Welcome to the Neonatal Intensive Care Unit (NICU)

A guide for parents and families with NICU babies





905 • 521 • 2100 ext. 76146

Our Family!

Please fill out this page, tear it out and leave it at your baby's bedside. This Information will help us get to know your family and how we can best support you.

Our family includes...

Who are the members of your family? Who will support you during your stay in NICU? What other people are important to your family? Please let us know their names and ages (if they are children).

Where we live...

Where do you live? How far away is this? How do you get here?

We plan to be with our baby...

When are you able to be with your baby? What days and times are best? Do you work outside your home? Do you care for other children or people at home?

We communicate best by...

What is the best way to reach you? What are your contact phone numbers? Do you prefer to speak or write in a language other than English?

What we want you to know about our family...

What else would help us get to know your family and meet **your** needs? For example: past experiences with pregnancy, childbirth and neonatal, current worries or concerns, interests and upcoming special events.

☐ I received my "Welcome" book on _	(date)	(initials)

Welcome to the Neonatal Intensive Care Unit (NICU) & Level 2 at McMaster Children's Hospital

Congratulations on your new bundle (or bundles) of joy!

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.

When your baby is in the NICU, they need you more than anyone else.

- 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 this. You are not considered a visitor and are welcome here 24 hours a day.

- We want you to be with your baby as much as possible, and we are here to help you in any way that we can.
- We want you to take part in your baby's care as much as possible.
 We will give you the information, teaching and support you need to do this.

This book is written as a guide for you during your baby's stay in NICU.

- 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.

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Introduction to NICU



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

The NICU staff are available for help and support, so please ask questions if you have any! It's OK if you need to ask a question many times, since there is a lot for you to learn.

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, so all parents are welcome 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

From outside the hospital:

- 905-521-2100 ext. 76146
- Toll-free 1-866-207-1971

From inside the hospital:

- Neonatal Intensive Care Unit (NICU) ext. 76146
- Level 2 ext. 73753

Each time you call the NICU, please provide:

- √ your name
- √ your baby's name
- the last 4 numbers of your baby's identification number, which is printed on your parent/support person identification badge

What do I do when I get to the NICU?



This picture shows the front desk at the entrance to 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.

During the day (7:30 am to 7:30 pm)

A staff member may be at the front desk to:

- welcome you
- answer any questions you may have
- open the doors for you
- make sure you are ready to enter the NICU!

If there is no staff member at the desk, please use the phone on the front desk to call inside the NICU.

Prior to entering the NICU please:

- Take off your jacket and hang in the family lounge or in the closets next to the front desk
- Take off all jewelry
- Wipe down cell phone with an alcohol wipe for electronics provided at the NICU front desk or place your cellphone into the UV device sanitizer found at the handwashing sinks in the NICU and Level 2.

During the evening and night (7:30 pm to 7:30 am)

Use the phone on the front desk to call inside the NICU. A staff member will answer the phone and open the door for you.

Getting your identification badge

The first time you come to the NICU, we will give you a badge that lets staff know you are a parent or support person. The badge has your baby's ID number on it. You will use this number when you call the unit to get information about your baby.



Cleaning your hands when you enter NICU

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

Cleaning your hands is the best way to stop the spread of germs and keep your baby healthy.

Each time you arrive at the nursery:

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

Look for this poster with instructions for cleaning your hands!





For the rest of your visit, you may wash your hands with soap and water, or use the alcohol-based 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, and
- ✓ before leaving the NICU.

You're not just a parent – you are your child's top safety officer!

As a safety officer, we encourage you to ask anyone who is going to touch your baby if they have cleaned their hands. This includes all staff!

Protect your baby: Tips for all parents & visitors

- Be bare below the elbows at all times. No wrist watches, bracelets, rings 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.

Other visitors may wait in the family room just outside the NICU entrance.



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?

Of course! Children of any age can visit you and your baby. It is very important for brothers and sisters to visit. We want them to be involved as much as possible.

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.
 - Siblings will only need to show this on their first visit. Other visiting children must bring proof of vaccination every time they 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 is unwell we ask they not visit.
- If you or your visitor have been exposed to chicken pox or measles, please let us know, we will let you know when you can visit again.
- Please do not let a child visit if there is any chance they could spread an infection to others.

When children visit, please keep them with you so you can watch them carefully.

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

If you are not feeling well, we ask that you do not come to 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
- a cold, cough, or a runny nose
- diarrhea (loose or watery bowel movements)
- vomiting (throwing up)
- fever
- recent exposure to someone with chicken pox, measles, or the flu

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

Cold sores



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.

