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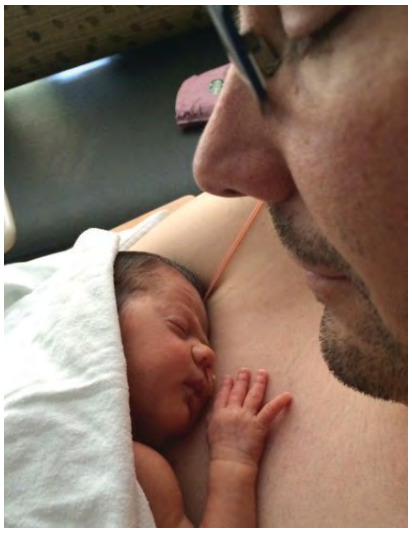
Caring for Your Baby in the NICU

At University of Washington Medical Center



Fourth Edition March 2022

Caring for Your Baby in the NICU
Neonatal Intensive Care Unit | Box 356077
1959 N.E. Pacific St., Seattle, WA 98195 | 206.598.4606

Pandemic Notice:

Other visitors, such as siblings, family and friends are not able to come to the NICU during the Pandemic. At this time, only the birth parent and one consistent significant other may come to the NICU during the infant's hospitalization.

Please disregard any of this booklet's information regarding Siblings, Family and Friends as it is not applicable at this time.

Please visit the Visitor Policy and Patient Guidance Site for the most recent policy.

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Caring for Your Baby in the NICU

Learning About the NICU

Learning About Your Baby

For more on this subject, please read these handouts: "Helping your Baby Grow and Develop in the NICU," "Stages of Behavior," "Your Baby's Sleep and Wake States," "Your Baby's Comfort," and "Helping Your Baby Calm." These handouts are in the booklet *Getting to Know Your Baby and the NICU Therapy Team*. Ask your nurse for copies, or find them online at *https://healthonline.washington.edu*.

Learning Your Needs

For more on this subject, please read: "Balancing Act: Time in the NICU and Time at Home," "Coping with Stress When You Have a Baby in the NICU," "Emotions after Giving Birth," and "NICU Family Resources: Websites and Books." Ask your nurse for copies, or find them online at *https://healthonline.washington.edu*.

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Learning About Lactation and Feeding in the NICU

Ask a NICU nurse for "Breastfeeding Your Hospitalized Baby" and "Getting to Know Your Baby and the NICU Therapy Team." You can also visit *https://healthonline.washington.edu* and read the handout "Safe Feeding."

Learning What You Need to Go Home

Learning About Home

Questions?

Your questions are important. Talk with your NICU doctor or nurse if you have questions or concerns.

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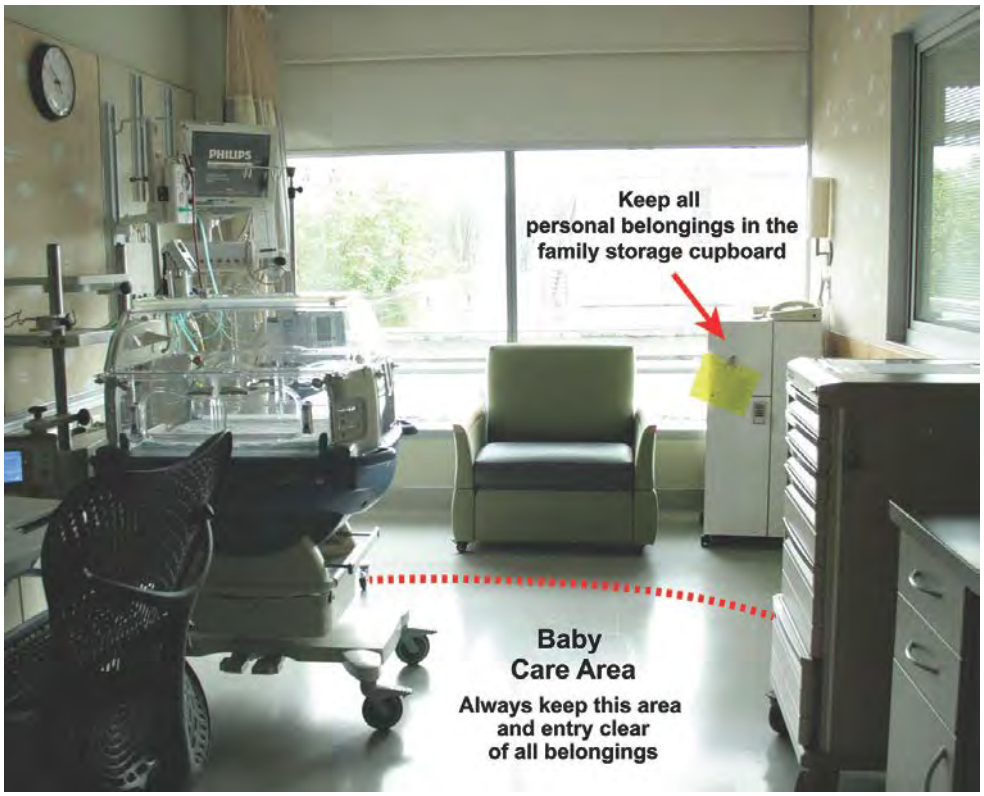
A Safe Place for Your Baby

About our NICU code of conduct

Your baby's care and safety are our top priority.

We know that having a baby in the NICU can be a very stressful time in your family's life. Our NICU code of conduct was created to provide clarity and consistency for our families. By following this code of conduct, NICU staff, families, and visitors all work together. We create a safe and positive environment, keep NICU babies safe, and help them receive the best possible care.

Please let us know if you have any questions or concerns about our code of conduct.



For your baby's care and safety, some areas in your baby's room must be kept clear. Please keep all of your family's personal belongings in the family storage cupboard.

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"I wish someone had told me that even with all of the hard days and sadness, there is truly something wonderful and magical about the NICU. It can be a really wonderful place."

– Lucy's Mom

Parents as Partners in Your Baby's Care

- We want you to feel welcome and safe here. Parents may stay with their infant 24 hours a day, 7 days a week.
- You and your baby are the center of our care team. Our guiding principal is that parents do not "visit" their baby, but are here providing care and parenting.
- We will work with you to manage your baby's daily plan so that you can be present to provide important care and parenting. You can take part in essential activities such as holding, feeding, diapering, and bathing, as much or as little as you choose.

Safety

- **Doctors and nurses must be able to get to your baby easily during all hours of the day and night.** Always make sure the entry into your baby's room and the area around your baby's bed are completely clear of all personal belongings (see photo on page 1).
- To give your baby the best care:
  - We will turn on the lights when they are needed.
  - Care tasks will be done as needed, even in the middle of the night.
- Rarely, a nurse or doctor will ask parents and visitors to step outside the room. This is done when treatment is needed or if there is a medical emergency. **This may happen at any time day or night.**
- Hold your baby **only** if sitting in a chair that does **NOT** have wheels.
- It's easy to become drowsy while holding your baby. We will wake you or move your baby back to their incubator or bassinet if you start to fall asleep while holding your baby.
- **Never turn off alarms in your baby's room.** Alarms tell us when your baby might need help.
- Most medical equipment is meant to be used by trained medical professionals. Please ask your nurse before using any equipment in your baby's room.
- Do **not** wear perfume, aftershave, or other scented products when you plan to visit the hospital.
- The door to your room can have only your baby's name on it.
- Inside your room, if there is a window, you may decorate it with flat, laminated items: photos, drawings, and written sentiments. Please keep everything else at home.
- For safety and infection control, all family members and visitors must have shoes on their feet when walking in the NICU.

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Preventing Infection

Premature and ill infants are at risk for infections. To help prevent infection in the NICU, please do **not** come to the NICU when you are ill.

Sick family members and friends must stay home until they have been free of symptoms for at least 24 hours. If you have questions, please talk with the Charge Nurse.

Daily Health Screening

Even minor cold symptoms can be a serious health risk to premature infants. To keep your baby and others safe, we screen everyone for health concerns before they enter the NICU. You and your guests will answer a short health survey every day that you visit the NICU.

We may ask you more questions about your health if we know that colds, flu, and other illnesses are active in the hospital and community.

Hand Washing

Everyone who visits the NICU must wash their hands and arms up to the elbows before they enter the unit.

Everyone who visits the NICU must wash their hands and arms up to the elbows before they enter the unit. Scrub sinks are at the front and rear entrances of the NICU. Since you will need to remove any jewelry from your wrists and hands, it is best to leave valuables at home.

Please:

- Remove any jewelry from your wrists and hands. Do not put the jewelry back on until you leave the NICU.
- If you have long sleeves, roll them up above your elbows.
- Wash your hands and arms to your elbows with soap and water for at least 30 seconds.
- Then, when you enter your baby's room, wash or gel your hands again before you touch your baby.
- After touching your baby, wash or gel again.
- If you do not see staff, providers, or others wash or gel our hands before touching your baby, please feel free to remind us.

Keeping Your Baby's Room Clean

- Always keep countertops, tables, and sinks free of family items. Keep all personal belongings in the family storage cupboard.
- Our environmental services staff must be able to clean and disinfect your baby's room every day. To allow them to do this important work, please:
  - Fold your linens when you get up and leave them on the day bed.

- Put all of your personal belongings in the small family storage cupboard by 10 a.m. each morning. This includes all items that do not belong to the hospital, and small food items that do not need to be refrigerated.
- Put food in a tightly closed container before you place it in the family cupboard. Keep food items to a minimum.
- Keep the floor and window sill clear.

- Room refrigerators are used to hold infant formula and milk. They are carefully monitored to make sure they stay at the right temperature. Please do **not** place any drinks or food items in the refrigerator. If you have something that needs to be refrigerated, please label it and place in the refrigerator in the parent lounge.

Room Decorations

Families are welcome to decorate your baby's room and door. All decorations must meet Department of Health and Fire safety regulations. Decorations:

- Must be able to be cleaned with alcohol wipes
- Cannot be a fire hazard
- Must be secured using only tape, and only to a non-painted surface

We understand that decorating your baby's space can be a very important part of NICU life. But, your baby's safety is our first priority. If you have any questions about how to personalize your space safely, please ask NICU staff.

Staying Overnight in Your Baby's Room

We care for your baby all during the day and all night, too. Nurses must interact with your baby around the clock to help your baby make progress. If you stay overnight in your baby's room, be aware that nurses often need to turn on lights in the middle of the night.

For your comfort, we offer sheets, pillows, and other linens. We ask that you please keep your child's room tidy, folding and storing bed linens when you are not using them.

If you plan to stay overnight in your baby's room:

- Please be aware that space in your baby's room is limited. Only 1 parent can sleep comfortably overnight in the baby's room. Siblings may **not** spend the night (see "Siblings" on page 5).
- Pull the curtain closed if you would like to sleep.
- Please remain fully clothed while in your baby's room and wear shoes when you get up.

- Before you go to sleep, talk with your baby's nurse about your baby's care plan for the night:
  - Options for skin-to-skin (kangaroo care) time
  - When mom would like to pump and/or feed baby
  - How you can participate in your baby's care
  - Plans for parent sleep time
- Remember that anyone who is feeding your baby must sit in a chair that does not have wheels. During the night, your nurse may need to use the sleeper chair you are sleeping in for feedings. When it is time to feed your baby, be prepared to get up so that either you or your nurse can sit in the sleeper chair to feed your baby.

Visitors in the NICU

Parents Who Spend the Night

Our unit is closed from 11:30 p.m. to 5 a.m. If you are a parent who is spending the night, please make sure you arrive before 11:30 p.m. If you leave the unit during time that the unit is closed, you will not be able to re-enter until after 5 a.m.

Siblings

- **An adult must supervise children at all times while they are in the hospital.**
- Your baby's brothers and sisters may visit at the bedside:
  - If they are well
  - When a parent is in the room
  - During the day (we cannot accommodate overnight stays for siblings)
- You will need to fill out a special health-screening questionnaire for siblings under the age of 13. Screening includes a temperature check.
- Remember that toddlers and preschoolers have short attention spans, so please keep their visits short.
- If your NICU baby is part of a multiple birth, their same-age sibling may visit, but must arrive and leave the NICU in a car seat or stroller.
- Please ask a staff member if you have any questions about bringing your children to visit their sibling.

An adult must supervise children at all times when they are in the hospital.

Family and Friends

- Your family and friends, age 13 and older, are welcome to visit your baby when you are in the room.

- Because of limited space, we ask that no more than 3 or 4 visitors (**including you**) be in your baby's room at a time.
- During nursing change of shift, guests will need to wait in the visitor area outside the NICU.
- Please tell your family and friends that we cannot provide patient information to anyone other than you. You will decide what information you wish to share with your family and friends about your baby's condition and keep them up to date.
- If you have information you do not want us to talk about when family or friends are present, please tell your baby's nurse or doctor so that we can take extra privacy measures.
- In special circumstances, you may choose a close family member or friend to spend time with your baby when you cannot be in the NICU. We will need to get your written consent for this to happen. Please talk with your baby's nurse about this.

Meals

As soon as you are done eating a meal in your room or in the Family Lounge, please:

- If you have a hospital tray, ask for it to be removed right away.
- If you eat a meal that you brought with you, take your dishes to the Family Lounge and clean them right away.
- Use a wet paper towel to wipe up any crumbs around your eating area.

Courtesy for Others

- If you have a concern during your stay in the NICU, please talk directly with your nurse. If you cannot talk with your nurse, ask to talk with the charge nurse or the nurse manager. Speak calmly so that we can work together to meet your needs.
- We do not allow yelling, using threats, and/or abusive language in the NICU. If anyone's behavior causes concern for staff, hospital Security will be called and they will be asked to leave.
- Do not use drugs or drink alcohol in the NICU.
- Do not engage in sexual activity in the NICU.

Respecting Others' Privacy

Please respect the privacy of care providers and other families in the NICU:

- Ask for their permission if you would like to take a picture or a video that may contain a nurse, doctor, or other staff member.

- Never take a photo or video of another family, baby, or another baby's name card.

Cell Phones

- You may use your cell phone in the NICU, but leave the ringer in silent or vibration mode. A ringing cell phone could disturb your baby or the other babies nearby.
- When talking on the phone, speak quietly to help keep noise low.
- If you need to talk on the phone during nursing hand-off, please leave the room.
- Also, if you will be talking on your cell phone for a long time, please consider having your conversation outside your baby's room.
- Please consider limiting your cell phone use while you are in the NICU. If you must make or receive a call:
  - It is best go to a private area away from your baby and other patients.
  - Make sure that you are at least 3 feet (an arm's length) away from all medical equipment.
- You may text, read emails, use personal tablets or laptops, and search the internet in your baby's room. It may help you to stay close to your baby while also taking your mind away from the stress of the NICU for short periods of time.
- Do not use cell phones and personal electronics while you are holding your baby.
- Use Wi-Fi or airplane mode whenever you can. You can easily log on to free Wi-Fi while you are in the hospital.

Infection Control

Please be aware that **cell phones and other electronic devices have many germs on them**. This means that they can expose your baby to illness. To protect your baby and others in the NICU:

- Use an alcohol wipe to wipe down your cell phone when you enter your baby's room. You can find wipes next to the sink in the room.
- After you sanitize your hands and are visiting with your baby, do **not** use your cell phone.
- If you do touch your cell phone while you are visiting your baby, please re-wash or gel your hands.
- If you use personal tablets or laptops in your baby's room, always remember to wash your hands or use gel after touching or using them.

The Family Lounge has a kitchen and other amenities to help make your time in the NICU more comfortable.

