Welcome to Children's Hospital NICU



Family Handbook





The staff of the NICU welcomes you and your baby to the Neonatal Intensive Care Unit (NICU). The NICU is part of the Children's Hospital London Health Sciences Centre. Your baby is here because he or she needs special care from a highly skilled health care team.

As a parent, you have a special role. Your baby needs your love and care every day. During your baby's stay in the hospital, your baby's health care team will give you information, help and support. We will help you learn about your baby's health and how to care for your baby. We encourage you to take part in your baby's care as much as possible.

Sincerely,

NICU staff, physicians and families

We hope this information booklet will be helpful to you. You will also find more specific information about programs and services

on the **INFORMATION RINGS AT THE BEDSIDE**

or on the Children's Hospital website.





Patient and Family-Centred Care



Our commitment to you

Respect & Dignity - Family members deserve the same respect as members of the team. Families' choices, values, beliefs and cultural backgrounds are respected. Patients and families are part of the team!

Information Sharing & Communication - As important members of the team, families are entitled to timely, complete and unbiased information offered in a supportive way, to ensure informed decisions are made about their baby's care.

Collaboration & Empowerment - Families are active participants, in decisions on care and the best treatment plans are created using medical and other technical expertise, and the families' knowledge, strengths, and circumstances.

Coordination & Comprehensiveness - Patients and families receive care that provides physical and emotional comfort and is safe. Patients and families will receive care that has continuity and smooth transitions.

NICU Infant and Family Rights and Responsibilities

We have the right to...

Be seen as an infant and family first, then as a patient

Be listened to

Be called by our names

Be treated with kindness and respect

Be recognized as a unique infant and family

Know the members of our health care team, their roles and what care they provide

Have our emotional, cultural, spiritual and developmental needs respected

Know our plan of care and participate in daily rounds

Discuss our fears and concerns with the health care team

Have our questions answered in a way we understand

Have our privacy protected



Our family has the responsibility to...

Be polite and respectful to other families, the staff and environment of the NICU

Respect the privacy of other infants and families

Follow the NICU infection prevention practices

Be open and honest with care providers

Ask questions to make sure we understand our infant's care

Be involved in making decisions about our infant

Take an active role in learning our infant's cues and participating in our infant's care

Provide feedback to staff



Table of Contents

NICU Infant and Family Rights and Responsibilities	4
You're Here, Now What?	
Ongoing Communications about your Baby	
Coming to the NICU	
Hand Washing	
Caring for You and Your Baby	
Getting Involved in your Baby's Care	11
Our Family-Centred Care Practices in the NICU	
Developmental Care in the NICU	
Taking Care of Yourself and Your Family	
NICO Paletti Hout	14
Support for Families	
Patient & Family Spaces	15
Support Services at Children's	
Preparing to go Home	
Getting ready to leave our NICU	18
Discharge Goals Checklist	19
Miscellaneous	
Research and your Baby	20
Notes	
Tell Us How We're Doing	
Do you want to make a difference at Children's Hospital? Links and Resources	
Pound/Gram Weight Conversion Chart	
	 .



Ongoing Communication about Your Baby

When can I see my baby?

You will be able to see your baby usually within an hour of birth. Please come and stay with your baby as often as you can. You are very important to your baby and your baby's health care team.

How can I find out how my baby is doing?

When you are in the NICU, the nurse will talk with you about your baby. Please ask the nurse any questions you have about your baby's health.

Feel free to call any time to find out information about your baby. Identify your baby by their full name, and ask to speak directly to your baby's nurse. We will try our best to answer calls; however it is more difficult to answer calls during nurse shift change in the NICU, which occurs daily between 7:15 am - 7:45 am and 7:15 pm - 7:45 pm.

To respect your privacy, we are not able to give information about you or your baby to other family members or friends.

The nurse can arrange for you to speak with other members of the health care team. If you would like to review your baby's chart, please ask a member of your baby's health care team. They would be happy to go over the chart with you and answer any of your questions.

