



JOHNS HOPKINS

CHILDREN'S CENTER

A Parent's Guide to the Neonatal Intensive Care Unit



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Welcome to The Johns Hopkins Children's Center Neonatal Intensive Care Unit

We know this is a difficult time for your family and you may have many questions. This guide has information to help you during your baby's stay in the NICU. Please ask any member of your baby's health care team about questions you may have. We are all here to care for your baby and your family in any way that we can.

*** Please note that during this time of COVID 19, there may be things in our Parent's Guide to the NICU that have changed, or are on hold to keep our patients, families, and staff safe. Please talk with any NICU team member if you have questions.**

OUR MISSION STATEMENT

Our mission as staff of the Neonatal Intensive Care Unit at the Johns Hopkins Children's Center is to offer excellence in care for babies and their families in a supportive and compassionate environment.



PHONE CALLS

You may call the NICU to ask about your baby anytime day or night except during shift change (6:30-7:30 AM & PM).

The phone number for the NICU is **410-955-5255**.

A toll free number is available for parents to call long distance **1-800-999-NICU**.

Medical information will **ONLY** be given to the baby's parents.

Please be sure that we always have a way to contact you by phone. Also let us know if your address changes. Give this information to the CCSR at the front desk.

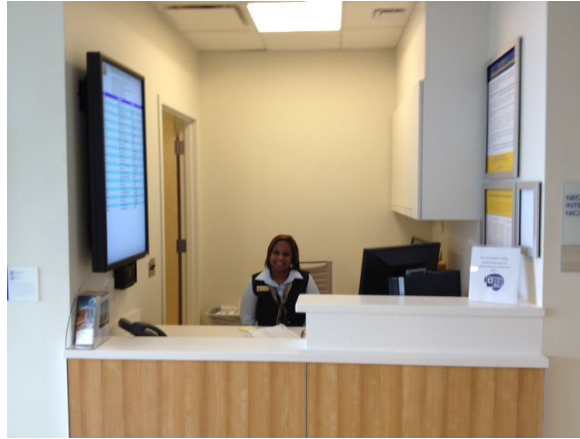
CELL PHONES AND ELECTRONIC DEVICES

You and your visitors must keep cell phones and personal electronic devices on vibrate or silence when visiting with your baby. **After touching your cell phone, hands must be washed with either Purell or soap and water before touching your baby or the bedside.**

Communicating with your baby's nurse and NICU staff - Your baby's nurse, as well as your Medical Team, Respiratory Therapists and other care providers will have a phone with them at all times. Always call the main number for the NICU and you will be transferred to the person you wish to speak with. At times, your baby's nurse or other care providers may be busy and you will be asked to call back. This is how the NICU staff communicates with families and each other. This system has been put into place to make the NICU environment quieter for your baby.

Nurse Call System - There is a system in each room to help you reach your baby's nurse if needed. There is a hand-held "call bell" at each bedside. If you need help, you can use this "call bell" to call for your baby's nurse. **Only push the button once**, pushing the button more than once will cancel your "call."

THE FRONT DESK



THE CLINICAL CUSTOMER SERVICE REPRESENTATIVES

CCSR's are located at our front desk and will greet you each time you enter the NICU. They can be a great help with questions or special needs. They answer the phone when you call the NICU. They will also answer when you use the nurse call bell and let your baby's nurse know that you need help.

VISITATION

***Please note that during this time of COVID 19 the visitation guidelines below may change to keep patients, visitors, and staff safe. Please ask for the most recent guidelines.**

- **Parents may visit their baby 24 hours a day.** You are considered part of the NICU team.
- **Four persons 18 years or older can be identified as a Support Circle** and visit 24 hours a day without the baby's parents. This Support Circle should not change, and members may not bring others in to visit. They will not be given medical information. Please give the names of those in your Support Circle to your baby's nurse or the CCSR.
- Only 2 visitors are permitted at the bedside at a time.
- Siblings, 13 years and older may visit with parents from 9AM to 9PM. Four persons are allowed at the bedside at a time when siblings are visiting. This includes parents.

- Please DO NOT let anyone who is not feeling well or has been exposed to a contagious disease visit.
- The NICU reserves the right to limit visitors in the best interest of patients, families, and guests.

SIBLING VISITATION

Brothers and sisters aged 2-12 may visit during Sibling visitation on Sunday, Wednesday, and Friday from 4PM to 6PM. Children, like all visitors, should be in good health when they come to visit. Visiting siblings under the age of 13 will need to wash their hands when they enter the NICU. This visit with siblings is different than your regular visit as parents. The focus should be on your older children and their emotional response and behavior during this visit. Short visits are best. Five to ten minutes is best for a toddler or preschooler, while older siblings may be able to stay for 15 to 30 minutes.

Sibling visitation may be suspended at any time if there is a contagious disease outbreak in the community.

SECURITY IN THE BLOOMBERG CHILDREN'S CENTER

- For the safety of our patients, all visitors including parents and their Support Circle will be asked to provide a picture ID at the Security Desk on the Ground and Main levels of the Children's Center to gain access. A Parent or Visitor Access Badge will be provided. This badge must be scanned outside of the NICU entrance to unlock the door.
- Parents will be given a parent card at the NICU front desk, which must be shown along with your ID at the Security Desk to receive a Parent Badge. The Parent Badge will expire after 7 days, and will need to be renewed.
- Visitor badges expire at 11:59PM nightly.
- Once you have scanned your badge and enter the NICU, you will be asked to stop at the NICU front desk to identify yourself as a parent or visitor.