About the NICU Family Lounge

- The Family Lounge is a place for families to take a break from being in their infant's room.
- The Family Lounge is only for parents and siblings of NICU babies. Other family members and friends should use other facilities in the hospital.
- There is no maid service in the Family Lounge. Please always clean up after yourself promptly.
- As many as 40 NICU families may want to use the Family Lounge at any time. Please be considerate of others while you are using the lounge, so that all NICU families can benefit from a much-needed break.
- Environmental Services staff will clean the Family Lounge daily, but they will not do dishes. Please help keep the area neat and tidy, and wash your dishes as soon as you can after using them.

Bathroom

When using the bathroom, please:

- Limit your bathroom time to no longer than 20 to 30 minutes.
- Place used towels and washcloths in the laundry hamper.
- Clean your toiletries and bring them back to your baby's room.

Dishes

- When you are done with your dishes, either:
  - Rinse your dishes and place them in the dishwasher;
  - Or, wash your dishes with soap and water, dry them with a towel, and put them away.
- If the dishwasher is full, please run it.
- If the dishwasher needs to be emptied and dishes put away, please help out.

Food Storage

- If you put food in the refrigerator, label it with your name and the date. Use the refrigerator to store only small amounts of food.
- Eat only your own food.
- The refrigerator will be cleaned every 2 weeks. We will post signs with cleaning dates. Any food left in the refrigerator on cleaning day will be thrown away.

Washer and Dryer

- Remove your clothing from these machines as soon as the wash or dry cycle is done.
- Clothing left in the washer and dryer may be removed and left out in the room.

Computer Use

- Limit your use of the shared computer to 30 minutes or less at a time.

Personal Belongings

You are responsible for your own belongings at all times.

- Please do **not** bring anything sharp into the NICU.
- Do not leave any belongings unattended in the NICU.
- Keep all personal belongings inside the family storage cupboard. It is very important to keep the entry area and the Baby Care Area clear (see photo on page 1).

Family Lounge and Waiting Room Guidelines

Our large family and waiting rooms have comfortable chairs and sofas where families can relax and take a break. **For safety reasons, do not leave children unattended in the Family Lounge or in the waiting room.**

TV Use

There are TVs in both the Family Lounge and the waiting room. Feel free to watch your favorite show.

Please be considerate and remember that the TV is for everyone's use:

- Keep the volume at a moderate level.
- Make sure that what you are watching is appropriate for all viewers.

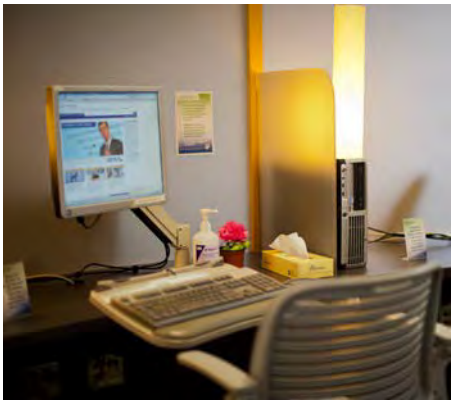
Internet Access

- Most areas of the NICU have wireless access, if you want to use your laptop computer or tablet.
- The Family Lounge also has computers with internet access.

Computers, Printers, and Business Services

If you need to print something from your email or the internet, please visit the hospital's Health Information Resource Center. The center has computers, a printer, and other business services.

The Resource Center is in the 3rd floor lobby, next to the Gift Shop. It is open weekdays from 10 a.m. to 4 p.m.



The Health Information Resource Center is on the 3rd floor of the hospital, next to the Gift Shop.

Thank you for working with us to create a safe, healing, and positive environment in the NICU!

Questions?

Your questions are important. Talk with your NICU doctor or nurse if you have questions or concerns.

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Parenting in the NICU

For parents of NICU infants

Parenting is defined as "the attention and love of parents." Parenting is essential to the well-being of all newborns. Your baby needs **you** – especially while they are in the NICU.

We know you want and need to be close to your baby during this time. **You are welcome to be with your baby 24 hours a day.**

We also know there are times when you're not able to be here as much as you would like. Please know that the quality of the time you spend in the NICU is more important than the quantity.

How Parenting Looks in the NICU

Parenting your baby in the NICU will evolve as your child progresses. You may start by sitting quietly by your baby's bedside. Later, your baby may hold your finger in a tiny fist. Or, you may comfort your baby by "containing" your child with your hands.

How you are able to parent your baby will change over time.

Self-care

During this stressful time, we encourage you to take care of yourself, as well as your baby. Be at your baby's bedside as often as you need, but be aware that you may not be able to rest well in the NICU.

Your baby's care continues day and night, sometimes every hour or more often. We have a space for you to rest or sleep in your baby's room, but it may be more restful to return to your own home to rest and recover.

Your baby's health and safety are our top priority – but your health and safety are also a priority! We support you, both in parentingand in self-care, so that you can stay healthy and rested for your infant.

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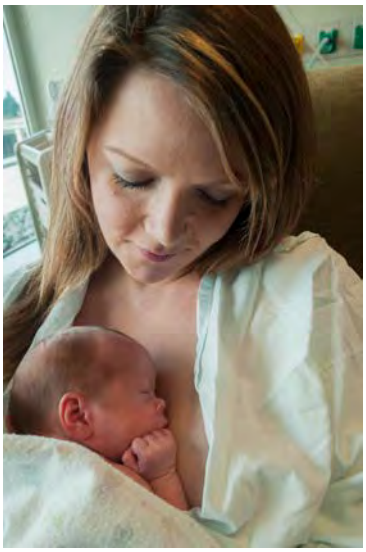

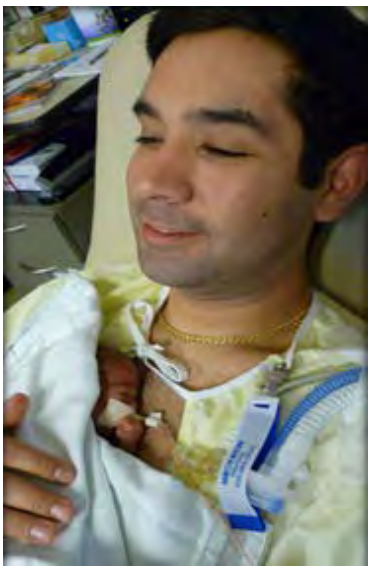

"Kangaroo care is so important. It helps the babies thrive. My husband did kangaroo care, too. There were days when Kylie was held for many hours. This made me feel close to her."

-- Kylie's Mom

Kangaroo Care: Skin-to-skin Contact

Kangaroo care is the practice of babies having skin-to-skin contact with their parents for long periods of time. During kangaroo care, the baby is:

- Naked except for a diaper
- Held upright on the parent's chest
- Covered with a blanket

Usually, mothers and fathers "wear" their babies for 2 to 3 hours at a time. Talk with your nurse about best timing for you to do kangaroo care.

Research shows that babies benefit in many ways during skin-to-skin care:

- Breathing, heart rate, and oxygen saturation levels are more stable during kangaroo care.
- Babies stay warm because the parent's body helps regulate the baby's body temperature.
- Babies sleep better, which leads to improved growth.
- Mothers who give kangaroo care and are breastfeeding produce more milk.
- Parents report less anxiety and feel more comfortable caring for their infants.

Kangaroo care can also:

- Help with bonding and attachment
- Improve digestion
- Help fight infections
- Promote brain growth

What Parents Say About Kangaroo Care

"I love my kangaroo care time with Henry. As a dad, it can be hard finding a way to contribute directly to his progress. Kangaroo care is the best way I have found to help him grow while building a bond with him."

Nate (father of NICU baby)

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"Holding your baby for the first time is an overwhelming experience, no matter what the circumstances surrounding the moment. Joy, comfort, hope; each moment generates a different emotion. Kangaroo care builds an immeasurable bond, a lasting connection between parent and baby that elicits memories that cannot be put into words."

Gretchen (mother of NICU baby)

What to Bring to the NICU from Home

You may find it useful to have these items during your time in the NICU:

- Laptop computer or notebook (the hospital has wireless internet access)
- Small electronics that play music or movies. Please use headphones when watching a movie or listening to music.
- Books, magazines, and small handcrafts such as knitting or crochet
- Your own toothbrush, toothpaste, shampoo, body wash, and other toiletries
- Your own pillow, comforter or quilt, or other items to make you comfortable

"To survive the NICU, try to get out of the room, go on walks, or go to Art Group.

-- Austin's Mom

"Art Group helped me cope with the NICU experience."

-- Wyatt's Mom

Library, Classes, and Support Groups

- The NICU has a small library with educational children's books. Feel free to borrow them. P lease return them when you are done with them so other families can use them.
- Next door to the Family Lounge is the NICU classroom. We hold a variety of daily classes to educate you on your baby's care. Please see the schedule of classes posted on bulletin boards in the Family Lounge and outside the classroom.
- There are also many support groups, such as the Art Group, that NICU parents and families can attend. Please see the bulletin board just outside the Family Lounge.

Notes

Questions?

If there is something you do not understand, please ask questions. Every question you ask is important!

- When you don't understand a term, ask any care provider to clarify its meaning.
- Ask for more information when you don't understand a treatment or why it needs to be done. Ask about possible side effects.
- Keep asking questions until you are satisfied that you understand what you need to know.

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Your Baby's Care Team

For parents of NICU infants

Parents and Family

You and your baby are the center of the NICU care team. As parents, you will give input and take part in your baby's care during your time in the NICU.

Medical Rounds

- Every morning, the NICU attending doctor, resident doctors, nurse practitioners, your baby's nurse, and other staff involved in your baby's care meet. They review what has happened with your baby in the past 24 hours and decide on the plan of care for the next day. These meetings are called "rounds."
- As an important member of your baby's care team, you are welcome to join rounds. Talk with your baby's nurse to find out when the team will be "rounding" to talk about your baby's plan. If you are not able to be here during rounds, ask to talk with a care provider for an update on your baby's current status and plan.
- We have two teams caring for your baby. The first team begins their rounds at 8 a.m. The second team's rounds begin at 9:30 a.m. Be sure to ask your nurse when to expect medical rounds to occur.

A neonatal nurse is an RN who has special training in caring for NICU babies and their families.

Nursing Report (Change of Shift)

- During "nursing report," nursing staff review your baby's history and plan of care at the bedside. This occurs when nurses are changing shifts. Usual times for nursing report are from 7 to 7:30 a.m. and from 7 to 7:30 p.m. Nursing report may also occur at 3 p.m. and 11 p.m.

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"Although having a baby in the NICU was emotionally taxing, we found the staff at UWMC absolutely incredible. They became people we could lean on and trust, an extension of our family. They cared for my heart, and helped support me emotionally through the toughest time in my life."

-- Kylie's Mom

- Parents are welcome during nursing report. If you arrive after report has started, please enter the room quietly.
- The nursing report on each baby usually lasts 5 to 15 minutes. Please save your questions until the nurses finish their report. If you have more input or questions than time allows, a nurse will return to talk with you about your concerns after they finish their reports on the other NICU babies.
- During nursing report, the nurses must pay close attention. To avoid interruption, we ask that siblings not be in the room during the report.

Nurses

Highly skilled nurses care for the babies in the NICU 24 hours a day:

- A *neonatal nurse* is a registered nurse (RN) who has special training in caring for newborns and their families.
- The nurse caring for your baby was carefully trained in the specific skills needed for caring for NICU babies.
- You may see an RN with the credentials *RNC-NIC*. This means the RN has passed a national specialty exam in neonatal intensive care nursing.

Your baby's nurses will:

- Assess your baby's current condition and progress
- Carry out the care provider's orders
- Tell the doctor or neonatal nurse practitioner of any changes in your baby's status

The RNs also:

- Advise the care team based on their assessment of your baby
- Plan and carry out all nursing care, including bathing, feeding, positioning, giving prescribed medicines, and managing medical equipment
- Are very involved in parent education and discharge planning

The nursing team is supported and led by a *charge nurse* who oversees the work of the nursing team for each nursing shift. Behind the scenes, there are assistant nurse managers and a NICU nurse manager who supervise all of the nursing staff and provide leadership for the unit.

Nurses in the NICU also take on roles outside of directly caring for babies (see "Nursing Specialty Teams" on page 22). Most importantly, they provide support to parents in the NICU. The nurses also stay updated on new care methods in order to improve their nursing practice, maintain standards of care, and provide updated education to other nurses.

"It helped to see Frankie every day and call the nurses every night. I never missed rounds with all of her doctors. I needed to hear from them!"

-- Frankie's Mom

Advanced Practice Provider (APP) Team

Neonatal nurse practitioners (NNPs) have attended graduate school to learn how to be a primary care provider for premature and sick newborns. NNPs specialize in managing the medical care for your baby.

Physician Assistants (PAs) have attended PA school and done an extended residency in a NICU.

NNPs and PAs are part of the medical staff. They offer expert medical advice to the entire NICU care team and do many of the procedures that may be needed. The NNP and *hospitalist* team works with an *attending neonatologist* to direct provide your baby's care. Read the next section below to learn more about these care team members.

Doctors

A team of *pediatricians* (doctors who specialize in caring for children) will care for your baby. This team is supervised by an attending pediatrician or *neonatologist* (a pediatrician who specializes in caring for babies).

Your baby's attending doctor:

- Oversees all aspects of your baby's medical care
- Supervises other providers on your baby's care team
- Orders tests, medicines, and treatments
- Is a faculty member of University of Washington School of Medicine
- Serves a 1- to 2-week shift in the NICU (see "Staff Rotation" on page 18)

Other providers on your baby's care team include *fellows* and *residents*. They are in the NICU 24 hours a day.

Residents

A resident is a doctor who has graduated from medical school and is in a 3-year training program to become a pediatrician. Residents in their first year of training are called *interns*. *Senior residents* are in their 2nd or 3rd year of pediatric residency.

Each resident is in the NICU for 4 weeks (see "Staff Rotation" on page 18).

Fellows

A NICU fellow has completed 3 years of training to become a pediatrician, and has chosen to specialize in neonatology. This special training also lasts 3 years.

Hospitalists

A hospitalist is a pediatrician who has finished their residency and provides care in a hospital setting. Hospitalists work with our Advanced Practice Team (NNAPPs).

"While Lucy's stay was fairly uneventful, we struggled greatly with feeding issues. I wanted to breastfeed, but it was so hard for Lucy and we had very discouraging days. But we felt supported by the nurses and lactation consultants. I encourage moms who want to breastfeed to let NICU staff know – they are an amazing resource!"

-- Lucy's Mom

Staff Rotation

UWMC is a *teaching hospital*. This means that some of the providers who work in the NICU are receiving training in special areas of medicine. These providers "rotate" through the unit as part of their training program. They will be on your baby's care team for a set length of time.

When your baby is admitted to the NICU, a care team will be assigned to your baby's care. If your baby is on the:

- **Resident team**:
  - You will work with a new attending doctor every week.
  - You will work with a new resident every month.
- **APP team**:
  - You will work with a new attending doctor every week.
  - There is a core group of APPs who will provide ongoing care to your baby. They do not rotate regularly.

The rest of your baby's care team do not rotate. They help provide continuity for you, your family, and your infant.

Rounds

As an important member of your baby's care team, you are invited to join in *rounds*. This is when your baby's care team meets to talk about your baby's progress and plan of care. (Also see "Medical Rounds" on page 15.)

During rounds, if your baby is on the:

- **APP team**, an APP will explain your baby's progress and propose a plan of care
- **Resident team**, the intern will explain your baby's progress and propose a plan of care

Your nurses, attending doctor, residents, fellow, pharmacist, dietitian, and respiratory therapist will then offer input, if needed. The care team will also ask for your input. Our goal is to have everyone agree with and support the plan of care.

At the end of rounds, the attending doctor will state your baby's plan of care for the next day. This plan will be carried out by the entire care team.

