

Introduction

The Neonatal (newborn) Intensive Care Unit (NICU) of the Floating Hospital for Children is a 40-bed unit designed to provide highly specialized and technically advanced care to ill, premature, or high-risk babies. Skilled nurses, physicians, nurse practitioners and respiratory therapists staff the unit. This team of health care providers function together to provide the finest and most comprehensive care possible for your newborn.

Some of the babies admitted to the NICU are born here at Tufts Medical Center, and some are born in community hospitals and then transported to us by members of our Neonatal Transport Team. Babies are admitted to the NICU for many reasons. Whatever the reason for admission, a wide range of pediatric subspecialty services is readily available for your newborn if necessary. Some of our specialty services include newborn medicine, pediatric cardiology, pediatric surgery, pediatric neurology, pediatric otolaryngology, pediatric urology and many others, all available 24-hours/day.

Soon after admission, your baby will be assigned a primary nurse and will be assigned to a team of physicians on the newborn medicine service. Tufts Medical Center is the principal teaching hospital for Tufts University School of Medicine; there are many doctors at various levels of specialty training who will be involved with your baby's care. At all times, the attending physician is ultimately responsible for the medical care your baby receives.

If you have already chosen a pediatrician, please give his or her name to your baby's nurse. Once identified, the pediatrician will receive routine updates, about once a week, while your baby is in the NICU.

Family Presence

The following parenting guidelines have been developed to educate, assist and guide you through your journey in our unique unit. While we strive to be as accommodating as possible, however, we ask for your assistance in following these guidelines so that we may maintain the nurturing environment that is necessary for all of our patients and their families.

**NEONATAL
INTENSIVE
CARE UNIT
617-636-5008**

**TOLL FREE
PARENT LINE
1-800-442-
NICU (6428)
(Parents only
please)**

When you arrive at the NICU please ring the doorbell to enter, and then check in at the reception desk before you enter the patient care area.

Parents are a valued and essential members of the healthcare team and are welcome in the unit any time, day or night. We understand the importance of family and friends to the overall well being of our patients and their families, so we do not have designated or limited visiting hours. The time of your visit is generally not limited but there may be some rare exception to that practice. We do require at least one parent at the bedside to accompany all visitors you may have. We also ask that each family have no more than three people visiting in the unit at one time. This is to help staff maintain a quiet environment for the babies to heal and grow.

For your convenience a family area is located in the NICU across from the reception desk. The kitchen has a refrigerator, microwave, dishwasher and television. The lounge area located just across from the kitchen also has a TV and computer for parents' use. Tufts Medical Center does have wireless internet throughout the hospital. Laptops can be used at your baby's bedside however cell phones will need to be turned off while you are with your baby. Young siblings must be accompanied by an adult when they are in the family area.

It is important to keep our nursery as germ free as possible for the safety and well being of our babies, therefore we ask that anyone who has had a sore throat, fever, diarrhea, cold or flu symptoms or was exposed to a contagious disease within that last two weeks to not visit the NICU.

We do regret that during cold and flu season, no one under the age of 16, including siblings, may visit in the NICU for the safety of the infants.

While you and your visitors are in the NICU, please remain at your baby's bedside. It is important to respect the privacy of other infants and their families. Please refrain from asking staff questions regarding other patients in the unit.

When you are away from the NICU you may call and ask about your baby anytime, 24 hours a day. A toll-free number is available solely for parents to use. We ask that no other family members or friends call the NICU to ask about your baby.

The staff of the NICU is dedicated to making your parenting experience as comfortable, compassionate and caring as possible. Please feel free to discuss concerns you may have with any staff member.

If you wish, you may bring in small toys, music boxes, stuffed animals, hats or clothes for your baby. If you do bring in any of these items please make sure they are clearly labeled with your baby's last name.

PARENT OVERNIGHT ROOMS

In memory of their son Matan, the Lazar-Baker family generously redecorated our parent rooms to provide a quiet and comforting place for you during your NICU stay.

Three overnight rooms are available for parents in the NICU at no cost. The rooms are reserved on a day-to-day basis. Priority will be given to those parents of critically ill infants. They are also available to those parents who live long distances or are breastfeeding. For questions regarding the overnight rooms please speak to the unit coordinators at the front desk or the charge nurse.

