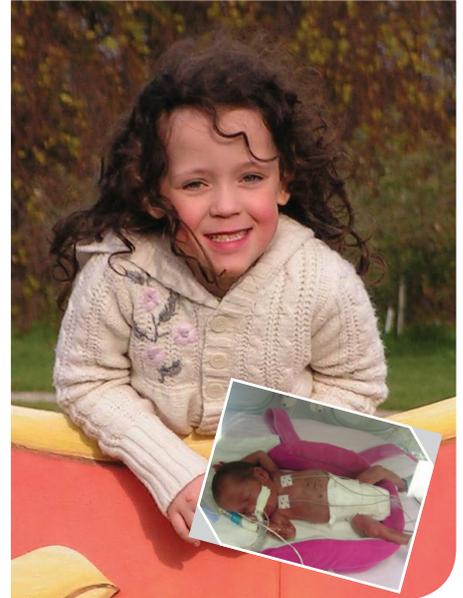




Welcome to Sunnybrook NICU



A Guide for Parents and Families of NICU Babies



As a parent in the NICU, you are not a visitor. You are your baby's voice, you are a vital part of your baby's team, and you are welcome here 24 hours a day. You are the most important person for your baby.

When your baby is in the NICU, he/she needs you. We can provide excellent, state of the art medical and technical care, and we can provide comfort, warmth and affection for your baby, but we cannot parent your baby.

As a parent, you provide love and devotion to your baby that only a parent can. We in the NICU want you to be with your baby as often as you can.

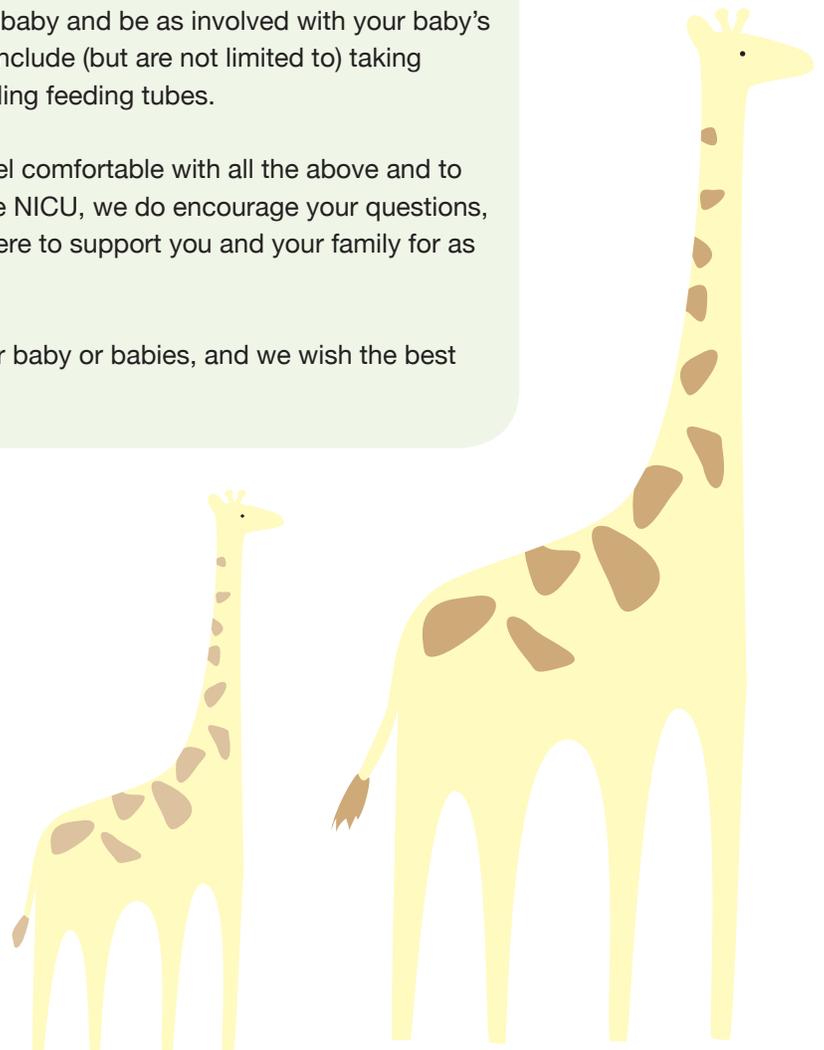
Only you can tell family stories, sing your favorite songs, wear the HUG buddy blanket, do Kangaroo Care, provide breastmilk, breastfeed, bottle feed, and cuddle or "hand hug" with your baby in a way that is unique to you.

Some babies need the NICU in order to survive; all babies in the NICU need a parent's loving touch to thrive.

We encourage you to interact with your baby and be as involved with your baby's care as possible. Activities you can do include (but are not limited to) taking temperatures, changing diapers, or holding feeding tubes.

While this guide is meant to help you feel comfortable with all the above and to give you information you need about the NICU, we do encourage your questions, and we want you to know our team is here to support you and your family for as long as you are with us.

We congratulate you on the birth of your baby or babies, and we wish the best for you and your family.



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An Intro to the NICU

We want to help parents who are new to the NICU world understand how it works.

It is OKAY to:

- Ask questions. There are no stupid questions in the NICU. It's also OK if you need to ask a question again; there's a lot for you to learn.
- Read your baby's medical and clipboard chart. We want you to ask questions if you do not understand words or meanings.
- Ask for the name of any of the health care providers who are caring for your baby.
- Ask to speak with the doctor.
- Be at your baby's bedside whenever you can. We encourage you to take part in medical rounds. Ask your nurse when they will take place. Also, you do not need to leave during shift change.
- Write your question(s) down so you can be reminded to ask them during rounds, when you call in, or when speaking to the doctor
- Ask people if they have cleaned their hands or remind them to do so before they handle your baby. Hand washing, with alcohol hand scrub or with soap and water if they are visibly soiled, can save lives in the NICU.
- Find out who your social worker is. Social workers are here to help all families.
- Be present during procedures performed on your baby; you may be able to hold your baby's soother or hand. However, when the procedure requires a 'sterile' field, this may not be possible. It may be difficult for you to watch your baby having a procedure done. It is okay for you to wait outside the room or leave part way through and come back to comfort your baby when the procedure has been completed. If you stay with your baby, you may not interfere with the procedure. If you feel faint, ask for help to sit down or to move out of the room.
- Ask your baby's nurse if your baby is ready to do Kangaroo Care. Many babies on ventilators, though not all, are able to come out for Kangaroo Care.
- Ask for help. If you are feeling sad, anxious or isolated, let us know. If a friend, partner, spouse or family member is hurting you, please ask us to help. You may ask your nurse to arrange for a social worker to meet with you. You do not need to explain why. You may also contact the social worker on your own (see pg. 19). Abuse often starts during pregnancy or becomes worse during this time. Abuse incidents are higher in families with premature babies. Please let us help you, so you can be healthy to help your baby.