Mac Cuddler Program

cuddler cuddler program

What is the MacCuddler Program?

We understand that sometimes parents and family members cannot always be with their baby for as long or as often as they would like. Many parents work, live far from the hospital or have other children to care for. Our MacCuddlers program helps give babies important positive touch and comfort when parents and family members can't be here.

Research shows that human touch improves babies' health and brain development. It can also help them develop healthy relationships with people later in life. Our medical team recommends that NICU babies are held and comforted every day. Holding, rocking, singing and talking to babies can also help them gain weight, grow faster, lower their stress and get into a deeper sleep.

Our Cuddlers can...

- ▼ Hold, rock, sing, or read to your baby
- Provide hand hugs, hold baby's hand or soother during procedures
- Respond to baby's cues and work with medical team to support baby
- Change baby's position from bed to swing after speaking to nurse
- Bring blankets or fresh clothing for babies

MacCuddlers do not change diapers or feed babies. When you arrive, the cuddler will visit another baby.

Bables in the NICU are able to be held or comforted by our MacCuddlers but parents can say no to this program. Please ask your team for more information.

"Of all the things our hands have held, the best by far is you."



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.

Every baby's stay in the NICU is different.

While other parents may have had similar experiences, we ask that you refer to your baby's health care team for the most accurate information.

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 or another 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.



To all our staff, doctors, volunteers, patients, families, learners and others

We expect everyone to treat others with dignity and respect.

Purposeful, aggressive behaviour, language and/or violence is not acceptable at Hamilton Health Sciences.

Thank you for helping maintain a safe and healthy environment for everyone.



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.

We will protect the privacy and confidentiality of all the personal information you give us.

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:

- See the poster at the front entrance to NICU, or
- Go to <u>www.hamiltonhealthsciences.ca</u>. At the very bottom of the page, select 'Patient Privacy'.

How parents can help with patient privacy

McMaster Children's Hospital is a teaching hospital. During teaching sessions called 'rounds', the health care team discusses the care of each baby. The team will make every effort to maintain privacy for each family; however, you may overhear these discussions.

If you do hear something about another baby or family, please keep this information to yourself. Confidentiality for each family is important to us at McMaster Children's Hospital.

Rights and responsibilities

As a parent you have rights and responsibilities. These outline how you can expect to be treated and how you can be involved in your baby's care. See your health care team for more information.

What are some things I should know about the hospital?

Directions and parking

For directions, information about parking and hospital floor plans, go to https://www.hamiltonhealthsciences.ca/mcmaster-childrens-hospital/parking/

There is an hourly rate for parking with a daily maximum. You pay at the machines by the elevators 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 the red section of the parking garage near the Main Street exit.

For more information about hospital parking:

- Call 905-521-2100, ext. 76156
- E-mail: <u>parkingoffice@hhsc.ca</u>
- Visit the Parking Office. Open Monday to Friday 8 am to 8 pm, Weekends and holidays 10 am to 4 pm.



Internet access

 Wi-Fi (iVisitor) access can be purchased using your credit card. There are packages for short and longer term access.

Shops and services

Please see the family information board that is located behind the red elevators for more information on shops and services within the hospital.



Corner Café

Main Lobby on the 2nd floor

- Open 24 hours a day,
 7 days week. Special hours on holidays.
- Serves coffee, tea, cold drinks, soup, wraps, sandwiches and snacks.



Baywest Cafe (cafeteria)

Red area, 1st floor

- Open Monday to Friday,7 am to 6 pm.
- Serves made to order meals, baked goods, coffee, tea, cold drinks, soup, salads and snacks.



McMaster Give Shop Main Lobby, 2nd floor

- Monday to Friday, 830 am to 730 pm. Saturday and Sunday 10 am to 5 pm.
- Sells gifts and home décor items, magazines, books, cards, balloons, plants and fresh flowers.



McMaster Drugstore Main Lobby, 2nd floor

Monday to Friday, 9 am to 5 pm.

Places for parents

The family room is located just outside the NICU. It has a closet for your coat, seating, a table for eating and a children's play area. It also has a sink for cleaning breast pump kits.

There are lockers beside the red elevators outside the NICU. Talk to the business clerk at the front desk if you would like one to use for the day.

At your baby's bedside there is usually a reclining chair for you to sit on. Ask your baby's nurse for one if it is not there.

The Ronald McDonald Family Room is on the 3rd floor next to the Pediatric Units 3B and 3C. It is open from 8 am to 11 pm and has:

- A comfortable seating area with a TV and fireplace
- A kitchenette with a toaster and microwave
- Laundry facilities
- Free tea, coffee, and snacks



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

Finding a place to stay

If you need to find a place to stay overnight, please ask to speak with a Social Worker.



