

## Welcome to Niagara Health's Neonatal Intensive Care Unit

CONGRATULATIONS ON YOUR NEW BUNDLE/OR BUNDLES OF JOY!

## niagarahealth Extraordinary Caring. Every Person. Every Time.

This booklet has been written as a guide for you during your newborn's stay in NICU.

The St. Catharines Neonatal Intensive Care Unit (NICU) is a 17-bed unit that is designated as a level 2C facility, taking care of newborns 30 weeks and above.

If you have any questions or concerns, please ask any member of your baby's health care team.

We welcome your questions at any time of day. Our team is here to support you and your family.

Introduction to NICU	2
When can I spend time with my baby?	3
What do I do when I get to the NICU?	1
Protect your baby: Tips for all parents & visitors	õ
Who can visit my baby?	õ
Can children visit?	ō
Can I be with my baby if I am not feeling well?	7
What are some common types of equipment?	3
How long will my baby need to be in the NICU?	9
When will I be asked to leave my baby's bedside?	9
How does the NICU keep information about each baby private and confidential?	)
What are some things I should know about the hospital?	)
Hauser Pharmacy1	L
Part 2: Parenting in the NICU	3
How can I care for my baby in the NICU?13	3
What you can do?13	3
What can I bring in for my baby?16	ŝ
What else should I know about being a NICU parent?16	ŝ
Discharge – Time to go home	9
Part 3: NICU Environment and Equipment	)
How is the NICU different than a newborn nursery?	)
Why are babies admitted to the NICU?22	L
Why is my baby surrounded by so much equipment?22	L
Part 4: Who's who in NICU?	3
Who is involved in my baby's care?23	3
When can I talk to my baby's doctor?	5
Can I call and to speak to my baby's nurse?25	5
Part 5: Information and resources for parents	5
Finding information on the internet	õ
Part 6: Your questions, notes and family information 29	9

## Introduction to NICU

The birth of your baby is a joyful event, but when your baby comes to the Neonatal Intensive Care Unit (NICU), you may feel a whirlwind of emotions. This is normal.

As a parent in the NICU, you are the most important person for your baby.

You are your baby's voice, your baby's source of comfort, warmth and affection, your baby's advocate, and the most vital member of your baby's care team.

Although we, as NICU staff, can provide specialized medical and technical care, we cannot be a parent to your baby.

As a parent, only you can provide the love and devotion that your baby needs – by doing Kangaroo Care, providing breast milk, telling stories, or singing to your baby. These are unique things that you can do to help your baby thrive.

As NICU staff, we recognize you are not considered a visitor. Parents are welcome here 24 hours a day. We want you to be with your baby as much as possible and take part in your baby's care.

We are here to help and support you in any way that we can and will provide you the information, teaching and answer any questions you may have.

#### When can I spend time with my baby?

As a parent, spending time with your baby will help them thrive. We want you to spend as much time with them as possible; therefore, all parents are welcome in the nursery 24 hours a day.

After your baby is born or arrives from another hospital, you will be able to spend time with them right away. If you are not able to be with your baby in the NICU for any reason, call us at any time to get information on how your baby is doing.

#### **Calling the NICU**

Hospital Contact Number 905-378-4647 ext:43200

#### Each time you call the NICU, please provide:

- your name
- your newborn baby's LAST name
- the 5 digit numbers located on your matching infant and parent ID bands



#### What do I do when I get to the NICU?

For the safety of the babies, the NICU is a **secured unit.** 

This means the doors are locked and need to be opened by a staff member.

Please pick up the phone located directly beside the locked entrance and one of our receptionist will answer. Once stating who you are and the name of the infant you wish to visit, a team member will come to the door and allow you through.

#### Cleaning your hands when you enter NICU

When you enter the NICU, you must clean your hands or scrub in.

#### Each time you arrive at the nursery:

- ✓ Roll up your sleeves so that you are "bare below the elbows".
- ✓ Take off all jewelry, rings, watches, bracelets, etc.
- ✓ Clean your hands with soap and water for at least 30 seconds.
- ✓ Use paper towels to turn off the taps so you do not dirty your hands again.