What is not okay in the NICU, for anyone...

- Not respecting the NICU infection control policies. If you are not well, you must stay home. Babies need healthy parents and are also very vulnerable to infections. Also, everyone in the NICU must follow strict hand hygiene guidelines which will help keep everyone safe.
- Not respecting other NICU families or staff. If you encounter a personality problem with an individual, take it to the charge nurse for immediate response. You can contact the Program Director, Patient Care manager, Parent Coordinator, Chief Neonatologist or the Sunnybrook Patient Relations Office. (See telephone numbers, pg 19).
- Violence by anyone in our workspace is not tolerated; security personnel and/or Toronto Police will be called if these situations occur.

Everyone needs to feel safe in the NICU environment.

While the NICU is caring for your baby, who is caring for you?

Spending even a short time in the NICU may be stressful. The NICU staff is concerned not only for your baby's well-being, but for yours as well. Babies need healthy, confident families to take them home. Emotions in the NICU are different for each person; you may find it is like being on a roller coaster, up one minute and down the next. The uncertainty is not easy to deal with, along with all your "outside the NICU" life commitments. Your bedside nurse, charge nurse, social worker, lactation consultant, parent coordinator and other consultant(s) can help with:

- Emotional support (professional counseling or just a shoulder to lean on)
- Financial guidance (from learning about social assistance to finding out about community and/or hospital resources)
- Knowledge (we'll help you get your questions answered by the best person).



Here are some tips

- You are not alone in this NICU experience. **Please ask for help.**
- **All families** in the NICU can ask to see a social worker. They are part of the Women and Babies Program. They offer a significant source of support and practical help too. You are encouraged to meet and talk with them.
- **Talk to our Parent Coordinator.** As someone who has been through the NICU as a parent, the Coordinator can offer support and help from the perspective of personal, not clinical, experience.
- **Attend our regular parent get-togethers** in the Parent Lounge. Dates and times will be posted on the notice boards in the Parent Corridor. Talking with other NICU families can be a source of comfort, and we also offer regular education sessions as part of these get-togethers.



Bottom line: The best way for the NICU staff to help you is for you to help us. Talk with the nurse caring for your baby or the charge nurse. If we are aware of the issues you may be dealing with, in and outside of the NICU, the staff will do our best to help find solutions.

Getting Around the NICU

When you arrive on the 4th floor and enter the NICU area, you will first walk past the **Family Lounge** (M4-201). This is a room open to all NICU families and your family members as well. There are tables, a kitchenette, computers, a play area for siblings, a TV/DVD player, a bathroom, and telephones available for your use.

We ask you to work with us to keep the space tidy and pleasant. Children should not be left unsupervised. This is a good place for your visitors and friends to wait for you if they are coming to see you and your baby. It's also a good place for you to eat, since food and beverages other than water are not allowed in your baby's room. There is a feedback box in the lounge where you can leave comments, kudos or suggestions.

Across the hallway is the **Follow Up Clinic**, where we see babies after discharge to offer developmental assessments and support.

Past the family lounge, you come to the family corridor, which is the entrance to the NICU that is on the right. You will be given an **electronic fob** which is your key to the parent corridor, your baby's room and other family-only areas. Each family receives two fobs; there is a \$20.00 fee to replace a lost fob. We ask you to return your fobs to us if you are transferred or discharged.

In the family corridor, there are entrances to the pods where the baby rooms are, social worker offices, bathrooms with showers, care-by-parent rooms for families who need to stay over in a separate room, a pump room where mothers can go to pump milk (M4-311), and the milk preparation area (known as the Dairy Queen).

When you are coming to be with your baby, you will use your fob to open the door of your pod. After washing your hands at the sink, you can use your fob to open the door to your baby's room. You will notice message boards outside each baby's room; you can use these to communicate to other family members or to NICU families you meet during your stay with us.



Your Baby's Room



You are welcome to be with your baby whenever you can. Most rooms have a bench at the back that you can sleep on or a comfortable chair, and there is a curtained area if you want privacy for pumping, sleeping or reflecting. You can use your cell phone or computer in your baby's room within the curtained area; please keep in mind that a quiet environment is best for your baby. Please turn down volume or use head-phones, and put phones on vibrate. There is guest access to Wi-Fi in the room. Bluetooth devices should not be used in the NICU because they can interfere with other communication devices.

Please keep your electronic items clean and clean your hands between every use. Electronics can be a pathway for germs. Only water is permitted in your baby's room. There are water and ice machines in the hallway; your baby's nurse can show you where they are. Please use the family lounge for meals and snacks. For safety reasons, please keep all personal items within the curtained area.

When you arrive in your baby's room, please greet your baby's nurse and talk about hopes and plans for the day. You are also welcome to share this via telephone prior to arriving. Please know as well that you are always welcome to phone in for information about your baby. It is helpful for us to know your schedule, and we will also need your contact information.

Visitor Policies

You may have as many visitors as you wish as long as you are present and as long as your visitors are healthy. Healthy visitors keep babies, families and staff members healthy. Siblings are welcome as are family members and friends. Everyone who visits must respect our policies regarding hand hygiene, privacy and patient safety. At times you may be asked to limit the number of visitors you have, based on your baby's medical condition. The bedside nurse will let you know.

You may have people in your life whom you would like to be able to visit your baby or get updates about your baby when you are not there. This is possible with your written permission. Talk to your baby's nurse to find out how this can be done. If you have not given written permission for us to release information about your baby, please tell your family and friends that the NICU staff is unable to share information about your baby with them over the phone or in person. We can arrange for Skype sessions to connect with faraway family and friends; talk to the Parent Coordinator or a Staff Nurse if you're interested.

Tips for Your Families & Friends

These tips were written by graduate NICU parents; feel free to share them with people close to you who may want to help.