SPENDING THE NIGHT IN THE NICU

In Your Baby's Room

Each baby's room has one reclining sleep chair, for one parent to spend the night. Depending on your baby's condition, you may not be able to sleep in the room. Please discuss this with your baby's nurse.



TEMPORARY LODGING

Families living a distance of 30 miles or more may be eligible for temporary lodging at the Ronald McDonald House. Families living a distance of 60 miles or more may be eligible for The Children's House. Each house provides families with their own room and access to a common living and kitchen area. There is a small nightly fee at both the Ronald McDonald House and The Children's House. Both houses have parking. The Ronald McDonald House is located at 201 Aisquith Street, Baltimore MD 21202, and provides shuttle service to and from Johns Hopkins Hospital. The Children's House is across the street from our hospital at 1915 McElderry Street, Baltimore MD 21205. Space is limited, and there is often a waiting list. Please speak with your Social Worker if interested. You will need a referral for temporary lodging. You must be 21 years of age to stay at either house.

NICU FAMILY LOUNGE



Family Lounge



Kitchen, Laundry and Shower Area

There is a shower area available in the Family Lounge. There is a kitchen area with a microwave, refrigerator, washer, and dryer for family use. Please eat in the area provided in the Family Lounge. **No food is allowed in the baby's room but you may have a covered drink.**

Please be considerate and clean up after yourself so the room remains available for all our families. Sleeping in the family lounge overnight is not permitted.

NURSING SHIFT REPORT



Parental Involvement

Parents are encouraged to take part in nursing shift report. At the end of each shift, the off-going nurse will report to the on-coming nurse at your baby's bedside. The nurses will discuss mom's history and baby's history. We will review current orders and recent changes. When you are present, you may listen to report and add information that you feel will help us take better care of your baby. Your input is important to us.

Questions

Please hold all questions until the end of the report. Safety checks will be taking place and we ask that you hold questions until this process is complete. This will decrease the possibility of making mistakes.

Shift Report Times

Shift reports will happen several times during each 24 hour period. This will change daily. Nurses work 12 hour, 8 hour or 4 hour shifts. The following times are when shift report may take place:

7:00 AM 3:00 PM 7:00 PM 11:00 PM

BEDSIDE ROUNDS

Every morning, rounds take place at the bedside. This will take place between 9:00 AM and 1:00 PM. We rotate where we begin rounding. The Resident, Hospitalist, or Neonatal Nurse Practitioner assigned to your baby will talk about your baby's plan with the rest of the team. The team consists of an Attending Physician, a Fellow, a Neonatal Nurse Practitioner, Residents, your baby's Nurse, Respiratory Therapist, Pharmacist, and Nutritionist. Parents are encouraged to participate as part of the team. Parents may ask any questions they have at the end of the presentation.

VISITORS AND MEDICAL INFORMATION

During both NURSING SHIFT REPORT and BEDSIDE ROUNDS, private medical information about mother and baby will be discussed. If you as the parent do not want your visitors to hear this information, please ask them to wait in the Family Lounge during these times.

PATIENT IDENTIFICATION/SAFETY

- All patients will have an ID Safety Band with their name and hospital number, which staff use when giving medications, scanning breastmilk, performing procedures, etc.
- NICU patients are identified by the mother's last name.
- Most babies do not have allergies, but if there is a reaction to a medication, an Allergy band will be placed on your baby.
- After you are finished touching or holding your baby, please make sure to close doors to the incubator or place side rails/crib rails up.

WIRELESS INTERNET ACCESS

Free wireless internet service is available throughout the hospital and in all patient rooms. The “**JHGuestnet**” wireless network is for hospital guests and visitors. To connect, click on the wifi icon or find wifi settings, click on JHGuestnet, based on your operation system platform, launch web browser and enter your email address, click accept.

HANDWASHING

ALL parents and visitors coming into the NICU must follow these handwashing steps to help keep the NICU babies safe from infection:

1. Remove all jewelry from your hands and wrists. Keep jewelry off for the entire visit.
2. Turn on water by tapping the WATER panel with your knee. Wet hands, then tap the SOAP panel with your knee (tap lightly).
3. Wash your hands and wrists following the steps printed on the poster next to the sink (making sure to include your fingernails and thumbs). There are white picks inside the cabinet to remove dirt from under your fingernails.
4. Turn off the water, dry hands and wrists with paper towels and throw them away (trash can is inside the cabinet at the bottom).
5. Please wash your hands each time you come in from outside of the hospital.

How to Handwash?

WASH HANDS WHEN VISIBLY SOILED! OTHERWISE, USE HANDRUB

Duration of the entire procedure: 40-60 seconds

 0 Wet hands with water;	 1 Apply enough soap to cover all hand surfaces;	 2 Rub hands palm to palm;
 3 Right palm over left dorsum with interlaced fingers and vice versa;	 4 Palm to palm with fingers interlaced;	 5 Backs of fingers to opposing palms with fingers interlocked;
 6 Rotational rubbing of left thumb clasped in right palm and vice versa;	 7 Rotational rubbing, backwards and forwards with clasped fingers of right hand in left palm and vice versa;	 8 Rinse hands with water;
 9 Dry hands thoroughly with a single use towel;	 10 Use towel to turn off faucet;	 11 Your hands are now safe.