NICU NUMBER
From outside the hospital:
519-685-8500 extension 64427





Coming to the NICU

What should we know about coming to the NICU?

- Your baby's safety and security is important to us. The NICU is a secured
 unit with controlled access. We ask that you do not allow other visitors to
 follow you into the unit.
- The first time you come to the NICU, you will be provided with a swipe card
 that will give you access to the NICU while your baby is in this unit. We ask
 that you do not share this card with others. Please report any lost or
 misplaced card to the NICU staff immediately. Please return this card to the
 NICU when your baby is discharged or transferred.
- A parent needs to be with any visitors. If a visitor arrives unattended by
 a parent, they can call into the unit from the phone located to the left of the
 main doors. Unattended visitors need to be on the visitors list to be admitted
 to the NICU.

Please speak with your nurse to find out if there are visiting restrictions.

Brothers and sisters of the baby are welcome in the NICU if:

- 1. They are healthy at the time of their visit.
- 2. Their vaccinations are up-to-date and a copy of the vaccination record has been provided to the NICU. If your child(ren) have recently been vaccinated it is not possible to visit for at least 21 days after the date of the vaccination.
- 3. They have had chicken pox or have been vaccinated against chicken pox.

To keep your baby healthy no other children may visit the NICU. When are visitors not allowed into the NICU?

Your child(ren), family members and visitors will not be allowed to visit if they have any of these problems:

- A rash, itchy skin or an infection on the skin or hands
- A cold or a runny nose
- A cold sore, or feel a cold sore is starting
- Diarrhea (loose or watery bowel movements) for at least 48 hours
- Vomiting (throwing up)
- Fever
- Have been in contact with any communicable diseases (le. chicken pox, measles, mumps) in the last three weeks prior to their visit.



During the RSV (Respiratory Syncytial Virus) season, usually November to May, only brothers and sisters who have had their second birthday may come to the NICU. Brothers and sisters under two years have an increased chance of getting the virus and can easily spread it to the baby. This virus is similar to the common cold but can lead to serious illness in premature and ill infants.

Can I use my cell phone in the NICU?

Cell phone use is restricted at bedside as it may interfere with the technology that is being used to care for your baby. Please find designated green zones within the NICU to use your cell phone. For more information regarding cell phone use in the NICU, refer to the information rings located in your baby's room.







We are a fragrance restricted hospital.

The chemicals used in scented products can make some people sick, especially those with fragrance sensitivities, asthma, allergies and other medical conditions. Some people and babies are also sensitive to smoke and latex. Latex balloons are not allowed in the NICU.

Staying With Your Baby

What is available for parents and families?

Kangaroo and sleeper chairs are available for use in the NICU. Due to limited space and large equipment, there is not always space to stay directly at your baby's bedside. Please speak with your nurse about your wishes to stay.

Please Note:

- Please do not leave valuables out in the open. All common areas are under video surveillance in the NICU.
- Each bedside has a comfortable chair, a breast pump shared within the room and cupboards for personal belongings.
- We understand there are times that you may have to leave the bedside.
 Please inform the staff member caring for your baby so they know he/she will be alone.
- If you require personal care items such as a toothbrush, deodorant, or shampoo, please visit the Paediatric Family Resource Centre, Ronald McDonald Room or Gift Shops.

*For those that live outside of London, Ronald McDonald House may be an option; please speak with a member of your health care team.

A **family lounge** is **located at the back of Pod A.** It has a washroom with shower, refrigerator, microwave oven, kettle, toaster, areas to eat, and a television.

A **family waiting area** is located at the entrance of the unit for you to meet with friends and family. There is a television and children's activity centres in this area.

A **quiet room** is located just past the family waiting area for your use.

There are **2 breast pump sterilization areas** located in NICU. One is in Pod A, the other is located behind the main communication station in Pods B and C.



Hand Washing

The most important way you can help minimize the spread of germs is to wash your hands. Wash your hands with warm water; be sure to scrub between your fingers, your fingertips and fingernails, the back of your hands and wrists. You should scrub for at least 20 seconds, the time it takes to sing "Happy Birthday" twice.

