NICU Family Guide

Information to help you during your baby’s hospital stay in the Connecticut Children’s Neonatal Intensive Care Unit
Welcome

Welcome to the Neonatal Intensive Care Unit (NICU) at Connecticut Children’s.

Congratulations! The birth of your baby is a joyous time and should be celebrated. However, we understand that having your baby admitted to the NICU may be scary or stressful. We are here to help and are dedicated to providing the very best care for you and your newborn.

This guide contains information about the NICU, what to expect during your baby’s stay in the NICU, and ways to participate in your baby’s care. We look forward to working together to get your baby safely home as soon as possible.
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THE NICU: GENERAL INFORMATION
“Sometimes” said Pooh, “the smallest things take up the most room in your heart.”

A. A. Milne
The NICU: General Information

What is a NICU?

A Neonatal Intensive Care Unit (NICU), pronounced “nick you,” specializes in the care of babies who are either born sick, or have come into this world prematurely (less than 37 weeks into pregnancy).

The Connecticut Children’s NICU is a “level 3” NICU. This means we are able to care for even the sickest babies. While the NICU is located within Hartford Hospital, we are part of the Connecticut Children’s Medical Center. Our doctors, neonatal nurse practitioners, physician assistants, registered nurses, and other professionals work as a team with you to meet your baby’s needs.

As a parent, you are the most important member of your baby’s team. We encourage you to voice any concerns and questions and be as involved as possible in your baby’s care.

Visiting your baby

• **Parents** or other designated support persons are welcome in the NICU anytime they wish.

• **Other family and friends** may visit between 8:00 am and 8:00 pm, seven days a week.
Visiting during regular visiting hours
(8:00 am – 8:00 pm)

• For the security of all the babies, when you arrive at the Connecticut Children’s NICU entrance, stop at the window on the right and check in with a NICU staff member.

• The staff member at the window will ask for your name and the name of the baby you are visiting. You will be given a badge, which should be kept on at all times.

• Parents may call the NICU anytime for an update. You will be asked for a number to confirm your identity. You will receive this number during one of your first visits.

• After you check in, the door will be opened remotely by a staff member. Upon entering, please wash your hands at one of the NICU scrub sinks.

Parents coming to the NICU outside regular visiting hours should press the button outside the main NICU doors and wait for assistance.

Entering and leaving the NICU

Entering the NICU. Enter through the main entrance of Hartford Hospital and walk through the lobby to the elevators. Take any elevator to the 5th floor and follow the signs to the Neonatal Intensive Care Unit. Ask at the front window which wing (north, east, or west) your baby is on. Each wing has a name board listing each baby’s bed space number (like a room number). It also lists the nurses and doctors caring for your baby during each shift.

Leaving the NICU. Push the call button to the right of the doors to request to be let out of the unit, and stop at the window to check out.
**Who can visit**

<table>
<thead>
<tr>
<th>Role</th>
<th>Visit Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parents</td>
<td>Please come anytime.</td>
</tr>
<tr>
<td>Grandparents</td>
<td>Between 8:00 am and 8:00 pm unless you tell your nurse you do not want them to visit alone.</td>
</tr>
<tr>
<td>Baby's brothers and sisters</td>
<td>Between 8:00 am and 8:00 pm with a parent who must be present at the bedside. Siblings under the age of 14 must be accompanied by a parent of the baby at all times.</td>
</tr>
<tr>
<td>Other family and friends over 14 years old</td>
<td>Between 8:00 am and 8:00 pm with a parent who must be present at the bedside.</td>
</tr>
</tbody>
</table>

Newborns can become sick very easily. Please help us protect all the babies by cooperating with these rules:

- Non-sibling children under 14 years old may not visit the NICU.
- No one who is sick or has been sick recently will be allowed into the NICU (“sick” includes anyone with colds, fever, stomach aches, diarrhea, sore throats, pinkeye, or any other illnesses that can be passed person to person). When in doubt, please ask your baby’s nurse.
- Sibling visits are restricted during cold and flu season. Since flu season varies from year to year, you will see notices posted about these restrictions. If you are a parent who is under 18 years old, this limitation does not apply to you. If you have any questions, ask your baby’s nurse.

**Hand-washing**

Hand washing is extremely important in the NICU to protect the babies from catching any germs. Before you or any visitors go to your baby’s bedside, you must “scrub” by rolling up your sleeves and washing to your elbows with the special soap provided. Each wing of the NICU has a scrub station. Please help us keep a healthy environment for the babies by following the directions at the scrub sinks and by scrubbing each time you return to the NICU.
Obtaining information about your baby

• Ask questions at any time, day or night!

• Join us on “rounds.” Rounding is the practice of having doctors, mid-level practitioners (nurse practitioners and physician assistants), nurses, and other members of your baby’s care team meet at the bedside to discuss his or her medical condition, plan for care, other updates, and your concerns. We encourage you to participate in rounds as often as you can. Your nurse can provide more information on timing of rounds on your baby. For more information on rounds, see page 21.

• Call the NICU at any time for an update. When you call, you will be asked for a number to confirm your identity. You will receive this number during one of your first visits. Please do not give out this number to others; it is meant to be used only by parents.

• Parents are the only people allowed to receive information about their babies. Please let relatives and friends know that if they call or come to the NICU, they will not receive any information.

Your baby’s safety in the NICU

We take many steps to keep the babies safe. These include:

• The NICU is a locked unit. You may enter and leave only if a staff member unlocks the doors.

• If your baby needs to leave the NICU for a test or procedure, he or she will be accompanied by NICU staff and security.

• Video cameras throughout the NICU allow us to see who is in the hallways at all times. Sometimes, the doors may appear to open “magically”! This happens because the NICU staff can see you on video screens and can open the doors from remote locations.

• Once your baby is stable and big enough to sleep in a crib or cot, an electronic security tag will be placed on his or her leg. If this tag is moved or cut, an alarm will sound throughout the NICU. If your baby is able to be carried around the unit, please be sure to check with staff about the boundaries of the security system so you don’t accidentally set off the alert.
TAKING CARE OF YOU
Babies are always more trouble than you thought — and more wonderful.

Charles Osgood
Taking care of you

Throughout your pregnancy, you probably pictured the birth of your baby as a time of joy that you would never forget. Having your baby separated from you and your family and brought to the NICU is rarely part of that picture. In addition, you may be facing other issues. These may include: managing trips to the hospital with other child(ren) at home, financial concerns, and your own physical and emotional well-being.

Coping while your baby is in the NICU means both taking care of yourself, and being with your baby in a way that is comfortable and comforting for both of you. During this time, you may be reluctant to think about your own needs. However, taking care of yourself — body, mind, and spirit — will keep you at your best as you learn to care for your new baby.

Common thoughts and feelings

While you may rejoice at the birth of your baby, you may also feel frightened and vulnerable or even angry because your baby has to stay in the NICU. You may feel helpless as you see health care team members providing much of your baby’s care, and you may want more physical contact than your baby’s condition allows. Our goal is for you to be as involved in your baby’s care as possible since you are the most important person in your baby’s life. Please know that all these feelings are normal, and that support is available from a variety of sources, many of which are listed below and in the section “Finding more information and support” on page 43.
Take care of yourself

• Take care physically by trying to get regular sleep. Eat healthy, regular meals and drink plenty of water, juice, or other non-caffeinated fluids. Family rooms are available for overnight use on a first-come, first-served basis. Your nurse can help you sign up for a sleep room. If you choose to sleep at home, we welcome calls for updates at any time of day or night.