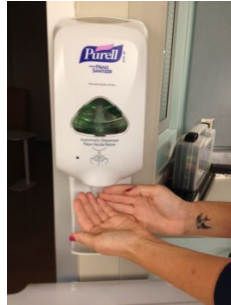
World Health Organization
A World Alliance for Safer Health Care

SAVE LIVES
Clean Your Hands

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PURELL



PURELL hand sanitizer may be used at other times throughout the day. Use the same steps for handwashing to make sure your hands and wrists (including thumbs and nails) are clean.

INFECTION CONTROL

We have an **Advanced Ultra-Violet Systems (AUVS)** box located next to the scrub sink as you enter the NICU **for cell phone cleaning**. The AUVS cleans your phone with ultraviolet light in less than one minute. The ultraviolet light is safe for both cell phones and cases. Please use the AUVS when washing your hands to disinfect your phone prior to visiting your baby.

Along with hand washing, Respiratory hygiene is very important in preventing infections. Cover your mouth and nose when sneezing or coughing by using tissues or the bend of your elbow. Both tissues and masks are available at the entrance to the hospital or upon request. Please use these if you have a runny nose, sneeze or cough. Please remember to wash your hands frequently and after coughing and sneezing.

Babies in the NICU are at high risk for infection. No stuffed toys are allowed in the NICU to help prevent the spread of infection. This also is best for safe sleep practices. Pictures of your family and things that can be wiped off with disinfectant (plastic toys) are acceptable for your baby's bed.

You can bring in clothes for your baby once he/she is old enough to wear them. All clothing/blankets must be washed **BEFORE** they come in contact with your baby. Once these items are dirty, you must take them home to be washed. There is also a washer and dryer available in the Family Lounge for your use. If your baby has any kind of IV access, they will not be allowed to wear their own clothes. We will provide a hospital t-shirt for your baby to wear, which provides easy access to your baby's IV. Please do not bring valuable things for your baby in the NICU. There is a chance they may be misplaced.

PARKING INFORMATION



Parking is available in the Orleans Street Garage. The bridge to the Children's Center is marked "CHILDRENS." Parking is also available at the McElderry Street Garage near the Johns Hopkins Outpatient Center.

"Parking coupons" are available at a reduced rate in books of 5 or 10. Each coupon is good for one 24 hour period. This does not include

Valet parking. There is no refund for unused coupons, but they can be used after your baby's discharge for return visits. You can buy coupons at the Orleans Street or McElderry Garage Offices 24 hours a day. You can also purchase them at the Cashier's Window in the Main Admitting Office in the Wolfe Street Lobby, Nelson 161, between 7:30 am and 4:45 pm Monday through Friday. The phone number is (410) 955-5923.

Long Term Parking Relief- Families that have been here for 10 consecutive days may be eligible for discounted parking. Please contact your Social Worker for more information. They will provide a letter that can be taken to the Parking Office to purchase a preloaded parking card. The card will provide in and out access to the Orleans Street Garage for 15 days.

BIRTH CERTIFICATES

All babies receive a birth certificate. Every new mother should fill out the forms on the Postpartum Floor prior to discharge. It usually takes 4 to 6 weeks to get the birth certificate by mail after the form is filled out. More information can be found at:

The Division of Vital Records
6550 Reisterstown Road
Baltimore, Maryland 21215
410-764-3063
<http://vsa.maryland.gov>

The Johns Hopkins Birth Registrar's Office – 410-955-5444

NICU STAFF



Many people work together as a team to care for your baby. These are some of the people you will meet:

Attending Physician: The Attending Physician is a Neonatologist. Our doctors have specialized training in critically ill newborns. He/she will oversee and coordinate your baby's care. The Attending Physician changes every 2 weeks and a different Attending usually covers at night and on the weekend.

Johns Hopkins is a teaching hospital. We have other doctors in the NICU who are in training. These doctors work closely and are always under supervision of the Attending. You will meet 2 types of doctors in training:

Fellow: A Fellow is a Pediatrician who is training to be a Neonatologist. The Fellow works closely with the Attending in overseeing the care of all the babies in the NICU. The Fellow also changes every 2 weeks.

Resident: The Residents are doctors who have finished medical school and are now training to be Pediatricians. Each baby is assigned to one of the Residents or to the Neonatal Nurse Practitioners (see below). The Residents rotate every 4 weeks to a new part of the Children's Center.

Neonatal Nurse Practitioner (NNP): The NNPs are a team of care providers with advanced degrees, specializing in the care of critically ill newborns. They oversee and coordinate your baby's care directly with the Attending.

Hospitalist: The Hospitalist is a Pediatrician that will coordinate your baby's care. The Hospitalist usually works weekdays until 5 PM and the NNP team covers for the Hospitalist at night and on weekends.

Nurse Manager: The nurse manager for the NICU is Barbara Buckley. Feel free to contact her with any concerns you may have about your baby's care while in the NICU.

Assistant Nurse Manager: Stephanie Mianulli is the Assistant Nurse Manager. You may meet her during your baby's stay in the NICU. She can also be contacted with any concerns you have about your baby's care.

Nurses: The nurses in the NICU have extensive experience and training in the care of critically ill newborns.

Primary Nurse: Each baby has one or more primary nurses. The primary nurse may not actually take care of your baby every day, but he/she will coordinate your baby's care until discharge.

Social Worker: Each baby is assigned to one of our NICU Social Workers. The Social Worker assists families in dealing with their concerns and worries while their baby is in the hospital. They can also help with information about community resources, insurance, transportation and a place to stay in Baltimore, if you are from out of town. The NICU Social Workers are

Emily Vanwiel, LMSW, 667-208-4906
Courtney Reaves, LGSW 667-776-3781

Case Manager: The case manager will work with your insurance company to coordinate plans for your baby's transfer or discharge.