For the rest of your visit, you may wash your hands with soap and water, or use the alcoholbased hand rub (if your hands are not visibly dirty).

#### This is especially important to do:

- before and after touching your baby
- before and after touching any object or surface
- before leaving the NICU.





#### Protect your baby: Tips for all parents & visitors

- Be bare below the elbows at all times. No wristwatches, bracelets, rings (other than a plain gold band), or other jewelry.
- No fake nails, shellac, or nail polish.
- No food or drink, other than water in an unbreakable container or bottle with a closed top.
- Please leave stuffed toys at home, as they cannot be cleaned easily.
- Limit the number of visitors who touch your baby.
- Do not visit if you are feeling unwell.

#### Who can visit my baby?

- We encourage you to let people who are special to you visit you and your baby. You can bring visitors in any time of the day.
- For the safety of the babies:
- Only 2 people may be at a baby's bedside at any one time. This means that you can bring 1 visitor with you.
- Parents of multiples (twins or triplets) may have 2 visitors for each baby.
- Please ask friends and family members about their health before visiting.
- If they are feeling unwell, please ask them not to visit.

#### Can children visit?

Only siblings of the newborn baby are allowed to visit. It is very important for brothers and sisters to visit as we want them to be involved as much as possible.

If your baby's aunt or uncle are less they 16 years old, they are still considered a child and not allowed to visit as they are not a direct sibling.

#### Before a child visits, there are a few things to keep in mind:

- Make sure their vaccinations are up-to-date. Before entering the NICU, all visiting children need to show a copy of their vaccination record. We need to know whether they have had chicken pox or have been vaccinated against chicken pox.
- A photocopy of the vaccination record will be placed in your baby's chart and siblings will only need to show this on their first visit.
- If you do not provide this information, they will not be allowed to visit.
- If a child has recently been vaccinated, they will need to wait 21 days after the vaccination before visiting.
- If a child has been exposed to chicken pox, please let us know.
- Please do not let a child visit if there is any chance they could spread an infection to others.

#### Can I be with my baby if I am not feeling well?

If you are not feeling well, we ask that you do not visit the NICU.

Instead, please call to get information about your baby. We do this to protect babies from getting sick, since their bodies are not strong enough to fight germs.

#### If you have any of the following, please stay home:

a rash, itchy skin, or an infection on the skin or hands	vomiting (throwing up)
diarrhea (loose or watery bowel movements)	fever
recent exposure to someone with chicken pox, measles, or the flu	a cold, cough, or a runny nose

## If you are in doubt, call the NICU and speak with your baby's nurse. Together, you can decide the best thing to do.

If your baby is showing any of the above signs, we will insolate your baby to help stop the potential spread of infection to other babies on the unit. This means your baby will have swabs or blood tests completed to test for suspected infection. Your baby will remain under isolation until negative results are received and baby's symptoms improve. While your baby is isolated, all members of the health care team along with any visitors will be gowning, gloving and/or wearing a mask whenever they enter your baby's room. Upon leaving your baby's room, it is imperative that thorough hand hygiene be completed and all gowns, gloves and/or mask be discarded prior to exiting.