Are you a family member or friend? You can...

- Prepare meals and help coordinate meal preparation with others while baby is in the hospital and for those first few months at home.
- Drive parents back and forth to the hospital.
- Do laundry, take care of pets, mow lawns, and shovel walkways.
- Babysit siblings; arrange for special outings and be available for last minute childcare.
- Respect the parents' wishes about how they want to mark the birth. Some may wish to celebrate. Others may want to wait until the baby is home. It is for the parents to decide and for you to support their wishes.
- Learn about prematurity, but don't feel the need to share what you're learning with the parents. Be careful about what resources you use, especially if you're researching online.
- Try not to be offended if parents exclude you temporarily. The NICU can be difficult and some people turn inwards in order to cope.
- Shop for necessities when the baby is discharged from the hospital.
- Respect the rules of the NICU. Don't visit if you're sick or if people close to you are sick. Respect the privacy of other parents and their babies.
- Offer to communicate with other family and friends so that the parents don't have to spend all their time updating everyone.
- Coordinate other offers of help so that the parents don't need to organize who does what.
- Resist the urge to compare the new baby with other babies. Please don't make comments on size or weight, and please don't talk about other birth experiences unless you have personal experience as a parent of a premature baby.
- Keep offering help when the baby is home. The first few months can be isolating and difficult and parents can really use continued assistance.
- When a baby goes home, remember that preemies, especially during the winter months, are at risk for infections and sickness. Never visit the parents and baby at home if you're sick, and respect their wish to keep their baby healthy. They are not being over-protective. They are being good parents.
- Follow the lead of the parent. If he or she wants to talk, listen. If she or he wants to be distracted, be entertaining. If you don't know what to say, say, "I don't know what to say, but I hope you know I'm here for you whenever you need me." Sometimes that's what a parent needs to know.

Hugs are good too!

What Can You Do in the NICU?

It's so good for babies to have parents with them, yet the prospect of spending time here can feel very daunting. How can you fill the hours? We asked some parents and nurses for suggestions.



Kangaroo Care

Holding babies skin-to-skin is great for them AND wonderful for parents too. Research shows it helps babies learn to breathe, soothes their stress and helps their brain develop. It also helps with milk production and protects babies from infection.

Hand Hugging

If you can't do kangaroo care, you can still do hand-hugging where you gently cup your baby's head and feet. Ask your nurse to show you how.



Come to Rounds

Rounds happen every morning. The medical team comes together to discuss your baby and we encourage you to be there. Ask your nurse for more information about when rounds will be. While the health care team discusses other babies in the pod, we will close the door to your baby's room until your baby is the focus of discussion. Confidentiality is important for all in the NICU.

Record Keeping

You can scrapbook, journal or blog; ask the parent coordinator for help getting started. There are many special milestones to remember!



Talking to your baby

A recent study from McGill University showed that quietly reading and singing to your babies helps you bond with them, even when they are very small. It also helps you develop routines that you can carry from the NICU to home.

Baby Care

We encourage you to get involved in your baby's care. Your baby's nurse can help you learn and grow comfortable with tasks like diapering or holding feeds.



Attend Family Events

We have weekly drop-ins for parents and family members in the Family Lounge, and we also hold special events to mark holidays or share info. All events will be posted in the Family Lounge and on the notice boards in the Family Corridor. We encourage you to attend; the NICU can be an isolating experience and connecting with other NICU families can help.

Working Together for Safety

You're not just the parent to your child - you're also Chief Safety Officer!

Parents and families play an essential safety role in the NICU. Here's what you can do to promote safety and protect your baby.

Clean your hands and ask those around you to do the same

Use soap and water after using the bathroom or any time you have visible soil (such as milk, stool or mucous) on your hands. You can use alcohol hand sanitizer when hands are not visibly soiled. Use sanitizer before and after touching your baby. Become aware of what your hands are doing and what they're touching. Remember that electronic items like phones or laptops can be a pathway for germs; keep them clean!



Take off hand and arm jewelry and artificial nails

Germs can hide under rings, watches, bracelets and artificial nails. That is why we ask you to take off hand and arm jewelry and to remove artificial nails. If you have any questions about safety and hand hygiene, ask a Staff Nurse.

Stay home if you're sick

We want you to be with your baby, but if you're sick it's better to stay home. For one, you don't want to pass germs to your baby or to others in the NICU. For another, you need to be well to take care of your baby. If you are wondering if you should come in or stay home, err on the side of caution and call the NICU to talk to a nurse for advice. Ask your family and friends to do the same. Even if they come to the visiting areas of the hospital, if they're ill they're spreading germs.

Be careful about what you bring to your baby's room

No food or drinks other than water can be in your baby's room since they can be a source of infection. Make sure to keep all personal belongings behind the curtained area.

Let us support you

Sometimes it's hard to get family and friends to understand how important safety rules are. If you're running into resistance, let us help. A Staff Nurse, Doctor or the Parent Coordinator can help educate your nearest and dearest about our policies, leaving you to focus on your baby or babies.

Ask about medication and medical apparatus

Feel free to ask questions about any medication we give your baby or any medical apparatus (like ventilators) that we use, so that you have a clear understanding of what is being used, why it is being used and how it functions. Some parents take notes or add medication and equipment info into their daily journal.

And you can support us. Talk to us about safety; share your thoughts, concerns and questions

We need to hear from you when we're doing something right and when we can be doing something better. There are never any repercussions for speaking up; rather, when parents help educate us they make the whole NICU better for everyone. If you have any questions or concerns you can speak to a Staff Nurse, the Charge Nurse, the Patient Care Manager or the Parent Coordinator, or leave a note in the Feedback box in the Family Lounge. We really want to hear what you have to say.



Breastfeeding/Pumping Support and Services

The evidence from research is very clear:

Breastmilk is best for babies! This is true for all babies but particularly for premature or sick babies. In the NICU, breastmilk represents more than just food. It is medicine that protects your baby from infection, reduces the severity of illness if they should become sick and promotes healing, growth and development within your baby that will last a lifetime. In fact, at Sunnybrook, we value breastmilk so much that we also have adopted a donor milk program that can be used to bridge your supply unit you are producing enough.