Social Worker

All NICU parents can get help from a social worker with special training and experience working with parents of premature or sick infants. Your social worker can provide support and help you and your family cope with having a premature or sick baby:

- Worry about your baby's health
- Confusion about how the hospital works
- Emotions around having delivered early and having to leave the hospital without your baby
- Frustration over not always being able to be with your baby
- Financial concerns

Your social worker can also:

- Provide information on local housing and transportation
- Help you communicate with employers, schools, the Department of Social and Health Services (DSHS), public health nurses, the courts, community agencies, and others, as needed
- Provide information on community resources such as DSHS; Women, Infants, and Children (WIC); counseling services; help with buying gas and food; public transportation; Social Security services; and more
- Provide information, educational materials, and referrals for issues such as post-partum mood disorders and domestic violence

If you would like meet with a social worker, please call 206.598.4629 or ask your baby's nurse to page the social worker for you.

Consultants

Breastfeeding Support

- **Certified lactation consultants** can answer your questions about breastfeeding, breast pumps, storing your milk, and other concerns. Call Lactation Services at 206.598.4628. If you reach voicemail, leave a message. Or, tell your nurse that you want to talk with a lactation consultant.
- Please read the **handout on lactation** you were given.
- You may use one of our **electric breast pumps** at your baby's bedside while your baby is in the NICU.
- To **rent an electric breast pump** to use at home, call your insurance company and ask about getting a pump. All insurance companies pay for either buying or renting a breast pump. We can provide you with a prescription for a breast pump if your insurance requires one. If you have questions, ask your baby's nurse, the breastfeeding resource nurse, or the lactation consultant.

Neonatal Dietitian

This dietitian has special training in the nutritional needs of newborn babies, including premature infants. The neonatal dietitian will assess your baby's growth and nutritional status, and attend rounds.

Neonatal Pharmacists

Neonatal pharmacists have specific knowledge about the medicines used to treat conditions that often affect newborn and premature babies. They monitor medicine therapy and talk with other care team members to help choose the best medicines and doses for your baby.

If your baby needs medicines for a while after discharge from the NICU, the neonatal pharmacists will help you understand what the medicines are for, their possible side effects, how they are given, and what to do about storing the medicine and getting prescription refills.

Palliative Care Services

Even when everything goes as smoothly as it can, being in the NICU is a difficult time for families. Palliative care offers extra support for your family to help you during this stressful time.

Palliative care includes supporting you and your family emotionally, psychologically, practically, and spiritually. It includes talking about what's most important to your family, and about your hopes and concerns as parents. We also support your family when it's time to make important care decisions.

In the NICU, palliative care is provided by a doctor or other medical provider who has been specially trained in palliative care for NICU families. You can ask for palliative care at any stage of your baby's NICU journey.

Spiritual Care Services

Having a baby in the NICU can be a time of concern and uncertainty. Many parents find it helpful to talk with a Spiritual Care provider during this time. As an important part of your care team, our Spiritual Care providers are available 24 hours a day. They provide a caring presence, offer spiritual and emotional support, and listen with openness and understanding.

Spiritual Care respects each person's spiritual, cultural, and personal perspectives and does not impose any religious beliefs. Spiritual Care providers may offer a compassionate presence during a stressful time, even for those who have no spiritual beliefs. Others may feel supported through prayer or a baby blessing.

If you wish to talk with a Spiritual Care provider, please ask your nurse.

Special Therapists

Child Life Specialist

There is a Certified Child Life Specialist who has a background in Child Psychology and Child Development. This specialist has worked with patients in both hospital and clinic settings. In 2011, Erika Beckstrom founded the ISEEU ("I See You") Sibling Support Program at UWMC. The program is designed to help children cope with having a sibling in the NICU.

When siblings do not have support, it can lead to acting out, regressing to a younger age, and withdrawal. These symptoms can get worse when NICU parents have to be away from their families for long periods.

Our Sibling Support Program can help resolve some of the issues that can occur when siblings visit the NICU, and help them cope with the stress of having a sibling in the hospital. Erika has also been very helpful when parents must explain death to a NICU sibling.

The Child Life Specialist also works with our Super Seniors to assure they receive developmentally appropriate interactions. Super Seniors are infants older than 38 weeks corrected gestational age. The Child Life Specialist works directly with the infant or educates the families to provide these interactions.

Respiratory Therapists

Respiratory therapists (RTs) have special training in treating breathing problems, including how to use oxygen delivery systems and mechanical ventilators. An RT who has special training in caring for infants is available 24 hours a day for NICU patients.

Neurodevelopmental Therapist

NICU neurodevelopmental therapists are physical and occupational therapists with special training in the motor and cognitive development of newborns and medically fragile infants.

Neurodevelopmental therapists will:

- Look at how the NICU environment affects your baby's development
- Help change the environment to help your baby's brain and body grow
- Help your baby stay calm and ready for caring interactions
- Help your baby learn to move in ways that will help development
- Help you understand how to support your baby's development over the first years

Feeding Therapist

NICU feeding therapists are speech language pathologists (SLPs) and occupational therapists (OTs). They have special training in helping develop sucking and swallowing in newborns and medically fragile infants.

Feeding therapists will:

- Look at how your baby is learning to suck and swallow

- Help your baby learn to suck to prepare for eating
- Help your baby learn to coordinate sucking and swallowing
- Help problem solve if learning to eat is hard for your baby
- Explain how you can support your baby's eating over the first years

Other Support Staff

Patient Services Specialists (PSS)

Patient Services Specialists are at the front desk of the NICU. They greet visitors and take care of office work.

Discharge Coordinator

A discharge coordinator is a nurse who helps families and caregivers learn about caring for their baby after discharge. This nurse will coordinate your baby's care needs with providers both here in the hospital and in the community to help your transition to community care be safe and smooth.

After you go home, your discharge coordinator will continue to follow your baby's course of care through follow-up phone calls. If you would like to talk with our unit's discharge coordinator, please ask your nurse.

Patient Care Technicians (PCTs)

Patient Care Technicians work in the NICU to support the nursing staff in the care of infants.

NICU Family Advisory Council

We want to learn from our NICU families. We invite former NICU family members to become Advisors on our NICU Patient and Family Advisory Council.

The NICU Council meets monthly to provide input on NICU programs and policies. Many of our programs, including the Parent Mentor Program, Pizza Night, and Resident Orientation, started as ideas from NICU parents.

If you would like to apply to become a Patient and Family Advisor or have questions about the council, please email UWMC's Coordinator of Patient and Family Centered Care, at pfcc@uw.edu.

Nursing Specialty Teams

NICU nurses also work on specialty teams. These groups provide education to other nurses on staff. They also develop and put into effect policies to keep care in the NICU at the highest quality. They include:

- **Feeding Committee:** Eating is essential to a baby's growth and health. The feeding committee provides education to nursing staff about the latest developments in feeding. This committee also puts changes into effect in NICU feeding practices as needed.

- **Healing Hearts:** NICU nurses not only care for your baby – they also support you, the parents, during your baby's NICU stay. The Healing Hearts team provides education to nursing staff on the grief process and communication in difficult situations. Healing Hearts also offers support groups and other resources and activities for NICU parents.
- **Local Practice Council (LPC):** This group reviews current nursing practices to ensure the highest quality care for NICU babies. They develop policies and procedures for nursing care in the NICU, and keep standards of care current.
- **Partners in Care Committee:** One of the goals in the NICU is to provide a consistent group of nurses for a baby and family. This is called *nursing continuity*. Continuity for NICU families is a top priority, but can be hard to maintain. Partners in Care helps develop strategies to provide continuity for a family and increase their satisfaction.

Notes

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Notes

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Medical Terms in the NICU

For parents of NICU infants

This handout defines many of the terms you will hear in the NICU. Please ask a nurse or other staff member to explain more, as needed.

ABD: *Apnea*, *bradycardia*, and *desaturation* (see those entries).

Air leak: When air leaks out of the airways or air sacs of the lungs and into the space around them. Two kinds of air leaks are most common in preemies: *pneumothorax* and *pulmonary interstitial emphysema*.

Analgesia: Pain medicine that relieves or decreases awareness of pain. Analgesia does not cause unconsciousness or loss of sensation (numbness).

Anemia: A lower than normal number of red blood cells (see *Hematocrit*). Preemies often have anemia because they are slower to make red blood cells than full-term babies, their blood is drawn often, and some are sick with infections or other illnesses that can make anemia more severe.

Antibiotic: A drug that kills bacteria and is used to treat infection.

Apnea: A pause in breathing. Apnea is common in premature babies because their breathing system is not fully formed. It often begins during the first week of life. When apnea occurs in the NICU, a monitor sounds an alarm. A nurse will know the apnea is happening and will help as needed.

Axillary temperature: Temperature that is taken by placing a thermometer snugly between the baby's chest and the inner upper arm.

Please ask your baby's nurse if you have any questions about medical terms you hear in the NICU.

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Bacteria: Tiny, single-cell germs. Some bacteria are helpful, but some can cause infection. To learn more about bacteria, ask your care team.

Bagging: Extra breaths of oxygen the nurse gives to the baby. In bagging, a mask is placed over the baby's nose and mouth. This mask connects either to a device on the wall or to a small rubber bag. The device or bag connects to an oxygen source. If the baby is on a ventilator, extra oxygen breaths may be given through the breathing tube (see *Endotracheal tube*).

Bilirubin (bili): A normal byproduct of the breakdown of red blood cells. If bilirubin gathers in the blood and skin, the skin takes on a yellowish tinge (see *Jaundice*). Bili also refers to the blood test done to determine the level of this substance.

Blood gas: A sample of the baby's blood, taken from an artery (also called "ABG") or a heel (also called "CBG"). It is used to check for acid-base balance, oxygen, and carbon dioxide levels. Blood gas gives us information about the baby's breathing and lungs.

Blood transfusion: A small amount of blood given to the baby through an IV (see *Intravenous tube*).

Bradycardia ("brady"): A short-term slowing of the heart rate. It often occurs with apnea (see *Apnea*). If this occurs, the baby's monitor will sound an alarm. A nurse will know the bradycardia is happening and will help as needed.

Bronchopulmonary dysplasia (BPD): A form of chronic lung disease in newborns, especially preemies who have less mature lungs. It may be caused by the mechanical ventilation and oxygen therapy. Healing of the lungs takes time, and it occurs more slowly if the infant has needed mechanical ventilation or oxygen for more than a few days. Infants with BPD often need extra oxygen during this period of healing.

Caffeine: A medicine given to preemies to decrease apnea (see *Apnea*).

Carbon dioxide (CO_2): A waste product of energy production in the body. Carbon dioxide is removed from the blood as it is exhaled and passes through the lungs.

Care conference: A scheduled meeting at which members of a baby's healthcare team update parents on their baby's health status, talk about changes in the care plan, and explain what improvements they expect. As a parent and advocate for your baby, you can ask for a care conference to review your baby's care plan.

Corrected age: A baby's age figured from the due date, instead of the date of birth. For example, if a baby was born 3 months early and is now 7 months old, the corrected age is 4 months.

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Cue: An action or behavior that can show a baby's readiness for and reaction to stimuli. A cue is one way that infants communicate.

Culture: A lab test used to determine whether the baby has an infection. Samples of the baby's blood, urine, and sometimes spinal fluid are sent to the lab and watched for several days to see if any bacteria grow. If bacteria grow, the baby is said to have a *positive* culture. If no bacteria grow, the culture is *negative*.

Cyanosis: A blue color seen in the skin, caused by not having enough oxygen in the blood. Cyanosis often occurs with apnea and bradycardia, or because of poor circulation. It usually does not last long. (See *Apnea* and *Bradycardia*.)

Desaturation (desats): An episode when a baby's oxygen saturation is low. "Desats" are very common in preemies. These drops in oxygen saturation may occur suddenly and last only seconds or minutes, or a desat can last hours, days, or longer. When desats occur, an alarm sounds. A nurse will know the desats are happening and will help as needed.

Distention: An enlargement or swelling, often caused by pressure from the inside.

Diuretic: A medicine that removes excess fluid from the body by increasing urine production.

Echocardiogram (echo): An ultrasound of the heart.

Edema: A gathering of excess fluid in body tissues, that usually causes swelling.

Electrolytes (lytes): Sodium, potassium, chloride, and bicarbonate substances in the cells and bloodstream. Electrolytes are important for nearly all bodily functions.

Endotracheal tube (ET tube): A small plastic tube that goes down a baby's windpipe through either the nose or the mouth. The ET tube is connected to a ventilator and provides extra oxygen to help the baby breathe. The tube is suctioned to remove mucus from the baby's lungs.

Extubate: To remove the ET tube (see *Endotracheal tube*). The care team will decide when a baby is ready for extubation. They will base their decision on how deeply and easily the baby is breathing, how much support the ventilator is providing, and how much oxygen is being used.

Gastroesophageal reflux (GE reflux): When milk or other food in the stomach comes back up into the esophagus.

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Gavage: A way to feed babies who are not yet strong enough to feed from bottle or breast. In gavage, a soft plastic tube is placed through the mouth or nose into the stomach. Fluids are poured into the tube and flow into the stomach by gravity.

Hearing test: Screening to see if there is hearing loss. All infants will get their hearing checked before they leave the hospital.

Hematocrit ("crit"): An estimate of the number of red blood cells in the baby's blood. The baby's hematocrit often changes daily and may drop as a result of removing blood for tests. If needed, the baby will be given a small transfusion to replace this blood (see *Blood transfusion*).

Hyperglycemia (high blood sugar): Too much *glucose* (the sugar that cells use for fuel) in the blood.

Hypertension (high blood pressure): Blood pressure that is greater than the 90th percentile for a baby's age (higher than 90 out of 100 babies at that age).

Hypoglycemia (low blood sugar): Too little glucose (the sugar that cells use for fuel) in the blood.

Hypotension (low blood pressure): Blood pressure that is too low and does not bring enough blood to all the tissues of the body.

Intrauterine growth restriction (IUGR): When a baby is very underweight for gestational age. There are 2 forms of IUGR and it can be caused by many different things. If you would like more specific information about your baby, please ask your care provider.

Intravenous tube (IV): A thin tube placed in one of the baby's veins, often in the hand, foot, or scalp. Fluids and medicines are given through the IV.

Intraventricular hemorrhage (IVH): Bleeding in the *ventricles* (chambers) of the brain. A premature baby's brain is still developing, and some small blood vessels in and around the lining of the ventricles are very fragile.

Intubate: To insert a small plastic tube through a baby's mouth and into the windpipe. The tube is connected to a ventilator to supply oxygen and help with breathing (see *Endotracheal tube*).

Jaundice: A yellow color in the skin. It is caused when bilirubin gathers in the blood and skin (see *Bilirubin*). Jaundice is common in newborns.

Large for gestational age (LGA): An infant who is larger in size and weighs more than average for an infant of the same gestational age.

Late preterm baby: A premature baby who is born shortly before term, at 34, 35, or 36 weeks of gestation.

Magnetic resonance imaging (MRI): A type of scan that uses strong magnets and radio waves to take clear pictures of the inside of the body. MRI does not use radiation.

Medium-chain triglyceride (MCT) oil: An additive for breast milk or formula for premature newborns who are not yet producing certain enzymes and bile salts. MCT oil contains fats that the baby can easily digest and absorb.

Micropreemie: A term sometimes used for the youngest and smallest of premature babies. These babies are often born between 22 weeks and 25 weeks of gestation.

Murmur: A soft "whoosh" sound in the heart that can be heard through a stethoscope. Heart murmur is very common in preemies. (See also *Patent ductus arteriosus*.)

Necrotizing entercolitis (NEC): An inflammation in the intestines that most often affects preemies. NEC starts when there is an injury to the intestine. This injury may be caused by a lack of blood flow or oxygen, an infection, or large amounts of undigested formula in the bowel. The intestinal lining becomes inflamed, is invaded by bacteria, and stops absorbing gas and food and moving them forward.