Please remember these rooms are reserved for parents only.

SECURITY

For the continuous safety and security of our precious little patients, their families and our staff, access to the NICU is restricted by a locked door system. Select hospital staff may enter the unit using a private keypad code. All others must ring the doorbell outside the main entrance to the unit.

All babies in the NICU wear an identification band on their wrist or ankle with their name and unique ID number. Bands with matching ID numbers are worn by the mother and father. Once your infant is admitted to the NICU, within 1-3 days you will receive a visitor badge with your picture on it and your baby's 5-digit ID number. **Your badge must be worn at all times while you are in the NICU.** Upon discharge you will be asked to return your badge for safety and security reasons. The 5-digit ID number must be provided for entry to the NICU and for telephone information to be given. At certain times one parent may be unable to visit for various circumstances or only one parent is involved with baby. In these situations the parent may identify one additional support person.

Babies in the NICU never leave the unit unless accompanied by a member of the NICU staff. All NICU staff who care for your baby wear bright pink ID badges (Think Pink). Please alert your baby's nurse if you have any security concerns or questions.

PARENT DINNER AND ACTIVITIES IN THE NICU

Parent Dinner is usually on the 3rd Tuesday of each month at 6:30pm

Parents are invited to attend our monthly get together. It is a great opportunity to meet other parents whose infants are being cared for in the NICU. Dinner and dessert is provided.

The group includes a staff nurse, social worker and a pastoral care member who prepares a different topic each month that is pertinent to parents who have a baby in the NICU.

The March of Dimes also offers activities about once a week. Parent education hours are offered with a variety of topics that are helpful to understand your baby in the NICU. A craft activity such as scrapbooking is offered once or twice a month.

Check your baby's bedside for dates and times.

Your Baby's Health Care Team

The infants in the Neonatal Intensive Care Unit are cared for by a team of doctors, nurse practitioners, nurses, and other medical personnel who work together to manage the infants' medical problems, convalescence, growth, and discharge planning. The specific members of the team will be different at different times, but will always include members of the following groups:

ATTENDING NEONATOLOGISTS

Neonatologists are pediatricians who are specially trained to care for and treat premature and/or sick newborns, and to teach doctors in training how to care for and treat these infants. The Attending supervises the team, and is the one physician ultimately responsible for the care of your baby. The Attending physicians are on a rotating schedule which means your baby will have a new doctor every three weeks. Prior to rotation, the new Attending physician will be thoroughly briefed on the status of your baby's care, therefore, the transition will be seamless.

This same group of doctors also manages the care of the infants in the Special Care Nursery of the following Boston area community hospitals: Lowell General Hospital, Lawrence General Hospital, Melrose-Wakefield Hospital, Jordan Hospital, Brockton Hospital, and MetroWest Medical Center.

NEONATOLOGY FELLOWS

Fellows are fully-trained pediatricians who are completing an additional three year training program to become neonatologists.

PEDIATRIC RESIDENTS

The residents are doctors who are training to be pediatricians. First year residents are also called interns.

NEONATAL NURSE PRACTITIONERS (NNP)

Nurse practitioners are advanced practice nurses who attended graduate school to receive specialized training and education in the management of premature and sick newborns. NNPs work in collaboration with the neonatology medical staff.

NEONATAL NURSES

The nurses who provide the bedside care of the infants in the NICU complete a specific, comprehensive orientation program for this specialized type of nursing. All of the nurses in the NICU are registered nurses (RN's).

RESPIRATORY THERAPISTS

Respiratory Therapists are extremely important members of the NICU team. These therapists have specialized training in the care and management of patients with lung and airway concerns. They are experts in the use of oxygen and specialized breathing equipment including ventilators.

LACTATION CONSULTANTS

Registered nurses who are Internationally Board Certified Lactation Consultants (IBCLC) are available to assist you with all of your breast-feeding and breast milk pumping questions.

SOCIAL WORKERS

Social workers are professionals trained to assist parents with multiple aspects related to having a hospitalized child. Through the NICU social worker, families can receive assistance on numerous issues including community agency referrals, financial questions, parking and transportation aid and other questions as they arise throughout your baby's stay in the NICU.

