The Neonatal Intensive Care Unit at Children’s
THIS BOOK BELONGS TO

BABY

PARENTS
Who may visit your baby?

During the first few hours after admission to the neonatal intensive care unit, you will be asked to list who may visit your child and under what conditions they may visit. Until then, only legal guardians and grandparents will be allowed past the security doors. You may change this list at any time.

• First, name a small number of adults. These are the primary support group. These people will have full access to your child’s room from 7 a.m. to 9 p.m. They are intended to provide support for your child and breaks for you.

• Second, identify a second group of extended family and friends. They may visit between the hours of 9 a.m. to 9 p.m. Care should be taken that they not overstimulate the patient. Anyone in this group must be accompanied by someone in the primary support group when beyond the security doors.

• Only people listed in one of the groups above will be allowed beyond the security doors. Anyone not on either of these lists will be allowed to remain in the CCS waiting room for no more than 30 minutes.

• A maximum of three adults are allowed inside the security doors at any time.

Shift change in the NICU

Entry and exit of the care area is not allowed during nursing shift changes. Shift changes are from 7 to 7:30 a.m. and 7 to 7:30 p.m. This gives the highest protection to your child’s health information.
When you visit the NICU

For the safety of your child:

- All family members and friends must check in and out with the waiting room concierge (front desk staff).
- ID badges are required for entry beyond the security doors and will be provided by the concierge.
- The concierge will ask all visitors questions regarding potential contagious illnesses. You can help protect your child by not allowing anyone who has a fever, vomiting, diarrhea or symptoms of a cold to visit.
- Visitors must provide a contact phone number to this concierge.
- Sick and injured children are extremely at risk of infection. You must wash your hands thoroughly or use the hand gel provided before and after each visit.
- Everyone, including staff, entering your child’s room should also either wash their hands or use the gel. Please remind anyone who forgets.
- Children younger than 3 should not be brought to visit in the NICU. Children between 3 and 12 must be accompanied by an adult at all times and may not be in the waiting room, even with adult supervision, for more than two (2) hours. Babysitting for visiting children is not available, so please make personal arrangements before coming to the hospital. It is difficult for children to sit quietly in the waiting area. Taking them for walks down to the lower level by the trains or outside will provide them with a break.
- Up to two adults, either parents or primary support members, may be in the hospital between 9 p.m. and 7 a.m. These two individuals may sleep in the patient room or in the waiting room. Some of the patient rooms have a couch; however, there are recliners in the waiting room. We will provide linens for these two individuals. Please do not bring your personal linens.
- For your benefit the waiting room lights will be turned off at approximately 10 p.m.
- The waiting room will be closed for approximately one hour daily for cleaning.
NICU etiquette

- Please be courteous to others, and use behavior appropriate for a children’s hospital (Including language and dress).
- Shoes must be worn at all times.
- Personal communication devices such as cell phones, PDAs and laptop computers may not be used within three feet of any healthcare equipment. This is to avoid potential signal interference.
- Personal phones/beepers must be set to silent or vibrate mode.
- Water with a secured lid is allowed in the patient room.
- For sanitation reasons, food and drinks are not allowed in the waiting room or patient room, but are allowed in the family lounge.
- A limited number of lockers are available for your use. Individually sealed, uncooked food items may be stored in these lockers.
- Please see the concierge if you need a locker or a list of local restaurants.

Specialized care for unique needs

We recognize that every family is unique, and every day in the NICU is different. As special situations come up, the nurse caring for your child may adjust these guidelines. Please understand that her/his decision will be based not only on your situation, but that of the entire unit. If you have any concerns please discuss them with a team leader, who is available at all times.
Parental support in the NICU

We realize that having your baby in the NICU is an unexpected and stressful event. When your child is in the hospital, changes occur for everyone in the family. This section will help you during your baby's stay in the NICU. It includes information about the staff and support services offered at Children's Medical Center.