Symptoms include a swollen abdomen and blood in the stool. If the baby has NEC, an X-ray of the abdomen will show bubbles of gas in the swollen intestinal lining. NEC can be mild or severe.

Neonatal Individualized Developmental Care and Assessment Program (NIDCAP): NIDCAP is a system used by NICU staff to assess an infant's behavior. They watch the baby carefully to see how much activity, handling, noise, and light the baby can handle without having a decreased oxygen level or becoming upset. Caregiving is then designed to meet the baby's specific needs.

Non-nutritive sucking: Sucking on a pacifier or a finger, either the baby's own finger or a caregiver's. Non-nutritive sucking helps *oral-motor development* (the ability to use the lips, tongue, jaw, and teeth). It may also help digestion and food absorption, and improve weight gain and oxygenation. It does not supply nutrition.

NPO: When the baby is not receiving anything by mouth or gavage (see *Gavage*). Nutrients and water will be provided through an IV (see *Intravenous tube*). NPO comes from the Latin *nil per os*, which means "nothing by mouth."

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Oxygen saturation ("O2 sat"): A measure of how much oxygen is in a baby's blood cells. Oxygen is carried through the body by red blood cells. In the NICU, a baby's "O2 sat" is measured all the time. This is done using a *pulse oximeter* (see "Medical Equipment in the NICU") around the baby's wrist or foot. The usual goal is to keep oxygen saturation in the high 80s to 90s. If a baby is breathing room air, they may even be saturating at 100%. The baby's current "O2 sat" percentage is the number in blue on their monitor.

Parenteral nutrition: Fluid that contains the vitamins, minerals, and energy the baby needs. Parenteral nutrition is given through an IV. It is started when the baby cannot eat for a long time.

Patent ductus arteriosus (PDA): A *heart murmur* common in premature babies. It occurs when the connection between the pulmonary artery and the aorta either does not close after birth or re-opens after closing. PDA usually repairs itself as the baby matures.

Periodic breathing: A pattern of breathing. The baby may take a few short breaths, a long breath, and then pause before breathing again. This pause is much shorter than the pause that occurs in apnea.

Periventricular leukomalacia (PVL): Cysts near the ventricles in the brain. PVL is a sign that there was some damage to brain tissues.

Pneumothorax: When air leaks into the space between the lung and chest wall, usually because an air sac ruptures. If a lot of air leaks out, it can put pressure on the lung and keep it from expanding. Sometimes a *chest tube* (see "Medical Equipment in the NICU") is needed to remove air from the chest cavity.

Probiotics: Probiotics are a mixture of live bacteria. When eaten, probiotics support the "good" bacteria naturally found in the intestines of healthy people. These "good" bacteria are needed for normal digestion. Probiotics are sometimes given to the very youngest NICU babies. (See "Probiotics" handout.)

Pulmonary hemorrhage: Bleeding in the lungs.

Pulmonary interstitial emphysema (PIE): Tiny amount of air that has leaked out around the small airways in the lungs. PIE is most common in infants with a low birth weight.

Residual: Food that remains in the stomach from the previous feeding at the time of the next feeding. Large residuals may mean that the baby has *feeding intolerance* (is not digesting well).

Respiratory distress syndrome/hyaline membrane disease (RDS/HMD): RDS/HMD affects many premature babies because their lungs are not fully mature. Babies with RDS/HMD have a hard time exchanging oxygen and carbon dioxide. They often need extra oxygen, help with breathing, or both.

Retinopathy of prematurity (ROP): An overgrowth of the blood vessels of the *retina*, the membrane that lines the inside of the eye. Most babies with ROP do not have vision damage. But, a few babies may lose all or some of their vision in one or both eyes.

Retractions: Indentations in the chest wall when the baby is working hard to breathe.

Room air: The air around us. Room air usually contains about 21% oxygen.

ROP check: A special eye exam to detect retinopathy of prematurity (see *Retinopathy of prematurity*). An ROP check is done on infants who weigh less than 1,500 grams (3 pounds, 5 ounces) at birth, who have received extra oxygen.

Sepsis: An infection in the baby that must be treated with antibiotics.

Small for gestational age (SGA): An infant who is smaller in size and weighs less than average for an infant of the same gestational age.

Suction: Removing mucus from the baby's mouth, nose, or lungs through a soft flexible tube. Premature babies do not cough very well and need help in removing this mucus.

Surfactant: A foamy substance that naturally coats the air sacs of the lungs and helps them stay open. Sometimes when babies are born, they do not have enough surfactant to keep their lungs open. If this happens, doctors may prescribe artificial surfactant to help keep the baby's lungs open. If your care team believes surfactant will help your baby, they will explain how this is done.

Tachycardia: Heart rate that is faster than normal for the baby's age.

Tachypnea: Breathing rate that is faster than normal for the baby's age.

Ultrasound: A diagnostic imaging procedure that uses high-frequency sound waves to take pictures of internal organs.

Urinary tract infection (UTI): An infection of the bladder or kidneys. **X-ray:** A diagnostic imaging procedure that uses radiation to take pictures of internal organs.

Vital signs: Vital signs include temperature, heart rate, respiratory rate, and sometimes blood pressure. A baby's vital signs are checked often by the nurse.

Questions?

Your questions are important. Talk with a member of your baby's healthcare team if you have questions or concerns.

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Medical Equipment in the NICU

What you will see

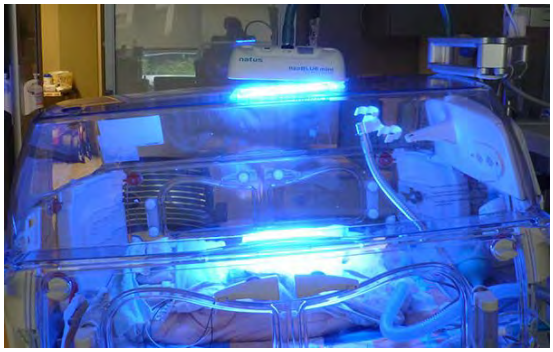
Accu-Chek: A machine that measures blood glucose.

Accu-Chek

Bili lights (phototherapy): Special blu lights that help break down bilirubin in babies with jaundice. The lights may be placed over the baby's incubator or placed beneath the baby in a "bili blanket." Bili lights do not affect the baby's skin or change their body temperature.

Bili mask: These soft cotton patches are placed over the baby's eyes during phototherapy.

Blanket warmer: This machine keeps bedding and clothes warm so that the baby will not lose heat when these items are changed. The warmer uses a blue light instead of white light. Blue light is easier on the eyes, uses less power, and lasts longer.



Bili lights

Breathing tube: A tube that connects to a ventilator to provide oxygen and breathing support to the baby. A breathing tube is also called an endotracheal tube. (See *Endotracheal tube*. Also see the photo on page 38.)

Blanket warmer

Chest tube: A small plastic tube inserted through the baby's skin and into the space between the lung and chest wall. This tube removes excess air, fluid, or both. A chest tube may be in place for several days until the problem goes away.

Continuous positive airway pressure (CPAP): A way to provide oxygen and keep the lungs expanded. A CPAP machine keeps a constant pressure of air in the baby's airways (*positive airway pressure*). It delivers pressure through a mask that goes over the baby's mouth.

Crib: A baby who is ready to leave the incubator is moved to a crib, also called a *bassinet*. The NICU has small cribs and large cribs. This move usually happens when the baby is able to maintain body temperature without losing weight, and is no longer having problems when outside the incubator.

Endotracheal tube (ET tube): A small plastic breathing tube that goes through the baby's mouth and down the windpipe. The ET tube is connected to a ventilator and provides extra oxygen to help the baby breathe. The tube is suctioned to remove mucus from the baby's lungs. (See *Breathing tube*. Also see photo on page 38.)

Feeding pump: A machine that delivers a set amount of food over a set period.

Feeding tube: A tube that may be used for feeding until the baby is ready to feed at the breast or from a bottle. (See photo on page 38.)

Feeding pump

Hand sanitizer: Gel with an alcohol base that kills germs that could cause infection. There is a hand sanitizer bottle outside and inside every patient room. Everyone who enters the room should "gel in," and then "gel out" when they leave.

Hand sanitizer

High-frequency jet ventilator (HFJV): A way to provide air to the baby. HFJV delivers small *tidal volumes* (the amount of air inhaled and exhaled with each normal breath) at very high speeds. Most babies breathe 40 to 60 times a minute. An HFJV breathes for a baby up to 650 times a minute. Air flows through the baby's breathing tube, and into their airway. The baby then exhales the air. A ventilator (see *Ventilator*) is used with the HFJV to provide back-up support. HFJV is very useful for babies who have breathing problems like *pulmonary interstitial emphysema* (see handout "Medical Terms in the NICU").

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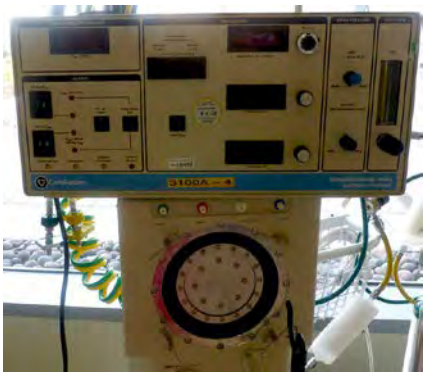
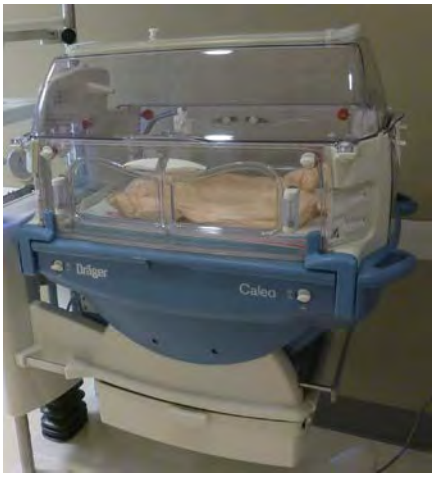
High-frequency oscillator ventilator (HFOV): A way to provide air to the baby. HFOV delivers small *tidal volumes* (the amount of air inhaled and exhaled with each normal breath) at very high speeds. A HFOV breathes for a baby up to 900 times a minute. It sends air through the breathing tube and into the baby's airway, then pulls air back out. HFOV is very useful for babies who cannot keep their *oxygen saturation* (level of oxygen in a baby's blood cells) in the normal range.



High-frequency oscillator ventilator

Incubator: An enclosed bed with clear walls that allows the care team to watch the baby. The temperature inside the incubator is adjusted to meet the baby's needs. Air in the incubator is circulated through a filter. Babies are moved to a newly sterilized incubator once a month to help prevent infection.



Incubator

Intravenous line (IV): A thin tube placed in one of the baby's veins, often in the hand, foot, or scalp. Fluids and medicines are given through the IV. (See photo on page 38.)

EPOC Machine: A handheld tool that quickly provides lab results for testing that is done at the bedside.

IV pole: If a baby needs an intravenous line (IV), an IV pole will be beside the baby's bed. Bags or syringes holding medicines and fluids will be placed on this pole. IV tubing is used to connect the bags or syringes to the baby's IV. (See photo on page 36.)

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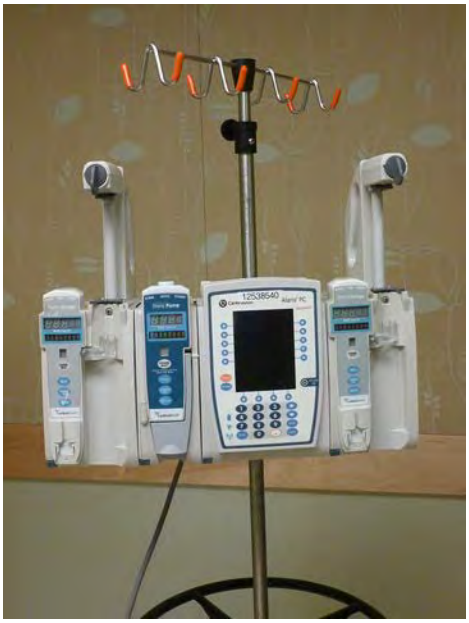
Leads: Small, sticky paper discs with wires that carry information about the baby's *vital signs* to a monitor. Several leads are taped on the baby's chest. Nothing enters the baby's skin. Also called *cardiorespiratory* leads. (See photo on page 38.)

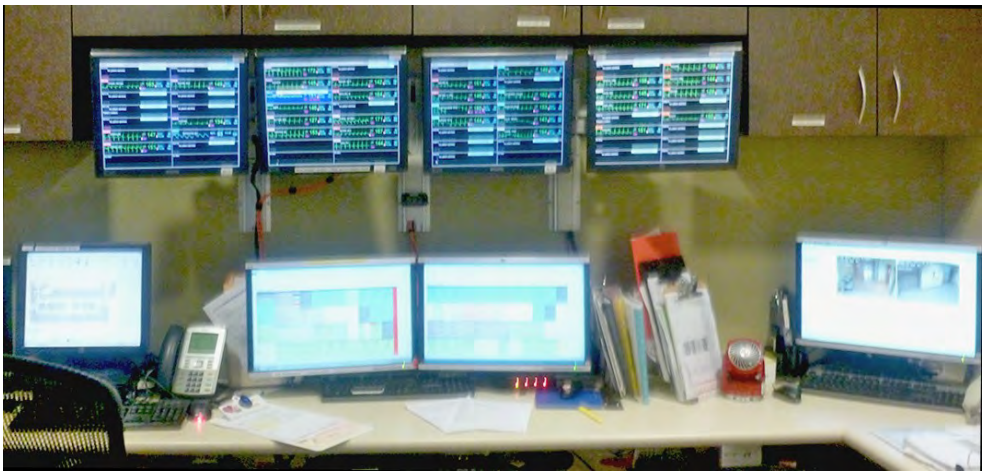
Leads help us monitor your baby's:

- *Respiratory rate*: The white number on the monitor shows how many breaths your baby takes in 1 minute.
- *Heart rate*: The green number on the monitor shows how many times your baby's heart beats in 1 minute.
- *Oxygen saturation*: The blue number on the monitor shows how much oxygen is in your baby's blood.



IV pole

Monitor: A screen that is used to watch and record the baby's vital signs. There is a monitor in each room. The information on the monitor is displayed other places in the unit as well, so that nurses can watch the baby's vital signs at all times. (See *Leads*.)



Monitors at the nurses' station

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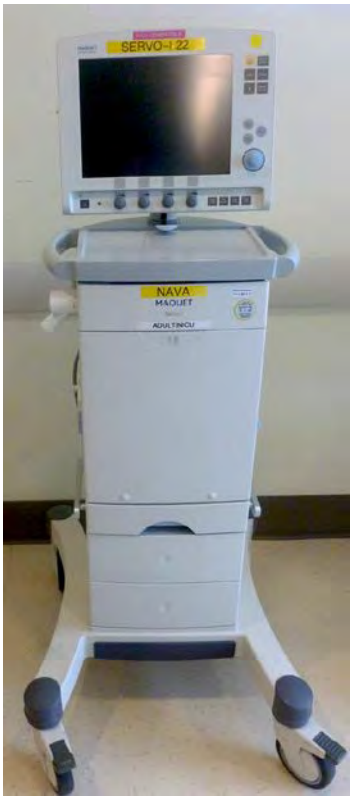


A NAVA machine

Nasal prongs: Thin, flexible tubes placed in the nostrils that deliver air flow and oxygen to the baby.

Near-infrared spectroscopy (NIRS): This device measures how well blood and oxygen are reaching the brain or kidneys. Small sticky leads are placed on the baby's head or back, or both.