OCCUPATIONAL THERAPIST

Occupational therapists (OT's) evaluate a baby's nervous system development. The OT's focus is on feeding and swallowing issues, range of motion in the arms and legs and developmental positioning.

PHYSICAL THERAPIST

Physical therapists (PT's) evaluate how a baby moves and how movement problems may affect development and milestones. The physical therapist's goal is to improve muscle strength and coordination.

MARCH OF DIMES FAMILY SUPPORT SPECIALIST

A part-time March of Dimes member is on staff at Tufts Medical Center. The support specialist serves to provide comfort and information while families are in the NICU.

CUDDLERS VOLUNTEER

Cuddlers volunteers will hold and comfort babies when parents are unable to be in the NICU. All cuddlers volunteers have gone through HIPPA and baby handling training.

OTHER NICU TEAM MEMBERS

Other members of the health care team in the NICU who participate in the daily care of our patients and their families include the following: unit coordinators, clinical nutritionists, registered pharmacists, quality support specialists, patient members of the clergy, patient service assistants and our NICU volunteers.

You and your baby might also meet doctors who are specialists in many other areas such as:

- ▷ Cardiologists – Heart
- ▷ Neurologist – Brain and nervous system
- ▷ Nephrologist/Urologist – Kidney and urine (Circumcisions are often done by a Urologist)
- ▷ Gastroenterologist – Stomach and intestines
- ▷ Endocrinologist – Glands and hormones
- ▷ Hematologist – Blood
- ▷ Ophthalmologist – Eyes
- ▷ Pediatric Surgeon – Performs surgery
- ▷ Otolaryngologist – Ear, nose and throat

Taking Care of Your Baby in the NICU

YOUR BABY'S COMFORT

Newborn babies, even those born very prematurely, can feel pain. Being sick, NICU babies often require treatment or procedures which may cause pain or discomfort. Please know that your baby's doctors and nurses try to prevent pain whenever possible, and minimize and treat pain when unavoidable. It is not always easy to tell the difference between a fussy baby and a baby in pain. Here in the Floating NICU, we use a scientifically tested observation tool that attempts to make this distinction, on every baby, every day.

Some measures have been found to reduce babies' pain responses, including swaddling, offering a pacifier, and breastfeeding. A particular mixture of sugar water has been widely studied and found to reduce the pain of many treatments and procedures. In addition, some pain medications used in older patients are safe and effective in newborns. All these treatments are regularly used for babies in the NICU. We invite you to help us observe your baby's comfort and to tell us of any questions or concerns you may have.

KANGAROO CARE

The NICU encourages parents to experience Kangaroo Care or skin to skin holding with their newborn. Skin to skin holding helps bring you closer to your baby.

Kangaroo Care was introduced in the 1970's in Columbia as an attempt to increase bonding with mother and baby and promote earlier discharge. Studies have found that infants tend to have increased periods of deep sleep, increased weight gain, lower oxygen requirements and faster weaning from isolettes. Parents have also found holding their baby skin to skin increases their confidence as a parent and they experience stronger bonding. Mothers have found it increases their milk production.

When you hold your baby skin to skin or Kangaroo, your infant is placed upright directly against your bare chest wearing only a diaper and hat, a light blanket is placed over your baby's body. You are encouraged to wear a button front shirt to make it easier for you. The heat of your body naturally keeps your baby warm. Mother's skin temperature will automatically increase if the baby is cold. To minimize stress keep movement to a minimum and talk in a soft voice to allow your baby to sleep. The March of Dimes provides a hand held mirror for you to use while kangarooing so that you can see your baby's face.

Mothers and fathers are encouraged to hold their baby skin to skin or kangaroo as much as they want and at any age in the NICU. Some babies however may be too medically fragile to be held right away. Make sure to let your nurse know you would like to "Kangaroo" your baby and they will tell you when your baby is ready.

Many parents have found this to be a very positive part of their NICU experience.

BREASTFEEDING/PUMPING

If you are planning to breastfeed your baby, we encourage you to begin pumping your breasts to establish your milk supply as soon after delivery as possible. If you are a patient at another hospital, please ask your nurse to assist you with pumping. Many hospitals have electric breast pumps for you to use while you are a patient. When your baby is ready to begin eating we will use your expressed milk, when available, whenever possible.