• Seek support from family, friends, and spiritual leaders. Allow others to help by listening or assisting with meals, chores, or child care. Some towns even have websites allowing friends to sign up to help with specific tasks to assist you. If you are comfortable, you may tell your boss and co-workers about your baby’s condition. Ask to speak with the NICU social worker. She can offer support, and coordinate resources.

• Connect with other families. We offer a weekly scrapbooking hour and a coffee/tea hour for families. These events allow families time to talk casually and support each other.

• Establish a routine. Organize your life so that it has a pattern that works for you and helps you feel more in control.

• Take breaks. Spending all day, every day in the NICU may seem important. However, by taking time for yourself, you can also improve the quality of the time with your baby. If you want to take a break or nap during your visit, use the family rooms or take a walk outside.
Become involved and comfortable with your baby

• Touch, talk to, and hold your baby. If you have concerns about disturbing your baby, the caregivers can assist you in offering comfort and closeness. Once your baby is well enough, your nurse can help you position your baby in your arms. Ask about kangaroo (skin-to-skin) care (see page 35), which is very good for both you and your baby.

• Care for your baby. You can change diapers and take temperature. Eventually you will be able to bathe and dress your baby. Basic caregiving can initially feel overwhelming — especially when handling wires and tubes. The NICU staff will work with you until you are comfortable handling these tasks on your own.

• Make your baby’s space welcoming and comfortable by bringing in items such as clothing, blankets, and family photos.

• Help with decision making. Attending daily rounds (see page 21) is one way to be involved in decisions regarding your baby’s care. If you are unable to be present for rounds, talking with your baby’s nurse and other team members can keep you informed.

• Take pictures. If you do not have a camera or would like an immediate print to share with family members, ask your baby’s nurse. The NICU has a digital camera and printer and can provide this service. Some families purchase disposable cameras to leave at the bedside.
Brothers and sisters

Siblings are welcome to visit except during cold and flu season. Below are some tips for helping siblings understand what is happening and how to relate to their new brother or sister. Also, the NICU social worker is available to provide age-appropriate information for your other child(ren). Ask your baby’s nurse to explain the sibling visiting procedure.

• For everyone’s safety, child(ren) must be supervised at all times, including in the family lounge and hallways. They should never be left unattended in or around the NICU.

• Prepare child(ren) before the first visit with simple explanations and pictures. Update them directly and honestly and talk about their experiences.

• Portable DVD and VHS players can be wheeled to the bedside. Child- and family-friendly movies are available for you to borrow — just ask your baby’s nurse or a health unit coordinator.

• Books written for siblings of NICU babies are available in the family resource room. These books describe the NICU environment and discuss some of the emotions your child(ren) may be feeling.

Caring Bridge

Caringbridge.org is a free website that offers the ability to post photos and update friends and family on your baby’s progress. The site guides you through a simple setup which includes putting together your own personal page. While you are here, you may use the computer in room 501 to access this website or other helpful online materials (see page 44 for a listing).

• Using this site helps to avoid numerous calls and repetition of the same information over and over. It also allows friends and family to write back with words of support.

• The site is specifically designed for sharing information in a secure manner.

• This site can be accessed through the Connecticut Children’s website (www.connecticutchildrens.org) or through www.caringbridge.org.
Making the decision to have a child is momentous. It is to decide forever to have your heart go walking around outside your body.

Elizabeth Stone
The daily routine in the NICU

When your baby first arrives in the NICU, many staff will be caring for and examining your baby to make sure he or she is comfortable and getting the appropriate medical and nursing care. During the first hours and perhaps days, your baby will be watched very closely. We will do our best to answer your questions. You are welcome to be with your baby at all times, but do not be afraid to leave your baby’s bedside for a break.

Babies in this NICU are classified as either Neonatal Intensive Care Unit (NICU) or special care nursery (SCN) babies. When your baby first arrives, he or she will be considered a NICU baby. As your baby becomes healthier, he or she will be considered a special care nursery baby. We encourage you to communicate your visiting plans to the nurse. Care (such as bathing, holding, or feeding) can often be planned to occur during the time you will be in the NICU. If you wish to feed your baby, please arrive 15 minutes before feeding time so that you can scrub and settle in.

NICU babies

- are checked frequently by the nursing staff and medical team;
- may need help breathing;
- often need X-rays and other tests;
- may not be eating and need IVs (nutrition through an intravenous tube);
- need lots of rest to help them grow and heal.
**Special care nursery (SCN) babies**

- typically have fewer medical concerns and problems;
- can breathe on their own;
- usually will eat every three to four hours — we will make a schedule together with you so that you can be here to feed and care for your baby as much as possible;
- will be examined by the caregiver just before each feeding time;
- still need rest, but can usually tolerate being held more often, so there will be many opportunities to change diapers, bathe and dress your baby, and take a temperature.

**A typical NICU day**

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>7:00 am</td>
<td>Daytime nurses arrive. Caregivers exchange information about your baby’s care when the shifts change (usually three times a day). Try to schedule visits or calls at least a half hour before or after shift change.</td>
</tr>
<tr>
<td>8:00 am</td>
<td>Visiting hours begin.</td>
</tr>
<tr>
<td>9:00 am – 2:00 pm</td>
<td>Rounds begin. The NICU staff will discuss the plan for the day. We welcome you to join us whenever you can. (See page 21 for more on rounds.)</td>
</tr>
<tr>
<td>3:00 pm</td>
<td>Some evening nurses arrive.</td>
</tr>
<tr>
<td>5:00 pm – 7:00 pm</td>
<td>If your baby receives nutrition through an intravenous (IV) line, the tube will be changed daily around this time.</td>
</tr>
<tr>
<td>7:00 pm</td>
<td>Night nurses arrive.</td>
</tr>
<tr>
<td>8:00 pm</td>
<td>General visiting hours end, but parents are welcome to stay.</td>
</tr>
<tr>
<td>8:00 pm – midnight</td>
<td>Your baby will be weighed every evening. Every Saturday, the nurses will also measure your baby’s head size.</td>
</tr>
<tr>
<td>11:00 pm</td>
<td>Some night nurses arrive.</td>
</tr>
<tr>
<td>midnight – 6:00 am</td>
<td>If your baby needs to have blood drawn, it is often done during the night just before a scheduled feeding time.</td>
</tr>
</tbody>
</table>
**Family-centered rounds in the NICU**

Please join in on family-centered rounds in the NICU. Rounding is the practice of having doctors, mid-level practitioners (nurse practitioners and physician assistants), nurses, and other staff meet at your baby’s bedside to discuss his or her medical condition, plan of care, updates, and your concerns. We encourage you to participate in rounds as often as you can, as you are the most important caregiver in your baby’s world. Your nurse can provide more information on timing of rounds.