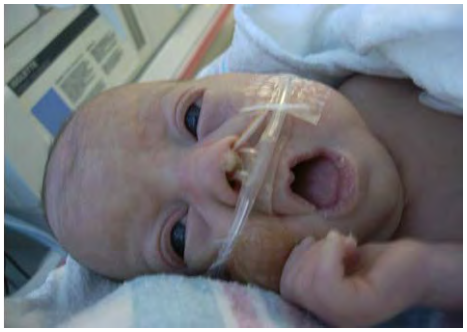
Neopuff: This machine is used to help babies who have stopped breathing. A nurse gives *positive pressure breaths* by hand to the baby using the Neopuff. There is a Neopuff machine in every patient room in the NICU.

Neurally adjusted ventilatory assist (NAVA): This machine helps the baby breathe while your baby is still intubated. A feeding tube in the baby's mouth or nose picks up the electrical signals sent by the brain to the diaphragm. These signals tell the machine what air pressure the baby needs.

A NAVA is often used as *non-invasive NAVA* (NIV NAVA) when a mask or prongs are used to provide air.

Nitric oxide (NO or "nitric"): A special gas that helps the baby's lungs use oxygen. It may be added to the oxygen that is given through nasal prongs or a ventilator *(see Nasal Prongs, Ventilator).*

Oximeter: A device that monitors how much oxygen is in the blood. (See photo on page 38.)

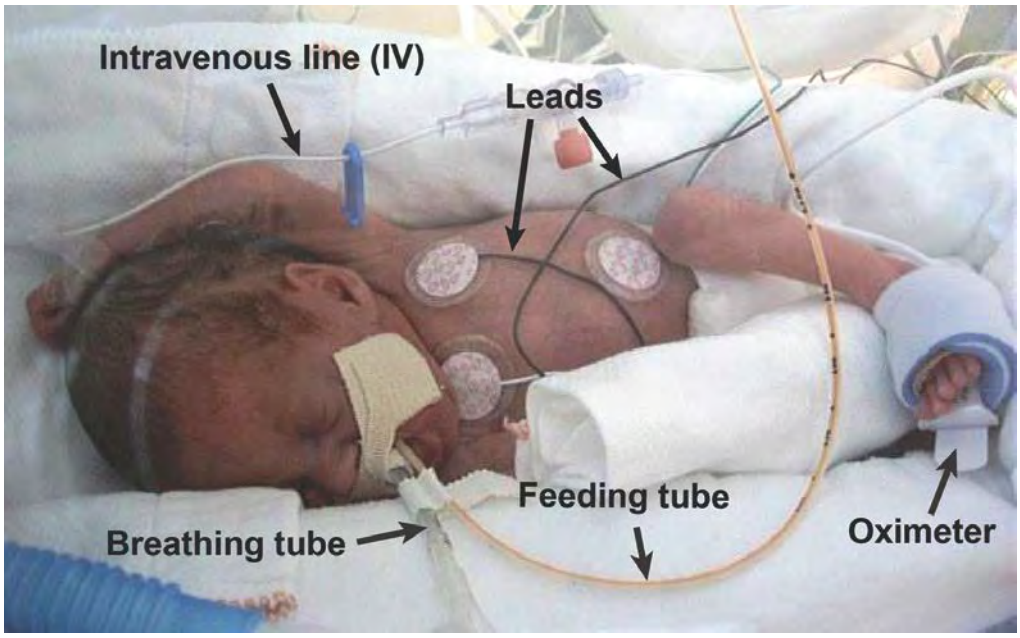


A baby with nasal prongs

A baby with NIRS leads
(Medtronic photo used by permission)

Neopuff machine

Oxygen: A compound in the air that all humans need to live. Room air is 21% oxygen. Babies who have a hard time breathing may receive up to 100% oxygen. The amount of oxygen needed is determined by the ABG *(*see *ABG* in the handout "Medical Terms in the NICU"*)*.



This baby has an IV, leads, a breathing tube (endotracheal tube), a feeding tube, and an oximeter.

Peripherally inserted central catheter (PICC): A kind of intravenous line (IV) that is used when a baby needs an IV for more than a few days. A PICC is a long, flexible tube. It is inserted into an arm or leg vein and threaded into a large blood vessel deep inside the body. It is used to give medicines, fluids, and nutrients. Placing a PICC means the baby will have fewer needle sticks than if regular IVs are used.

Stethoscope: A tool used to listen to the baby's heart or breathing. A stethoscope usually has a small disk called a chest piece that is placed against the baby's chest and 2 tubes that connect to earpieces.

Transcutaneous monitor (trans Q or TCoM): A monitor that shows an estimate of how much oxygen or carbon dioxide is in the baby's blood. A round sticky pad that contains wires (an *electrode*) is placed on the baby's skin. This electrode warms the skin and brings the blood closer to the surface. This way, the oxygen or carbon dioxide can be measured. The electrode is moved every 8 hours. The electrode may leave a red mark on the skin. This mark will go away about 24 hours after the electrode is removed.

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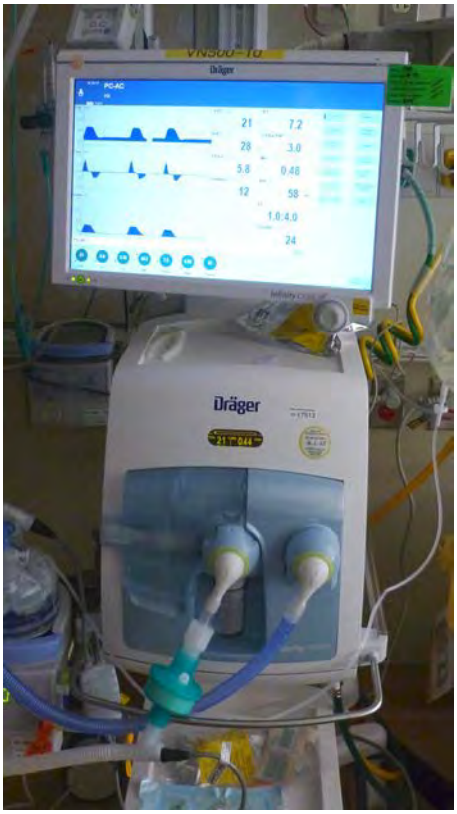
Umbilical artery catheter (UAC): A thin, flexible tube placed in an artery of the umbilical cord. The nurse uses the UAC to give the baby fluids, draw blood samples, and measure blood pressure.

Umbilical vein catheter (UVC): A thin, flexible tube placed in the vein of the umbilical cord. The nurse gives the baby fluids and medicines through the UVC.

Ventilator: A machine that helps the baby breathe. It delivers a certain number of breaths per minute, pressure to expand the lungs, and oxygen.

Z-Flo: A device that looks like a gel pillow. It holds babies in a comfortable position, even with their health condition and all the medical equipment around them.



Ventilator

Z-Flo device inside an incubator

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Notes

Questions?

Your questions are important. Talk with a member of your baby's healthcare team if you have questions or concerns.

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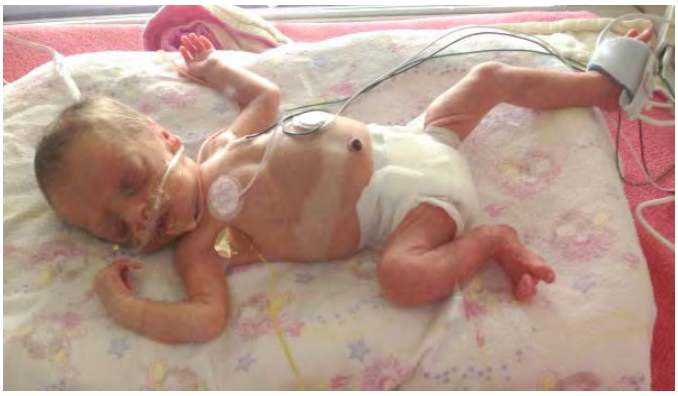
NICU Alumni: Kylie and Frankie

If you would like to read more about these alumni journeys, please visit Health Online at *https://healthonline.washington.edu* and click on "Neonatal Intensive Care Unit" in the Departments drop-down box.



Kylie in the NICU

Kylie at 8 months

Frankie in the NICU

Frankie at 2 years

Questions?

Your questions are important. Talk with your NICU doctor or nurse if you have questions or concerns.

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Your Baby's Unique Needs

How NICU staff care for your preterm or sick baby

This handout explains the care needs a premature or sick full-term infant might have, and how Neonatal Intensive Care Unit (NICU) staff will provide for those needs.

What causes a preterm birth?

A full-term pregnancy usually lasts 40 weeks. When a baby is born before 37 weeks, it is called a *premature* or *preterm* birth.

Please do not assume that your baby was born early because of something you did or did not do while you were pregnant. If you had a *high-risk pregnancy*, your doctor may be able to explain why you had an early delivery. But, we often do not know what has caused a premature birth.

Why is my full-term baby in the NICU?

A full-term baby may need to be in the NICU for many reasons. If you have any questions about why your baby needs to be cared for in the NICU, please ask your baby's care team.

How will NICU staff care for my baby?

The NICU is specially designed to care for premature and sick babies. When your baby is admitted to the NICU, the nurses and doctors will watch closely for changes in skin color, breathing, heart rate, temperature, and blood test results.

Common health concerns for premature and sick babies include:

- Nutrition needs
- Body temperature control
- *Respiratory distress syndrome* (RDS) (see page 29)
- *Sepsis* (infection) (see page 29)
- *Apnea, bradycardia*, and *desaturations* (see page 30)

NICU nurses and doctors will watch closely for any changes in your baby's health.

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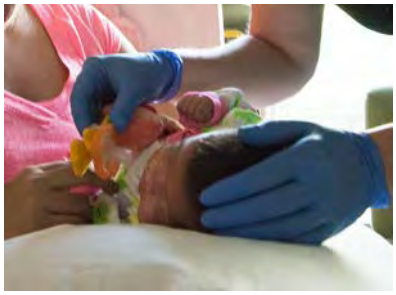

"The staff always kept me informed. We all worked together to get Austin healthy."

-- Austin's Mom

Please know that this handout does not cover all the health concerns your baby might have. And, all babies will not have all the issues that are listed in this handout. If you have questions about any issue your baby has, please talk with your baby's care team.

Nutrition Needs

Every day during rounds, a neonatal dietitian and the rest of your baby's care team will talk about your baby's nutrition needs. We want to make sure we are giving your baby everything they need for best growth and development. Your baby's age and weight will tell us what to feed.

Until your baby can eat by sucking from your breast or a bottle, we will feed fortified breast milk that you pumped or a nutrient-rich formula, along with other fluids. This feeding will be done in one of these ways:

- Through an *intravenous (IV) line*, a thin, flexible tube that goes directly into the baby's vein
- By *gavage*, a soft, flexible tube that passes through the baby's nose or mouth and into their stomach

Feeding is one of the earliest ways parents bond with their babies. This is why feeding by IV or gavage can be hard for parents at first. Your baby's care team will do their best to support and involve you as much as we can in your baby's feeding.

As soon as your baby is ready, we will help you breastfeed. If we cannot feed breast milk for any reason, we will feed a special formula for premature infants.

Supplementing Breast Milk

Breast milk contains nutrients that all babies need. But, since preterm babies have different nutritional needs than full-term babies, we may add these supplements to your baby's food:

- **Fortifiers:** Preterm infants need more protein, calories, and minerals than full-term babies. This is why we may add *fortifiers* to the breast milk your baby receives. Fortifiers are powders or liquids that contain protein, calories, and minerals such as calcium and phosphorus. These supplements build stronger bones and help your baby grow.
- **Probiotics:** We may add *probiotics* to your baby's food. Probiotics are bacteria that occur naturally in healthy intestines. We need probiotics for normal digestion. Live-culture yogurts and many cheeses contain some of these bacteria. To learn more, ask your nurse for the handout "Probiotics: For our most premature babies." You can also find the handout online at *https://healthonline.washington.edu*.

To learn more about fortifiers and probiotics, please talk with your baby's care team.

Breast Pumping

If you want to breastfeed your baby, start pumping your breasts regularly as soon as you can after your baby is born. We can feed your baby your breast milk through a gavage if your baby is not yet ready to go to your breast. Breast pumping will also ensure that you will have enough milk when your baby is able to breastfeed.

We can teach you how to pump your breasts and store your milk to use later. We will also answer your questions about breastfeeding your premature baby.

Ask your nurse for more information about breastfeeding and breast pumping. To learn more, ask your nurse for the booklet "Breastfeeding Your Hospitalized Baby."

Donor Milk

Your baby may also be eligible to receive donor breast milk. If this is an option for your baby, a member of the care team will talk with you about it. To learn more, ask your nurse for the handout "Donor Human Milk Program." You can also find the handout online at *https://healthonline.washington.edu*.

Feeding Readiness

The ability to suck on a pacifier is called *reflex sucking*. Most times, this skill develops before 28 weeks of gestational age.

We might think that if a baby can do reflex sucking, they are ready to start breastfeeding or feeding from a bottle. But the ability to do reflex sucking comes much earlier than the ability to suck milk from a nipple.

"Suck-swallow-breathe" sucking is needed for taking milk from a nipple. Most times, this skill does not develop until 33 to 36 weeks.

Most premature babies are ready to feed from the breast or bottle when they:

- **Are at least 33 weeks corrected gestational age.** Before this age, babies are not physically mature enough to manage sucking, swallowing, and breathing in the way that is needed when taking food by mouth.
- **Have stable vital signs.** This means that your baby's breathing rate is less than 70 breaths a minute, and their heart rate is mostly steady. (To learn more about what unstable vital signs mean, read about "ABDs" in the handout "Medical Terms in the NICU.")

If a baby is not old enough or does not have stable vital signs, it may be harmful to offer them a breast or bottle. The NICU care team will assess when your baby is ready to begin to breast or bottle feed.

When your baby is ready to feed from a nipple:

- First, try breastfeeding your baby. If that goes well, choose breastfeeding instead of bottle feeding as much as you can.
- If breastfeeding is not possible, we will use the same criteria for feeding readiness to know when your baby is ready to feed from a bottle.

Please note that feeding plans and goals are unique for every baby. We will work with you to decide the best feeding plan for your baby. To learn more about feeding, see "Safe Feeding" in *Getting to Know Your Baby and the NICU Therapy Team*.

If It Is Time to Try Breastfeeding

- The first step in trying breastfeeding is usually to offer a breast after it has been pumped.
- After your baby tolerates a pumped breast, it's time to offer a non-pumped breast.
- When breastfeeding has been working well for a long time, you can also try bottle feeding. But, choose breastfeeding over bottle feeding as often as you can.

Feeding is a complex skill for a baby. There are many steps to learn along the way. It may take time for your baby to learn all the things they need to do in order to be safe while eating. Try to be patient if your breastfeeding journey is different than you expected.

We have many tools and resources to help you and your baby find success with feeding. There are also many resources to support you with feeding after you leave the NICU. If needed, your healthcare team will make referrals for you after discharge.

Temperature Control

Premature babies have very little body fat. Their skin is thinner than a full-term baby's skin. This means they get cold easily.

To make sure your baby stays warm:

- Your baby will spend most of the time in an *incubator, a* plastic, enclosed bed with warmed and/or moist air.
- The care team will work to "cluster" your baby's care tasks. This means they will do several tasks at the same time. This way, your baby is not exposed to the cool air for very long.

Most times, your baby can come out of the incubator for you to hold. If your baby can handle it, hold them next to your body, skin-to-skin. This gives you the chance to hold your baby while the heat of your body helps keep them warm. This is called *kangaroo care*.

As your baby grows, they can be out of the incubator for longer periods. We can teach you how to dress your baby to stay warm while in your arms, even if you are not giving kangaroo care.

Respiratory Distress Syndrome

Some babies have *respiratory distress syndrome* (RDS). This condition occurs when a baby's lungs are immature and do not produce enough of a chemical called *surfactant*.