If you had not planned to breastfeed, and now have a baby who is sick and/or premature, we encourage you to consider pumping your breasts for breastmilk, even temporarily, for your baby's early feedings. We now know that babies fed breast milk do much better and have a lower risk of some of the complications of prematurity.

You will need a breast pump once you are discharged from the hospital. Most insurance carriers cover this. The Lactation Consultants at the Floating Hospital can help obtain a pump for you if your insurance will allow. Pumps are also available for rent or purchase through the Floating Hospital Lactation Office. When you visit, we have pumps and private rooms available for you to use for pumping when visiting your baby.

The nursing staff can provide you with containers and labels to use. Please use a new container each time you pump, labeling it with your name, the date, and time it was collected. Breast milk should be refrigerated or frozen immediately after being obtained. When being transported to us to give to your baby, it should be kept on ice. We will accept your breast milk either refrigerated or frozen.

Refrigerated milk is only kept for 48 hours and is then discarded. Frozen breast milk is kept indefinitely and thawed as needed.

When your baby is able to do so, you will be provided privacy to nurse your baby directly from the breast. Lisa Enger, RN and Katherine Kane-Petit, RN are Certified Lactation Consultants available to assist you with breastfeeding.

Breastfeeding Resources

- ▷ Lactation support at Tufts Medical Center: **617-636-0175**
- ▷ Massachusetts Lactation Consultant Association **781-893-3553**
- ▷ Nursing Mother's Council, Division of Boston Association for Childbirth Education (BACE) **617-244-5102** or **www.bace-nmc.org**
- ▷ La Leche League **617-298-2540** or **www.lalecheleague.org**

CUE-BASED FEEDING IN THE NICU

Beginning around 33 weeks gestation babies in the NICU are cue-based fed, meaning they eat by mouth, also called "PO", when they show signs they are ready to eat. Babies that do not show these cues will be fed through a tube either in their nose or mouth, this is called gavage feeding.

Babies are assessed with two scales at all feedings. The first is a Feeding Readiness Scale© which checks to see if the baby is ready to eat. A few of the things it looks at are the following: is if the baby is awake at feeding time, taking a pacifier or showing hunger cues. The second is a Quality of Nippling Scale© which looks at how your baby feeds. This scale reviews coordination of suck, swallows and breath, fatigue during feeding or need for external pacing to name a few.

Once your baby is allowed to cue-base feed you will be given more information from your baby's nurse. As always, ask if you have any questions.

Family Support

Being the parent of a sick baby who is in the hospital can be very stressful. You may feel anxious, sad, tired, isolated, in shock, empty, worried, confused, guilty or angry. You might be wondering why this happened to you, and how you will cope with everything. All these thoughts and emotions are very understandable, with your baby sick and in the hospital rather than healthy and at home with you.

Social workers are members of the NICU team who are available to help address your concerns, questions, and feelings about what you are experiencing. **Laura Paradis**, LICSW, and **Ashley Ferguson**, LICSW are our NICU and maternity social workers. You may have met one of them if you were hospitalized here with pregnancy complications prior to delivery.

Some ideas that may be helpful during this time include:

TAKE GOOD CARE OF YOURSELF

- ▶ Get as much information as you want or need about your baby.
- ▶ Write down your questions about your baby and keep a record of information about him or her.
- ▶ Keep a journal of your thoughts, feelings and your baby's progress.
- ▶ Let friends and family know how you are feeling and how they can be supportive and helpful.
- ▶ Do something special for yourself during this stressful time, with or without your partner, a friend, or relative.
- ▶ If you are a single parent, think about asking a close friend or family member to come to the hospital with you on a regular basis to get to know your baby, hear information, and be a support for you.
- ▶ Remember to tend to your own health needs such as post-partum check-ups, eating and resting regularly.
- ▶ Ask your nurse to arrange a meeting with a NICU social worker.

TAKING CARE OF OTHER CHILDREN

Children usually know when their parents are upset and/or when major changes are happening at home or in their family. Your baby's siblings may be upset that their baby sister or brother has not come right home as they thought he/she would. They may be sad, angry, or afraid. They may show other signs of being under stress such as not eating or sleeping as well as usual and/or returning to younger behaviors.

