin contact is one of the best ways to help your baby and you. It is best to start as soon as possible and can often start soon after birth. Ask your baby's nurse or therapist about holding baby's bare chest on your bare chest or giving hand hugs in the isolette.



Scan this QR code to learn more about skin-to-skin contact.

Or, visit patienteduc.fraserhealth.ca.

Then, search "skin to skin neonatal".

Handling Times

During the first few days in the NICU, your baby's nurse gives care to your baby at specific times. We call them handling times or handles. Handles can include all of these activities:

- checking how your baby is growing and developing, called an "assessment"
- changing baby's diaper
- taking baby's temperature
- feeding

You can expect handles about every 4 to 6 hours. Sleep is very important to tiny babies. It is best not to wake them between their handles.

Your baby's nurse can tell you the handling times for that day. Please plan your day so that you are here at these times. You can bring comfort to your baby and take part in their care. As you get more comfortable, you can help weigh your baby during the night shift.

Pumping

To help start and increase your milk supply, use the pump in your baby's room every 2 to 3 hours. Please keep this pump in your baby's room. Your baby's nurse or lactation consultant can teach you about the pump.

Your milk is the best food for your baby. Your first milk is called colostrum. It is best to give colostrum, with all its important nutrients, to your baby as soon as possible.



Scan this QR code to learn more about pumping.

Or, visit patienteduc.fraserhealth.ca.

Then, search "expressing your breast milk".

What to expect in your tiny baby's first 2 weeks

Every person and situation is different but it is good to know about the activities, tubes, and ultrasounds you might expect in your tiny baby's first 2 weeks.

Activities

First few hours: focus on breathing and stay warm

This is a busy time in your baby's life. Expect the focus to be on helping baby breathe and stay warm.

Days 1 to 3: hand hugs and handles

Hand hugs and handles are great ways to bond with your baby. Ask your baby's nurse how you can take part in these activities safely.

Days 1 to 7: phototherapy

Phototherapy can help babies with jaundice (say *jon-diss*). This special light helps baby reduce their bilirubin. Baby wears an eye shield to protect their eyes from this light.

Jaundice is yellowing of baby's skin, palms of their hands, and soles of their feet. Usually, the liver removes bilirubin from the body, but a tiny baby's liver does not do this fast enough. This is why it is common to see jaundice in tiny babies.

Days 3 to 4: more therapy

Expect to meet with a physiotherapist or occupational therapist to learn different ways you can support how your baby develops.

Tubes

First few hours: umbilical catheters (also called “umbilical lines”)

Most tiny babies need these special intravenous tubes.

They are used to take blood and deliver fluids, medicines, and nutrition. Umbilical lines are placed in baby’s belly button.

Days 1 to 3: feeding tube

When baby is ready, they get milk through a feeding tube that passes from their mouth or nose into their stomach. We gently insert one of these feeding tubes:

- An orogastric or “OG” tube passes through baby’s mouth.
- A nasogastric or “NG” tube passes through baby’s nose.

Your milk is the best food for your baby. If your milk is not yet “in”, we talk to you about feeding with pasteurized milk from a donor.

Days 5 to 7: PICC (*saypick*, peripherally inserted central catheter)

This special intravenous tube can be placed in baby’s arm or leg. When babies need antibiotics or nutrition for more than a few days, we consider placing a PICC.

Ultrasounds

Head ultrasound: day 3 or 4 and between days 10 to 14

Tiny babies can have bleeding in the brain. This is called intraventricular hemorrhage (*say in-tra-vent-trick-cue-lurr hem-rudge* or “IVH”). We use ultrasound to check for bleeding.

Heart ultrasound, called an “echocardiogram” or “echo”:
between days 7 to 14

If we need to check how your baby’s heart is developing, they can get this ultrasound.

Bringing your tiny baby home

It is normal for parents who are starting their journey in the NICU to wonder when they can take baby home.

Babies in the NICU go home when they are ready. They are ready when they are doing all of these things:

- breathing on their own
- feeding by mouth
- gaining enough weight
- meeting the minimum height and weight limits for their car seat
- showing no breathing or heartbeat alarms on the monitor for 5 days

Often, babies born early go home close to their due date. It is normal for some tiny babies to stay in the hospital a few weeks longer.

Words to know

Antepartum unit	The place in the hospital where you find people expecting to give birth.
Cesarean section Also called “c-section”.	Surgery when a baby is delivered through a cut in the parent’s abdomen and womb.
Feeding tube	<p>A soft, thin tube put in through the mouth or nose, down the throat, and into the stomach. This tube is a temporary way to feed baby.</p> <p>There are 2 types of feeding tubes:</p> <ul style="list-style-type: none"> - orogastric or “OG” tube - nasogastric or “NG” tube
Handles or handling times	When your baby’s nurse gives care, such as feeding or changing diapers.
Intrauterine growth restriction	When baby in the womb is not growing as expected.
Intravenous (say <i>in-tra-vee-nuss</i>)	<p>Also called “IV” (sounds like eye-vee).</p> <p>An IV tube is a small, soft, thin tube put in your baby’s vein. We can use it to deliver fluids, medicines, and nutrition.</p> <p>An IV pump is a machine that controls the fluids we give through the IV tube.</p>

Nasogastric (NG) feeding tube	A soft, thin tube put in through one nostril, down the throat, and into the stomach. This tube is a temporary way to feed baby.
Neonatal Intensive Care Unit (NICU)	The place in the hospital where staff have extra training to give care to ill or premature newborn babies.
Orogastric (OG) feeding tube	A soft, thin tube put in through the mouth, down the throat, and into the stomach. This tube is a temporary way to feed baby.
Tiny babies	<p>Babies born either:</p> <ul style="list-style-type: none"> - before the person giving birth is 28 weeks pregnant - weighing less than 1000 grams
Ultrasound	Scan that can show different parts of the inside of the body using high-frequency sound waves.
Whiteboard	<p>Poster in baby's room in the NICU that any member of the care team can write on, including you. It can help you remember these things and more:</p> <ul style="list-style-type: none"> - your questions and comments for us - names of members of your baby's care team - plan for the day

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This information does not replace the advice given to you by your healthcare provider.

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