The NICU has an open floor design, but every effort will be made to ensure the privacy of the information that is shared. Although you are a welcome part of the team, you can tell your nurse if you would rather not speak in front of the group. She would be happy to ask the group your questions or help arrange a more comfortable meeting time and place for updates on your baby.

**If you are not able to be a part of rounds, but would like to have your questions answered, you have other options:**

- Write down your questions as soon as you think of them. When the opportunity arises you can have them answered. If you write down the answers, you can remember the information and more easily share it.

- You can ask to speak to your baby’s doctor or primary caregiver at a time that is more convenient to you.
Other activities in the NICU

Remember that you may call 24 hours a day — we are always here to answer your questions or provide an update. Please never feel that you are inconveniencing the staff. Remember to have your baby’s identification number ready when you call. Without this number, the nurse cannot provide any information.

• **What if my baby needs tests or procedures?** Most can be done right in the NICU. These tests include X-rays, blood tests, and ultrasounds.

  • Occasionally your baby may need to travel to the main building of Connecticut Children’s. Transfers are done in heated incubators or cots, which have all the monitoring equipment available in the NICU. We travel through an underground tunnel, so there is no need to go outside. You are welcome to come with us to any of these procedures.

  • The room in the NICU called the “procedure room” is used for sterile procedures, including circumcisions, placing central catheters for nutrition, and some surgeries. All of these procedures require your permission. We will make sure that you are aware of the location of all tests and procedures needed by your baby.

• **Why are some babies in cots and some in incubators?** Before they are born, babies are kept warm and cozy inside their mothers. Babies born prematurely do not have enough fat on their bodies to keep them warm, so they are kept warm in incubators. Sometimes bigger babies who are very ill also need incubators so the staff can easily see them. When a baby reaches about four pounds, the incubator temperature is slowly turned down until it matches room temperature; then the baby can be moved safely to a crib or cot.

• **Will my baby ever be moved to another location?** Usually babies stay in the same bed area with the same team of nurses from admission to discharge or transfer to another unit. Sometimes, however, movement may be necessary. Common reasons for moving babies include trying to keep twins or triplets together, or moving a baby who needs heart surgery to the pediatric ICU (intensive care unit). Some babies will move to the main building of Connecticut Children’s (across the street) to be cared for by other specialized doctors and nurses when they have progressed enough to benefit from that care, yet still need to be hospitalized.
There is only one pretty child in the world, and every mother has it.

Chinese proverb
Taking care of your baby

How your baby will grow and change

Parents are the most important people in their babies’ lives. We value your presence and welcome you to be with your baby as often as you wish. Please ask questions and participate in the care of your newborn as much as you want, and bring personal items for your baby’s bed space. Let us know how we can help you to be comfortable when you are in the nursery.

Many resources are available for information on your baby’s development.

• Your baby’s nurse can answer many of your questions.

• Many babies are cared for by members of the developmental team, who have expertise in the development of premature and sick babies.

• The family library in Room 501 offers many books.

We look forward to getting to know you and your baby. And please remember that your baby will grow and develop in his or her own unique way.
Your baby’s senses and activities

Your baby’s development is delicately timed by nature, and we will work with you throughout your baby’s NICU stay to support your baby.

**VISION**
- As babies mature, they begin to open their eyes, focus on faces and objects, and stay awake for longer periods of time.
- To protect your baby’s developing eyes from bright lights, we suggest gradually removing the incubator cover and shielding your baby’s face.

**HEARING**
- Even the youngest babies are calmed by their parents’ voices. They prefer low, soft sounds.
- As your baby matures, your baby may be ready for soft, rhythmic sounds such as quiet singing.

**TOUCH**
- Your baby is comforted by your presence, voice, and touch. A “preemie hug” — where you gently cradle your hands around your baby — is often calming.
- As your baby becomes healthier, we will encourage you to place your baby “skin to skin” for kangaroo care. See page 35.

**FEEDING**
- Even the youngest babies may enjoy “non-nutritive” sucking (sucking that does not provide any nutrition) on a pacifier or finger.
- Like all the other systems, your baby’s brain and stomach are immature. As your baby matures, he or she will receive nutrition in different ways.
- For example, before 32–34 weeks, most babies cannot coordinate sucking, swallowing and breathing, so they will receive food through a tube from the nose or mouth to the stomach.
- Holding your baby during feedings in a calm and quiet environment can create positive experiences for both of you.
All babies need a lot of sleep to promote growth and development. The youngest babies need the most sleep. Even babies who are born on or near their due dates sleep 16 to 20 hours a day!

The staff will combine their caregiving tasks during wakeful times to maximize sleep time for your baby.

You may wish to wake your baby gradually by placing your hands gently around him or her before talking or beginning caregiving tasks.

As babies get close to discharge, we place them to sleep on their backs as this is the safest position for them. You will hear more about this in safety class. (See page 43.)

Even very young babies have well-developed senses of smell and will be comforted by their parents’ unique scents.

Holding your baby close is one way for your baby to get to know your scent.

Also, you can keep your scent near your baby when you are not there by wearing a soft cloth next to your skin and placing it on the mattress near your baby’s face. Your nurse can offer additional suggestions.

Individualized developmental care

The hi-tech environment of the NICU often involves exposure to sounds, bright lights, and frequent procedures, all of which can be stressful to the brains of premature or very ill babies. Working closely with each family, the health care team provides individualized developmental care to reduce this stress and meet each baby’s specific needs. We use a nationally recognized model called NIDCAP (Newborn Individualized Developmental Care and Assessment Program). Please ask us if you would like more details.
Your baby’s bedside monitor

What does the monitor do?

The monitor screen provides the NICU staff with information about how your baby is doing. Each baby has different numbers on the screen. The NICU caregivers will set the screen and alarms to meet your baby’s needs.

Some colors you may see:

<table>
<thead>
<tr>
<th>Color</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Green number</td>
<td>Heart rate (how often your baby’s heart beats each minute).</td>
</tr>
<tr>
<td>Red/pink number</td>
<td>Blood pressure.</td>
</tr>
<tr>
<td>Blue number</td>
<td>Oxygen saturation (also called “sats” or “O₂ sats”). This number tells us how well oxygen is getting to your baby’s body.</td>
</tr>
<tr>
<td>White number</td>
<td>Breathing rate (how often your baby breathes each minute).</td>
</tr>
</tbody>
</table>
What are normal readings?

Each baby is unique, so normal numbers can vary from baby to baby.

The answer to this question depends on how early your baby was born OR the condition that your baby is being treated for in the NICU.

We encourage you to ask your caregivers what is okay for your baby. Please remember that what is considered okay may change from day to day, depending on your baby’s medical condition.

What do the alarms mean?

You may find yourself watching the monitor. With numbers blinking and alarms ringing, the monitor seems hard to ignore. Please feel safe knowing that these machines are always keeping track of your baby’s health — even when a health care provider is not right at the bedside.

All the NICU monitors are connected. If a monitor is alarming for a baby across the hall, the alarm will show up on every screen in that wing, so the nurses know which alarms are ringing no matter where they are. In the same way, a nurse can look at any monitor screen on the wing to see if your baby is okay and take any action your baby needs.