#### Cold sores

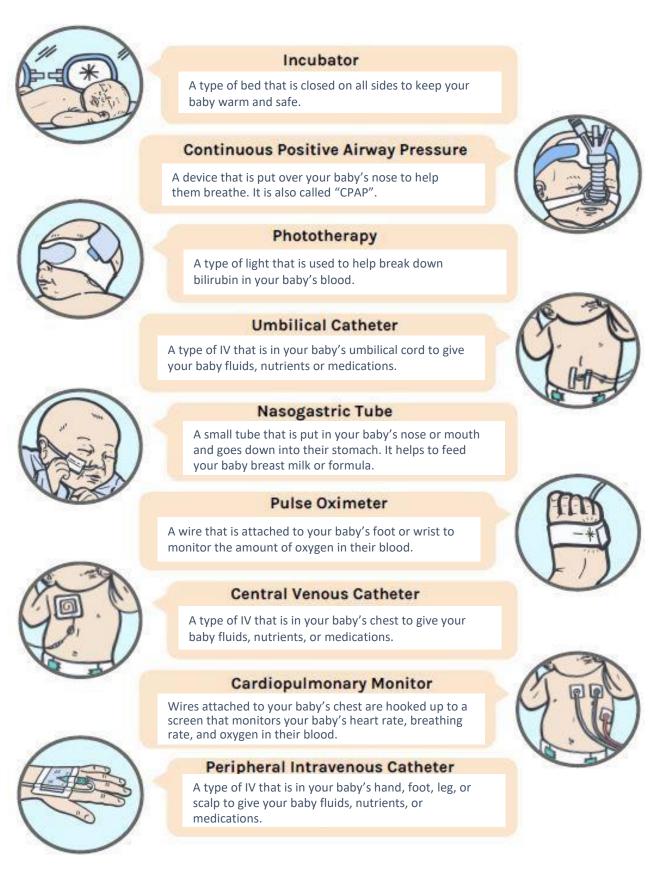
Caution

Parents or visitors with a cold sore that is open and draining can visit the NICU; however, they must:

- Wash their hands often.
- Cover the lesion with a bandage or mask.
- Wear gloves during any direct contact with a baby and avoid touching their face.

#### Welcome to Niagara Health's Neonatal Intensive Care Unit Introduction to the NICU

#### What are some common types of equipment?



#### How long will my baby need to be in the NICU?

This is a difficult question to answer, since every baby is different and has a different path to recovery.

Although each baby is different, there are a few things babies need to be doing before they can go home:

- breathing on their own
- eating well on their own
- maintaining their body temperature
- gaining weight

Your health care team will talk with you about your baby's condition and expected length of stay.

#### When will I be asked to leave my baby's bedside?

We want you to spend as much time with your baby as possible. However, there are a few times when you may be asked to leave your baby's bedside.

#### Surgical or sterile procedures

- Procedures may need to be done with very little notice.
- During procedures for your baby, we will ask you to leave so we can keep the area sterile and provide enough space. We know this may be upsetting, but you can come back when the procedure is over.

#### The safety of the babies

- If you are not feeling well, please stay home. Babies in the NICU are more likely to get infections and can easily become sick.
- If you enter the NICU when you are ill, you will be asked to leave until you are feeling better.

#### The safety of parents and staff

- Everyone needs to feel safe in the NICU, including parents and staff.
- For the hospital to be a place where everyone is treated with respect, we follow a Code of Conduct based on values such as dignity, professionalism, communication, and teamwork.
- Violence, whether it be verbal or physical by anyone in the NICU, is not tolerated.
   Security personnel will be called if these situations occur, and you will be asked to leave the NICU.

# How does the NICU keep information about each baby private and confidential?

No information about you or your baby will be given over the phone or in person to other

family members or friends. We will tell people that only you, the parents, can share this information.

Information about your baby is shared only with you and the other members of your baby's health care team. The information is used to:

- plan care for your baby
- plan for future needs of all babies
- contact you for special NICU celebrations and events

For a complete statement about our privacy practices visit the Niagara Health website.

#### What are some things I should know about the hospital?

Visitor information is available on NH website: <u>NiagaraHealth.on.ca</u>

#### Directions and parking

For directions, information about parking and hospital floor plans: www.NiagaraHealth.on.ca/site/parking

There is an hourly rate for parking with a daily maximum. You pay at the kiosk by the service desk when you leave the hospital. The machines take cash and credit card payments.

#### Long-term Parking Passes

If your baby is in NICU for more than a few days, it will cost less to buy a long-term parking pass. Depending on your needs, there are several options from 5 to 30 days.

You can buy a parking pass at the Parking Office, located in parking lot B.