Most premature babies, especially ones born before 35 weeks, aren't ready to breastfeed all the time, if at all. That is why we encourage moms to pump. Your milk is designed to be the best possible food and medicine for your baby. There are several breast pumps in each pod for you to share. While your baby is with us you will be given a breast pump to use at home free of charge when you bring in a valid credit card for a security hold.

Kits will be delivered to your baby's room and should be dropped off in the pumping room for cleaning or in the pod reprocessing bin. You can place an order for the kits in the pumping room. Please indicate the size flange you need and how many pumpings you will be here for. Typically you will receive 2 kits; once they are used you may exchange them for more. The kits you receive in the NICU are **NOT** to go home. After discharge or transfer you can continue to rent a pump for home use through our Breastfeeding clinic.

Please note that we have limited space for storing frozen breastmilk, so we ask you to make arrangements before discharge to take frozen milk home. If you need help storing it for a limited time post-discharge, talk to a feeding room technician.

When or if you are ready to start breastfeeding, please know that it often takes a while to get the hang of it. Breastfeeding is natural but doesn't always come naturally! Both you and your baby are learning. Remember that we are here to help.

A Lactation Consultant is available from Monday to Friday and can meet with you in your baby's room. You can ask your baby's nurse to call or you can call directly at 416.480.6100 Ext. 87814. The LC office is located just outside the parent access doors, at the front of the unit—feel free to just drop in. No appointment necessary! If the LC is not available many of our nurses are very knowledgeable about breastfeeding and can offer help.

When your baby is discharged from Sunnybrook you may still use the services of the Breastfeeding clinic any time you need. The clinic does not accept walk in visits; please phone 416.480.5900 to arrange an appointment.



Pumping Tips & Tricks

These tips come from Lactation Consultant Luisa King and some graduate moms.

- Don't worry if it takes a few days of pumping before you see much milk. Once you move from hand expression to using the pump, you may see production stall. That's normal. It can take five or six days for your milk to come in. Keep pumping regularly, record how much you're getting, and if you have concerns contact the lactation consultant.
- If you'd like to bump up milk production, try pumping more frequently. For example, pump every 2 hours during the day rather than every 3. It's better to pump more frequently rather than for longer sessions.
- "Prime" the pump. Always drink a glass or two of water before pumping.
- Make a hands-free pumping bra by cutting holes in an old sports bra.
- Avoid wearing underwire bras; the pressure can encourage blockages.
- Get milk flowing by massaging before you pump, which can stimulate the "let down" of the milk.
- Warm compresses can help ease blockages and get milk moving. Hot water in a diaper can be effective; some moms use a sock filled with rice that they heat in a microwave.
- You can pump either in your baby's room or in the pump room (for women only). The pump room is a good place to connect with other moms.
- The most important tip is if you've got any questions or concerns, talk to your nurse or call the Lactation Consultant. And remember... pumping can be challenging, but the rewards are great.



Leaving the NICU

Although we do everything we can to make the NICU feel like home to you and your family, we realize you are all hoping to get to your real home as soon as possible. Here is some information about **transfer** (when babies are sent to other hospitals) and **discharge** (when babies are sent home).

Transfer

Many babies will spend some time at our NICU and then be transferred to another Level II hospital. Level II hospitals care for babies who do not need full neonatal intensive care but still need support as they grow. Transfer can be a stressful time for families, but it can also be seen as an important step on the road to home. We can provide you with some information about Level II hospitals close to your home, and your nurse or other staff members will speak to you about transfers as well.

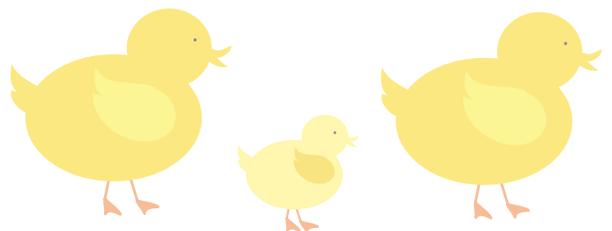
When and why are babies transferred to other hospitals?

- To be closer to the family home.
- A baby is stable and more mature and no longer requires the intensive level of care that we provide.
- A baby is no longer on a ventilator but may still have an IV, low flow oxygen, tube feeds and be on medications. Some babies still on CPAP may be eligible for transfer to appropriate NICUs.
- A baby has no medical issues requiring specific follow up at this hospital.
- A bed is available at a receiving hospital.
- A bed is required at Sunnybrook for a baby who needs intensive care.

Discharge

All parents want to know when their babies can go home. Some babies go home a few weeks after their due date, some go home around their due date, and some go home a bit before. Generally speaking the earlier the baby, the longer the hospital stay. Babies are ready to go home when their breathing is stable (no spells for a week), they are feeding by breast or bottle well, they are gaining weight reliably, they have passed a car seat test, and they have no pressing clinical issues that need monitoring at this hospital.

The discharge co-ordinator will meet with you before your baby is ready to go home to discuss with you the steps that are involved. We can help you find an appropriate pediatrician, will give you copies of discharge letters, and will arrange for any necessary follow up appointments before you go.



Who's Who in the NICU

Charge Nurse/Team Leader

Co-ordinates all NICU activities.

Patient Administrative Assistant

Assists the Charge Nurse/Team Leader in the coordination of NICU activities.

Staff Nurse

A Registered Nurse who has specialized knowledge in caring for babies in the NICU. Of all the caregivers you will meet, the Staff Nurse is the person with whom you will have the most contact with during your baby's stay.

Staff Neonatologist

A pediatrician with advanced education and training in the care of critically ill premature or term infants. They co-ordinate and direct the care of all babies in the NICU.

Neonatal Fellow

Pediatricians who are continuing their education to be neonatologists.

Nurse Practitioner-Pediatrics (NP)

An experienced neonatal nurse with a Master's degree and specialized education in caring for the needs of critically ill premature or term infants. NPs work together with the rest of the team to plan the best course of treatment for babies in the NICU.

NICU Resident

A doctor who is specializing in pediatrics, obstetrics, or family practice. In consultation with the Staff Neonatologist and Fellow, they participate in the medical management of your baby.

Clinical Clerk

A medical student doing clinical placement in the NICU. They work under the supervision of the physician.

Discharge Co-ordinator

Prepares babies and families for transfer to another hospital or discharge home.

Registered Respiratory Therapist (RRT)

A therapist with education and training in all aspects of respiratory care to provide support for your baby's breathing.