Ronald McDonald House

If you live more than a 45 minute drive away, the Social Worker may be able to arrange for you to stay at the Ronald McDonald House near the hospital.

The hospital also has 'Bunk Rooms' and 'Care-by-Parent Rooms'. These rooms are usually reserved for breastfeeding mothers or parents of babies who are close to going home. Ask a staff member to see if any of these rooms may be available for you.



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.
- Some pumping rooms are available for mothers and we also encourage you to pump at your baby's bedside. Privacy curtains and screens are available.
- Fill Snappies containers to the 60mL volume line (2 ounces). When the bottle is frozen, milk expands and may cause the lid to open Unsealed Snappies will be discarded for safety. Please place labels on each Snappie as seen in the photo below.



We hope that you will take part in your baby's care as much as possible.



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

At time of discharge or transfer from the NICU:

- Please ask your nurse how to get your breast milk from storage before you leave the hospital.
- Before you go home, please make sure the name on each breast milk label has your baby's name on it.
- If you have a large quantity of milk to take home, please ask friends and relatives with deep freezers if they could allow you space for storage.
- We will keep your breast milk up to one month after you leave the hospital, then it will be discarded.
- If you plan to donate your extra milk, please let your nurse, social worker or MOM room know (x72786) and ensure you follow the process for donation according to the Rogers Hixon Milk Bank in Toronto (https://www.milkbankontario.ca/) in a timely fashion as the paperwork, doctors' visit and blood work do take some time to determine if you are eligible to donate.

Provide Oral Immune Therapy (OIT)

You can provide your baby with OIT. The goal is to give drops of fresh breastmilk in the corner of your baby's mouth at least 4 times a day. This milk is absorbed in your baby's cheek and may boost your baby's ability to fight infections. With hand expression or pumping, you can fill the provided purple syringes or mini Snappies with your breastmilk that are then stored in the bedside fridge. When the baby is being handled or is awake you can give OIT. Ask your baby's nurse if you have any questions!

Kangaroo Care

- Holding your baby skin-to-skin is one of the best things you can do for your baby and it's 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.
- Kangaroo Care wraps are available to help support your baby during Kangaroo Care. Ask your baby's nurse if you would like to use one.

Hand Hugging

For babies that aren't 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.
- If you would like to borrow a book, visit our library in the family room, outside the main entrance to NICU.

Be at your baby's bedside during rounds

- Rounds happen every day 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.

Celebrate your baby's NICU Milestones

- There are lots of milestones to celebrate during your baby's journey through the NICU.
- We have cards that help you record them.
- You may choose to record the date and milestone reached or to take a picture of your baby to go with the card.
- You can put them in a baby book, in a journal you are keeping or in a special place for safe keeping.

A Milestone Card



NICU Milestones – here are some reasons to celebrate!

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

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. You can also borrow baby books from our library to read to your baby.

Write your baby's last name on any items you bring to the nursery, so that there is less chance that they will get lost.

Please leave anything valuable at home.



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 post-traumatic 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.

Family Education Sessions

Snack Chat

Families are invited to attend weekly "Snack Chat" sessions every Wednesday from 10:30-11:30 in the family lounge. Come enjoy a snack and a discussion on a variety of topics relevant to the NICU and beyond. Pick up a brochure at the NICU Front Entrance or ask a member of your healthcare team.

Milk and Cookies

Families are invited to attend weekly "Milk and Cookies" sessions hosted by our Lactation Consultants every Thursday afternoon from 1:30-2:30. All things breastfeeding are discussed.

Special Events

There are special event nights (e.g. Dad's Pizza Night) for parents. Watch for advertisements in the unit or ask a member of your healthcare team.

We recognize that parents need information, reassurance and support during this time.

Taking care of yourself

Sometimes parents get 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 in order to protect the privacy of other babies and families.

Posting information online

You may want to post pictures of your baby on a personal website or a social networking site such as Facebook[®].

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 <u>and</u> to post it online.

Please help us protect the privacy of staff, patients and families. Do not put pictures or names of other people on the internet without their permission.

Requesting a family meeting

You may have questions about your baby's care. You can request to have a family meeting. To have one arranged contact your Social Worker, nurse, doctor or nurse practitioner on your baby's care team.

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.

While the Ethics Consultation Service may make suggestions, the final decisions rest with the families and caregivers.

The Ethics Consultation Service is free, confidential, and available to all.

The team can begin helping you within 48 hours of receiving your request.