Hand sanitizing must be done upon:

- · Entering and exiting hospital
- Entering and exiting any of the clinical areas and units.
- Entering and exiting your baby's room
- Before and after you touch your baby



Caring for You and Your Child

Getting Involved in Your Baby's Care

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.

Participate in Bedside Rounds

Rounds happen every morning. The health care team comes together to discuss your baby and we encourage you to participate. Ask your nurse for more information about when rounds will be. Write down your questions or observations about your baby and share them with your team. Do not hesitate to ask to have something explained again or in a different way.

Talk to your Baby

Quietly reading or singing to your baby helps you bond with them, even when they are very small. It also helps you develop routines that you can continue once you leave the NICU. Please share your cultural customs or religious beliefs so that we can be sensitive to your needs.

Participate in your Baby's Care

We encourage you to get involved in your baby's care. Your nurse is here to support you as you become comfortable with tasks such as diapering, feeds and bathing.

Providing your Milk for your Baby

Your bedside nurse will instruct you so that you can provide breast milk for your baby. Even if your baby is not ready to eat, drops of milk (OIT) will be given to your baby.

Our Family-Centred Care Practices in the NICU

As part of our focus on patient and family-centred care, we invite parents to participate in the Bedside Shift Change Report.

During Bedside Shift Change Report, which can take three to five minutes, you can expect the following:

- Family and visiting friends will be asked to leave the room during bedside shift change report
- The nurse coming onto shift will introduce him/ herself
- The nurses will review your baby's plan of care
- The nurses will complete the mandatory safety checks
- The nurses will ask you if you have any questions or any additional information to share



• You will be encouraged to participate in a way that works for you and your child

Prior to leaving the room, your baby's nurse will let you know when you can expect him/her to return.

Developmental Care in the NICU

Developmental Care is a strategy used in neonatal intensive care units (NICUs) to help reduce the amount of stress that a premature infant experiences. NICU units can be loud, bright places making it hard for babies to rest, grow and get better. Developmental Care helps the NICU be more "baby friendly."



There are many specific strategies that are part of developmental care.

- · Positioning babies in comfortable, flexed positions to help develop strong muscles
- Clustering nursing care to provide longer uninterrupted sleep to help brain development
- Turning down lights and providing a quiet, darkened environment minimizes stress
- Kangaroo Care: skin to skin holding by parents
- · Minimizing pain
- Oral Immune Therapy (OIT) tiny amounts of breast milk for your baby to help fight infections and make digestion better

Using Developmental Care in the NICU may help babies grow and get well faster and promote brain development. Developmental Care helps make the transition from womb to world a little bit easier for premature or sick infants.

Please ask the nurse to borrow a copy of the DVD "No Matter How Small: a parent guide to preterm infant development."

This DVD will help you learn how your baby communicates and ways we can support your babies' development together.

"CARING FOR MY BABY IN THE NICU" has been inluded in this booklet to help guide you with your baby's care.

What if I need to make a difficult decision about my 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 their caregivers reach common ground. A team of health professionals with experience and training in medical ethics runs the service. The team helps all those who are responsible make the best possible decisions about patient care.

They help identify and clarify problems, explore implications and consider options.

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



Taking Care of Yourself and Your Family

Parents have described feeling overwhelmed with emotions after the birth of their premature or ill baby. You may experience many different emotions. For many families with a baby in the NICU, their stay is like a roller coaster ride, with ups and downs, triumphs and set backs. Families who have been in the NICU have provided some suggestions to help you and your family get through the ups and downs that you will experience.

- Establish a routine to balance work, home and hospital
- Many physical and emotional changes happen with childbirth. Make sure
 that you take time to eat well, drink plenty of water and avoid caffeinated
 beverages. If you are not hungry, have several small portions throughout the
 day.
- Take time to rest and relax every day
- Celebrate even the smallest of accomplishments
- Make a list of things your family and friends can do to help
- Accept that you, your partner and family will all cope differently
- Connect with other NICU parents
- Designate one support person to be the contact for information about your baby

NICU Parent Hour

Everyone is invited to attend Parent Hour!