Respiratory Therapist: A team of respiratory therapists helps with every baby who has breathing problems. They manage the respiratory equipment.

Pharmacist: A pediatric pharmacist is part of the team to help with information and advice on prescribing medications for your baby.

Nutritionist: The nutritionist works with the team to assist in providing the best nutrition for your baby.

Clinical Customer Service Representative: (CCSR) -Manages the front desk, and works throughout the NICU performing a variety of customer service and unit activities to assist families and staff.

Clinical Customer Service Coordinator: (CCSC) Helps support and care for families while they are in the NICU. The "CCSC" is a good person to go to with unit questions or concerns. The CCSC's focus is on helping families navigate their NICU experience.

Child Life Specialist: The NICU Child Life Specialist works with families, including siblings to help them cope with the stress and uncertainty of illness, and treatment. They support NICU babies by providing developmental stimulation, play, and pain control during procedures.

Chaplain: The NICU Chaplain is available to help families by providing spiritual care and support during their NICU stay.

Neonatal Therapists: Include Physical Therapists, Occupational Therapists, and Speech Language Pathologists. They have special training to help your baby meet developmental milestones. Physical Therapists (PT) and Occupational Therapists (OT) will be part of your baby's care team from the beginning of your NICU journey and will work with your family and the nurses and doctors to support your baby's development. They will help your baby gain strength in all their muscles including the ones that help them suck their pacifier, take a bottle, or breast feed. PT will focus on gross motor development such as kicking, building neck strength, and tummy time. OT will focus on the use of your baby's eyes, hands, and mouth. Some babies may need a Speech Language Pathologist to make sure they are swallowing safely.

EQUIPMENT

There are many different types of equipment that are used to care for the babies in the NICU. Some you may see include:



Isolette

Isolette - Premature babies cannot maintain their body temperature without some source of heat until they are about 33 or 34 weeks gestation. The incubator helps your baby maintain proper body temperature.

Warmer - Full term babies are placed on warmers for evaluation



Warmer

and will remain on the warmers as long as they are sick. Once they are more stable, they could move to a crib or bassinette.



Crib



Basinette

Crib and Bassinette – Both are used for bigger babies that can maintain their body temperature outside of an incubator.

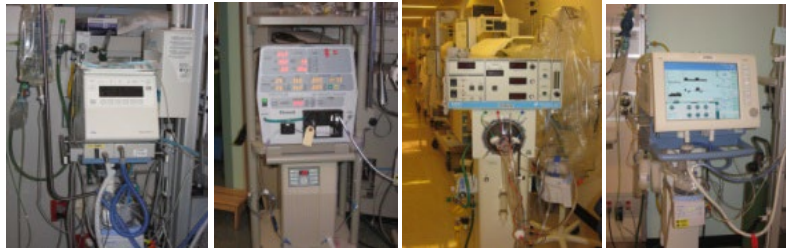
Monitor- Every baby in the NICU is on a monitor that shows the baby's heart rate, breathing rate, and blood pressure. Soft leads or wires are placed on the baby's chest to pick up these measurements.



Pulse Oximeter- Most babies are also on another monitor, called a pulse oximeter that gives a reading of the amount of oxygen in the baby's blood. A small cloth tape with a red light in it is wrapped around the baby's hand or foot to take this measurement.



Ventilator- A ventilator is a machine that helps the baby breathe and can provide extra oxygen. Many babies in the NICU need this help with their breathing. There are several different types of ventilators used in the NICU, and the medical team will help with choosing the right one for your baby.



Endotracheal tube - The ventilator is connected to a breathing tube, or endotracheal tube, that passes through the baby's mouth into his/her airway. This tube is taped to the baby's face to hold it in place.



Endotracheal tube

Nasal CPAP- CPAP stands for "continuous positive airway pressure". When a baby is on CPAP, he/she is breathing by his/herself. Soft prongs are placed in the baby's nose, providing pressurized air to help keep the lungs expanded. Extra oxygen can be given as well.



Nasal CPAP

Nasal Cannula-A nasal cannula is a small, soft plastic tube with short prongs that fit into the baby's nose. The cannula gives the baby extra oxygen or air flow to help remind the baby to breathe.



Nasal cannula

TUBES AND LINES IN THE NICU

Feeding Tube-Premature babies initially are unable to eat by mouth, since they are not able to coordinate sucking, swallowing and breathing. They are usually able to do this at about 33-34 weeks gestation. Feedings are started before 33-34 weeks by inserting a small, soft plastic tube, either through the nose or mouth, into the baby's stomach.



Intravenous (IV) Line-Most of the babies in the NICU need an IV line at some time. This is a thin catheter placed into a vein in the hand or foot, or occasionally the scalp. Medications, blood products, IV fluids and even IV nutrition can be given through an IV line.



Central Line-A central line is special type of IV that is longer in length than a regular IV, and can reach to a larger and deeper vein in the body. There are several types of central lines. One type, which is used most frequently in the NICU, is a *PICC* line. Since these lines are much longer, they are able to stay in place for several weeks. IV fluids, medications and IV nutrition can be provided through a PICC. Another type of central line is placed by surgeons, usually in the chest or leg. This type can also last for several weeks and IV fluids, medications, IV nutrition, and even blood products may be provided through this line.