Sometimes an alarm will sound because the monitor is not picking up the information properly (the nurse can tell by what she sees on the screen). When this happens, someone will fix the situation, but a nurse will not need to run to that baby. Rest assured, if a baby needs help, someone will always be there right away.
Feeding in the NICU

Sick or prematurely born babies need special nutrition. Most babies staying in the NICU will not eat for at least the first day of life. Some will not be able to eat for several days or even longer.

When babies are born prematurely, their body systems have not had time to develop fully. Premature babies may not be able to digest food as well as healthy full-term babies. They are not able to eat by breast or bottle safely until around 32–34 weeks — when they learn to coordinate sucking, swallowing, and breathing.

Older babies who are sick may also have trouble digesting food or having enough energy to breast- or bottle-feed. This is especially true for babies who needed help with breathing when they were first born.

How well is my baby growing?

For the first week or so, babies usually lose weight. Your baby will be weighed every night. Head size and body length are measured once a week. The information is plotted on a graph so that the NICU staff knows how well your baby is growing.

Everything that goes into your baby (IV nutrition or feedings) and everything that comes out will be carefully measured. Your baby’s care team includes a neonatal dietician who will work with the team to make sure we are providing everything your baby needs to grow.
What can I expect?

Our goal is always for your baby to progress from IV nutrition to feedings by mouth as soon as possible and as development and medical conditions allow. However, no two babies, even those born at the same point in pregnancy, or even twins and triplets, are exactly alike.
First steps: Feeding through an IV (intravenous) line

• Most babies who stay in the NICU will not be given food for a period of time, depending on how early they were born or how sick they have been. Your baby will still get all the right nutrition through an IV (into the vein) line in the belly button, arm, or leg. Many babies will receive a yellow fluid, TPN (total parenteral nutrition), that contains fats, sugars, and proteins.

• Because the veins in babies’ hands and feet are very fragile, many babies will need long-term IVs. In that case, the NICU team will need to place a PICC (see glossary) or other IV that can provide long-term nutrition. Your caregivers will explain this procedure.

• If you have chosen to provide breast milk for your baby, the milk that you pump during the first few days — called “colostrum” — is very important. You may pump only small drops of it for several days. Don’t throw it out! It is rich in protective factors and can often be swabbed to coat the inside of your baby’s mouth where it will be absorbed.

Second steps: Tube feeding

• Many premature and some full-term babies are not able to coordinate sucking, swallowing, and breathing, so they are not yet ready to nurse at the breast or from a bottle. These babies will receive nutrition through a tube. The tube goes into the nose or mouth and down into the stomach, and most babies don’t even notice that the tube is there. When your baby starts to receive food through the tube, it will be in very small amounts, and the NICU staff will watch closely to make sure that your baby is digesting well.
Next steps: Feeding by breast or bottle

- As your baby gets older or healthier, he or she will begin to show readiness to eat by breast or bottle. These cues include sucking on a pacifier or the tip of your finger, or rooting (see page 63) with the mouth for a nipple. Your baby may begin trying to eat by breast or bottle at around 32–34 weeks. While this is a wonderful moment, your baby will need some time to get all his or her nutrition at breast or bottle. The transition may take several weeks and can feel frustrating, but think of how far your baby has come.

- Also, there are many different types of bottles and nipples. Babies born early may have an easier time drinking from a nipple with a slower flow — the milk will not come out as quickly. Other babies may require a nipple that is very long or one that doesn’t permit the swallowing of a lot of air.

Should I breast-feed?

YES! The American Academy of Pediatricians and Connecticut Children’s staff believe that breast milk is the best food for babies. Premature or sick babies have a greater need for the many qualities that only breast milk can offer:

- It contains antibodies and other immune factors that can help protect your baby from some infections.

- It is easier for many babies to digest.

- Mothers of premature babies produce milk that is different from the milk of moms with full-term babies. This milk is uniquely suited to premature infants although we may need to provide some additional nutrition as your premature baby grows.

In a few situations, another form of nutrition may need to be substituted for breast milk; however, the vast majority of premature and full-term sick babies will thrive on their mothers’ milk.
Breast-feeding overview

We offer a very supportive lactation program to meet all of your breast-feeding needs, including lactation consultants who are available in the NICU almost every day. Connecticut Children’s lactation consultants are nurses trained to help mothers breast-feed or provide milk for their babies. From the day your baby is born until he or she goes home, they will work with you on providing all the tools necessary for a positive breast-feeding experience. **Moms who are breast-feeding will receive a brochure with detailed information.**

If you are not pumping milk: donor milk and other options

We strongly encourage mothers to provide as much of their own breast milk as they can, as studies show that mothers’ own milk is most protective against serious intestinal problems and has other benefits for babies’ future health.

Some mothers are unable to provide the breast milk their babies need. These mothers may not make enough milk or be able to pump milk. When babies are very tiny or premature, breast milk helps to protect against some serious digestive problems. For this reason, we offer pasteurized banked human donor breast milk as an alternative for babies born at less than 32 weeks or who weigh less than four pounds at birth. This milk is tested and safe. It is pasteurized by a milk bank and delivered to the NICU.

A member of the health care team will discuss with you if donated milk may be appropriate for your baby. Your consent is required for your baby to receive donor milk.

If you do decide on formula feeding rather than breast-feeding, there are many types of formulas, including formulas specifically made for premature babies as well as formulas for babies with milk allergies.

Some mothers may choose to combine breast-feeding and formula feeding, often because the mother needs to return to work shortly after the birth. While the benefits of breast-feeding are great, we will support the decision you make, and provide whatever help you need.
Skin-to-skin care ("kangaroo care")

What is skin-to-skin ("kangaroo") care?

Your baby, wearing only a diaper, is placed skin to skin against your bare chest. A blanket is wrapped around you and your baby for warmth and privacy. Doing this gives you the chance to spend close time with your baby and is a way for your baby to relax, sleep, feel safe, and stay warm.

What are the benefits?

Research has shown many benefits, including better sleep, weight gain, temperature control, and easier breathing. Sometimes mothers who provide skin-to-skin care have better milk production and find their babies may transition better to breast-feeding. Parents may find that their babies calm with hearing their heartbeats. Since babies connect through their senses, spending time against your skin teaches your baby that YOU are the special person in his or her life. Skin-to-skin care is something only YOU can do in the NICU.
Are there any risks?

Skin-to-skin care may not be appropriate for very premature babies or those who are sick. Your baby’s nurse will let you know when your baby is stable enough to be moved. If you think your baby might be stable enough and this option has not been offered, ask the nurse. She will help you with the process. Your baby may be excited or restless at first, and may need time to settle and relax.

How do I do skin-to-skin care?

• Be sure to take care of your personal needs. Have something to eat and/or drink and go to the bathroom before you settle in.
• Your baby should have all clothing removed except for a diaper.
• Tubes and wires will be organized to make moving your baby easy.
• Your baby will be placed on your chest skin to skin. Turn your baby’s head so that it rests against your chest.
• A blanket will be placed around both of you. Sit back, relax, and enjoy parenting!