#### For more information about hospital parking:

Email: <u>parking@niagarahealth.on.ca</u> Parking office: 1-888-783-7275 Visit the Parking Office (Lot B). Open Monday to Friday 8 am to 4 pm, closed weekends and holidays.



#### WIFI is available for Purchase

For all pricing and available packages visit please visit our website <u>NiagaraHealth.on.ca</u>

#### iVisitor rates are as follows:

4 Hours: \$ 5.95 + HST 1 Day: \$ 9.95 + HST 3 Days: \$18.95 + HST 7 Days: \$28.95 + HST Monthly: \$47.95 + HST

#### **Public Wifi Access**





#### Shops and Services

#### Bank Machine/ATM:

Bank machines can be found in the main lobby. A branch of the FirstOntario Credit Union is also located in the main lobby.

#### Food:

There are cafeterias and coffee shops, as well as vending machines providing hot and cold beverages and snacks are available 24 hours a day in Emergency Department and Urgent Care waiting areas and cafeterias.

#### **Gift Shops:**

The gift shop is run by hospital Auxiliary members as a main fundraising program. Personal items such as soap, toothpaste and shampoo can be purchased in the gift shops. A wide selection of gift items.

#### **Hauser Pharmacy**







#### **Places for parents**

Families are welcome to visit their infants 24 hours a day. Parents may stay overnight in their infants rooms in an available beside cot.

A fridge is available along with a microwave for cleaning breast pump kits in the NICU across from the public washroom.

No food or beverages are allowed in the NICU. Water is acceptable. For storing personal food, there is a family room located just outside the NICU on Postpartum with an available fridge and microwave.

We are a fragrance free hospital. Many people have asthma and other allergies. Please do not wear perfume, cologne, aftershave, scented hairspray or other scented products when you visit

## Part 2: Parenting in the NICU

#### How can I care for my baby in the NICU?

Your baby needs you with them as much as possible. You are a key member of your baby's health care team

#### What you can do?

#### Pump or Breastfeed

Providing breast milk for your baby is important and helps their development. A specialized nurse, called a lactation consultant, will support you in hand expression and pumping if needed.

If your baby is ready for breastfeeding, your baby's nurse (and a lactation consultant if needed) will support you with this as well.

#### Kangaroo Care

Holding your baby skin-to-skin is one of the best things you can do for your baby and it is great for you as well!

Kangaroo Care helps babies breathe, calms them, protects them from infection and helps their brain develop. It can also help you with breast milk production and bonding with your baby.

#### Hand Hugging

For babies that are not quite well enough for Kangaroo Care, you can still provide comfort by doing a hand-hug. This involves gently cupping your baby's head and feet. Ask your nurse to show you how.

#### Read to your baby

Reading helps you feel close to your baby.

#### Be at your baby's bedside during rounds

Rounds happen every morning and we encourage you to be there.

This is a chance to get information and ask questions. Ask your nurse for more information on when rounds happen.

#### Baby care and comfort

Your baby's nurse can help you learn and be comfortable with changing diapers, helping with feeds, checking temperature and bathing your baby. This will also help you get to know your baby and your baby's needs.

You can also provide comfort to your baby by reading to them, singing to them, or talking softly to them.

#### Keep a record

Many parents keep a written journal while their baby is in the NICU.