Umbilical Lines- Two types of lines can be placed directly into the baby's umbilical cord just after birth. One is called an *Umbilical Venous Catheter (UVC)*. This is an IV line that can be used for medications, blood products and IV fluids. The other is an *Umbilical Arterial Catheter (UAC)*. This can be used to monitor the baby's blood pressure and draw blood samples without having to stick the baby.

PROCEDURES AND TESTS

To provide the best care for your baby, we may need to perform certain procedures and tests. Your baby's doctor will discuss any procedures with you when they are needed unless the situation is an emergency. These are some procedures and tests you may hear about:

Intubation-This is the procedure to place a breathing tube, or endotracheal tube, through the baby's mouth and into the main airway. Once this tube is in place, it will help the baby breathe better.

Lumbar Puncture/Spinal Tap-This is the procedure to sample the fluid around the brain and spinal cord. This fluid is called cerebrospinal fluid or CSF. A small needle placed in the baby's lower back is used to collect the sample. This is an extremely important test to look for an infection called meningitis.

Transfusion-A transfusion is the procedure to give a baby blood, or a part of blood, that the baby needs. Some babies need red blood cells (the part of blood needed to carry oxygen). Others need platelets (the part of blood needed to stop bleeding and help blood clot). Most premature babies will need a transfusion at some point while they are in the NICU. The smaller the baby, the more likely he/she will need a transfusion.

Phototherapy-Many babies are jaundiced. They develop a yellow color in their skin and eyes from a chemical called bilirubin. To get rid of bilirubin, the baby

may need to be put under bright lights that help break down bilirubin. A soft mask will be placed over the baby's eyes to protect him/her from the light.

Electrolytes (CMP/BMP)-This is a test that measures the level of several chemicals in the baby's blood. We use this test to adjust the baby's nutrition and/or medications.

Complete Blood Count (CBC)-This test measures the number of red blood cells (that carry oxygen), white blood cells (that fight infection), and platelets (that help blood clot). We use this test to determine if the baby needs a blood transfusion. It also helps us if we think the baby has an infection.

Blood Gas-This is a blood test to measure the amount of oxygen and carbon dioxide in the baby's blood. It tells us if we need to make any changes in the baby's ventilator, or if he/she is not on a ventilator, how well he/she is breathing.

Blood Culture-This is a specific blood test to look for an infection in the baby's blood.

MRSA Surveillance - (Methicillin Resistant Staphylococcus Aureus). Every week on Tuesday, we send a swab from your baby's nose to screen for MRSA, which can be acquired in the community or in the hospital. Infrequently, babies test positive for MRSA and then require special isolation (with gowns and gloves) so that MRSA does not spread to other patients. Medicated cloths or ointments may be used to help decrease the amount of this bacteria on your baby.

Karyotype/Chromosome Study/SNP array-Chromosomes are the part of every cell that contains the genes, or genetic traits, that make each of us a unique individual. A small blood sample can be obtained to study the number and structure of the baby's chromosomes.

PREMATURE BABIES

There are certain problems that most premature babies face. Your baby's nurse and doctor will discuss these with you.

Temperature Control

Most premature babies need help to keep their body temperature at the right level. We use warmer beds and incubators to provide warmth for the babies. As your baby grows and develops, he/she will gradually need less warmth to maintain his/her temperature. Once your baby is able to remain warm at a low incubator temperature, he/she will be dressed and bundled in a blanket inside the incubator. Then the incubator temperature will be turned down to room

temperature. If your baby maintains a normal temperature for about 24 hours while bundled in the incubator, he/she will be moved to a bassinet or crib

Pain

Since babies are unable to tell us if they are in pain, we assess pain levels based on the following: crying, facial expression, muscle tone, and vital signs. If your baby's nurse thinks your baby is in pain, various comforts (pacifier, swaddling, music, etc.) and/or pain medication will be offered. Our goal is to minimize pain, so please let staff know if you believe your child is in pain.

Apnea and Bradycardia

Apnea is when a baby forgets to breathe for about 20 seconds or longer. When a baby has apnea, his/her heart rate may also drop below normal, and this is called bradycardia. The alarms on the monitor let us know whenever a baby has an apnea or bradycardia. Premature babies commonly have this problem because the centers in the brain that control breathing and heart rate are immature. During some of these episodes, the baby may start breathing again on his/her own and then the heart rate will return to normal. At other times, the baby will need to be stimulated to start breathing again. This is done by gently flicking the baby's foot, or patting her back or bottom. Most babies outgrow this problem as they get closer to the date they were due. There are medications that can help reduce the amount of apnea. If your baby is on medication, it will be stopped as he/she gets close to discharge. He/she will then be watched closely for any episodes of apnea or bradycardia. If your baby continues to have episodes, discharge may be delayed for a few days. In some cases, the baby may need to go home on a monitor. This monitor will alarm and alert you if apnea or bradycardia occurs. You will be taught what to do if this happens and your pediatrician will follow the baby's progress and decide when the monitor can be discontinued

Feeding your Baby

Coordinating sucking, swallowing and breathing at the same time does not happen until about 34 weeks gestation. Some babies are able to do this earlier, others later. Until this coordination develops, the baby will not be able to take a bottle or nurse at the breast. The baby will be fed with a small feeding tube through the nose or mouth that passes into the stomach. This is called a tube feeding or a gavage feeding.