TIPS

• Wear a top that opens in the front. If you forgot, please ask for a hospital gown.

• The skin-to-skin time will be determined by your baby’s well-being and your wishes. Often the first experience is about an hour, or less if your baby shows signs of stress.

• Talk with your nurse about your desire to provide skin-to-skin care. Doing this will help the nurse plan care so that it will not interfere with your skin-to-skin time.
BABY’S BIG DAY (AND YOURS): GOING HOME!
Babies are such a nice way to start people!

Don Herrold
Baby’s big day (and yours): going home!

When can my baby come home?

This is one of the most frequently asked questions in the NICU! Every baby is different, and your baby’s going-home date will depend on how early your baby was born or how sick your baby was. Keep your original due date in mind as an indicator of when your baby might be ready to go home. The actual date may be a few weeks earlier, or it could be much later, but the due date gives a general idea.

What does my baby need to do before coming home?

In most situations, your baby needs to:

• **Stay warm in a cot or crib.** Babies who are very small don’t have a lot of fat on their bodies to keep them warm. They need to grow and gain weight before they are able to keep themselves warm without an incubator.

• **Be “spell-free” for seven days.** A spell is a pause in breathing for a period of time. Spells are very common in premature babies because the brain has not developed enough to regulate breathing. With each passing day, your baby’s brain is developing and these spells will eventually stop altogether.

• **Take all food by mouth; either breast-feeding or bottle feeding.** A very small number of babies may need to be sent home with surgically-inserted feeding tubes; those babies must be tolerating all feedings through the tube.

• **Have consistent weight gain.** Your baby is weighed every day and growth is monitored closely.
How soon should I/we get ready?

Many families who have had a baby born early have not yet had the chance to prepare for the newest family member. If you are feeling anxious about preparing too early, talk with a support person or a staff member; these feelings are totally normal. Once you are confident that your baby will be coming home within a few weeks, it’s time to start getting ready. As your baby gets closer to discharge, we will provide more information.

Congratulations to you and your family on the birth of your baby!
FINDING MORE INFORMATION AND SUPPORT
A new baby is like the beginning of all things — wonder, hope, a dream of possibilities.

Eda J. Le Shan
Resources at Connecticut Children’s

The NICU at Connecticut Children’s offers information and support to get you through this challenging time. Ask a staff member if you have questions about programs and resources.

• **Family library:** Located outside the NICU in the family resource room (501), the library has books on many NICU topics including premature birth, Down syndrome, heart problems in newborns, breast-feeding, and immunizations. It also offers books for siblings and young children. Books are lent for two weeks. The NICU secretary can assist you with checking books out.

• **Parent education board:** Located in the north wing hallway across from the bathroom, information changes monthly and includes an educational “topic of the month” for NICU families, plus information about and a schedule of NICU support programs and classes.

• **NICU monthly family newsletter:** The newsletter provides information about NICU support programs and classes, as well as information about the NICU physicians on duty during the upcoming month.

• **Family safety class:** Anyone who will be caring for your baby is welcome to attend. Attendance is highly recommended so that you are prepared to bring your baby home safely. Topics covered include: CPR, car seat safety, safe sleep recommendations, and basic newborn safety. The class is taught by nurses. Interpreters are available upon request.

• **Videos and DVDs:** A variety of teaching videos — on topics including coping, breast-feeding, and caring for your baby in the NICU — are available for viewing at any time. The NICU has portable televisions that can be brought right to your baby’s bedside. Just ask your nurse.
• NICU scrapbook hour: Record your baby’s milestones! This weekly hour is led by a NICU nurse and a scrapbooking expert, with supplies that have been donated.

• NICU parent drop-in: Meets twice a month in the family lounge, coordinated by NICU staff. It provides an opportunity for families to share a light breakfast, ask questions, and discuss concerns with other parents.

• Baby Steps bereavement support group: First Tuesday of every month. This group is led by a family who has experienced loss, along with nursing staff from Connecticut Children’s.

• NICU family advisory board (FAB): Meets monthly to provide feedback on care practices from families’ perspectives. Composed of parents who have had babies in the NICU. If you are interested in becoming a member of the NICU FAB, speak to your nurse about adding your name to our list of possible future members.

Recommended websites

With the overwhelming amount of material available on the Internet, finding accurate information is very important. Below are some useful and reliable sites. A computer is available in room 501. Ask your nurse or a health unit coordinator if you need help using it.

American Academy of Pediatrics (AAP) www.aap.org
Made up of more than 60,000 doctors, the AAP is dedicated to providing the best health care for infants, children, and young adults. This site provides a “parenting corner” on topics of interest, and includes a section for families with premature babies.

Birth Certificates www.ct.gov
(Select “living,” then select “children and family,” then “birth certificates.”) Guides you through the process of obtaining a birth certificate.

Birth to Three www.birth23.org
The mission of the Birth to Three system is to strengthen the capacity of families to meet the developmental and health needs of their infants and toddlers with delays or disabilities. The site includes information on qualifying for services, program offerings, and other support information.
Breast-feeding [www.womenshealth.gov/breastfeeding](http://www.womenshealth.gov/breastfeeding)
General breast-feeding information.

Caring Bridge [www.caringbridge.org](http://www.caringbridge.org)
A free, secure place for you to post updates on your baby’s progress, including photos and journal entries. The information will be shared only with the people you choose and also allows your family and friends to send electronic cards and notes of support.

CDC — vaccines and immunizations [www.cdc.gov/vaccines](http://www.cdc.gov/vaccines)
Centers for Disease Control. Information about vaccinations, including state requirements, common questions, and safety information.

CDC, National Center on Birth Defects and Developmental Disabilities: [www.cdc.gov/ncbddd](http://www.cdc.gov/ncbddd)
Information about different birth defects and developmental disabilities. The website is also available in Spanish.

Connecticut Cares 4 Kids [www.ctcare4kids.com](http://www.ctcare4kids.com) or 1-888-214-kids(5437)
Helps low- to moderate-income families in Connecticut pay for child care costs.

Connecticut Children’s Medical Center [www.connecticutchildrens.org](http://www.connecticutchildrens.org)
Offers many resources for families. Health information is formatted in a “kids,” “teens,” or “parents” version on many topics.

Connecticut Commission on the Deaf and Hearing Impaired [www.state.ct.us/cdhi](http://www.state.ct.us/cdhi)
Provides a listing of services available for those who are deaf or hearing impaired.

A network of families who have children with disabilities. It consists of parents interested in helping other parents find the supports they need.

Information about blood screens, environmental health, breast-feeding, and sudden infant death syndrome (SIDS).

Down Syndrome – National Down Syndrome Society [www.ndss.org](http://www.ndss.org)
The National Down Syndrome Society benefits people with Down syndrome and their families through national leadership in education, research, and advocacy.

Every Child By Two [www.ecbt.org](http://www.ecbt.org)
A federally funded program that works in conjunction with the Centers for Disease Control and Prevention. It offers information for families about immunizations.

Hispanic Health Council [www.hispanichealth.com](http://www.hispanichealth.com)
Committed to improving the health and social well-being of Puerto Rican/Latino and other underserved communities through community-based research, direct service, training, and advocacy.
La Leche League www.lalecheleague.org or 1-800-525-3243
Information and support for breast-feeding mothers, including help in locating breast-feeding consultants in the community.