You may want to keep a record of special moments and milestones

#### My Space boards



#### NICU Milestones – here are some reasons to celebrate!

Breathing	Beds, Seats and Swings
Image: Second system         Image: Wass able to breathe on my own         Image: Came off oxygen         Image: Wass able to breathing tube         Image: Wass off CPAP         Image: Came off CPAP         Image: Wass held by mum or dad for the first time         Image: Wass held by mum or dad for the first time         Image: Wass held by mum or came         Image: Wass held by mum or dad for the first time         Image: Wass held by mum or came         Image: Wass held by first kangaroo care         Image: Wass held by first cuddle with mom or dad	Beds, Seats and Swings         ✓ moved to a crib         ✓ sat in a bouncy chair         ✓ sat in a swing         ✓ went for a stroller ride         Growth         ✓ weigh over 1kg         ✓ weigh over 2kg         ✓ weigh over 3kg         ✓ weigh over 4kg
<ul> <li>✓ met my(insert name of visitor)</li> <li>Transitions</li> <li>✓ graduated to the Level 2 Nursery</li> <li>✓ went to Care by Parent</li> <li>✓ went home</li> <li>✓ Today is my due date</li> </ul>	Activities of Daily Living         ✓       opened my eyes         ✓       wore clothes         ✓       had my first smile         ✓       had my first bath         ✓       started tummy time         ✓       had my first haircut
Feeding	Tests and Procedures
<ul> <li>started sucking on my soother</li> <li>graduated to the term soother</li> <li>had milk for the first time</li> <li>had first non-nutritive breast feed</li> <li>went to the breast</li> <li>had formula for the first time</li> <li>reached full feeds</li> <li>had a bottle feed</li> <li>fed tube free</li> </ul>	<ul> <li>✓ got my first immunizations</li> <li>✓ passed my Hearing Test</li> </ul>

#### What can I bring in for my baby?

You are welcome to bring things from home for your baby. These things make your baby 'feel at home' and part of your family.

#### Clothes and blankets

- Babies can usually wear their own socks and hats. If your baby is doing well, you can bring in clothes for them.
- If you like, you can also bring in blankets for your baby's bed.
- You are responsible for taking these items home to clean. Ask your nurse for a bag to store dirty items before taking them home.

#### Toys and books

- You can bring in plastic toys that can be easily cleaned.
- Do not bring in stuffed toys because they are harder to clean. They could hold germs that cause infections.
- You may also bring in books to keep at your baby's bedside.

#### What else should I know about being a NICU parent?

#### How you may feel

- When your baby has a health problem that requires care in the NICU,
  - You will feel many emotions. Please know that you are not alone with your feelings. Many NICU parents feel depressed, anxious, and stressed.
- When your baby's birth does not happen as hoped,
  - you may feel sadness, anger, guilt, or a strong sense of loss. All these feelings are normal. It is also normal for you to feel a loss of control as staff members provide care for your baby.
- We know that all parents can experience mental health issues after the birth of a baby,
  - Many are common to NICU parents, including postpartum depression, postpartum anxiety, and posttraumatic stress disorder (PTSD).

#### Reach out for support

- Social Workers are available for any questions or concerns you may have. They can provide you with support, coping strategies, and tips that you may find useful.
- Your own healthcare provider (such as your obstetrician or family doctor) can also help you find support.

#### Taking care of yourself

Sometimes parents are so focused on their babies that they lose touch with how they are doing. Take time to care for yourself! Try to keep your mind and body healthy.

#### Tips for all parents and family members

- Allow time and space for your thoughts and feelings. Give yourself permission to feel overwhelmed and cry.
- Use coping skills that have worked for you in the past. Explore what works for you during difficult times.
- Consider ways to express yourself and be creative. For example, keep a journal, write a blog, write poetry or draw.
- Set a routine. Putting some structure in your day can help give you a sense of control.
- Rest whenever possible. Rest and sleep can help with your emotions.
- Find a balance that works for you with visitors. To get enough rest, you may need to limit the number of visitors.
- Accept help from others. Tell friends and family how they can help you. You may need help with shopping, cooking, cleaning and caring for your other children.
- You will benefit from eating well, getting fresh air, and enjoying regular physical activity or exercise.
- Connect with peers and friends. Other families you meet in the NICU can be a great source of support as you are experiencing the same things.

#### Taking pictures in the NICU

You can take pictures and videos of your own baby at any time. However, our hospital policy requires that you get permission in advance from any other person you would like to photograph or video (such as a staff member).

Recognizing this, we ask that you please be mindful of your surroundings when you are taking pictures in the NICU.

Posting information online: You may want to post pictures of your baby on a personal website or a social networking site such as Facebook<sup>®</sup>.