Breastfeeding or providing your breast milk for your baby is recommended for at least the first 6 months of your baby's life, followed by continued breastfeeding for 1 year or longer as mutually desired by mom and baby as other foods are introduced. There are very few times when breastfeeding is not recommended. When you breastfeed, pumping takes the place of baby nursing until baby can nurse all of his/her feedings. You will need to pump your breasts often to build

your milk supply, initially pumping at least 8 times a day with up to one 5-hour break at night. Breast pumps are available in the NICU for you to pump at your baby's bedside. You will also need to pump when you are not at the NICU. A pump for home use may be obtained through insurance, self-purchased, or borrowed from the NICU if available and returned prior to baby's discharge. Please review the information in your baby's room for washing and sterilizing your pump kit and storing your breast milk for your baby in the NICU. Save all your pumped breastmilk in the NICU provided bottles so it can be fed to your baby when your baby is ready. The NICU lactation consultant, Julie Murphy, RN, IBCLC will be available to discuss any breast-feeding concerns or questions you may have.

When breastfeeding, your baby may be able to be placed at your breast sooner than 34 weeks gestation. Most babies will not begin to use a bottle until they reach about 34 weeks gestation. Until your baby can breastfeed or bottle feed all of his/her feedings, your baby will also be fed through a feeding tube. When your baby first nurses at the breast or bottle feeds, the nurse will watch how your baby does. Your baby's time at the breast and bottle feeding will be increased as your baby progresses. Your baby must continue to gain weight while increasing his/her time breastfeeding and bottle feeding. It takes a lot of energy and calories to do both compared to tube feeding. The medical team will pay close attention to your baby's weight gain once breastfeeding and bottle feeding begins to make sure your baby continues to gain weight.

YOUR PREMATURE BABY'S EYES

At the request of your baby's doctor, eye exams may be performed on your infant. Children less than 1500 grams (3.5 pounds) birth weight, less than 30 weeks gestation, as well as other children designated by the NICU doctors will be examined. These exams begin around 4-6 weeks of age, or by 31 weeks post-conceptual age, and are repeated every 2 weeks or as needed.

What is Retinopathy of Prematurity?

Think of the eye as being like a camera and the retina is like the film. The retina is the inner lining of the eye that receives light and turns it into pictures that are sent to the brain. Blood vessels that supply the retina are one of the last structures of the eye to mature; they have barely completed growing when a full-term baby is born. This means that a premature infant's retina is not yet completely developed. For reasons not yet understood, the blood vessels in the immature part of the retina may develop abnormally in some premature infants. This is called retinopathy of prematurity, or **ROP**.

When **ROP** develops, one of three things can happen:

- In most babies, the abnormal blood vessels will heal themselves completely, usually during the first year of life.
- In some babies the abnormal blood vessels heal only partially. In these infants, nearsightedness, lazy eye, or a wandering eye commonly develops. Glasses may be required in early life. In some cases a scar may be left in the retina, resulting in vision problems that are not entirely correctable with glasses.
- In the most severe cases, the abnormal blood vessels form scar tissue, which can damage or dislodge the retina. This problem results in a severe loss of vision. There is treatment to minimize severe vision loss. Occasionally, despite all treatment, this condition can lead to blindness.

If your baby is discharged to another hospital or to home, be certain you know when the next eye exam is to be scheduled (usually in 1 to 3 weeks). When your baby is sent home this appointment may be here at Johns Hopkins Hospital or at another ophthalmologist's office near your home.

This follow-up eye appointment is extremely important for the health of your baby's eyes. Missing this appointment may result in blindness in your baby.

For more information please ask your baby's doctor or call
Pediatric Ophthalmology 410-955-8314.

TOUCHING, INTERACTING, and HANDLING YOUR BABY

At times, the NICU may be overstimulating and stressful for your baby. This section will help you learn more about your baby's responses and suggest specific ways to help your baby deal with the stress.

All babies communicate with the world around them. They use specific body language, and babies who are born prematurely communicate with us in their own manner.

Most full term babies thrive on stimulation, but for a premature baby too much stimulation may be overwhelming. By observing and learning to read your baby's body language, you will soon learn what causes stress and can then change your actions to suit the baby's needs.

Signs of Overstimulation

- Color change (pale/flushed)
- Hiccups, gagging, spitting up
- Changes in breathing pattern
- Oxygen levels drop
- Frowning, grimacing, worried expression
- Changes in muscle tone (floppy, limp, stiff)
- Avoids eye contact
- Sneezing or yawning
- Trying to change position
- Getting into a drowsy or light sleep to shut out stimulation

Signs of Comfort

- Bracing legs or back against side of bed
- Hands clasped
- Hands near mouth
- Sucking on pacifier, hands or fingers
- Relaxed limbs
- Eyes open
- Stays in a cuddled position

All of these behaviors are used frequently by the babies to reduce overloading stimulation. These skills require a lot of energy from the babies and may tire them out easily so NEVER WAKE A SLEEPING BABY while visiting in the NICU.

The NICU practices *Cycled Lighting* to help your baby's sleep wake cycle. Lights will be on during the day, and low at night. There is a nap time from 2-3 PM when the lights are low. For safety, and good care of your baby, the ceiling light must be on during cares, even at night.

Ways to Help Your Baby

- Open and close doors of the incubator quietly. Speak to your baby in a quiet voice, before touching him/her, letting the baby know you are there. Offer a finger for the baby to hold.
- Swaddling is soothing. If your baby is big enough, he/she can be swaddled in a blanket. Smaller babies do well with cupping your hands around their head and bottom.
- Provide boundaries with blanket rolls to offer containment similar to that of the womb.
- Hold your baby skin to skin, also known as *Kangaroo Care*. Holding skin to skin benefits both you and your baby. Baby rests on your bare chest, only wearing a diaper and possibly a hat. Baby is then covered with a blanket. Skin to skin is ideally done for at least an hour. Ask your baby's nurse when your baby can be held skin to skin.