Little Hearts, Inc. www.littlehearts.net
A national non-profit organization that provides support, resources, networking, and hope to families affected by congenital heart defects.

March of Dimes www.marchofdimes.com/nicu
The March of Dimes’ mission is to “improve the health of babies by preventing birth defects, premature birth, and infant mortality.” This website offers support and information about caring for your baby in the NICU.

 Mothers of Multiples www.nomotc.org
National Organization of Mothers of Twins Clubs, Inc. is a support group for parents of multiples that can also connect you locally with other parents of multiples.

Nurturing Families Network www.take5parenting.com
A state-run organization offering community support and advice to new parents and families.

Parents Available to Help (PATH) www.pathct.org or 1.800.399.7284
A network of families providing informational and emotional support to others who have children with developmental or health-related needs.

Safe Kids, Connecticut www.ctsafekids.org
Information on car seat safety, safe sleep, general child safety, and product recalls. Also offers a list of locations in Connecticut that offer car seat checks to make sure your car seat is properly installed.

Spina Bifida Association www.sbaa.org
Information and support for patients and families affected by spina bifida.

United Cerebral Palsy Association www.ucp.org or 1.800.424.2246
Information and support for patients and families affected by cerebral palsy and other disabilities.

United Ostomy Association www.uoa.org or 1.800.826.0826
If your baby has an ostomy, this website is a great resource for information, teaching materials, and finding support networks.

WIC www.ct.gov/dph (Click on “parents and children,” then select WIC.)
WIC is the “special supplemental nutrition program for women, infants, and children.” It assists low-income women, infants, and children up to age five with nutritious foods to supplement diets, information on healthy eating, and referrals to care. This site includes information on who qualifies for WIC, breast-feeding support, and how to eat healthier. It also lists local WIC offices, the towns that they cover, and contact info.
ABOUT THE NICU STAFF
Children reinvent your world for you.

Susan Sarandon
About the NICU staff

With so many people in the NICU, you may initially have a hard time keeping track of everyone. We recommend keeping a journal in which you write the names of your baby’s caregivers, as well as notes about your baby’s progress. You can also use it to write your questions for the care team.

The following list explains the roles of many of the professionals you will see during your baby’s stay in the NICU.

Advanced practice registered nurses (APRN): Also called nurse practitioners. They work in collaboration with the attending physician. They are able to perform exams, diagnose and treat illnesses, and write orders and prescriptions for patients. They may also be called MLPs (mid-level practitioners).

Attending physician: The doctor in charge of your baby’s care during his or her stay in the NICU. This doctor, a neonatologist, is specially trained in the care of newborns.

Case manager: Also called a discharge planner. A pediatric nurse who is an expert at working with you to set up the care for your baby at home: coordinating home nursing visits, ordering medical equipment, or any other special services that you may need.

Clinical educators: Nurses who coordinate the education of the staff and families at Connecticut Children’s.

Consulting physicians: Doctors with specialized training and expertise in a particular field of medicine or surgery. A pediatric cardiologist (children’s heart doctor) is an example of a consulting physician.
Developmental specialists: Experts in newborn development who work with the medical and nursing team. They will also watch how your baby responds to the environment and what helps your baby to cope with changes. They may also assist with feedings and may educate parents about newborn development and infant massage.

Fellow: A doctor who has graduated from medical school, finished a pediatric residency program, and is training to become an attending physician/neonatologist.

Health unit coordinator (HUC): A medical secretary who helps manage the communications of the unit, including answering the phone, maintaining patient charts, and monitoring and directing visitors.

Lactation consultant (LC): A nurse with specialized training in breast-feeding. LCs will work with you and your baby during your entire stay in the NICU to make your breast-feeding experience as successful as possible.

Medical students: Students studying to become doctors. The medical students you will see in the NICU are in their third or fourth year of medical school.

Mid-level practitioner (MLP): An advance-practice registered nurse (APRN) or physician assistant (PA) who is able to perform exams, diagnose and treat illnesses, and write orders and prescriptions for patients.
Nurse managers and assistant nurse managers (NM and ANM): Trained pediatric nurses who manage the unit activities and staff.

Patient care assistant (PCA): Also called a nurse’s aide. Works under the supervision of the nurse caring for your baby and is responsible for taking vital signs, feeding, and bathing.

Physician assistants (PA): PAs are able to perform exams, diagnose and treat illnesses, and write orders and prescriptions for patients under the supervision of the attending physician. They may also be called MLPs (mid-level practitioners).

Primary nurse: NICU nurses have had extensive training in caring for newborns. Our nurses provide the day-to-day care for your baby, offer instruction to parents, and coordinate discharges. A primary nurse is assigned to take care specifically of your baby; she will get to know you and your baby well.
Registered dietician (RD): The RD works with the NICU team, makes recommendations on nutrition, and follows your baby’s growth.

Rehabilitation services (occupational therapy, physical therapy, and speech therapy): These professionals will see your baby if asked by the medical team.

Resident: A doctor who has graduated from medical school and is receiving clinical training in a specialty. Pediatric residents, anesthesia residents, family medicine residents, and obstetric residents come to the NICU for training.

Resource nurse: The resource nurse is in charge of the NICU for a shift.

Respiratory therapist: Works with the NICU team to treat babies with breathing difficulties and maintains the respiratory equipment at your baby’s bedside.

Social worker: Provides support to families. This support often includes a review of family coping strategies and resources; it can also include assistance in finding financial support or support from community-based programs.
WHERE TO EAT, REST, AND READ
Sometimes the most urgent thing you can possibly do is take a complete rest.

Ashleigh Brilliant
Where to eat, rest, and read

**Family use rooms**

While our main concern is your newborn, your comfort is also a priority. Five family use rooms are located both within and just outside the NICU. Some have attached bathrooms, and all can be locked.

- All rooms are available for one-hour time periods during the day (from 8:00 am to 8:00 pm) for parents who would like to nap, pump, or take a break. Parents may sign up for multiple one-hour periods during the day.

- You are welcome to stay overnight in one of the family use rooms. Sleeping at your baby’s bedside is not suggested. Rooms are available for overnight use from 8:00 pm to 8:00 am. Overnight stays are reserved primarily for the parents of critically ill babies, mothers who are breast-feeding throughout the night, and parents preparing for discharge.

- One of the family use rooms is equipped with a monitor, suction, and oxygen. Babies who are almost ready to go home may stay in this room overnight with you.

- If you’d like to use one of these rooms, ask your baby’s nurse. Signing up for a room is simple but necessary.

**Family resource room**

This room has a computer with Internet access, a television, and a library. Family members are welcome to use this room at any time. The library is stocked with books regarding many NICU topics. Please obtain the key from the health unit coordinator, who can also check out books for you.
**Can I use my cell phone?**

Because cell phones can interfere with some of the medical equipment in the NICU, cell phone use is not permitted in the unit. You may not use your cell phone to make or receive calls, take photos of your infant, or write text messages. Please turn off your cell phone as you enter the NICU.