Physicians and nurses will be dedicated to the care of your baby while staying in the NICU 24 hours a day. If you have any questions or concerns, please talk with your baby’s bedside nurse.

**Neonatologist**
A neonatologist is a doctor with advanced training in the care of sick and premature babies. Sometimes, the neonatologist may be called the attending physician. This doctor is in charge of your baby’s care.

**Neonatal Nurse Practitioner**
A neonatal nurse practitioner (NNP) is a nurse with advanced specialized training in the care of sick and premature babies. This practitioner works under the direction of a neonatologist. In addition, the practitioner is able to direct your baby’s care and perform many different procedures.

**Registered Nurse/Bedside Nurse**
A registered nurse is the member of the healthcare team that you will visit with most while your baby is in the NICU. This nurse will help to provide all of the care your baby needs at their bedside while here.
Other support staff

Respiratory Therapists
A respiratory therapist is trained to care for babies with breathing problems. They use special materials to care for these babies.

Chaplains
Pastoral care encourages families to draw on faith. When children come to the hospital, they and their families have many questions. Why is my child ill? Why did this happen to our family? What did I do wrong?

Chaplains in the Pastoral Care department listen to these questions and offer spiritual guidance, emotional support, hope and compassion. Chaplains are available at the hospital 24 hours a day, seven days a week. The unit chaplain may be contacted by calling the Pastoral Care department at 214-456-2822 or ask the operator to page the chaplain.

Chaplains are available for patient and family support as they face:

- Spiritual distress
- Religious rituals or celebrations such as baptisms or christenings
- Deaths (spiritual and grief support and funeral planning)
- Health crises/difficult diagnoses
- Need of religious resources
- Any medical emergencies (Code Blue, CPR, withdrawal of life support)
- Ethics consultations

Pharmacists
The NICU has a dedicated clinical pharmacist that sees patients and discusses drug therapy with physicians and nurses.

To help you cope
The Neonatal Intensive Care Unit at Children’s has a full-time Social Worker. The social worker is committed to providing you support during your baby’s stay.

Your social worker will meet with you to do an assessment. This assessment will help find out which services would be most helpful to you and your family. The services include: support with a difficult diagnosis, assistance with needs during a lengthy hospital stay, crisis counseling and locating community resources (financial assistance, food, etc).

Social workers work closely with the medical team and family. Their goal is to promote comfort around the medical environment and to assist in a safe discharge home for your baby.

Order entry is completed on the unit. This way, questions, concerns or clarifications are easily and quickly handled. In the unit, your baby’s pharmacist has a closer watch on lab results and patient reactions, and can be involved in patient/family medication teaching.
Physical Therapy and Occupational Therapy

Physical Therapists (PTs) and Occupational Therapists (OTs) are licensed healthcare professionals. They provide therapeutic and consult services for children with medical, neurological, orthopedic, genetic and developmental conditions. After receiving orders from a doctor, they will perform an evaluation. This evaluation looks at behavioral responses, self-regulatory skills, movement patterns, muscle tone, visual-perceptual skills, auditory responses and infant and parent interactions. A plan of care is then developed with the family. Services provided may include:

- Range of motion, positioning, stretching
- Muscle re-education, strengthening
- Gross-motor activities and development
- Development of self-regulating skills
- Custom splinting
- Neurobehavioral maturation
- Read and understand baby’s “cues” in order to foster successful interactions
- Family/caregiver education

Speech Therapists

Speech Language Pathologists (SLPs) are licensed healthcare professionals. They specialize in the areas of feeding and swallowing. After receiving orders from a doctor, the speech therapist will provide an evaluation of reflexes, strength and tone of the mouth/oral motor area, as well as the level of arousal.