Surfactant is a soapy substance. It keeps the air sacs of the lungs open during *expiration* (breathing out). If the air sacs are not open, the lungs cannot exchange oxygen (O_2) and carbon dioxide (CO_2) as well as they should. This makes it hard for your baby to breathe.

When this happens, your baby's body will try other ways to get more oxygen and get rid of carbon dioxide:

- Your baby will begin to "grunt." This sound results from the effort needed to keep the air sacs open.
- Your baby will start to breathe faster. This occurs because many air sacs have collapsed, and the remaining open air sacs have to work harder. This rapid breathing is called *tachypnea* ("tak-**ip**-ne-ah").
- You will see indentations, called *retractions*, in your baby's chest during *inspiration* (breathing in).

Even with this extra effort, your baby will need help breathing until their lungs heal and produce more surfactant. Your baby's care providers will monitor your baby's progress and provide breathing support as long as it is needed.

Here are 2 ways we support a baby while their lungs heal and grow:

- We may give your baby extra oxygen through nasal prongs or a mask.
- If RDS is severe, we may use a *ventilator*, a machine that either helps the baby breathe or breathes for the baby.

To learn more about the equipment we use to help NICU babies breathe, see "Medical Equipment in the NICU" in the Table of Contents.

Sepsis

Sepsis is an infection in the bloodstream or body tissues. All babies, especially those who are premature, are more at risk for infection because their *immune systems* are not mature at birth. Immune systems are a healthy body's natural defense against infection.

Without a strong immune system, an infection can enter the body and spread. A baby can become infected while in the uterus, during delivery, or in the nursery.

In the NICU, infection is usually spread by skin contact. This is why visitors to the NICU must scrub and gel their hands. Hand washing is a vital part of lowering the risk of infection.

Apnea, Bradycardia, and Desaturations

Apnea, *bradycardia*, and *desaturation*s are 3 conditions that often occur together while a baby is still learning how to breathe. Here are descriptions of these 3 conditions:

Apnea (**ap**-nee-ah)**:** While inside the womb, a baby receives oxygen through the umbilical cord. At birth, the baby's lungs must start working to breathe in the oxygen that is needed to live. Sometimes, while the brain is maturing, a baby can "forget" to breathe for a short time. If the baby stops breathing for 15 seconds or longer, it is called apnea.

- **Bradycardia** (bray-dee-**car**-dee-ah): When apnea occurs, a baby's heart often begins to beat more slowly. If the heart rate drops below 100 beats a minute for 15 seconds or more, it is called bradycardia.
- **Desaturations** (dee-sat-ur-**a**-shuns): When a baby's breathing and heart rates slow, the baby's blood is not as *saturated* (full) of oxygen as it should be. This is called desaturation. Without enough oxygen, a baby's skin may start to look blue, often around the eyes and mouth (*cyanosis*). But some babies do not show any change in skin color. This is why we watch for signs of desaturation on a monitor.

Because these three conditions tend to occur together, we call them "ABDs" for short. Most premature infants have episodes of ABDs because their central nervous systems are still developing. This is why all babies admitted to the NICU are monitored for breathing and heart rate.

The baby's monitor alarm will sound if either of these occurs:

- Apnea lasts 30 seconds or more
- The heart rate drops below 100 beats per minute

Your baby's monitor can be seen from many other places in the NICU, and all alarms are sent to the nurse's phone. If the alarm sounds, a nurse always makes sure the baby starts to breathe again. Once the baby is breathing, the heart rate also returns to normal.

Each time apnea, bradycardia, or desaturation occurs, a nurse records the event in the baby's *electronic medical record*. The nurse also notes the time, the lowest heart rate, and how much stimulation was needed to get the baby breathing again:

- In a *spontaneous* ABD, your baby began breathing again or the heart rate increased without help.

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- In a *mild* ABD, your baby needed help to start breathing, in oneof these ways:
  - Gentle stroking
  - Nose or mouth suction
  - Position change
- In a *moderate* ABD, your baby needed stronger stimulation, such as:
  - Position change
  - Giving more oxygen
- In a *severe* ABD, the nurse needed to give the baby breaths and use a device to deliver extra pressure to the baby's lungs. Sometimes this includes giving the baby more oxygen.

Over time, as your baby's brain matures, ABDs will happen less often. The day will come when there will not be even a spontaneous episode of apnea, bradycardia, or desaturation.

Your baby's doctor may also prescribe daily caffeine for your baby. Caffeine has been shown to lessen problems with apnea.

If you have any questions about apnea, bradycardia, or desaturation, ask your baby's nurse or care provider. Ask your baby's nurse to review ABDs with you, or read about ABDs in the section: "Medical Terms in the NICU."

Notes

Notes

Questions?

If there is something you do not understand, please ask questions. Every question you ask is important!

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Caring for Your Baby

Developmental care

When babies are premature or sick, they are very sensitive. They may be overwhelmed by bright lights, loud noises, and even being touched.

We try to make their world as calm and comforting as possible so that your baby's brain and body can rest and grow. We do this by making the NICU as much like the womb as we can. This way of caring for a baby is called *developmental care*.

Developmental care for your baby means that we will:

- Place your baby in a comfortable and comforting position
- Keep lights low
- Keep sounds soft

There are many ways you can take part in your baby's developmental care.

Find Out What Helps Comfort Your Baby

It may be that caring for a baby in the NICU was not what you were expecting or hoping for. But, we hope it helps to know that we are here to partner with you. We want to support you in any way we can.

Your baby's stay in the NICU is the perfect time to learn the best way to care for your baby. The skills you learn here can help your baby keep growing and thriving after you go home.

While you are in the NICU, you will see that:

- Your baby's care team always handles your baby very gently.
- Your baby is calmer and more comfortable in some positions.

Your baby will be calmer and more comfortable in certain positions.

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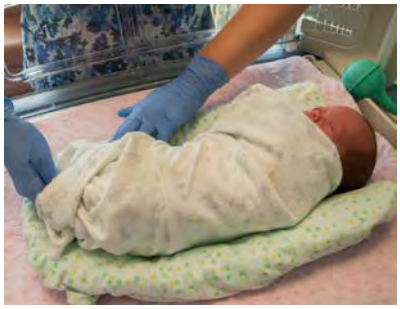

"I always felt guilty having my baby alone in a hospital room, but please know that your miracle needs time to grow. The best way they can do this is through sleep, just as they were doing in the womb."

-- Kylie's Mom

While your baby is in the incubator, we may use special positioning devices that are designed just for the NICU. These devices will help your baby stay in a position that is most calming.

Sleep Helps Healing

Babies do most of their healing and growing while they sleep. Ideally, your premature baby will sleep a lot. We want to avoid waking your baby, if we can. As preterm babies near full term and grow stronger, they start to stay awake longer.

Read Your Baby's Cues

Cues are the signals your baby uses to show their feelings and how they are coping with the world around them.

Cues that your baby is overwhelmed:

- Changes in breathing and heart rate
- Looking away
- Turning different colors
- Yawns
- Startles
- Hiccups
- Putting a hand over the face or behind the ear
- Stretching the arm out, with fingers spread out (*finger splaying*)
- Gags or vomits

Cues that your baby is stable and ready to be engaged:

- Good skin coloring
- Steady breathing and heart rate
- Turns toward sounds
- Calm, alert gaze
- Moves their hand to their mouth
- Smooth and steady movements
- Brings hands together over the center of their body
- Makes eye contact

Focus on One Sense at a Time

Preemies and sick babies are very sensitive to sounds, lights, and touch. Too much sensory stimulation can affect their healing and growth. Always watch your baby's cues for signs of too much stimulation.

To avoid overwhelming your baby, try focusing on only one sense at the time. For example, instead of talking and touching at the same time, talk to your baby first. Then, stop talking while you put your hands in the incubator.

Please know that if your baby shows signs of being overwhelmed, it does not mean that you have done anything wrong. Rather, it is a message to all their caregivers that it is time for rest and quiet.

Touch

Touch is the first sense to develop while a baby is still in the womb. It begins as early as 7 to 8 weeks of gestation. This is one reason a premature baby is very sensitive to touch.

Ask your baby's nurse to teach you how to use touch in a way that is best for your baby. Here are some tips:

- Keep your hands still when you touch your baby. Stroking or massaging can be too stimulating.
- Cup one hand behind your baby's head and the other hand on the bottom of the feet. Your baby may find this comforting, since it feels like the fetal position.
- Hold your baby skin-to-skin ("kangaroo care") as soon as you and your baby are ready for it. During kangaroo care, try putting your finger inside your baby's hand for your baby to hold. Do kangaroo care as often as you can.

Taste and Smell

Babies use their senses of taste and smell while they are still in the womb. In the NICU, your baby will use these senses to recognize you.

To help your baby get to know your smell:

- Do **not** wear perfumes or scented lotions when you visit the NICU.
- You may be able to place a cloth that smells like your breast milk in your baby's incubator. This smell is unique to you. It can help your baby connect and bond with you. Ask your nurse if this is something you can do.

Resources: Hand to Hold Resource Library documents, including *What Does That Mean,* and NANN's Baby Steps to Home handout *Developmental Care: Information for Parents*

Notes

Questions?

If there is something you do not understand, please ask questions. Every question you ask is important!

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Memories to Record

Special events you may want to remember

You may want to record special events in your baby's life in a journal or memory book. One of our alumni parents has created journals for our NICU parents to use. If you would like one, please ask your baby's nurse.

A memory book is a good place to write down the special events you want to remember.

Here are some ideas of what to include:

- First time you heard your baby cry
- First time you saw a tear
- First time you were able to change a diaper
- First time your baby was able to wear clothes
- First time you were able to touch your baby
- First time you saw your baby without any tubes, tape, or other devices
- Nicknames you or NICU staff gave to your preemie
- The names of your NICU neighbors
- Breathing needs
- Surgeries
- Medicines
- Blood gases
- Vital signs or other monitoring
- X-rays, scans, or other tests
- Any type of graduation, such as from NICU to Grad Unit, incubator to crib, or feeding tube to bottle feeding or breastfeeding

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- Dates your baby learned to suck, swallow, and breathe
- Temperature changes
- How siblings responded to being in the NICU
- Where you stayed while your baby was in the NICU
- Hospital or NICU transfers
- APGAR score (a number that shows how the birth process affected your baby)
- Nutrition or feeding issues
- Brain and nervous system issues
- Heart issues
- Measurements, such as your baby's head size, body length, or weight
- Therapies
- Developmental progress and growth

This information is adapted from a list by Erin E. Taylor, author of *Preemie Book of Memories*, a hardcover, spiral-bound book for recording events in a preemie's early months.

Questions?

If there is something you do not understand, please ask questions. Every question you ask is important!

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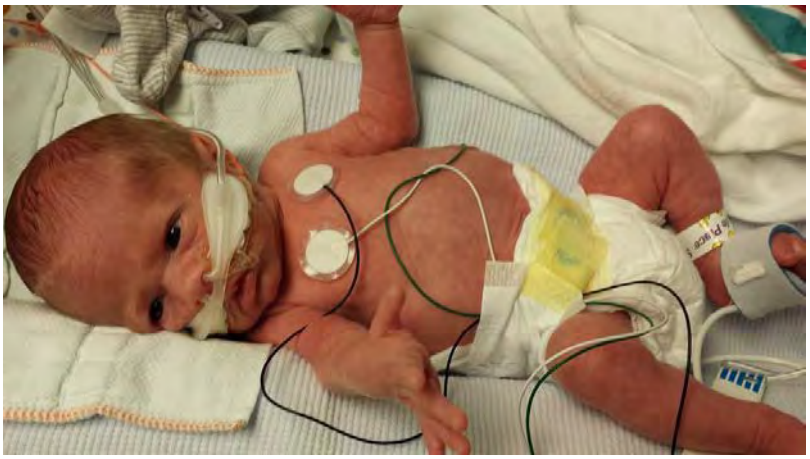
NICU Alumni: Wyatt and Austin

If you would like to read more about these alumni journeys, please visit Health Online at *https://healthonline.washington.edu* and click on "Neonatal Intensive Care Unit" in the Departments drop-down box.

Wyatt in the NICU

Wyatt at 9 months



Austin in the NICU

Austin at home

Questions?

Your questions are important. Talk with your NICU doctor or nurse if you have questions or concerns.

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Bonding with Your Baby

What to expect

You may not have been able to share your baby's first few minutes of life in the way that you had planned. When this happens, many parents worry that they have lost their chance to bond with their baby.

Your chance to bond is **not** lost if your birth experience was different than you expected. There are many ways you and your baby can bond while in the NICU.

Bonding can happen at many stages of your baby's development.

What will bonding with my baby be like?

Bonding looks different for every family. It is a very emotional and personal process. How bonding occurs will even vary among members of your family.

How you bond with your baby also depends on physical factors, such as your baby's gestational age and stability, and your own health. Some babies cannot be touched or held right away, while others can. Ask your baby's care team what is best for your baby at each phase of their growth and development.

How can I help the bonding process?

Here are some ways to help increase the bond you have with your baby:

Care for Yourself

- **Take care of yourself so you can take care of your baby.** Babies can tell whether you are stressed or relaxed. It helps bonding if you are calm, relaxed, and well rested when you visit.
- **Know what you're feeling.** Take deep breaths and check in with your emotions. Try to be aware of what you are feeling, and do your best to accept all of the feelings you have. When you are in tune with what is going on with you, it is easier to be in tune with your baby.

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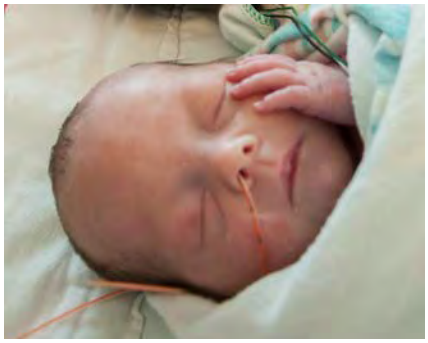

"The very first day of his life, we began a ritual that we have continued his entire life – we read books to him every day. It gave me something to do that felt like I was connecting with him, that felt like I was doing something."

-- Layne's Mom

"The first time I laid eyes on our babies was a very surreal and emotional moment. My babies looked so frail and lifeless with tubes and wires all over them. These babies I couldn't keep inside me were now my reality."

-- Timmy and Tessie's Mom

Use Touch to Bond

- Ask your nurse about the best ways to touch your baby. The answer will depend on your baby's gestational age and medical condition.
- Holding your baby skin-to-skin ("kangaroo care") creates an emotional and physical bond with your baby. It is also good for your baby's health.
- When you are not able to hold your baby, your touch lets your baby know you are there. Always touch your baby gently.
- If touching your baby is not possible, let your baby know you are there by placing your hands somewhere close to your baby.
- Notice what your baby likes and dislikes. This will help you know when they are most comfortable and ready to be touched.

Other Ways to Bond

- Visit your baby as often as you can.
- Bring pieces of your life into your baby's hospital room so they become a part of your baby's life, too. These could be items from your baby's room at home, a special blanket, pictures of family members, or other small items.
- Talk with your nurse about the best times to make eye contact and talk softly to your baby.
- Leave items that have your smell on them close to your baby's space. Always check with the nurse first if you want to put something very close to your baby.

Overcoming Barriers

All the medical equipment in the NICU can seem to keep you apart from your baby. Please try to overlook those barriers. You can learn new ways to bond even with all the equipment, ways you may not have thought about before.

Use the suggestions in this handout to get to know your new family member. You are just beginning your journey together, and hopefully the NICU will only be a small part of it.

Resource: Hand to Hold's *Bonding with Your Medically Fragile Baby* Resource Library

Questions?

Your questions are important. Talk with a member of your baby's healthcare team if you have questions or concerns.

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Becoming an Advocate for Your Baby

A guide for parents

Becoming a parent is a life-changing experience. This is especially true for parents of newborns in the NICU.