Some suggestions for helping your other children cope during this difficult time include the following:

- ▶ Tell them in terms they can understand why the baby is in the hospital. (Example: "Mark has a problem with his belly. The doctors and nurses at the hospital are trying to help him with this. When he is feeling better he'll be coming home to us").
- ▶ Be honest with them about your feelings. (Example: "Mommy is crying because I am sad that Joey is sick and that he has to be in the hospital"). Encourage them to share with you how they feel.

- ▷ Children often blame themselves and may think the baby got sick because of something they did or thought. Tell them that there was nothing they did that caused the baby to become sick.
- ▷ Ask the baby's nurse if your other children may visit the baby. Prepare them for the visit ahead of time by showing them photographs and describing the unit and the baby's appearance.
- ▷ Ask them to pick out or make things for their baby sister or brother, which can be placed in his or her crib. (Examples: drawings, stuffed animals, tape recording of family members talking and telling a story, tape recording of favorite music, photographs).
- ▷ Try to set aside special time with your children. If you are staying in the hospital, talk with each child by phone every day if they cannot visit.
- ▷ Try to keep as consistent a routine as possible for your other children.
- ▷ Call your children's teachers to let them know about the baby being in the hospital; teachers can then pay extra attention to your children and watch for any signs that they are having a hard time.
- ▷ Call your child's pediatrician if they are having a very difficult time coping.

RELATIVES AND FRIENDS

Now that your baby is hospitalized, you may have to decide whom to tell and what to tell them. You may find that you do not want to talk with other people right away. You may wish that some people contact you to try to help you out, but you find that they don't, or when they do, they don't seem to know what to say or do. Others may be right there when you need them or seem to know how to be helpful without you having to tell them.

Some ideas for staying in touch with people while also taking care of yourself include:

- ▷ Write a birth announcement with a short note about your baby and how you are doing. You may want to include a special note about how someone could help you out during this time.
- ▷ Ask a family member or friend to contact people whom you want to know about your baby, but whom you'd rather not talk to directly.
- ▷ Create a CarePage for your baby, ask your nurse for details.
- ▷ Leave an outgoing message on your answering machine: "Hi, this is John and Mary. Abigail's doing fine today. She weighs 2 pounds, 10 ounces and is tolerating her feedings..."
- ▷ Let people know what kinds of things they can do to be helpful; often, people just don't know how to help. Ideas include: grocery shopping, driving you to the hospital, picking up your other child at day care, walking the dog, answering the phone, sorting through the mail, making dinner, babysitting, getting books at the bookstore or library for you.

March of Dimes NICU Family Support

In 2003 the March of Dimes launched the Prematurity Campaign; its goal was to raise awareness about prematurity, to decrease the incidence of preterm birth and to support NICU families. The researchers are working on finding out why babies are born early or with birth defects. Those who support the March of Dimes are telling everyone and anyone they know how serious prematurity is. For those parents whose baby comes early or is sick the March of Dimes Family Support Program was created. The NICU Family Support program provides information and comfort to families who experience the hospitalization of their baby in the NICU.



The March of Dimes NICU Family Support Specialist gives each family a Parent Care Kit. The Parent Care Kit has information that was created by the March of Dimes that is helpful for you while your baby is in the NICU. If you have not received one please let your nurse know or the March of Dimes NICU Family Support Specialist and they can make sure one is given to you. The parent care kit is available in English and Spanish.

The March of Dimes Family Support Specialist organizes parent education hours for families. The parent education hours are held 3–4 times a month. They are very casual and variety of topics such as how your baby develops in the NICU, Kangaroo Care and things to know before you take your baby home are discussed. The parent education hour are co-facilitated by a member of the NICU medical team. The NICU Family Support Specialist also offers scrap booking and other craft activities for families to take a break from the intensity of the NICU.

The March of Dimes has also created an on-line community for NICU families called "Share your Story" This website is a great way to connect to other people who understand what you are going through because they are NICU families too. You can start a blog, read other families stories or post questions to other parents. Visit <http://shareyourstory.org>.