To include a picture with anyone else from the NICU (such as a staff member, another baby or another parent), you must have permission to take the picture and to post it online.

if You think my hands are full You should see my heart



#### Making difficult decisions about your baby's care

Families and staff must make difficult decisions every day in the NICU. Sometimes there are no obvious answers or easy solutions. There can be differences in opinions, values, and beliefs.

The Ethics Consultation Service helps families and staff reach a common ground. It is made up of a team of health professionals with experience and training in medical ethics. The team helps all those involved clarify problems, explore implications, and consider options in order to make the best possible decisions.

Ethics Consultation are available Monday to Friday 8:00 am to 5:00 pm. If it is after business hours or on weekends leave a message and someone from Professional Practice will get back to you the next business day.

The deliberations and the proceedings of the Ethics Consultation Service are strictly confidential (unless disclosure is required by law).

Request an ethics consultation by contacting Professional Practice through Niagara Health switchboard at 905-378-4647 or email <u>NHethicsquestions@niagarahealth.on.ca</u>

#### Spiritual and Religious Care:

Niagara Health Spiritual Care staff are interdisciplinary team members who work with patients, families, staff and volunteers at all sites.

#### They can help you:

- Connect with spiritual resources
- Face anxieties and fears
- Express feelings
- Think through healthcare decisions
- Participate in prayers or rituals

Spiritual and Religious Care staff also work with area faith communities/congregations in order for appointed visitors ('ordained' and 'lay') to attend to the spiritual needs of their people in hospital.

To contact someone from Spiritual Care, call the switchboard at 905-378-4647 and ask for Spiritual Care.

#### Discharge – Time to go home

- Your baby can go home when they no longer need monitoring in a hospital.
- Your baby's health care team will meet with you before your baby is ready to go home to discuss the steps that are involved.
- Sometimes parents need to spend 24 to 48 hours at their infant's bedside providing all infant care prior to discharge. This will help you feel better prepared and more confident when you take your baby home.
- All NICU staff share your ultimate goal: to bring your baby home!





## Part 3: NICU Environment and Equipment

#### How is the NICU different than a newborn nursery?

There are three levels of hospital care for babies. The NICU is a Level 3 Nursery, providing the highest level of care.

- Level 1 A hospital nursery that provides care to healthy newborn babies.
- Level 2 A hospital special care nursery that provides care to babies born after 32 weeks' gestation and weigh more than 1500 g.

Babies may need special care such as intravenous (IV) fluids, help with feeding, as well as help with their breathing or special medicine.

Babies in Level 2 may also be recovering from a more serious condition.

Level 3 A hospital NICU that provides life support and specialized 24-hour care for babies that are very sick. This includes babies born at all gestational ages and weights, and babies born with complex and critical illnesses.

Babies who need level 3 care need to be watched very closely and need very special care. This includes help with breathing and feeding.

Babies in Level 3 may also need special medication, testing/imaging, or surgery.



#### Why are babies admitted to the NICU?

Babies may be admitted to the NICU for many reasons, including:

- prematurity born before 37 weeks of pregnancy
- health problems low sugar levels, an infection or jaundice
- breathing problems
- health condition that requires surgery

The care your baby receives in the NICU is based on your baby's needs. Your baby's' health care team will help you learn about your baby's condition and care. They welcome your questions at any time.

#### Why is my baby surrounded by so much equipment?

The equipment around your baby helps the health care team take care of your baby. Each piece has a special purpose in your baby's treatment.



#### Equipment may be used to:

keep your baby warm	give your baby food, fluid or medicine.
give your baby oxygen	monitor your baby's weight, heart rate, breathing rate, oxygen saturation, and blood pressure

It can be overwhelming to see your baby connected to so many wires and tubes. We promise that the equipment is there to provide your baby with the care they need to get better.

As you sit with your baby, you will notice that most of the equipment shows numbers on a screen. Sometimes these numbers flash and you will hear an alarm or ringing sound. While this may be scary, your baby's health care team are trained to know what these numbers and alarms mean and how to respond if needed.