- When interacting with your baby, observe his/her behavioral cues. This is how he/she interacts with you. The baby will guide your interactions and you will soon learn your baby's needs. Eventually your baby will be able to maintain good eye contact and listen to the sound of your voice without becoming over-stimulated. It just takes time to grow and lots of patience on your part, but it is well worth it! Please feel free to talk with any of the nurses regarding your baby's special needs.

NEST Team-The **N**urturing **E**nvironmental **S**upport **T**eam is team of health care providers that promotes brain and sensory development (neurodevelopment) for infants in the NICU. Neurodevelopmental care is a set of protective strategies that reduces the environmental and sensory stress your baby might experience while in the NICU. The team meets every Wednesday and talks about a plan of care for your baby. You are welcome to join them. The plan will be on the big dots on the wall in your baby's room. It will provide suggestions for staff and parents.

WHERE TO GET MORE INFORMATION

Each room has a MyChart Bedside tablet. The tablet can be linked to the baby's medical record. Our NICU Clinical Customer Service Representative or your baby's nurse will help you get the tablet set up. From the tablet, you will have access to your baby's most recent vital signs, lab values, health care team members, education, music therapy and more. There is also a link to sign up for a MyChart account for your baby if you do not have one. The MyChart portal provides access to your baby's medical information once they leave the hospital.

The Children's Center also has a Family Resource Center and Children's Library on the 3rd floor of the Bloomberg Children's Center, Room 3352. This library contains over 1,000 books and videotapes on health related topics. There are also computers with internet access available for families to use. In addition, a Patient and Staff Library is open Monday-Friday 8:30 am-4 pm in Carnegie 173.

CLASSES FOR FAMILIES



Classes are held for parents of babies in the NICU. Sign-up sheets with class dates and times are located in the Family Lounge. Please plan ahead and sign up for these classes before the end of your baby's hospital stay.

Well Baby Care Class- This class is for all first time parents, as well as those that just need a review. This class will teach baby care, bathing, diapering, dressing, car seat and infant safety. Signs and symptoms of illness, and when to call the doctor will also be reviewed. Sign up for the next class is in the Family Lounge.

CPR Class-This class will teach you what to do if your baby stops breathing and his/her heart stops beating. Classes are limited to a small number every other week, so you need to sign up for this class 1 week in advance. Anyone who will be regularly caring for your baby should attend this class.

Introduction to Infant Massage-Touch helps with learning, emotional regulation, and social interaction. For a NICU baby, touch will help establish the foundation for survival and enhance the ability to thrive. This class is an introduction to infant message and is provided at the bedside. Sign up for a time slot in the Family Lounge.

Transfers to Another Facility



Most babies in the NICU are transferred to another hospital before they go home.

If your baby was born at Johns Hopkins but you live far away, we may be able to find a hospital closer to your home that can provide the appropriate care when your baby is stable enough to be transferred.

If your baby was born at another hospital and transferred to Johns Hopkins for a procedure or subspecialty service, we may transfer the baby back to the hospital of birth when that need has been met.

By transferring stable babies, we are able to continue to accept critically ill babies who need to come to Johns Hopkins for services that are not available in other hospitals. Also, many insurances will not continue to pay for NICU care when a baby is stable and intensive care is no longer necessary.

Most babies whose families live in the Baltimore area are transferred to Mt. Washington Pediatric Hospital (www.mwph.org) when they no longer require NICU care. This hospital is affiliated with Johns Hopkins and has specialized programs for preemies and older infants who are transitioning from NICU to home. Transfers may also occur to other units within our hospital if appropriate. If you have questions about transfer to another hospital, contact the NICU Case Manager Meg Barracato, MS, RN.

ANTICIPATING DISCHARGE

Below are the goals that must be met before your baby goes home. If your baby is being transferred to another hospital, these goals may only be partially met. Your baby will continue to make progress towards going home after transfer.

1. It is your responsibility to choose a doctor to provide follow-up care for your baby after discharge. Some factors to consider when choosing a pediatrician are:
 - Recommendations from friends/family
 - Does the doctor accept your insurance?
 - Location of the office
 - Office hours
 - Is there a doctor on-call?
 - If your baby has complex medical problems, does the doctor have experience caring for children with similar problems?
 - What hospital will your baby be referred to if he/she needs to be admitted?
2. Your baby should no longer require the ventilator or CPAP. Some babies may still need oxygen when they are ready to go home. Your baby has to be apnea and bradycardia free before discharge home. Your baby must be taking all of his/her feedings by mouth and showing a steady weight gain.
3. Your baby has to be out of the incubator and in a bassinet or crib and able to maintain his/her body temperature.
4. You will be given prescriptions for any medications your baby may need at home. You will need to bring the filled prescriptions to the

NICU to be checked. Your baby's nurse will show you how to give the medicine to your baby.