Social Workers

They assess psychosocial, emotional and financial needs of families and offer support as required. They also help families find resources in the hospital and in the community.

Dietitian

A specialist in the nutritional management of babies in the NICU, including both intravenous nutrition and oral feeds your baby will receive. They are also available for individual counselling about maternal nutritional needs and concerns.

Infection Control Co-ordinator

A healthcare worker with specialized education in infection control and prevention.

Lactation Consultant (LC)

A Registered Nurse with specialized training to help breast pumping and breast-feeding mothers in the NICU.

Pediatric Physical Therapist

A specialist in child development who answers questions about development, helps with therapeutic activities and makes referrals to other clinical services.

Pharmacist

A health care professional educated in drugs and their effects. NICU pharmacists have special training and experience with babies and ensure that babies receive the best possible drug therapy. They can also answer questions about medications for your baby or medications that you may be taking, especially related to breastfeeding.

Pharmacy Technicians

These specially trained technicians prepare and dispense medications for babies in the NICU. They prepare all medications and solutions for intravenous use in a special "clean room" using sterile techniques as an infection control process.

Patient Care Manager

Manages all nursing staff and patient relations. Questions and comments should be relayed to the Patient Care Manager.

Parent Coordinator

Has had infants in the NICU and has returned in a support role. Organizes parent activities and helps the NICU provide patient and family-centred care.

Feeding Room Technicians

Collect pumped milk, prepare feeds for all babies in the unit and manage stored breastmilk.



NICU Glossary

We use many medical terms in the NICU. Here are some you may come across during your stay with us; you are always welcome to ask questions about anything you hear.

ANEMIA - a low number of red blood cells in the blood. NICU babies are not always able to make red blood cells quickly enough to replace the ones lost when blood is taken from them for testing.

ANTIBIOTICS - a type of medication used to treat a suspected or actual bacterial infection. Until the specific bacterium is identified, babies receive combination antibiotics to treat them for the most “common” types of infections.

APGAR SCORE - a number given at one and five minutes of age that measures the baby’s condition based on heart rate, breathing, muscle tone, activity level and colour.

APNEA – the premature baby has an immature brain, and this means he/she may occasionally forget to breathe. Premature babies may then require stimulation (a gentle rub on the back) to remind them. This is common for premature babies and usually subsides by 34-35 weeks, as their brain matures.

ARTERY - blood vessels that carry oxygen-rich blood away from the heart and lungs to the body’s organs and tissues. Arteries are also the blood vessels that are used to feel the pulse or measure the body’s blood pressure.

ASPIRATE - breastmilk or formula that is left in the baby’s stomach from the previous feeding. Assessing the presence and amount of aspirate helps guide the nurse when deciding whether or not the baby is ready to have his or her feeding volume increased.

ASPIRATION - the direct result of inhaling any foreign matter into the lungs.

BAGGING - a special way to give babies oxygen and/or extra breaths using an air filled bag.

BILIRUBIN - a product of the breakdown of red blood cells, filtered out of the blood by the liver. The premature baby’s liver is immature and therefore does not filter as well as it should. This causes the bilirubin to build up in the blood resulting in jaundice (a yellow/orange hue to the skin).

BLOOD GAS - a sample of blood that measures the level of oxygen, carbon dioxide and acid (pH) in the blood. It is used to measure how well your baby is ventilating and or breathing.

BLOOD PRESSURE - a measure of the force of blood moving through blood vessels. Can be taken periodically using a cuff that is placed around the baby’s arm or leg, it can be monitored continuously using special equipment called a transducer that is connected to the umbilical artery catheter (UAC) inserted into your baby’s umbilical cord

BPD (BRONCHOPULMONARY DYSPLASIA) - is a form of chronic lung disease that occurs most often in babies who are very premature. Babies with BPD have inflammation and scarring in the lungs. Many infants with BPD recover and improve with time, achieving normal or near normal function.

BRADYCARDIA (BRADY) - any decrease in the baby’s heart rate below 100 beats per minute that lasts longer than 15 seconds and requires stimulation to correct. It is frequently associated with apnea (see above) and happens less often as the baby matures.

BREAST PUMP - an electric machine used by nursing mothers to express milk from their breasts.

CARBON DIOXIDE - the gas we breathe out as a waste product.





CBC (COMPLETE BLOOD COUNT) - a blood test done for several reasons, including to determine if an infection may be present and to see whether or not the baby is anemic (see anemia, above).

CENTRAL LINE - a special IV catheter used to give fluid, medication or nutrition to the baby; includes long lines or PICCs and UVCs. It can stay in for an extended time period, if needed.

CHEST TUBE - a tube surgically inserted through the baby's chest wall into the space around the lungs to reopen a partially or totally collapsed lung. (See pneumothorax).

CORRECTED AGE - the age of a baby from the due date, not the birth date.

CPAP (CONTINUOUS POSITIVE AIRWAY PRESSURE) - is a type of respiratory support used to deliver constant air pressure into a baby's nose, which helps the air sacs in the lungs stay open and helps prevent apnea.

CYANOSIS - dusky, bluish color of the skin, lips, and nail beds caused by having too little oxygen in the blood.

DESATURATION (DESATS) - when the oxygen level in the blood falls below the set value on the saturation monitor. Acceptable levels of oxygen vary depending upon the baby's age, and the monitor alarm limits are set accordingly.

DIP - when the heart rate drops below 100 beats per minute and comes up quickly without requiring any stimulation.

DONOR HUMAN BREASTMILK - this is Expressed Breastmilk donated by healthy mothers. This milk is pasteurized making it safe and is used as the preferred alternative to formula feeding in the very premature baby until a mother's own milk is available.

EBM (EXPRESSED BREASTMILK) - milk that mothers express using a breast pump or hand expression. This milk can be used soon after it is pumped, or it can be frozen and saved for later use.

ECG - a machine that is attached to a baby's chest in order to do a printed read-out of his heart beat. This may be done when a murmur is heard.

ECHOCARDIOGRAM - an ultrasound of the heart, usually performed by the cardiologist.

EDEMA - also known as "puffiness"; this is swelling due to extra fluid under the skin.

ETT (ENDOTRACHEAL TUBE) - a soft plastic tube placed into the baby's mouth or nose and into the windpipe (trachea) to help with breathing.

FORTIFIER - human milk fortifier is a powdered substance added to breastmilk to give it extra calories and minerals such as calcium and phosphorous.