For information about equipment, numbers or sounds, please talk with a member of the team. They welcome your questions at any time.

## Part 4: Who's who in NICU?

#### Who is involved in my baby's care?

A special team of people will help you care for your baby. Your baby's team will provide truthful, up-to-date information about your baby. Please speak with them whenever you need.

Here are the team members you may meet:

#### Neonatologist

A pediatrician with special training in the care of very sick and premature babies. The neonatologist is in charge of your baby's care.

#### **Medical Learners**

Pediatricians who are getting more training in the care of sick and premature babies. They work in the NICU and report to the neonatologist.

#### Resident

Residents are doctors who are learning about the care of sick children and premature babies. They are training to become pediatricians.

#### Nurse Practitioner (NP)

A nurse with advanced education and skills in the care of sick and premature babies, and their families.

#### Registered Nurse (RN)

The nurses who work in the NICU have training and experience in nursing care of sick babies and their families.

#### Charge Nurse (RN)

A Registered Nurse who is responsible for looking after the day-to-day activities in the unit.

#### Respiratory Therapist (RT)

The RT assists the nurses and doctors with the treatment and care of babies with breathing and lung problems.

#### Social Worker

Social Workers help individuals and families cope with problems they are facing, to improve their hospital stay. They can give you and your family practical and emotional support while your baby is in the hospital and when you are planning to go home.

#### Pharmacist

The pharmacist works very closely with the doctors and nurses to provide safe medication therapy.

#### Occupational Therapist (OT)

The occupational therapist assesses your baby's development. An OT can plan activities for your baby to learn new skills. This can help overcome problems such as feeding difficulties, long-term hospital stays, and positioning care.

#### Dietitian

The dietitian works with the doctors and nurses to plan the best nutrition for your baby. The dietitian also helps mothers with breastfeeding support and advice about healthy eating.

#### Lactation Consultant

The lactation consultant is a specially trained staff member who can support and help mothers with breastfeeding and pumping.

#### Ward Clerk

The business clerk greets and directs families and visitors in the NICU. The business clerk helps with telephone calls and mail, books tests and appointments for the babies. They help make the arrangements for babies' admission, transfer and discharge.

#### Environmental Aide/ Housekeeping (EVS)

The environmental aide helps to keep the nursery clean. The EA is the person who washes all the incubators and baby warmers.

#### Other members of the care team include:

- Clinical Manager
- Clinical Leader
- Access to Pediatric Cardiologist (heart specialist)
- Access to Pediatric Ophthalmologist (eye specialist)
- Access to Neonatal Follow-up Clinic
- Public Health Nurse

#### When can I talk to my baby's doctor?

During the day, the neonatal doctors (neonatologists) and other members of the health care team see their patients during "rounds." Rounds is the time when the team will review and discuss how your baby is doing and decide on a plan of care. You are welcome to take part in rounds, ask any questions, and gain as much information as you can. The timing and length of rounds varies within the nurseries, depending on the babies' needs.



If you are unable to be at rounds and have a question, please ask to speak to your baby's doctor at any time. If the doctor needs more time to answer your questions, they will schedule a family meeting with you and the rest of your baby's health care team.

#### Can I call and to speak to my baby's nurse?

Of course! We understand how hard it can be to be away from your baby.

If you are worried or want information on how your baby is doing, call your baby's nurse any time of day or night.

- Call 905-378-4647 ext. 43200 for the NICU
- Provide the 5 digit numbers located on your matching infant and parent ID bands.

## Part 5: Information and resources for parents

#### Finding information on the internet

Searching for information online can be challenging. There are so many websites and the information you find may not be accurate, complete, or relevant to your situation. Some of the information may be hard to understand.