- If you need to use your cell phone, please leave the unit or go to the hall beyond the north wing.
- Phones for local calls are available in the family rooms and lounge.

**Where can I eat?**

Taking a break from the NICU can be a good idea, and the hospital and surrounding area offer several eating options. Please remember that food is not allowed at your baby’s bedside, but you are welcome to bring your food into any of the family rooms.

- The Hartford Hospital cafeteria is located on the ground floor of Hartford Hospital. It is open for breakfast, lunch, dinner, snacks, and late-night dining.

- Other food options are available on the ground floor of Connecticut Children’s Medical Center (remember to bring your visitor badge). Our staff can provide you with a list of these, as well as with a list of nearby restaurants. Many of the outside restaurants will deliver food right to the NICU.
Knowledge is power.

Francis Bacon
Below is a list of medical terms you may hear while your baby is in the NICU. Some of the terms may be familiar; many others are technical and likely to be new to you. Please ask questions if you do not understand something.

**A**

**ABO incompatibility**
This may occur when mom has a blood type that does not match baby's blood type. It can cause jaundice and anemia in the baby.

**Acidosis**
An excess of acid in the blood.

**Anemia**
A low level of red blood cells in the body.

**Antibiotics**
Medicines used to treat a bacterial infection.

**Apgar score**
A score that tells how well your baby is doing in the first few minutes of life.

**Apnea**
A pause in breathing that lasts more than 15 seconds. It is often associated with a low heart rate. Apnea is common in premature infants.

**Aspiration**
1. When something other than air is breathed into the lungs (for example: formula).
2. When fluid is taken out of baby's body.

**B**

**Bilirubin**
A yellowish substance made when a baby breaks down red blood cells. Bilirubin normally comes out in your baby's stool. Sometimes, it does not and builds up under the skin, causing your baby to have a yellow or orange color.

**Blood gas**
A blood sample that tells us how well your baby is exchanging the important gases: oxygen and carbon dioxide.

**Bolus**
A certain amount of fluid given over a short period of time.

**Bradycardia**
A slow heart rate.

**Bronchopulmonary dysplasia (BPD)**
See chronic lung disease.

**C**

**Caffeine**
A medication given to babies whose spells are due to brain immaturity.

**Central line**
An IV (intravenous line) that is placed in a large vein. It is used to give fluid and medication to the baby. It can usually stay in for much longer than the small IVs placed in the hands or feet.

**Chest physical therapy (CPT or chest PT)**
A tapping or vibration on the chest to help loosen mucus and open the smaller airways.
**Chest tube**
A soft tube inserted into the chest. It is used to remove air or fluid from the space around the lungs.

**Chronic lung disease**
Lung scarring/damage that may occur in some babies who need oxygen or a breathing machine for long periods of time. This was previously known as bronchopulmonary dysplasia (BPD). It may be treated with oxygen, medications, and good nutrition. Babies generally improve over time as the lung grows new healthy tissue.

**Colostrum**
The milk that is made by mom in the first few days after baby is born. This milk is very nutritious and can also help baby to fight infections.

**Complete blood count (CBC)**
A blood test that measures the number of red blood cells, white blood cells, and platelets in the body. This test helps us to see if your baby has an infection or is anemic.

**Continuous positive airway pressure (CPAP)**
Through small, soft plastic prongs that rest in a baby’s nose. A gentle pressure of air is spread out into the baby’s lungs. This gentle pressure makes breathing easier.

**Corrected age**
The age that a premature baby would be if he or she had been born on the due date. For example, a baby born two months early is, at the actual age of six months, only four months old according to the corrected age. The corrected age is important in considering when your baby will reach certain developmental milestones (such as rolling over, sitting up, walking, and talking).

**Cranial ultrasound**
A test to check brain structure and for the presence of bleeding or areas of low blood flow. It is commonly done for babies born very early or very sick. The ultrasound machine is wheeled right to the bedside.

**Culture**
A test of body fluids (such as blood, urine, sputum) to check for infection.

**Diuretic**
A medication that helps baby to get rid of excess body fluids. It causes a baby to urinate (pee) more.

**Echocardiogram (echo)**
An ultrasound picture of the heart. This test is done to check the structure and function of the heart; it can be done right at baby’s bedside. An ultrasound uses sound waves to make the picture and does not involve radiation to your baby.

**ECMO (extracorporeal membrane oxygenation)**
A technique that involves removing blood with a machine that then provides oxygen to the blood and returns it to the baby. It is similar to heart-lung bypass.

**Edema**
A puffiness or swelling caused by the presence of too much fluid in the tissues.

**Electrolytes**
Chemicals in the blood that must be in balance for the body to work properly. These include sodium and potassium.

**Endotracheal tube (ET tube)**
A plastic tube placed in baby’s mouth. This tube goes into the windpipe (trachea) and is connected to a breathing machine (ventilator). You will not hear your baby’s voice or cry until after this tube is removed.

**Extubation**
The removal of the endotracheal tube from baby’s mouth. Often the baby will be placed on CPAP (see definition above) after the tube is removed.

**Fontanels**
Soft spots on the baby’s head. These are normal and will close up over the next year.

**Full term**
A baby born between 37 and 42 weeks gestation.
Gastroesophageal reflux (reflux)
A condition in which the liquid contents of the stomach come back up into the esophagus. This is similar to heartburn in adults and can be common in premature infants.

Gastrochisis
A birth defect that occurs when the abdominal wall does not close together and the skin is open. The organs of the abdomen, such as the stomach and intestine, bulge out.

Gastrostomy tube (G tube)
A feeding tube, inserted in the operating room, which is placed directly through the belly into the stomach.

Gavage feeds
When a baby’s feeding is given through a tube. This tube can go through the nose (NG tube) or the mouth (OG tube). This feeding method is common for babies who are too premature to eat by mouth or still need support with breathing.

Gestational age
The length of time between conception and birth.

Glucose screening
A blood test that determines the baby’s blood sugar level.

Hematocrit (crit)
A blood test that measures the red blood cell count.

Hyperal
See Total parenteral nutrition.

Hyperbilirubinemia
See Jaundice.

Hyperglycemia
High blood sugar.

Hypoglycemia
Low blood sugar.

Hypotension
Low blood pressure.

Incubator
A clear, plastic enclosed bed used to keep premature babies warm.

Intralipids
See Lipids.

Intrauterine growth restriction (IUGR)
Refers to a baby whose growth has fallen off in the womb and who is often small for the gestational age.

Intubation
The placing of a small tube into baby’s trachea (windpipe) through the mouth. This tube is connected to a ventilator (breathing machine) that helps the baby breath.

Jaundice
Yellowing of the eyes and skin caused by the buildup of bilirubin (see definition above) in the body. Usually treated with phototherapy (see definition below).

Kangaroo care
Holding baby, undressed, against a parent’s bare chest.
 Glossary

L

Letdown reflex
The release of milk in the breast, often associated with a tingling sensation.

Lipids
White liquid that is given through your baby’s IV. It is made of fat and will help your baby grow.