Like PTs and OTs, the speech therapist will help create a plan of care with the family. The speech therapist will determine when to begin oral feedings and will work closely with the family/caregivers to provide education and training to ensure successful and safe feeding.
The speech therapist focuses on areas that can impact oral feeding including:

- Muscle tone
- Respiratory control
- Gut development
- Postural support
- Endurance
- Autonomic stability (heart rate and respiratory rate)
- State control (sleepy vs. awake and alert)

### Psychosocial Team

Members of this team help to provide assistance in the areas of mental illness, postpartum depression and emotional distress.

### Guest Relations

Guest Relations consists of Guest Relations Representatives (Patient/Family Advocates) and Concierge staff. These two entities work together to provide support, resources and a positive hospital experience for patients and families. Guest Relations staff aid families by:

- Visiting all families within 24 hours of admission.
- Providing a means by which a patient/family or visitor can offer feedback regarding their hospital experience.
- Making recommendations for process improvement.
- Assisting in speeding up services on behalf of patient/family.
- Interpreting the Children’s philosophy, policies, procedures and services.
- Answering questions regarding Patient Rights and Responsibilities.

### Special help for preemies

A **Child Life Specialist**, dedicated to the NICU, is available for parental support. Child Life specialists are trained in child development specific to premature infants. They are available to provide families with the education and support they will need to cope with having a baby in the NICU. Child Life specialists can help parents learn to hold, handle and touch their premature or sick baby.

They are also available to help answer any questions you may have about how the baby’s brothers and sisters are reacting toward having a baby in the hospital.

These specialists know how to communicate with children of all ages in an honest way. This will help them understand the hospital and why their brother or sister is here. Please let your nurse know if you need to meet with your Child Life specialist.
Things you may see as you enter the Neonatal Intensive Care Unit

As you enter the NICU at Children’s, you will encounter machines and equipment that are unfamiliar to you. This section is focused on introducing you to the tools necessary for the care of your baby. Many of these terms may be new to you.

Our goal is to help you understand by explaining the more common terms used in our NICU.

Baby’s Bed
There are many different types of beds that your baby may be in. They include:

- Radiant warmer – an open bed that provides easy access to your baby for the initial moments of care. This bed measures temperature and keeps the baby warm (photo top right).
- Isolette – a closed incubator that reduces sound and keeps the baby warm while he is growing (photo bottom right).
- Bassinet/crib – where your baby will sleep after he has grown and is able to maintain body temperature.

Monitoring Your Baby
- Cardiac apnea monitor – measures your baby’s heart rate and respiratory rate through small wires that are placed on your baby’s chest.
- Pulse oximetry monitor (pulse ox) – tells how much oxygen is in your baby’s blood. It is placed on your baby with a Velcro strip.

Tubes You May See
- Breathing tube – a tube into the baby’s trachea (windpipe) to allow air to reach the lungs and help him breathe.
- CPAP (Continuous Positive Airway Pressure) – Plastic prongs with large tubing placed in the baby’s nose to help him breathe.
- Halo – a plastic dome placed over the baby’s head to deliver oxygen.
- Nasal cannula – small plastic prongs that sit in the nose of the infant delivering oxygen.
- IV (intravenous lines) – small tubes used to deliver nutrition and medications into the bloodstream of your baby. Because babies’ veins are small and fragile, your baby may require multiple IVs in varying locations of his body while he is in the NICU.
- Feeding tubes – placed in your baby’s nose or mouth and deliver nutrition to his stomach.
Learning how to parent your baby while in the NICU

- Remind yourself that all parents feel anxious or insecure. Whether or not this is your first baby, having a baby in the NICU is scary.

- Be patient with yourself if you feel hesitant, nervous or awkward. Nobody expects you to be comfortable right away. Give yourself the time you need to learn this new environment and your new baby.

- Become an informed parent. The more you know about your baby’s medical condition, the more you can do to look out for your baby. Ask questions. Sometimes it helps to write them down as you think of them so you can ask them later. Types of questions to ask include:
  - How is my baby doing?
  - Has anything changed?
  - What caused this condition?
  - How will this medicine, procedure and equipment help my baby?
  - What types of tests are being done? What will they tell us?
  - How will I be informed of any changes in my baby’s care?
  - Is there anything I should expect while we are in the hospital because of this condition?
  - What about when I go home?
  - What can I do to take care of my baby?