#### Here are three questions to help you find good information:

- Is the website a reliable source of information?
   Find out who provides the information and runs the website. This information may be found in the 'About Us' section.
  - *Look for:* government and university websites
    - websites of hospitals or health agencies
    - website of professional associations such as the Canadian Pediatric Society
    - the authors' education, experience and how to contact them
    - where the information comes from- facts should be backed up with references to medical research

#### Be cautious of:

- commercial sites ending with '.com' that are selling products or services
- claims that seem too good to be true or facts without supporting evidence
- personal websites that give opinions and testimonials
- websites that ask for personal information/ask you to subscribe or pay to become a member
- 2. How up-to-date is the information?

Health information changes all the time. Look for the date at the bottom of the webpage to see if the information was recently updated.

3. Is the information clear and easy to understand?

Many websites provide detailed medical information. If you prefer information written in plain language, look for websites that are created for parents and families. For example, the Canadian Pediatric Society has a website for parents and caregivers called 'Caring for Kids'.

\* If you are having trouble finding information that is easy to understand, ask a member of the health care team for help.

Suggested websites to find appropriate health information: <u>MedlinePlus Tutorial</u> <u>Evaluating internet health information</u> <u>A guide to healthy web surfing</u> Health ON the Net Foundation

#### Recommended websites for parents

Internet health information can help you have an informed discussion with the health care team. Please talk about the information you find on the internet with your baby's doctor or other members of the health care team. They know you and your baby, and can best answer your questions.

You can also find support groups online. It may be helpful to share information and discuss concerns with others, but be cautious about taking advice from people you do not know. Before taking any action, talk with a member of your baby's health care team.

#### **General Information**

McMaster Children's Hospital www.hamiltonhealthsciences.ca Click 'Patient Education' on the left. Search by key word.

Canadian Pediatric Society www.cps.ca/

Health Canada www.hc-sc.gc.ca

Canadian Neonatal Network www.canadianneonatalnetwork.org

Informed Health On-line www.informedhealthonline.org

Support 4 NICU parents http://support4nicuparents.org/

Canadian Coalition for Immunizations Awareness and Promotion www.immunize.cpha.ca

**Co-ordinated Access for Child Care in Hamilton** 

**Canadian Pediatric Society** 

Caring for kids www.caringforkids.cps.ca

**Breastfeeding Preterm babies** 

Hamilton Regional Lactation Committee www.breastfeedinghelphamilton.ca

Infact Canada www.infactcanada.ca

**Niagara Public Health** <u>https://www.niagararegion.ca/parents/feeding/breastfeeding.aspx</u>

LaLeche League Canada www.lllc.ca/

Premature Baby – Premature Child www.prematurity.org

Canadian Premature Babies Foundation <a href="http://www.cpbf-fbpc.org/">http://www.cpbf-fbpc.org/</a>

**Canadian Preemie Parent Support Network** <u>https://www.facebook.com/grou ps/CanadianPreemieParentSup portNetwork/</u>

Canadian Postpartum Depression Support Network https://www.facebook.com/grou ps/PPDSupportCanada/

Websites recommended for Rare Diseases Ontario Newborn Screening Program www.newbornscreening.on.ca

National Institutes of Health http://rarediseases.info.nih.gov Office of Rare Diseases



of Mental Health

## Part 6: Your questions, notes and family information

#### Questions : Your questions, notes and family information

Your health care team welcomes your questions at any time. Here are some questions you may want to ask them. You can write answers in the notes pages.

What is my baby's main or biggest problem? What is your biggest worry regarding my baby?

I am worried about \_ ; should I be? How is this problem being treated?

What tests have been done or will be done? What is involved in the daily care of my baby?

Who is involved in the daily care of my baby? What do these people do? What medications will my baby be on?

When can my baby eat, and how?

How long will my baby be in the hospital? What can I do to help my baby?

How can I be involved in my baby's care? When can I hold my baby?

Will I be able to breastfeed my baby?

What are the possible long-term problems that my baby will have? What care will my baby need at home?

What follow-up will be needed?

What supports are available to help our family through this stressful time?

# Thank you

We are grateful to all the families, NICU staff, McMaster parent panel, and students who helped develop this booklet.



## Notes