Low birth weight
A weight of less than 5 pounds, 8 ounces at birth. Very low birth weight (VLBW) is a weight at birth of under 3 pounds, 5 ounces. Extremely low birth weight (ELBW) is a weight at birth of under 2 pounds, 3 ounces.

Lumbar puncture
Also called a spinal tap. A test used to see if there is an infection in the fluid of the spine or brain. A needle is placed between the bones of the lower back to take out a small amount of fluid, which is sent for tests.

M

Meconium
The first several stools that a baby passes. These stools are dark, thick, and sticky.

Monitor
The machine that measures your baby’s heart rate, respiratory rate, and oxygen levels. An alarm will ring to alert your nurse if any of these processes are not normal.

N

Nasal cannula
Small, soft plastic prongs placed into the nose to help baby to breathe by providing oxygen.

Nasogastric tube (NG tube)
A small plastic tube placed in the baby’s nose and that goes all the way down to the stomach. It is used to give your baby food (breast milk or formula).

Necrotizing enterocolitis (NEC)
An inflammation or infection in the intestines (bowels). To help your baby get better, the intestines need to be rested, meaning that your baby won’t be able to have any food for a week or more. During this time, your baby’s nutrition will be delivered through an IV, and the infection will be treated with antibiotics. Some babies may need to have surgery.

Neonatologist
A doctor trained to care for newborn babies who are premature or sick. Our attending physicians are all neonatologists.

NICU
Neonatal Intensive Care Unit. The staff in the NICU have all been trained to care for newborn babies who are premature or sick.

Nitric oxide
A gas that helps improve blood flow to the lungs. It is commonly used to treat persistent pulmonary hypertension of the newborn (PPHN) and can be used to treat other lung illnesses as well.

NPO
An abbreviation that means that your baby should not or cannot eat or drink.

O

Oscillator
A type of breathing machine that helps make breathing easier by gently providing oxygen at a very fast rate. If this machine is being used with your baby, your baby’s chest will appear to be “wiggling” on the bed. This wiggling is normal and helps your baby to breathe better.

Oxygen saturation (O₂ sats)
This measure of oxygen in baby’s blood helps us to see how well your baby is breathing. Taken with a device called a pulse oximeter or “pulse ox” on your baby’s foot or arm. See page 63.

Oxyhood
A clear plastic box placed around the baby, supplying warm, moist oxygen to help ease breathing.

P

Patent ductus arteriosus (PDA)
A small blood vessel just outside of the heart that should close soon after a baby is born. Sometimes this vessel stays open in premature infants. It can be closed with medication or surgery.
Periodic breathing
A breathing pattern common in premature babies. Baby takes several quick breaths followed by a short pause in breathing for 10–15 seconds.

Persistent pulmonary hypertension of the newborn (PPHN)
High blood pressure in the lungs, which can lead to breathing problems. Babies with PPHN often need to be on a breathing machine and may require nitric oxide.

Phenylketonuria (PKU)
A rare condition in which a baby is born without the ability to break down a building block of nutrition called phenylalanine. Babies born in Connecticut have a blood test to check for this soon after birth. Many other conditions are checked in this same blood test, including cystic fibrosis and sickle cell disease.

Phototherapy (Bili-lights)
Blue fluorescent lights that help to lower bilirubin levels.

PICC (peripherally inserted central catheter)
A type of IV line that can be used for a long period of time because it is placed into a large vein rather than into the smaller veins of the hands and feet.

Pneumonia
Inflammation or infection of the lungs.

Pneumothorax
Also called collapsed lung. A pocket of air that leaks into the space between the lungs and the side of the chest. This air leak makes breathing difficult. A small air leak may not need any treatment, but larger air leaks may require the placement of a needle or chest tube to remove the air.

Premature baby (“preemie”)
A baby born three or more weeks before the due date (less than 37 weeks).

Pulse oximeter
A machine that measures how much oxygen is in baby’s blood (oxygen saturation). It looks like a bandaid with a light shining through it and is often placed on baby’s arm or foot.

Respiratory distress syndrome (RDS)
A breathing problem that occurs when a baby is born prematurely. It is caused by a lack of surfactant (see below).

Respiratory syncytial virus (RSV)
A respiratory infection that can be serious for premature infants. A medication can be given by injection to help prevent this infection. Some babies will receive this medication before leaving the NICU and monthly throughout the cold season.

Retinopathy of prematurity (ROP)
When babies are born prematurely, their eyes are not fully developed. ROP is a disease that affects the developing retinal blood vessels of a premature baby’s eyes. In severe cases, it can lead to vision loss or blindness. Infants born before 30 weeks or less than 3 pounds, 5 ounces are checked regularly by an eye doctor in the NICU. In severe cases, babies may require laser therapy to help protect their vision.

Retraction
A pulling appearance of the chest wall as the baby breathes, indicating that the baby is working hard to breathe.

Rooting reflex
A reflex in newborns that causes them to turn their heads to the side and open their mouths when their cheeks are stroked. Often seen when an infant is ready to eat from breast or bottle.

Sepsis
An infection in the blood. Antibiotics are used to treat the infection.

Skin to skin
See page 61 Kangaroo care.
Spell (also called apnea and bradycardia of prematurity or As & Bs)
A pause in breathing of more than 15 seconds (apnea), which can lead to a drop in the heart rate (bradycardia) and sometimes a change in color (baby may turn slightly blue). It is common in premature babies because the part of the brain that controls breathing is not completely mature. Spells can often be corrected with gentle touch to stimulate the baby. Sometimes medication or breathing support may be required.

Spell watch
The week prior to the expected discharge date, many babies will be on a “spell watch.” If a spell occurs, the NICU staff and parents will watch baby to see if baby can recover from the spell without assistance. This observation helps assure that your baby will be as safe as possible at home.

Spinal tap
See Lumbar puncture.

Suction
Many babies are not strong enough to cough up the mucus in their lungs. A thin, flexible tube is placed in the nose, mouth, or breathing tube for just a few seconds to suction (pull out) this mucus.

Surfactant
A liquid naturally made by the lungs to help make breathing easier. Babies born before 34 weeks may not have enough surfactant. Surfactant can be given to premature babies to help them breathe easier. Surfactant may also be given to babies who have pneumonia.

T

Tachycardia
An abnormally fast heart rate.

Tachypnea
Abnormally fast breathing.

Total parenteral nutrition (TPN or Hyperal/HAL)
Fluid that goes into an IV or central line. This fluid is filled with nutrients including proteins, carbohydrates, vitamins, minerals, and fats.

Transit tachypnea of the newborn (TTN)
TTN is caused by fluid that remains in baby’s lungs after birth. Your baby will appear to be breathing very fast. It may take time for the fluid to be absorbed. We will monitor your baby closely and help make breathing easier if necessary.

U

Umbilical catheter (UAC and UVC)
A soft plastic tube placed into an artery or vein in your baby’s belly button. It can be used to provide fluid, medicine, and nutrients. It can also be used to take blood for tests without causing any pain and to check your baby’s blood pressure.

V

Ventilator
A machine that helps your baby breathe.

X

X-ray
A picture that looks inside your baby’s body. The X-ray machine can be brought right to the bedside. Very small doses of radiation are used.
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