GESTATIONAL AGE - the number of weeks a woman is pregnant; the age at which a baby is born.

GLUCOSE - a type of sugar in the blood. Different types of glucose monitoring are done but the most common is done using a glucometer at the bedside.

GLYCERIN TIP - also known as a "silver bullet" because of its packaging. Occasionally a very small tip of a glycerin suppository is used to help babies pass stool.

HEART MONITOR - this monitor shows the heartbeat on a special computer screen. Three gelled electrodes (leads) sit on the baby's skin. An alarm rings if the readings are not within the normal limits. False alarms are common and usually happen when the baby wiggles or a lead falls off.

HEEL STICK - a method of getting blood from a baby's heel

HYPOGLYCEMIA - low blood sugar.

HYPOXEMIA - when not enough oxygen is flowing in the blood.

INTERSTITIAL - refers to an IV that is no longer in the vein and must be restarted.





INCUBATOR – a heated and humidified bed specifically for babies in the NICU. The incubator is often referred to by the manufacturer’s name - Drager®.

INTRAVENOUS (IV) - a small catheter placed a short distance into a vein to provide fluid and or medications. Babies can have IV’s in their scalp, hands, arms, legs, or feet. These sites are rotated regularly.

INTRAVENTRICULAR HEMORRHAGE (IVH) - is bleeding into the fluid-filled areas (ventricles) surrounded by the brain.

IUGR (INTRA-UTERINE GROWTH RESTRICTED) - when a baby’s growth slows or ceases while it is in the uterus.

JAUNDICE (HYPERBILIRUBINEMIA) - the yellow color seen in the skin usually during the first 2 weeks of life, due to the buildup of broken down blood cells.

LAB WORK – this is a collective term for any blood samples that a baby may need taken from him.

LGA (LARGE FOR GESTATIONAL AGE) - a baby born who is larger than usual for those born at the same gestational age.

LIPIDS - a white, high calorie fat solution that is delivered by IV or mixed in with your infant’s milk/formula.

LOW FLOW - refers to one of the many ways to deliver oxygen and/or air to babies.
(See nasal prongs)

LONG LINE (PICC) - a long intravenous line placed further into a large vein using sterile technique. This line can be left in for long periods of time.

LUMBAR PUNCTURE - a small needle is placed in the baby’s lower back using sterile technique to get a very small amount of spinal fluid for specialized testing.

LYTES (ELECTROLYTES) - the measurement of sodium, potassium, chloride in the baby’s blood. The results of this test help the medical staff treat the baby.

MECONIUM - the first, thick black stools passed by a baby. These stools can last for several days and are thick and tar-like.

MURMUR - a “whooshing” sound of blood going through the heart and surrounding blood vessels. It is detected by using a stethoscope and listening to the heartbeat on the chest or back. Murmurs are common in premature babies. They can be a sign of a PDA (see below) or other heart problem, or they can be benign.

NASOGASTRIC TUBE / OROGASTRIC TUBE (NGT/OGT) - this tube is placed through the nose or mouth to the stomach and is secured with tape. It is a way to feed the baby and to release built up air and gas in the stomach.

NASAL PRONGS - small soft plastic prongs that are placed in the baby’s nose to deliver oxygen or air.

NEC (NECROTIZING ENTEROCOLITIS) - a serious bowel condition that can arise unexpectedly in premature infants in the NICU. Babies with it can have bloating, blood in stools, and feeding intolerance; they can become very sick.

NEONATAL - the period of time from birth to 28 days.

NICU - Neonatal Intensive Care Unit.

NPO - nothing by mouth (not feeding)

NPT (NASAL PHARYNGEAL TUBE) - a short single breathing tube that goes to the back of the baby’s nose and is attached to a ventilator so the baby can receive positive pressure air, or puffs of air to help him/her breathe.

OVERBED WARMER - a large warmer that can be placed over the opened door of an incubator to keep the baby warm during procedures.

OXYGEN - an odourless, colourless gas needed by all body cells. The air around us, also called ‘room air,’ is 21% oxygen. If needed, a baby can be given up to 100% oxygen.





PDA (PATENT DUCTUS ARTERIOSIS) - the ductus is a blood vessel that keeps the blood away from the lungs before a baby is born because the lungs are filled with fluid. Usually the ductus closes shortly after birth. If the ductus stays open (or patent) it may interfere with normal blood flow, heart and lung function. The PDA may be treated with medication or surgery if necessary. For more information, please go to: <http://www.sickkids.ca/familyinformation/documents/pda/PDAwebsite.html>

PHOTOTHERAPY (BILI LIGHTS) - a special blue light used in the treatment of some types of jaundice. Eye shields are placed over the baby's eyes to protect them from the light.

PNEUMONIA - infection in the lungs.

PNEUMOTHORAX - a collection of air in the space between the lung and the chest wall, but outside the lung.

POST MATURE - a baby born after 42 weeks gestation.

PREMATURE - a baby born before 37 weeks gestation.

RESPIRATORY DISTRESS SYNDROME - the most common breathing problem found in premature babies. Because the baby may be too young to have developed an important substance called surfactant, the tiny air sacs in their lungs (alveoli) do not stay open easily, as they should. Without surfactant, the air sacs collapse and the baby cannot get enough air into his lungs to breathe effectively. Surfactant therapy sends surfactant down a tube into the lungs, which helps makes the lungs more flexible and eases ventilation.

ROOM AIR - refers to the concentration of oxygen in the air around us, which is 21 percent.

ROP (RETINOPATHY OF PREMATURITY) - abnormal growth of blood vessels in the eye that is most common in babies who were born very premature. Babies will have their eyes examined for ROP if they meet criteria, or on the advice of the medical team. Ask if your baby will be getting eye exams.

OXYGEN SATURATION (SAT) - a term that describes the amount of oxygen in the blood.

SATURATION ("SAT") MONITOR - a monitor that shows the amount of oxygen in the blood. The small monitor is placed around a baby's foot or hand/wrist and can be easily identified by the red light. The light does not produce heat.

SEPSIS - an infection that occurs in the blood. If there is any question that an infection may be developing, blood samples are drawn (culture, CBC) and antibiotics are started.

SEPTIC WORK-UP - includes blood drawn for CBC, and Blood Culture. If the baby is very ill the medical team may request that spinal fluid or urine be obtained and sent for culture.