As a parent of a premature or ill infant, you may feel helpless at times. Everything in the NICU is new and unfamiliar, and in many ways, you have to rely on the doctors and nurses to know what is best for your baby.

But you are a vital part of your baby's care team, and there are many things you can do to help make your baby's hospital stay better. You can learn to partner with the care team and provide important insights into the best way to care for your baby. In the process, you will become an expert on your baby's care needs and an advocate for your baby.

How can I become an advocate for my baby?

Your relationship with your baby is special. Being the parent makes you the most qualified person to be your baby's advocate. And, there are things you can do to help you be the best advocate possible:

- **Learn more about your baby.** Spend time at your baby's bedside. Watch and listen. Find out what your baby is like.
- **Ask the care team a lot of questions.** You cannot ask too many questions. If needed, ask the same question over and over again until you understand the answer.
- **Get to know the team members who care for your baby.** Read the handout "Your Baby's Care Team." As your baby's advocate, feel free to ask the care team to explain what is going on. Make sure you feel your concerns are heard, and that you understand your care options.

Always ask the care team to explain anything that you do not understand.

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"I learned to be my child's biggest advocate. I learned that if I had questions, I needed to ask them, and that my concerns would be fielded with warmth and thoughtfulness."

-- Kylie's Mom

"Prepare to meet people who will impact your life in many ways. Trust your judgement and ask for nurses that you trust and bond with to care for your child when they are working. It will make your days and nights less lonely if you have someone you trust alongside you."

-- Timmy and Tessie's Mom

- **Don't wait – write down questions and concerns when you think of them.** After a busy day in the NICU, it can be hard to remember all the questions that came up during the day. And, it can be very hard to remember what you wanted to ask during rounds, once you are talking face-to-face with the doctors and nurses.

  Writing things down also helps you think through your questions so that you make sure that you get the information you need.

- **Ask about your baby's care plan.** You may have a lot of choices to make during your baby's stay in the NICU. When you know the care plan the providers have in mind, it can help you learn more about the choices you may have to make. Planning ahead while also being flexible can help keep your baby's care plan on track.

- **Trust your instincts.** No one knows your baby better than you do. And, you may notice subtle changes in your baby that might not be obvious to someone else. Share what you observe, ask questions, and insist if you have to. Your care team respects your insights as a parent.

Resource: Hand to Hold's *Advocating for Your Baby* Resource Library

Questions?

Your questions are important. Talk with a member of your baby's healthcare team if you have questions or concerns.

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Finding Your Emotional Balance

Adjusting to the NICU rollercoaster

A new baby is a source of joy and hope. But, when a baby needs care in the NICU, many other emotions mix with those happy feelings.

Many parents of babies in the NICU talk about being on "an emotional rollercoaster" because of all the emotions they feel during this time. In the first few days to weeks, you will likely feel shock, panic, love, anxiety, delight, anger, frustration, amazement, numbness, hope, sadness, relief, confusion, and more. Sometimes you will feel many emotions at the same time. This emotional ride is not easy, but it is very normal.

It can feel overwhelming to have a baby in the NICU. Doing everyday tasks can take a lot of effort. You may feel lost or confused. The best way to manage your stay is different for each person. You can find your balance, but it will take time.

The number of hours you spend in the NICU may change from day to day and week to week. Please take time for yourself, even if it's only a few minutes.

How you and your partner react to the stress of having your baby in the NICU will be unique to you. But, here are some things to keep in mind that may help you cope with the "rollercoaster":

It is normal to feel overwhelmed. Please take time for yourself.

- **Know that all of your feelings are normal.** The strength of your feelings and reactions will slowly lessen over time. But, you can expect that the emotional impact of having a baby in the NICU will be profound and will last for a long time.
- Having a baby in the hospital is stressful for relationships. **We all react to trauma in different ways.** Your partner may respond to this situation in ways that are familiar to you or that surprise you. And, your responses may surprise your partner. Keep talking with your partner so you can each understand what the other is thinking and feeling. If you or your partner need more support, please tell your nurse. UWMC has resources that may help.

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- **The "unknowns" of having a baby in the NICU can be emotionally tiring.** One way to lessen that uncertainty is to be as informed as you can. How well you understand what is going on will vary. Keep asking questions, especially if you do not understand something. Ask your care team to find other words to explain something that is confusing. Some parents find it helpful to write down questions and concerns as they think of them, so that they can ask the care team later.
- **NICU staff realize how hard this situation is.** We sympathize with your emotions. We have seen all kinds of reactions from NICU parents. We will not think less of you or care any less for your baby if you let your emotions show.
- **You will have both good and bad days in the NICU.** One day your baby will be showing progress, and the next day a problem may arise. This is normal for premature babies, but parents can feel discouraged and drained by these ups and downs. It is OK to feel disappointed or sad if it seems like your baby isn't making progress. Each baby is on their own journey. Hopefully, over time, you andyour baby will have more and more good days.

Resource: *The Preemie Parents Companion: The Essential Guide for Your Premature Baby in the Hospital, at Home and Through the First Year* by Susan L. Madden, MS

Quotes from NICU Alumni Parents

"Everyone at UWMC was awesome, but it didn't help the emotional roller coaster. Will she survive? That's what I needed to know."

– Frankie's Mom

"I wish someone had told me that setbacks happen, and not to let them discourage me."

– Austin's Mom

"Nobody prepared me for what it would be like to grieve no longer being pregnant, or how lonely it would feel to pump milk for my baby who was too little to feed, or how stressful it would be for care for my baby in the NICU, while also caring for myself and my marriage."

– Kylie's Mom

"At first, I struggled with a lot of guilt. It took a long time to understand that this wasn't my fault. I grieved the loss of being pregnant, having a baby shower, packing a bag for the hospital, and leaving the hospital with our baby."

– Lucy's Mom

"Layne went through so much the first month of his life – central lines, needing the ventilator, belly infections, heart surgery, blood transfusions. There were days when he would do well, and days when we thought we would lose him."

– Layne's Mom

"I wish I could say our stay in the NICU was uneventful, but it was filled with many traumatic moments for our family. I wish I would have been more prepared for when my son became very sick and almost didn't make it, more than any other moment in our whole NICU stay."

– Timmie and Tessie's Mom

"The hardest thing is eating and resting to take care of yourself. Those things need to be done even though you don't want to leave the NICU."

– Wyatt's Mom

Questions?

Your questions are important. Talk with a member of your baby's healthcare team if you have questions or concerns.

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NICU Alumni: Layne and Lucy

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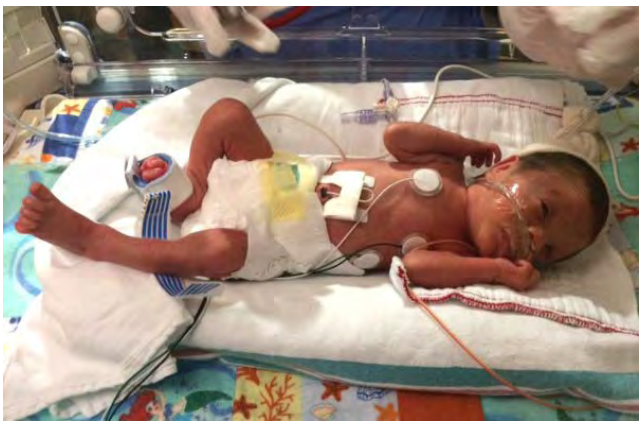
Layne in the NICU

Layne at 3 years



Lucy in the NICU

Lucy at 8 months

Questions?

Your questions are important. Talk with your NICU doctor or nurse if you have questions or concerns.

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When Can My Baby Come Home?

Planning for discharge

This handout explains what needs to be in place before your baby is ready to go home:

- *What your baby must be able to do physically*
- *What you need to learn about caring for your baby*
- *How to prepare yourself for taking your baby home*

Discharge Planning

The first thing many NICU families want to know is, "When can we go home?" *Discharge planning* is a process we will do together. We want to make sure you and your baby are as prepared as you can be to go home.

Your Baby's Health

Before it is safe for your baby to leave the hospital, your baby must:

- Be gaining weight regularly.
- Have a safe feeding plan with no breathing problems.
- Be able to maintain a normal body temperature when in an open crib.

Your baby is getting close to being able to go home when gaining enough weight.

- Not have needed stimulation after episodes of apnea, bradycardia, and deaturation (ABDs) for a certain length of time. The length of time will be based on your baby's unique needs. Please talk with your baby's care team about this.

Some NICU babies can go home even if they still need breathing or feeding support. We will talk with you if this might be true for your baby.

Tests and Treatments

When your baby has met the criteria listed above, your baby's care team will decide if more tests or treatments are needed before your baby can leave the hospital. Their decisions will be based on how prematurely your

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"I think families often reach a point in their NICU stay when they can see the finish line but can't quite get there. We had learned to care for our daughter, knew her noises and cues, and we wanted her home."

-- Lucy's Mom

baby was born. The care team will talk with you about what tests and treatments are needed.

These tests and treatments may include:

- An eye exam called a *retinopathy of prematurity* (ROP) exam
- A hearing test called a *brainstem auditory evoked response* (BAER) test
- A test called the *angle tolerance test* (ATT) to make sure your baby will be safe sitting in a car seat on the way home
- Immunizations (vaccines)
- Screening and treatment for *respiratory syncytial virus* (RSV)
- Assessing your baby for special home equipment and home care needs

Learning for Parents

The discharge process also involves learning for parents. Your readiness to take your baby home is just as important as your baby's health. This is both for your baby's well-being and for your own.

We encourage you to take part in caring for your baby as soon and as often as you can during your baby's NICU stay. This will help you learn many of the things you need to know to take care of your baby at home.

Getting Ready to Go Home

We have made a "Discharge Checklist" (see page 71) that you can use to keep track of all the steps that need to be done and information you need to know before your baby can go home with you. Everyone who will help you care for your baby at home needs to be ready. Ask your nurse for this checklist if you do not have it already.

Questions?

If there is something you do not understand, please ask questions. Every question you ask is important!

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References: NANN's *Preparing to Take Your Baby Home: Information for Parents* and Module AAP's *Hospital Discharge of the High Risk Neonate-Proposed Guidelines*

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Discharge Checklist

Getting ready to take your baby home

Plan for Your Baby's Healthcare Visits

Choose a primary care provider for your baby at least 2 weeks before your baby will leave the hospital.

- ❑ Choose a primary care provider (PCP) for your baby (see handout "Choosing a Primary Care Provider for your Baby"). Make sure that the PCP accepts your baby's health insurance.

  PCP's Name: _____

  Phone: _____

  Address: _____

  _____

  _____

- ❑ Call your baby's PCP 3 to 5 days before discharge from the NICU to set up your 1st visit. This visit should be 1 to 2 days after discharge.

  Date: _____ Time: _____

- ❑ If needed, a visit at the Infant Development Follow-up Clinic at the UW's Center on Human Development and Disability (CHDD):

  Date: _____ Time: _____

- ❑ See "Other Healthcare Visits" on page 56.

Screenings

These exams are done during your baby's hospital stay, before discharge:

- ❑ Hearing screen: Date: _____

  Results: _____

- ❑ Eye exam (ROP), if needed: Date: _____

  Results: _____

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"The day I got to bring Austin home was both exciting and scary. But, the NICU staff prepared me very well for taking him home."

-- Austin's Mom

Safe Feeds and Feeding Instructions for Home

(See handouts "Breastfeeding Your Preterm Baby at Home" and "Bottlefeeding Your Preterm Baby at Home.")

- ❑ Type of milk _____
- ❑ Recipe for milk _____
- ❑ Practice mixing milk with nurse _____
- ❑ How much your baby needs (based on your baby's weight on the day of discharge):
  - ❑ At each feeding _____
  - ❑ Every 24 hours _____
- ❑ How often to feed _____
- ❑ How to tell if baby is getting enough milk _____
- ❑ Know who to call if baby is having trouble feeding _____
- ❑ How to store milk _____
- ❑ How to thaw milk _____

Breastfeeding

Meet with a lactation consultant before discharge to talk about:

- ❑ Plans and goals for breastfeeding or pumping milk: _____

  _____

  _____
- ❑ How to progress to fully breastfeeding and what to expect: _____

  _____

  _____
- ❑ What to do with rental breast pump after discharge (either return it or rent it longer):

  _____
- ❑ Arranging for a breast feeding scale, if needed: _____

  _____
- ❑ Getting a pumping/feeding record sheet

After discharge, if you have questions about lactation or would like to make an appointment with a lactation consultant at UWMC, call 206.598.4628.

Immunizations

(See your packet for the immunization schedule from the Center for Disease Control and education handouts about immunizations.)

Use this table to track when your baby received vaccines. Also keep track of when you read the handout or the brochure about the vaccine and when you signed the consent form.

Name	Usually Given	Dates Given
Hepatitis B	At discharge or at 2 months	
Dtap, Hep B, Polio	At 2 months	
Pneumococcal	At 2 months	
Haemophilus B	At 2 months	
Synagis	Only given to some patients (seasonal)	

- ❑ Receive immunization card/record from UWMC

Medicines and Vitamins

Use this table to keep track of your baby's medicines and vitamins. Include the name, the dose, and when you need to give it to your baby.

Name	Dose	Time to Give

- ❑ Receive teaching on each medicine or vitamin that you need to give at home:
  - ❑ What the medicine or vitamin does
  - ❑ How often to give it
  - ❑ When to give it
  - ❑ How much to give
  - ❑ How to store the medicine or vitamin
- ❑ Before discharge, practice drawing up and giving each medicine or vitamin

Safe Travel and Car Seats

(See handout "Safe Travel.")

- ❑ Get a car seat. Do this at least 1 week before discharge.

  – Ask your nurse about car seats you can buy from the NICU.

- ❑ If you are buying a car seat from the NICU:
  - ❑ Ask your nurse for a cashier form.
  - ❑ Pay the hospital cashier (weekdays only).

    – If it is a weekend, ask your nurse how to pay for the car seat.
  - ❑ Return the receipt to the NICU.
- ❑ Read car seat materials.
- ❑ Ask about the NICU car seat class. Sign up to take the class, if you can.
- ❑ Watch the NICU car seat video.
- ❑ Bring the car seat to your baby's room to make sure it works for your baby:
  - ❑ Place your baby in the car seat and adjust the car straps correctly.
  - ❑ Secure your baby in the seat.
  - ❑ Place the empty car seat/base in your car and practice adjusting the seat belt.
- ❑ Call 1.800.BUCKLUP or visit *http://800bucklup.org* to check for car seat recalls and information.
- ❑ Your baby's car seat:
  - ❑ Name: _____
  - ❑ Model #: _____
  - ❑ Manufacturer date*: _____

    *Car seat must be less than 6 years old.
- ❑ Car Seat Angle Tolerance Test (ATT):*
  - ❑ Date: _____
  - ❑ Result: _____

    *Your baby's nurse will set this up.

Learn About Your Baby's Safety and Care

- ❑ **Watch safety videos**: You can ask to watch these any time. Tell your nurse when you are ready to watch them in your baby's room.
  - ❑ "Back to Sleep"
  - ❑ "CPR"
  - ❑ "Period of Purple Crying"
  - ❑ "Car Seat"
- ❑ **Learn more about safety:** Your baby's safety is a top priority, and we want to give you all the information you need to be an expert on keeping your baby safe.
  - ❑ Learn about safe sleep for your baby and how to check your baby's sleeping environment for safety (see handout "Safe Sleep")

    _____
  - ❑ Learn about checking your house to see if it is safe for your baby (see handout "Safe Home")

    _____
- ❑ **Learn care methods:** You will be learning how to care for your baby every day. Talk with your nurse if you have any questions about how to care for your baby. (See handout "Basic Baby Care.")