- Ask the staff or nurses for help. Don’t be afraid of making mistakes. We will help you learn everything you need to know.
Getting to know your premature baby

As a parent, you are beginning a new relationship. You are creating a new and special attachment by getting to know your special newborn. A Neonatal Intensive Care Unit can make this more difficult. You have to put forth more effort and find special ways to be a family. This section is made to help you understand your baby’s special characteristics. By watching your baby closely, you can understand how your baby is reacting to surroundings and what he is saying.

Invitation Signals
These are signs your baby gives you to let you know he is ready to interact with you. He will be quiet and in an alert state. His face will be relaxed, and his eyes will appear bright. Your baby will be able to look at you and focus on your face. His lips may “purse” as if he were saying “ooh.” Your baby’s arms and legs will be relaxed, and the fingers and toes may curl softly. At this time, your baby may bring their hands to her face.

Decorate baby’s space

- You can bring blankets from home to put in your baby’s bed.
- Hang photos and pictures on your baby’s bed and in the room.
- Leave a cloth with your scent in the baby’s bed near your baby’s face.
- Record a special message or lullaby to play for your baby while you are away.
- Make or ask for a name sign so we can call your baby by name.
SELF-COMFORTING SIGNALS
Your baby also has the ability to calm himself. Your baby will look away if he needs to give himself a break. He will wiggle to get tucked into a fetal position. He will snuggle himself against blanket rolls, the sides or bottom of the bed. Babies suck on their lips, tongue, pacifier, hands or fingers. They might also bring their hands to the center of their body or to their face, as if it looks like they are thinking.

Ways you can help your baby grow and develop:

• Watch your baby’s body language. Let your baby tell you what to do.
• Do only one thing at a time, especially at first. Stroke your baby, talk to your baby or let your baby see your face.
• Use a firm, gentle touch instead of a light ticklish touch.
• Speak to your baby softly and calmly.
• Shade your baby’s eyes from bright lights with your hand so baby can look at you easier.
• When you put your baby back to bed, help him get in a curved fetal position.
• Swaddle your baby if he is upset. Try to keep his hands together near his body.
• Encourage your baby to calm himself by having him suck on his hands, fingers or a pacifier. Try to stay relaxed yourself. Be patient. As your baby grows and gets stronger, there will be more awake times to spend with your baby.

Does baby need a break?

TIME-OUT SIGNALS
are signs that your baby has had enough and needs a break. There are a lot of ways babies tell us they need a time-out, such as yawns, hiccups, gagging and spitting up. His fingers may stiffen and straighten; if he is not given a break here, he will stiffen his arm out as if to say “stop.” His arms and legs will be stiff, and he may show jerky movements or startles.
Breastfeeding your premature or sick baby

Giving birth to a premature or sick baby is often a surprise to parents. They must make many important decisions about their baby’s care in the first few days after birth. One of those decisions is whether to provide mother’s milk for your baby’s feedings. This section will help you decide about providing mother’s milk for your premature baby.

**Benefits for Premature Babies**
All babies need breast milk for optimal growth and development. There are many reasons why premature infants need breast milk even more than full-term infants. When you have a premature baby, your milk is different from the milk of mothers who carry their pregnancies to full term. The breast milk of a mother who has given birth to a preterm infant is special for preterm growth needs. Even small amounts of breast milk can provide premature babies with health benefits that last through childhood and, potentially, their entire life.

There are many benefits for the baby to receive mother’s milk. Some of these are:

- Promotes eye and brain development of premature babies
- Boosts digestion
- Helps baby’s immune system fight infection
- Promotes proper tooth and jaw development
- Makes your baby smarter. The longer babies are breastfed, the higher the IQ.
- Provides bonding opportunities, warmth and physical closeness via skin-to-skin contact – something all babies need.