SGA (SMALL FOR GESTATIONAL AGE) - when a baby's length, weight or head circumference is below the 10 percentile for that gestational age.

SPELL - a term that also describes a brady, apnea or a desat (see above).

SUPRAPUBIC TAP - a sterile specimen of urine obtained from a needle tap into the bladder.

TACHYCARDIA - a heart rate that is faster than the average range. The average range for premature babies is 120-160. A full term baby's heart rate would be slightly lower at 90-140 beats per minute.

TACHYPNEA - a breathing rate that is faster than the average range. Premature babies breathe at an average rate of 40-60 breaths per minute. Full term babies breathe at an average rate of 30-60 breaths per minute.

TPN (TOTAL PARENTERAL NUTRITION) - an IV solution (often yellow) that contains nutrients to help a baby grow. TPN is used when a baby is not able, or is just starting to feed.

TRANSFUSION - giving blood or blood products through an IV.

UAC (UMBILICAL ARTERY CATHETER) - a soft, clear catheter placed into one of the arteries in the umbilical cord. This is used to monitor BP, draw blood for testing, and give fluids. In very sick or premature babies this line is placed at birth using sterile technique.





UVC (UMBILICAL VENOUS CATHETER) - a soft, clear catheter placed into the vein in the umbilical cord. This line is used to give fluids and medications. In very sick or premature babies this line is placed at birth using sterile technique.

ULTRASOUND - a procedure that uses sound waves to produce a picture of the baby's internal organs. (I.e.: brain, heart, kidneys, liver etc.) A series of head ultrasounds are done on babies who meet criteria, or on the advice of the medical team. Ask if your baby is getting head ultrasounds.

UMBILICUS - the belly button or cord. This cord has three major vessels (one vein and two arteries) and is clamped at birth. Usually, this cord dries up and falls off after a short time. However, with premature babies, the umbilical vessels are used to insert arterial and venous catheters.

VEINS - blood vessels that carry blood from the rest of the body back to the lungs to be oxygenated.

VENTILATOR ('VENT') - a machine used to help a baby breathe. The machine connects to the ETT or NPT.

VENTRICLES (OF THE BRAIN) - spaces in the brain where spinal fluid circulates.

VERNIX - the thick white creamy substance that protects the baby's skin inside the womb toward the end of pregnancy. Because premature babies are often born before their vernix has developed, they do not have this protective coating on their skin.

VITAL SIGNS - temperature, heart and breathing rate and blood pressure that are recorded on the baby's chart.

VITAMIN K - helps blood to clot normally; all babies receive one intramuscular injection at birth.

X-RAYS - a type of picture that shows the internal structures (bones and organs) of the body. In the NICU, x-rays are also used to help the health care team confirm the proper location of tubes or lines the baby may need. They are also used to check on the condition of the baby's heart, lungs and bowel.



Important Contact Information

Neonatal Intensive Care Unit:

416.480.6055

NICU Charge Nurse:

416.480.6100 Ext. 87990

NICU Clinical Director Dr. Eugene Ng:

416.480.6100 Ext. 87781

Patient Care Manager, Marion DeLand:

416.480.6100 Ext. 87779

NICU Lactation Consultant, Luisa King:

416.480.6100 Ext. 87814

Breastfeeding Clinic: 416.480.5900

Social Work

Jennifer Stannard: 416.480.6100 Ext. 87940

Kelly Polci: 416.480.6100 Ext. 87942

Suzanne Holmes: 416.480.6100 Ext. 87941

Discharge Co-ordinator, Peggy Mulligan:

416.480.6055

Parent Coordinator, Kate Robson:

416.480.6100 Ext. 87815

Parking Services: 416.480.4123

Chaplaincy: 416.480.4244

Follow-up Clinic: 416.480.6100 Ext. 87722

Dairy Queen (Milk Preparation Area):

416.480.6100 Ext. 87946

Sunnybrook Patient Relations Office:

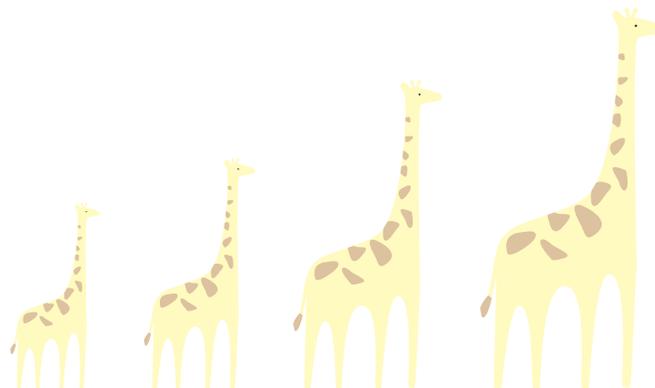
416.480.4940

Unit Fax Number: 416.480.5610

Grams to Pounds Conversion

		Pounds									
		0	1	2	3	4	5	6	7	8	9
Ounces	0	0	454	907	1361	1814	2266	2722	3175	3629	4082
	1	28	482	936	1399	1843	2268	2750	3203	3657	4111
	2	57	510	964	1417	1871	2325	2778	3232	3695	4139
	3	85	539	992	1446	1899	2353	2807	3260	3714	4167
	4	113	567	1021	1474	1928	2381	2835	3289	3742	4196
	5	142	595	1049	1503	1956	2410	2863	3317	3770	4224
	6	170	624	1077	1531	1984	2438	2892	3345	3799	4242
	7	198	652	1106	1559	2013	2466	2920	3374	3827	4281
	8	227	680	1134	1568	2041	2495	2948	3402	3856	4309
	9	255	709	1162	1616	2070	2523	2977	3430	3884	4337
	10	283	737	1191	1644	2098	2551	3005	3459	3912	4366
	11	312	765	1219	1673	2126	2580	3033	3487	3941	4394
	12	340	794	1247	1701	2155	2608	3062	3515	3969	4423
	13	369	822	1276	1729	2183	2637	3090	3544	3997	4451
	14	397	850	1304	1758	2211	2665	3118	3572	4026	4479

To find your baby's weight in pounds and ounces, first find his or her weight in grams on the chart. The number at the top will give you pounds and the number to the left side of the column will give you ounces.