Parent Hour is a wonderful way to connect with other parents in the NICU. A light meal is provided. Please see the posters in the NICU dates and times or visit the Paediatric Family Resource Centre, B1-006 for more information.



Patient and Family Spaces

Ronald McDonald Room, B6-258

The Ronald McDonald Family Room® is available to the families of all children receiving treatment at Children's Hospital. Our friendly volunteers are on site to make you feel at home and the coffee is always on!



Open 9:00a.m.—9:00 pm Daily (subject to change based on volunteer availability).

Ronald M^cDonald House

You will find the House directly out front of Children's Hospital, LHSC – only 165 steps from the B Unit entrance on 741 Baseline Road East London, ON N6C 2R6. For further information about admission requirements



please visit our website RMH-London: What you need to know http://www.rmhswo.ca/staying-at-our-house/what-you-need-to-know.

Paediatric Family Resource Centre, B1-006

Contact information: 519-685-2460.

The Paediatric Family Resource Centre offers a quiet place for patients, family members, and staff to find information on a variety of children's health care topics, and to access the internet.



Sanctuary, C3-402

All patients and families are welcome to enjoy the Sanctuary. This sacred space is available for prayer and quiet reflection 24/7.



Support Services at Children's

Service	Description
Bereavement	Bereavement care is offered by Spiritual Care and Social Work. LHSC/Children's Hospital has an annual "Remembering the Children" event each fall. If you would like to attend, please sign the "Consent to be Contacted" form which your nurse will have available. The Memorial is a simple non-religious event that acknowledges all infants and children who have passed away over the year at LHSC.
Bravery Beads	This program is designed to help children and youth document their unique and personal journey through a long-term or chronic illness or injury using beads. Each bead represents an element of care or treatment. This is a voluntary program for children of all ages.
Breast Pump Rental	There are numerous breast pumps available for use throughout the NICU. You will need to obtain a personal use breast pump kit, your nurse can help you with tis process. We encourage you to pump at your baby's bedside. If additional privacy is desired, your nurse will direct you to the Quiet Room. Before purchasing a pump, speak with a nurse or lactation consult to ensure that you obtain the proper pump. Not all breast pumps work in the same way and it is important that the appropriate pump is used.
Business Office, D3-400	Please be aware that there may be charges for supplies and devices not covered by OHIP, such as crutches, breast pumps, surgical supplies, etc. These items can be paid for at the Business Office before you go home or you will receive an invoice by mail.
Canada Post Mailbox	A mailbox is located in front of the B-tower level one or D3 walk out.
Internet	Wireless internet is available to be purchased for personal use. Payments can be made via a secure online credit card transaction. Support is available by calling DataValet at 1-800-642-3958. Free internet access is also available through patient and family computers located in the Paediatric Family Resource Centre, B1-006 or Ronald McDonald Room, B6-258.
Language Interpretation	Language interpretation is provided by Across Languages. If English is not your first language, this service will help you talk to your child's doctor about your child's illness. Please ask your nurse to call for the interpreter