You can contact the Ethics Consultation Service by asking any staff member to request an ethics consultation. Or you can call 905-521-2100, ext. 76443 and ask for the Clinical Ethics Consultant on-call.

Leaving the NICU

All NICU staff share your ultimate goal: to bring your baby home!

When your baby no longer needs the level of care provided in the NICU, the health care team will decide if your baby will be transferred to a Level 2 Nursery or discharged home.

Transfer

 Your baby's journey home may include a transfer to a Level 2, for continued support until they are ready to go home.

Level 2 at McMaster Children's Hospital	 For babies who need the special support provided at a children's hospital.
	 For babies who are not quite ready to go home and still need some support.
Level 2 at other hospitals	 These hospitals may be closer to your home. They are located in Cambridge, Guelph, Kitchener, Hamilton, Burlington, Oakville, St. Catharines, Milton and Brantford.

• When the decision to transfer your baby is made, your baby's nurse will tell you the approximate time of the transfer. Often this happens very quickly or with little notice, but we will do our best to prepare you and give you as much notice as we can before this happens.

Moving to a Level 2 can be a stressful time for you, but this is great news since it means you are one step closer to home!

Discharge - Going 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 in a 'Care by Parent room' with their baby before they can go home. Staying in this room lets you provide all of your baby's care, but still be close to the NICU if you have questions or would like some help. This will help you feel better prepared and more confident when you take your baby home.





The 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 weighing more than 1500g.
	 Babies may need special care such as intravenous (IV) fluids, help with feeding, help with 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 who are very sick. This includes babies born at all gestational ages and weights, and babies born with complex and critical illnesses.
	 Babies who require 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
- breathing problems
- · health problems such as low blood sugar levels, an infection or jaundice
- a 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 oxygen
- give your baby food, fluid or medicine
- 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.

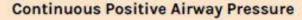
For information about equipment, numbers or sounds, please talk with a member of the team. They welcome your questions at any time.

What are some common types of equipment?



Incubator

A type of bed that is closed on all sides to keep your baby warm and safe.



A device that is put over your baby's nose to help them breathe. It is also called "CPAP".



Phototherapy

A type of light that is used to help break down bilirubin in your baby's blood.

Umbilical Catheter

A type of IV that is in your baby's umbilical cord to give your baby fluids, nutrients or medications.





Nasogastric Tube

A small tube that is put in your baby's nose or mouth and goes down into their stomach. It helps to feed your baby breast milk or formula.

Pulse Oximeter

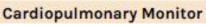
A wire that is attached to your baby's foot or wrist to monitor the amount of oxygen in their blood.





Central Venous Catheter

A type of IV that is in your baby's chest to give your baby fluids, nutrients, or medications.



Wires attached to your baby's chest are hooked up to a screen that monitors your baby's heart rate, breathing rate, and oxygen in their blood.





Peripheral Intravenous Catheter

A type of IV that is in your baby's hand, foot, leg, or scalp to give your baby fluids, nutrients, or medications.





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 to.

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.

Resident

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

Registered Nurse (RN)

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

Respiratory Therapist (RT)

The RT works with the nurses and doctors to treat and care for babies with breathing and lung problems.

Neonatal Fellow

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

Nurse Practitioner (NP)

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

Charge Nurse/Resource Nurse (RN)

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

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 nurse who can support and help mothers with breastfeeding and pumping.

Business 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.

Health Care Aide

The health care aide keeps equipment working, stocks the supplies in the unit, and takes specimens to the lab for testing. The HCA may also help the nurse during procedures, or when taking your baby for tests.

Environmental Aide (EA)

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

Learners

As this is a teaching hospital, you may meet student doctors, student nurses and other learners on the health care team. Each student works under the close supervision of a fully trained health professional. These learners may be involved in your baby's care.

Other members of the care team include:

- Clinical Manager
- Clinical Leader
- Education and Development Clinicians
- Pharmacy Technician
- Dietetic Assistant
- Pediatric Surgeon
- Pediatric Neurologist (brain specialist) or Neurosurgeon (brain surgeon)
- Pediatric Cardiologist (heart specialist)
- Pediatric Ophthalmologist (eye specialist)
- Pediatric Nephrologist (kidney specialist)
- Pediatric Hematologist (blood specialist)
- Neonatal Follow-Up Clinic
- Child Life Specialist
- Data Management Specialist

Primary Nursing

We try to provide as much nursing consistency as possible in the NICU with Primary Nursing. You can request to have a primary nurse and/or nursing team who will regularly care for your baby. We will make every attempt possible to try to provide this.