A Message for you from Graduate Families of the NICU at Sunnybrook and the Family Advisory Committee (FAC):

We are all parents of NICU babies though our stories are all very different. Some of us were in the hospital for a long time, and some for only a few weeks. Some of our children show no signs now of their prematurity or early struggles, and others have some challenges. Some of us endured losses and some had a quick and uncomplicated time with our babies in the NICU.

We hope that after you leave Sunnybrook you take some time to be with your family, and then when and if you're ready, we invite you back to join our Family Advisory Committee. We have many interesting projects to work on and we welcome your input. You and your family also have a standing invitation to our Premie Picnic which happens every summer.

We have all been forever changed by this experience, and we all love our children more than we ever could have imagined. While it's important to be aware of the risks and complications that could lie ahead, it's equally important to remember that it is also possible, even probable, that life a year from now will be joyful.

We wish the best for you and your family.



A graduate's drawing of one of our Premie Picnics

Recommended Reading

Many books and websites cover topics of interest to families of NICU babies, but not all are created equal. We encourage you to bring your questions, thoughts and concerns to a member of our care team, so that we can provide you with information that is relevant to your specific situation. If you are interested in other resources, we can recommend the following; we are always interested in hearing about additional resources that you find to be helpful.

A Sunnybrook graduate dad maintains a Facebook group for NICU graduate families; it's called "The Sunnybrook NICU Families" group and you can send a request to join. Families post interesting articles, personal stories and events.

Parentbooks, a parenting bookstore in downtown Toronto, maintains a bibliography of books related to prematurity on its website.

http://parentbooks.ca/Premature_Babies.html

Zerotothree promotes healthy development of infants and toddlers.

<http://zerotothree.org/>

Dr. Jen Gunter, a doctor, mother of preemies and author of The Preemie Primer, maintains an active blog and website.

<http://www.preemieprimer.com/>

The Canadian Paediatric Society helps parents make informed decisions about their children's health by producing reliable and accessible health information.

<http://cps.ca>

The March of Dimes (US) is a treasure trove of info for NICU families.

<http://www.marchofdimes.com/>

The Linden Fund is Canada's charity for premature babies.

<http://www.thelindenfund.com>

RSV Shield teaches you about protecting your baby from RSV.

<http://www.rsvshield.ca/en/cs/home.php>

Caring Bridge and CarePages are free patient and family blog services.

<http://www.caringbridge.org/>

<http://www.carepages.com/>

If you're a parent of multiples, you'll find Multiple Births Canada invaluable. Many of our families become members of local branches like MPOMBA in Mississauga or TPOMBA in Toronto.

<http://www.multiplebirthscanada.org/>

<http://www.mpomba.com/>

<http://tpomba.org/>

Perinatal Bereavement Services of Ontario offers help to those who have suffered an infant or pregnancy loss.

<http://pbso.ca>

Patient & Family Centred Care

Here in the NICU at Sunnybrook we practice a model of care known as Patient and Family Centred Care. The Institute of Patient and Family Centered Care (www.ipfcc.org) defines the core concepts of this model as:

- **Respect and dignity.** Health care practitioners listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs and cultural backgrounds are incorporated into the planning and delivery of care.
- **Information Sharing.** Health care practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete, and accurate information in order to effectively participate in care and decision-making.
- **Participation.** Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.
- **Collaboration.** Patients and families are also included on an institution-wide basis. Health care leaders collaborate with patients and families in policy and program development, implementation, and evaluation; in health care facility design; in professional education; as well as in the delivery of care.

Frequently Asked Questions

When can I be with my baby or babies?

You are not a visitor; you are a team member. You are welcome 24/7.

What are the most important things I can do for my baby/babies?

Be present, provide breastmilk, hold your baby/babies whenever possible, stay healthy, be involved, and clean your hands.

What is the phone number for the NICU?

416.480.6055

Where do I get parking passes? Are there discounted passes?

Parking passes can be purchased in Room CG03 (Ground Floor, C Wing). A weekly pass costs \$50, and allows for in and out privileges. If you have already paid for parking they will count some of your prior receipts toward the cost of a new pass. Discounted multi-use passes are also available.

Where can we stay if we live far away?

If you need to arrange for an extended stay, the best thing to do is contact a social worker who can help sort through the options with you. Let a staff nurse know you'd like to see a social worker.

If I have questions, compliments or concerns, who can I contact?

You can begin by speaking with your baby's staff nurse. You can also ask to speak with the Charge Nurse, the on-call Nurse Practitioner or the Staff MD. You may also wish to contact Marion DeLand, the Patient Care Manager, or Dr. Eugene Ng, the Clinical Director of the NICU. We welcome your feedback.

How do I contact a hospital chaplain?

Chaplains can be of great help in stressful times and in times of celebration. You can ask a social worker or call Chaplaincy at 416.480.4244.

How do I register my baby's birth?

You can use the Newborn Registration Service online at <https://www.orgforms.gov.on.ca/IBR/start.do> to register a child's birth, apply for a birth certificate, apply for a Social Insurance Number (SIN), and to register the mother for Canada Child Benefits. If you are a resident of Ontario, you must apply for your baby's OHIP card at the hospital where you gave birth. If your baby was born at Sunnybrook, go to Triage (on M5) to fill out and sign the application form. The Triage clerk will give you a temporary OHIP slip for your baby. The permanent OHIP card will be sent to your home in 4-6 weeks. The form completed in Triage is different than the one the NICU clerk asks you to sign that allows the Ministry of Health to disclose the OHIP number including version code to the hospital so that the bill for your baby's care is covered.

I have questions about EI or maternity leave. Who can help?

Your social worker can give guidance; ask a staff nurse to connect you.

Can I claim any of this on my taxes?

YES! Save all receipts associated with your hospital stay, including food and parking. Check with an accountant to see which deductions apply to you.

Your NICU Story



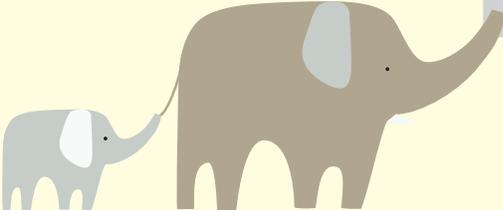
Name:

Birthday:

Gestational Age:

Weight at Birth:

What Your Family Wants You To Know:





*Thanks to all the families who shared their beautiful photographs with us.
This handbook is the result of collaboration between many of our families and the NICU staff.*



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