Is your baby ready for breastfeeding?

You will learn when your baby is hungry and ready to breastfeed. Ideally, your baby will be in a quiet alert state with a relaxed face and open eyes. Crying is a late hunger cue, and it is best to offer the breast before crying begins. Some early hunger cues are:

- rooting
- mouth opening
- lip licking
- placing hands or fingers in mouth
- flexion of arms
- clenching of fists
- increased activity
**Benefits for Mothers**
Providing breast milk to your baby can also help you. Some of the ways include:

- Promotes mother-baby bonding.
- The special feeling of closeness helps to make up for being separated from your baby in the early days and weeks after giving birth to your baby.
- Providing milk for your baby can help you cope with stress and the feelings of helplessness while your baby is in the NICU.
- Breastfeeding is free. There is no cost for formula, bottles, nipples or supplies.
- Breastfeeding is convenient. Breast milk is always fresh, warm and available. It doesn’t require preparation and warming as formulas do.
- Breastfeeding helps you to lose the extra weight you gained during pregnancy and speeds up your recovery after having a baby.

**Basic Principles of Positioning your Baby during Feeding**

- Mother should be comfortable and relaxed.
- Mother’s breasts should be easily accessible.
- Baby’s ear, shoulder and hips must be in a straight line.
- Mother’s hand should support baby’s shoulders, upper back and neck, not the head.

**Want to know more?**

If your baby is ready for breastfeeding and you want to learn more, please ask your baby’s nurse to coordinate a meeting for you and a Lactation Consultant in the NICU.
Kangaroo Care

Kangaroo Care is something special only you can do to help your baby.

Kangaroo Care is holding your baby against your bare chest under your clothes. The baby will be wearing only a diaper. Your baby will be put on your chest with your baby’s head near your heart. The nurse or doctor will help place the baby on your chest. You can use a warm blanket or your clothing to cover both you and the baby. Kangaroo Care is safe and beneficial, even if your baby is connected to machines.

Whatever your situation, this is a precious way to be close to your baby.

You may be a little nervous about trying Kangaroo Care. If your baby is very small or sick, you may be afraid you’ll hurt him. But you won’t. Your baby knows your scent, touch and the rhythms of your speech and breathing. He will enjoy feeling that closeness with you.

**KANGAROO CARE CAN HELP YOUR BABY:**
- Maintain his body warmth
- Regulate his heart and breathing rates
- Gain weight
- Spend more time in deep sleep
- Spend more time being quiet and alert and less time crying
- Have a better chance of successful breastfeeding (Kangaroo Care can improve the mother’s breast milk production)

**KANGAROO CARE HAS EMOTIONAL BENEFITS FOR MOTHERS, TOO:**
- It can build your confidence as you provide intimate care that can improve your baby’s health and well-being.
- You are giving something special to your baby that only you can give.
- This skin-to-skin interaction will help your breastmilk production.
- By holding your baby skin-to-skin, you may feel the experience of new parenthood and closeness to your baby.
Glossary of NICU Terms

During your baby’s stay in the NICU, you may hear many new terms that are unfamiliar to you. Here are some of the common ones used in our NICU and their meanings.

**Alveoli:** small sacs in the lungs where oxygen and other gases are exchanged in the blood stream.

**Anemia:** a low number of red blood cells. These cells carry oxygen to the tissues. Anemia is common for premature babies, and, in some cases, a blood transfusion may be necessary to correct it.

**Antibiotics:** medications that prevent or treat infections caused by bacteria.

**Antibodies:** produced by the body to fight bacteria or viruses in the blood.

**Aorta:** a large artery leaving the heart that carries blood with oxygen.

**Apnea:** a temporary stoppage of breathing.

**Bacteria:** organisms that cause disease and infection.

**Bililights:** special lights used to aid in the removal of bilirubin from the infant’s blood.

**Bilirubin:** a yellow-orange pigment to the infant’s skin due to the presence of excessive amounts of bilirubin. This byproduct of cell breakdown causes jaundice.