5. You need to attend the Well Baby Care and CPR classes in the NICU (Videos are also available).
6. You must bring a car seat to the NICU, so the nurses can see if any special adjustments need to be made. Your baby's nurse may perform a car-seat test close to the date of discharge to be sure that your baby can breathe effectively and travel safely in the car seat.
7. If you have a NICU loaner breast pump, it needs to be returned before baby's discharge.
8. If your baby needs any special care, the nurses will show you how to take care of these needs before discharge. You can spend the night in your baby's room and have the comfort of knowing that your baby's nurse is close by should you have any questions. The Case manager will help you get any special equipment or supplies that you will need to care for your baby at home.
9. All babies are due for important vaccinations (immunizations) at certain ages. If your baby is ready for any vaccinations before discharge, we will discuss this with you and ask for your permission. We will let your pediatrician or clinic know what shots, if any, your baby has received.

Use this checklist to keep track of your baby's progress. The more goals met, the closer discharge becomes.

Goal	Check if Goal Is Met		Notes
1. Pediatrician has been identified			
2. No breathing problems			
3. Feeding by mouth			
4. Steady weight gain			
5. Sleeps in a bassinet			
6. 5-7 days without apnea/ bradycardia			
7. Medicines ready			
8. Well Baby Care Education			
9. CPR			
10. Car seat ready			
11. Special teaching completed			

FOLLOW UP VISITS

Pediatrician: You must have a pediatrician or clinic to follow your baby after discharge. Your baby's doctor or clinic will have a summary of your baby's NICU course. We will also help you plan when your baby's first visit should be.

Eye Clinic (Ophthalmology): If your baby needs a follow-up eye exam, an appointment is necessary. You will need to make an appointment if we do not do so for you. If we do not make the appointment, we will provide the number for you to call and make the appointment.

Lung Clinic (Pulmonary): If your baby goes home on oxygen, the Lung Clinic will follow your baby. You will need to make an appointment if we do not do so for you. If we do not make the appointment, we will provide the number for you to call and make the appointment.

Developmental: Many babies who have been in the NICU will need careful follow-up to monitor their development. Your baby may be referred for developmental follow-up at the Infant Neurodevelopment Center at Kennedy Krieger Institute or with the Maryland Infants and Toddlers Program.

General Pediatric Surgery: Babies who have had surgery will be followed by their surgeon. You will need to make an appointment if we do not do so for you. If we do not make the appointment, we will provide the number for you to call and make the appointment.

MARYLAND STATE METABOLIC SCREENS

By Maryland State Law, newborn babies are tested for a number of conditions that can cause mental retardation or health problems. You will be asked for your permission for these tests to be performed on your baby. If your baby is transferred or discharged before this series of tests is completed, the other hospital or your pediatrician's office will finish the testing.

WIC PROGRAM

WIC (Women, Infants and Children) is a national program that supplies some food and formula to women and children less than 5 years of age. You may qualify whether you are breastfeeding or bottle-feeding your baby.

Once you have the WIC referral form, call your local WIC agency. The phone numbers are on the form to make an appointment. Contact the office where you already enrolled, or the office closest to your home.

When you go to your WIC appointment, remember to take proof of where you live, and a picture ID. You will also need proof of income.

MARYLAND CAR SEAT LAW



More infants and children are killed in car accidents than any other cause. A major factor is that car seats for infants or young children are often used incorrectly or not used all the time. Therefore, Maryland law requires the following:

1. **Every child** under 8 years old must ride in a car seat or booster seat, used according to car seat and vehicle manufacturers' instructions, unless the child is 4 feet, 9 inches or taller.
2. **Under 2 years old must ride rear-facing.**
3. **Every child** from 8 to 16 years old must be secured in a car seat, booster seat, or vehicle seat belt.

*Remember - Children under 13 years old are safest in the back seat!

GETTING A CAR SEAT & INSTALLING IT PROPERLY

An infant-only car seat, rather than a convertible infant/toddler-type seat, should be used for small infants. Check the lower weight limit before purchasing a seat; the lowest limit available is 4 pounds. It is important to have a seat with a weight limit that is appropriate for your baby's weight at discharge, so that your baby may be safely secured in the seat. Car seats with different weight limits are available in all price ranges and should be purchased by parents prior to discharge. The NICU staff work together with the Certified Child Passenger Safety Technicians, to help make sure that your baby is fitted in the proper seat.

*To ensure safety, if your baby's car seat has been used in the past, make sure it has not been recalled, reached the expiration date, or been involved in an car crash.

The Maryland KISS (Kids in Safety Seats) Program has car seat information and services available. Contact 1-800-370-SEAT (7328) or go to www.mdkiss.org. The website www.healthychildren.org sponsored by the American Academy of Pediatrics, includes information about car seat safety, as well as a current product listing of seats available for retail purchase, along with their height/weight limits and suggested retail prices.

For More Information

Additional information on restaurants and places to eat in the hospital, gift shops, pharmacy services, postal services, etc. go to:

https://www.hopkinsmedicine.org/the_johns_hopkins_hospital/services_amenities/services/index.html

PARENT FEEDBACK/ SURVEY

Our goal in the NICU is to make your stay with us the best experience possible. We take great pride in our unit and always accept any and all opinions or suggestions for improvement. Upon your baby's discharge from Johns Hopkins, you may receive a survey. The survey gives us the chance to improve the delivery of care to your precious newborn. Please take the time to complete and return the survey so that we can hear your opinion.

NICU GRADUATION PARTY



Every June or July, we have our “NICU Grad Party.” We invite all of the babies that have been on our unit, along with their families. This gives the staff an opportunity to see you and your child again. It is a big celebration and we look forward to it every year!

If you do not receive an invitation, please call us!
410-955-5255

A Parent’s Guide to the NICU – Updated December 2022