Legal Help Pro Bono Law Ontario (PBLO)	PBLO at Children's Hospital is a medical-legal partnership that helps families identify and resolve legal problems that can impact a child's health or the family's ability to care for their child. Through this program, free legal assistance is provided to low-income families whose child is an inpatient or outpatient of Children's Hospital. Your social worker can refer your case to our on-site Triage Lawyer.
Paediatric Symptom Management & Supportive Care Services (PSMSC)	PSMSC is a service at Children's Hospital that cares for infants, children and teens with serious illnesses no matter the underlying disease or medical problem. PSMSC goal is to ease all kinds of pain and suffering with the hope that children with serious illness and those approaching the end of their lives can have the best quality of life possible.
Office of Patient Experience	A Patient Experience Specialist helps patients and families bring feedback or concerns to staff and physicians to have them dealt with in a supportive and respectful way. They help with answering questions, looking into problems and receiving compliments.
Parking	Parking Office, Room 105 (at P8 parking garage lower level) The parking office is open 7:30 a.m 8:00 p.m.; Monday to Friday. Daily, weekly and monthly passes are available for purchase.
Pharmacy	Pharmacy is located on the 1st floor of Zone B and is open from 8:30 a.m 6:00 p.m. Monday to Friday, excluding holidays. Prescriptions may be filled at this location before you leave. Breast pump kits may be purchased.
Security	If you need an escort to or from your car or to the Ronald McDonald House, Security Patrols are available. Call dispatch at extension 52281 if you require Security assistance. The Emergency Response Extension is 55555.
Spiritual Care	Spiritual care at LHSC is about caring for the human spirit. While providing caring and compassionate presence, we support the spiritual well-being of our patients, their families and friends. For those who have specific religious needs, we are able to assist you in making connections with local faith communities.



Preparing to go Home



Getting ready to leave our NICU

Your baby may go home or be transferred to another hospital from the NICU.

Transferring to Another Hospital

When your baby's health is better and no longer requires our level of intensive care, the medical team will speak with you about transferring your baby to another hospital or unit. It can be a very stressful time but it is an important step to transitioning to the next level of care and eventually home. The Nurse Case Manger will work with the health care team and you to coordinate the planning for this move.

Going Home from the NICU

As discharge nears, you will be working with the Nurse Case Manager to plan your going home. A written summary of your baby's stay in the NICU will be given to you to take to your first doctor visit. The Nurse Case Manager will also arrange all of your baby's follow-up appointments and give you a written copy to take home.

Discharge Goals

Below is a list of goals that must be met prior to going home. Use this as a checklist to keep track of your baby's progress.

Follow Up Doctor identified. Your baby may be discharged with follow up care provided by paediatrician or family physician.
No respirator or ventilator support required. Your baby may still require some oxygen usually by low flow or be on room air at discharge.
Taking full feeds: IV fluids have been stopped and baby receives all nutrition by mouth.
Steady weight gain: Baby shows a steady weight gain pattern of 1 ounce a day (30 grams)
No longer requires intravenous antibiotics.
No apnea (baby forgets to breath) or bradycardia (drop in heart rate) within the past 7 days. Cardiorespiratory monitor removed.
Baby sleeps on their back in an open bassinet/crib with no temperature regulation problems.
Parents attend Baby Safe class: Check pamphlets in NICU for class schedule.
Car Seat brought to NICU prior to discharge must have CMVSS sticker, not have expired and be the correct weight and height for your baby. If your baby was born at less than 37 weeks of age or less than 2500 grams, a car seat challenge test will be done to determine if your baby can safely ride in a car seat. This test takes approximately one and a half hours to complete.
Special Discharge Teaching: If your baby requires special instructions, the nurses will need to spend time teaching you this information and evaluating your understanding of information provided.



Miscellaneous

Research and your baby

In the NICU, we strive to provide excellent care to our tiny patients and their families. Research is a very important part of the work that we do. Through research, we learn new information about how to best care for babies.

Who does the research?

Doing research is part of the staff's work at Children's Hospital. All research studies are led by a qualified health card provider who works with a research team that may include doctors, nurses, therapists, dieticians, and other staff.

What kind of research is being done?

We do research in many different areas. We do research to find ways of improving nutrition, medication, and respiratory care for babies. We also do research to find ways of reducing infection. Some of our research implements new techniques and procedures. Our research ofthen requires monitoring your baby more closely.



Should I allow my baby to take part?

It is your decision whether your baby will take part in research. Your choice will not affect the care your baby receives in the NICU.

A research staff member may approach you to talk about research that your baby could take part in. The research staff member will provide information, explain the study and answer any questions you may have. Participation is voluntary.

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. A study is not allowed in our nursery unless all risks have been minimized. All personal information gathered about you or your child will be kept confidential. All research in the NICU is approved by the Research Ethics Board at the University of Western Ontario.