**Blood gas:** a test that monitors the oxygen and other components of the infant’s blood.

**Blood pressure:** a measure of the amount of pressure on the walls of the blood vessels.

**Blood transfusion:** [with parental consent] blood from a donor is given to the baby through an intravenous line after careful matching of compatibility.

**Bonding:** the connection between parents and infant.

**Bradydaria:** a slower heartbeat than normal. This is usually accompanied by apnea.

**Catheter:** a thin tube used to give fluids and blood into or out of the body.

**Central line:** an intravenous line used for long-term treatment that enters the skin and rests just before the heart.

**Central nervous system:** brain and spinal cord.

**CLD:** Chronic Lung Disease. This is described as the need for oxygen by a premature baby for an extended period of time.

**Colostrum:** breast milk produced in the first days after delivery. This milk carries many antibodies and nutrients vital for your baby.

**CPAP:** Continuous Positive Airway Pressure. Pressurized air is delivered to the baby via small plastic prongs to aid in the expansion of the lungs.

**Endotracheal tube:** thin plastic tube inserted into the baby’s trachea to deliver air, oxygen and breaths to the infant.

**Full-term baby:** between 37 and 42 weeks gestation.

**Gavage feeding:** feeding through a tube that enters the nose and ends in the stomach.
Glucose: type of sugar that stays in the baby’s blood and provides energy.

Halo: a plastic dome placed over the baby’s face to concentrate oxygen available for the infant.

Hyperglycemia: excessively high amounts of sugar in the blood.

Hypoglycemia: abnormally low amounts of sugar in the blood.

Infusion pump: a pump used to deliver IV fluids to the baby for nutrition when feeding is not possible.

IVH: Intraventricular Hemorrhage. This describes bleeding in the infant’s brain. The condition can be mild or severe and should be discussed with your baby’s doctor.

Intubation: placement of an endotracheal tube into the trachea (windpipe) to ensure air and oxygen passage to the lungs.

Jaundice: yellowing of the skin associated with excessive amounts of bilirubin in the blood.

Low Birth Weight: birth weight less than 2500 grams (about 5.5 pounds).

Monitor: the machine recording and alerting the nurse of the status of your baby’s heartbeat and respiratory rate.

NEC: Necrotizing Enterocolitis. This is a condition where the intestines are compromised and require a temporary break from food and the need for antibiotics to treat an associated infection.

Neonatology: a special field in pediatric medicine and nursing that is devoted to the care of the premature or sick newborn.

NICU: Neonatal Intensive Care Unit

PDA: Patent Ductus Arteriosus. This is a condition in the infant’s heart where it has not transitioned to the extra-uterine environment. It can be treated by medication or may require surgery.

Pneumonia: an infection in the lungs that causes fluid accumulation and requires antibiotics to treat.

RDS: Respiratory Distress Syndrome. Due to poor lung development and prematurity, newborns have trouble breathing.

Red Blood Cells: cells that carry oxygen to the tissues.

Retinopathy: eye problem in premature infants with prolonged exposure to oxygen. It ranges in severity, and treatment depends on the severity.

Rooting: coordinated movements of the head and mouth as an infant is looking for a nipple to suck on.

Sepsis: an infection if the blood stream that is treated by antibiotics.

Surfactant: substance formed in the lungs that helps the alveoli with air exchange. Many premature infants are given surfactant at birth to aid their breathing.

Tachycardia: an unusually fast heart rate.

Trachea: the windpipe from the back of the throat to the lungs.

Umbilical Artery Catheter: a small plastic tube placed most often in the baby’s umbilical artery to serve as an IV for the administration of nutrients, medications or blood products.

Vein: a blood vessel that carries blood back to the heart.

Vital Signs: measurements of heart rate, respiratory rate, blood pressure and temperature.