If you have questions about patient care or nursery activities that your baby's nurse or the charge nurse cannot help you with, please ask to speak with a Clinical Leader or the Clinical Manager.

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 905-521-5025 or 1-866-207-1971

- Ext. 76146 for the NICU
- Ext. 73753 for the Level 2 Nursery

Who does research in the NICU?

Research is a very important part of the work we do. Through research, we learn new information about how to best care for babies.

Who does the research?

 Staff at McMaster Children's Hospital take part in research. The research team may include doctors, nurses, therapists, dietitians, and other staff and learners.

What kind of research is being done?

 We do research to find ways of improving nutrition, medication, breathing support, and ways to prevent or treat infection.

Should I allow my baby to take part?

- This is your decision and your choice will not affect the care of your baby.
- A research staff member may talk to you about research that your baby could take part in, will provide information about the study, and answer any questions you have.

Are there any risks to taking part in research?

- All of the risks of a study will be explained to you, so that you can decide
 if the study is right for your baby.
- All personal information gathered about you or your child will be kept confidential.
- The hospital's Research Ethics Board approves all research in the NICU to safeguard the rights, safety and well-being of all research participants.



Support for parents and families

If you would like to connect with another parent who has gone through a similar experience, please talk with a Social Worker.

Infant CPR sessions for families are available through McMaster Simulation and Outreach. You can register online by going to https://www.hamiltonhealthsciences.ca/learning/simulation-outreach-program

Health education in the NICU

We encourage parents to learn as much as they can. Learning will help you:

- understand your baby's condition
- make decisions with the health care team, and
- take part in your baby's care.

Your main source for information while your baby is in the NICU is your baby's health care team. Ask questions, attend rounds, and gain as much information from them as you can.

The NICU also has many educational materials on topics such as breastfeeding, health conditions, and tests or procedures that your baby may need.

The materials are available in print and online in the Patient Education Library https://www.hamiltonhealthsciences.ca/patient-education-library/. We keep this information accurate and up-to-date.

Your health care team can give you handouts to read or show you how to access the online library. The Social Worker also has books that you can borrow. Our Child Life Specialist can provide educational resources that are helpful for your baby's siblings.

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:

1. 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:	Be cautious of:
government and university websiteswebsites of hospitals or health agencies	 commercial sites ending with '.com' that are selling products or services
 websites of professional associations such as the Canadian Pediatric Society 	 claims that seem too good to be true or facts without supporting evidence
 the authors' education, experience and how to contact them 	 personal websites that give opinions and testimonials
 where the information comes from facts should be backed up with references to medical research 	websites that ask for personal information or ask you to subscribe or pay to become a member

Don't trust everything you read.

Anyone can put information on the web and make it look 'official'.

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.

These websites can help you find good health information

MedlinePlus Tutorial

http://www.nlm.nih.gov/medlineplus/webeval/webeval.html

Evaluating internet health information

http://www.nlm.nih.gov/medlineplus/evaluatinghealthinformation.html

A guide to healthy web surfing

http://www.nlm.nih.gov/medlineplus/healthywebsurfing.html

Health On the Net Foundation

http://www.hon.ch/pat.html

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	Child care
McMaster Children's Hospital • www.hamiltonhealthsciences.ca Patient Education Library • https://www.hamiltonhealthsciences.ca/patient-education-library/ 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 • www.cafcc.on.ca Transport Canada • www.tc.gc.ca/eng/roadsafety/safed rivers-childsafety-car-index-873.htm • road safety, car safety Canadian Pediatric Society • www.caringforkids.cps.ca

Breastfeeding	Preterm babies
Hamilton Regional Lactation Committee • www.breastfeedinghelphamilton. ca Infact Canada • www.infactcanada.ca Hamilton Community Breastfeeding • www.babyfriendlyhalton.ca LaLeche League Canada • www.lllc.ca/	Premature Baby - Premature Child • www.prematurity.org Canadian Premature Babies Foundation • http://www.cpbf-fbpc.org/ Canadian Postpartum Depression Support Network • https://www.facebook.com/groups/PPDSupportCanada/

Rare diseases	Facebook pages
Ontario Newborn Screening Program	Canadian Premature Babies Foundation
 www.newbornscreening.on.ca National Institutes of Health http://rarediseases.info.nih.gov Office of Rare Diseases 	https://www.facebook.com/Canadian-Premature-Babies-Foundation-301828639921863
	Canadian Preemie Parent Support Network • https://www.facebook.com/groups/CanadianPreemieParentSupportNetwork/



Your questions, notes and family information

Questions

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?

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Thank you!

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

A special 'thank you' to the families who shared their beautiful photographs with us.