We learn from babies... research helps bring better care.

Notes

You are the most important member of your baby's health care team.

You are encouraged to use this section to take notes, observations or write down questions that you have for the Doctors, Nurses, Therapists, Social Workers or Pharmacists. You may feel overwhelmed during this stressful time and this will help you to remember important information.

We recommend you record the names and roles of the caregivers on your team to help you understand all the people involved with your care.				

Notes	

Notes	
	_
	—
	—
	—

Notes	

Tell Us How We're Doing

We want your experience at Children's Hospital to be the best it can be, but we need your help!

We value your input. Please complete a Family Feedback Survey.

You can obtain a survey from the communication desk in each pediatric unit, at the Paediatric Family Resource Centre, or by visiting the Children's Hospital website.

Do you want to make a difference at Children's Hospital?

We are looking for parents, caregivers, and youth patients who would like to make a difference at Children's Hospital by becoming an Advisor. There are several roles with different time commitments that may be of interest to you.

We would love to hear from you if you are:

- Able to share your insights and information about your hospital experience
- Able to communicate your personal hospital experience (positive and negative) constructively
- Able to listen well and respect the perspectives of others
- Passionate about improving the hospital experience for others
- Interact well with different types of people
- Work well as a member of a team.

If you have questions or want more information, please feel free to drop into the Paediatric Family Resource Centre for an application or contact: PFRC@lhsc.on.ca

Links & Resources

AboutKidsHealth Trusted Answers from The Hospital for Sick Children-

www.aboutkidshealth.ca

Caring for Kids- Information for Parents from Canada's Paediatricians-

www.caringforkids.cps.ca

The Health Line Health Services for South West Ontario - www.thehealthline.ca

Middlesex London Health Unit - www.healthunit.com

Medline Plus Trusted Health Information - www.nlm.nih.gov/medlineplus

Canadian Premature Babies Foundation - www.cpbf-fbpc.org



Pound/Gram Weight Conversion Chart

POUNDS											
OZ.	0	1	2	3	4	5	6	7	8	9	10
0	0	454	907	1361	1814	2268	2722	3175	3629	4082	5536
1	28	482	936	1389	1843	2296	2780	3203	3657	4111	4564
2	57	510	964	1417	1871	2325	2778	3232	3685	4139	4593
3	85	539	992	1446	1899	2353	2807	3260	3714	4167	4621
4	113	567	1021	1474	1928	2381	2835	3289	3742	4196	4649
5	142	595	1049	1503	1956	2410	2863	3317	3770	4224	4678
6	170	624	1077	1531	1984	2438	2892	3345	3799	4252	4706
7	198	652	1106	1559	2013	2466	2920	3374	3827	4281	4734
8	227	680	1134	1588	2041	2495	2948	3402	3856	4309	4763
9	255	709	1162	1616	2070	2523	2977	3430	3884	4337	4791
10	283	737	1191	1644	2098	2551	3005	3459	3912	4366	4819
11	312	765	1219	1673	2126	2580	3033	3487	3941	4394	4848
12	340	794	1247	1701	2155	2608	3062	3515	3969	4423	4876
13	369	822	1276	1729	2183	2637	3090	3544	3997	4451	4904
14	397	850	1304	1758	2211	2665	3118	3572	4026	4479	4933
15	425	879	1332	1786	2240	2693	3147	3600	4054	4508	4961

Birth Date:	
Birth Weight:	
J	
Length:	

Thank you to the NICU at Sunnybrook Health Sciences Centre and McMaster Children's Hospital for the use and adaptation of their family material.

A special thank you to the Children's Hospital NICU staff, physicians and Family Advisors who also contributed to the development of this handbook.



Children's Hospital, London Health Sciences Centre 800 Commissioners Road East, London, Ontario N6A 5W9 519-685-8500 www.lhsc.on.ca/About_Us/Childrens_Hospital/

Generously Supported by:



childhealth.ca