  Learn about:

  - ❑ Elimination patterns_____
  - ❑ Using a bulb syringe _____
  - ❑ Giving a bath_____
  - ❑ Protecting your baby's skin _____
  - ❑ Adjusting the temperature _____
  - ❑ At home _____
  - ❑ For bath _____
  - ❑ For weather and outings_____
  - ❑ Signs of infection and how to protect your baby from infection (see handouts "Signs of Infection" and "Protecting Your Baby from Infection")

    _____
  - ❑ Signs of breathing problems (see handout "Signs of Breathing Problems")

    _____

Social Work

- ❑ Call and meet with the NICU social worker before discharge, if needed.
- ❑ Enroll your baby in a healthcare plan.
- ❑ Know if your baby can have a public healthcare nurse after discharge.
- ❑ If your baby has SSI benefits, call the Social Security office after your baby goes home.
- ❑ Sign up for WIC, you are eligible.

Notes/Questions: _____

Motor and Feeding Therapists

- ❑ Call and meet with your therapist before discharge, if needed.
- ❑ Ask about the NICU therapy discharge packet.

Notes/Questions: _____

Other Healthcare Visits

"As we got closer to taking Lucy home, it began to feel like the goal was just around the corner, but we couldn't quite get there. Then, suddenly, we were leaving the hospital with our daughter. Everything was surreal!"

-- Lucy's Dad

Day of Discharge

- ❑ Bring your name band that matches your baby's hospital number and/or your photo ID (driver's license).
- ❑ Bring clothes for your baby to wear home.
- ❑ Bring extra blankets for the car seat.
- ❑ Bring a cooler or insulated bag to take home your frozen breast milk.
- ❑ Collect all of the items around your room. Make sure to take your baby's name sign, and any crafts, pictures, or toys you brought into your room.
- ❑ Take home your baby's photo disc.
- ❑ Sign a "Consent for Contact" form if you want us to tell you about NICU events. These may include reunions, volunteer opportunities, and other events.
- ❑ Complete the survey that gives us your feedback about your infant's time in the NICU.

When You Are at Home

(See handout "Taking Your Baby Home.")

Visit our public Facebook page! Our Facebook name is "University of Washington NICU Alumni." On this site, you can:

- Keep us updated on your baby's progress
- Follow the lives of other UW NICU graduates and their families

More Room for Your Notes and Questions

Questions?

If there is something you do not understand, please ask questions. Every question you ask is important!

Neonatal Intensive Care Unit: 206.598.4606

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Choosing a Primary Care Provider for Your Baby

Tips for parents of NICU babies

One of the most important decisions that you will make as a new parent is choosing a primary care provider (PCP) for your baby. This healthcare provider will take care of your baby's medical needs after discharge. **We suggest you choose a provider who specializes in pediatric care** instead of a general practitioner.

Start thinking about who will be your baby's PCP now, while your baby is still in the NICU. Then, please choose your baby's PCP at least 2 weeks before your baby is discharged from the hospital. After your baby is discharged, we will send your baby's PCP:

- A copy of your baby's discharge summary
- A recap of everything that happened during your baby's hospital stay

How do I find the right PCP for my baby?

- Ask your health insurance company for a list of providers in your area that are covered by your insurance plan. (Look on your health insurance card for their customer service phone number.) If you have questions about your health insurance plan, please ask to talk with the NICU social worker.
- If you would like help choosing a PCP from the list, please ask the NICU care team.
- Once you have chosen a PCP, call their office. Ask if they are accepting new patients with your insurance. If they are, be ready to ask questions from your list (see next page). Find out if they are a good fit for you and your baby.

See your baby's primary care provider within 1 to 2 days after your baby is discharged from the hospital.

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Questions to Ask

Here are questions to think about when you are looking for a PCP for your baby:

- Does the PCP have training and experience in caring for high-risk infants?
- Does the PCP support you in your beliefs about issues such as breastfeeding, circumcision, feeding, and day care?
- Does the PCP offer lactation support in their office or clinic?
- Are you comfortable talking with the PCP? Do they listen to your concerns and respect what you say?
- Does the PCP have office hours that fit your family's needs?
- How does the PCP handle calls when the office is closed? Is there an after-hours phone number for parents to use if they have questions?
- How quickly does the PCP call back, if you leave a message?
- Is the PCP willing to answer your questions by phone or email?
- Is the PCP's office easy for you to get to? Is it close to your home or office? Is there parking nearby?
- Will you always see your PCP for visits or will you see other care providers in the same office from time to time?

Next Steps

Once you have chosen your baby's PCP:

- Give the PCP's name and contact information to NICU staff.
- Schedule an office visit with the PCP for 1 to 2 days after your baby has been discharged from the NICU. Try to set this up before your baby leaves the hospital.
- Tell the NICU care team the date and time of your baby's first PCP visit.
- If you need an interpreter, arrange to have one at your first visit.

Questions?

Your questions are important. Call your doctor or healthcare provider if you have questions or concerns.

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Breastfeeding Your Preterm Baby at Home

Your baby's home care plan

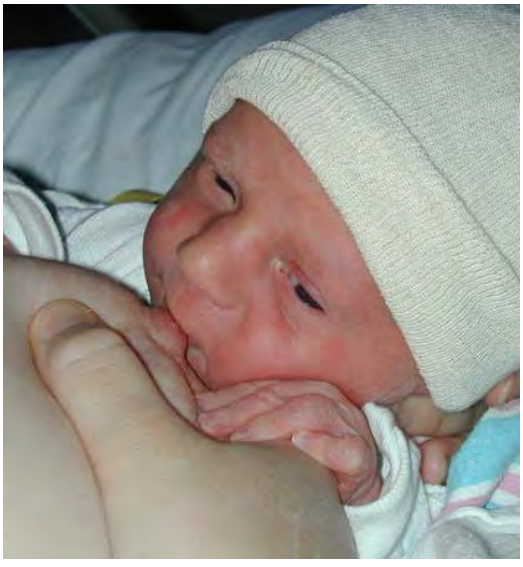
As we prepare you and your baby for discharge, we will work with you to create your baby's home care plan. You may talk with your baby's care providers, nurses, feeding therapists, nutritionists, breastfeeding resource nurses, and lactation consultants. You have many resources to help you create a plan that you feel comfortable and confident about!

Even if you started breastfeeding your baby in the hospital, you will need to be patient with yourself and your baby when you start to breastfeed at home. A full-term baby may nurse for 20 to 30 minutes, but a preterm baby may not have the energy to nurse that long.

You can call a NICU lactation consultant at 206.598.4628 if you have questions. Be sure to get the support you need.

What to Do

- Feed your baby when you see early "feeding cues" such as fluttering eyelids, making noises, moving arms and legs, and sucking motions.
- Offer your breast every time your baby is hungry, and give your baby time to latch on. Do this at least 8 to 12 times in 24 hours.
- Read your discharge sheet. Your NICU doctor may have advised you to supplement with pumped breast milk or formula if your baby:
  - Nurses less than 10 to 15 minutes
  - Does not latch on after 5 minutes of trying
  - Shows signs of stress, such as wrinkling the brow, stretching hands (this is a sign to stop), or fussing at the breast



Be patient with yourself and your baby as you start to breastfeed at home.

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- You should be able to breastfeed longer and supplement less as your baby grows. Keep supplementing until your baby is nursing at each breast for 15 to 20 minutes and is gaining weight well.
- Keep pumping to maintain your milk supply, even if you supplement. Pump after each feeding, or 8 times in 24 hours, until your baby is nursing at each breast for 15 to 20 minutes and is gaining weight well.

Questions?

If you do not understand something, please ask questions. Every question you ask is important!

- Ask any care provider when you do not understand a medical term.
- Ask for more information when you do not understand a treatment or why it needs to be done. Ask about possible side effects.
- Keep asking questions until you feel you understand what you need to know.

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Bottle Feeding Your Preterm Baby at Home

Your baby's home care plan

As you prepare for discharge, we will work with you to create your baby's home care plan. You may talk with your baby's care providers, nurses, feeding therapists, and nutritionists. You have many resources to help you create a plan that you feel comfortable and confident about!

Feeding Reminders

- Feed your baby every 2 to 4 hours. If your baby sleeps longer than 4 hours, wake your baby for a feeding.
- When and how much your baby eats at a feeding will vary. Focus on the total amount your baby takes over the whole day, not the amount taken at 1 feeding. Follow the instructions on your baby's discharge sheet.
- It is OK to give your baby breast milk or formula that is at room temperature. If the milk is cold, stand the bottle in a bowl of warm water for 15 minutes. Before you feed it to your baby, drip a little onto your wrist. It should feel warm, not hot.
- **Do not microwave breast milk or formula.** It will not heat evenly and can burn your baby. And, important vitamins may be destroyed.
- Hold your baby and the bottle while feeding. Do not prop up the bottle. Doing so can cause your baby to choke.

Be sure to hold both your baby and the bottle during feedings.

- Avoid changing nipple types when you first take your baby home.

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Formula and Bottle Care

- At first, your baby may be on a formula that contains iron and extra nutrients. If your baby is on formula:
  - Use it as directed on the discharge sheet. Your baby's pediatrician will tell you when to change formulas.
  - Throw away formula that has been at room temperature for 1 hour or more after feeding begins.
  - After 24 hours, throw out any prepared formula that was not used.
- Clean bottles and nipples with soap and clean, hot water.

Questions?

If you do not understand something, please ask questions. Every question you ask is important!

- Ask any care provider when you do not understand a medical term.
- Ask for more information when you do not understand a treatment or why it needs to be done. Ask about possible side effects.
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Safe Travel

Car seat and safety tips

Choosing the Right Car Seat

There are many car seat types and models. It can be a challenge to know which one is right for your infant.

When you look for a car seat, remember that some models are better suited than others for preterm babies. The right one will fit both your baby and your car.

Once you get the right car seat, be sure to use it correctly every time you travel.

A baby in an infant car seat.

Car Seat Checklist

Here is a checklist to help you to know if your car seat is safe. **All of these items must be true for your car seat to be safe to use:**

- ❑ My car seat is the right size for my infant. (Check your car seat's height and weight limits.)
- ❑ My car seat fits in my car. (Read the installation instructions for your vehicle and for the car seat.)
- ❑ My car seat has never been in an auto accident or crash.
- ❑ My car seat does not have any missing parts.
- ❑ My baby's shoulders are at or above the shoulder straps in the car seat.
- ❑ My car seat does not have any cracks in the frame.
- ❑ My car seat is not more than 6 years old.
- ❑ My car seat has instructions, either a manual, booklet, or a sticker on the seat.

How to Use Your Car Seat Safely

- The car seat should face the back of the car ("rear-facing") until your baby is at least 2 years old, or until their weight and height are greater than the guidelines for the car seat. Children under 2 who ride rear-facing are 5 times safer than those who ride facing the front.

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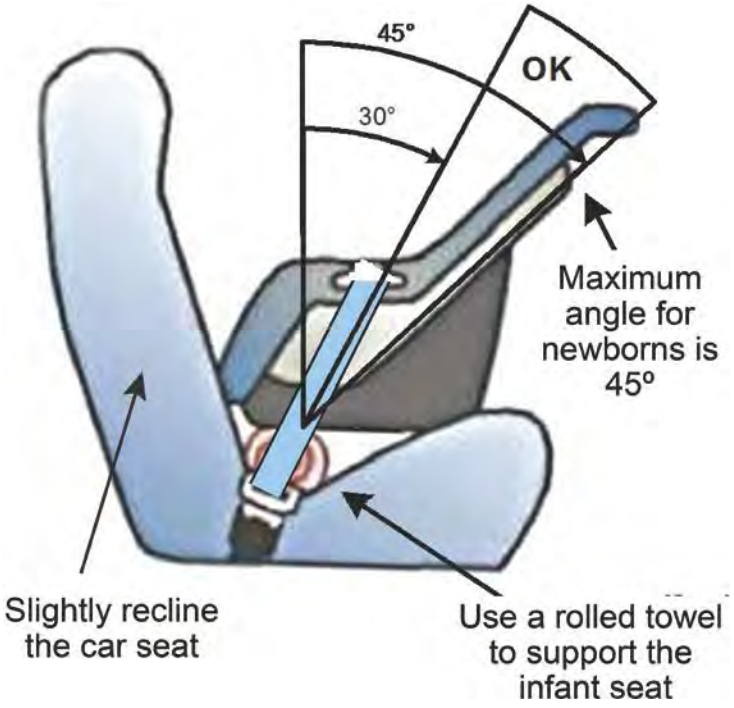
- You may want to buy a seat that you can adjust as your baby grows, in case your baby outgrows their car seat before their 2nd birthday. Some car seats can be used both rear-facing and front-facing. Please see the handouts "A Reference for Proper Child Restraint Use" and "Always Buckle Your Kids" that are included in your NICU materials.
- Car seats must be placed on a vehicle seat that faces forward. Do not place your infant car seat in a seat that faces sideways or backwards.
- It is safest to put the infant car seat in the center rear seat, if it will fit properly. The back of the infant car seat must not touch the back of either front seat of the vehicle. Check your car manual to see if it shows the safest place to put an infant car seat in your vehicle.
- **Never** place a rear-facing car seat in front of an active air bag.
- Install the infant car seat at no more than a 45° angle (see drawing on this page). Read the car seat manual for instructions.
- The handle should be locked and in the correct position when the car is moving. Read the car seat manual for instructions.
- When you are securing the car seat in your car, give a firm tug on the car seat where the vehicle's seat belt threads through the car seat belt path. The car seat should move no more than 1 inch in either direction.



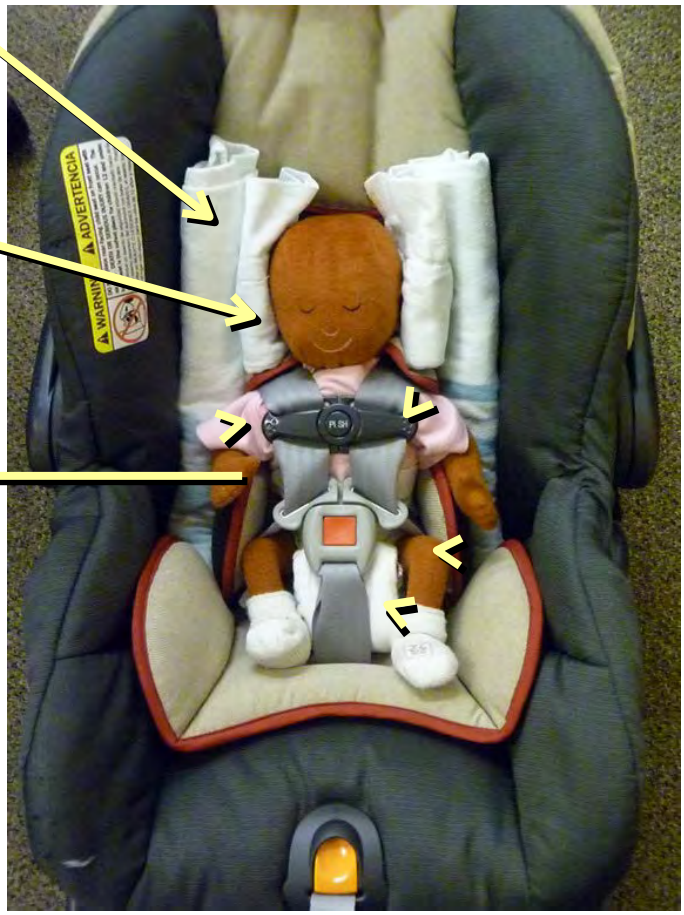
- Do **not** use products with your car seat that did not come with it. These products could interfere with how the seat performs in a crash and could put your baby at risk. These include fleece inserts, head rests, attachable toys, belt tighteners, and other items.
- It is OK to use soft fabric to help position your baby, if you learned how to do this at your baby's car seat test in the NICU (see photo on page 3).
- Do **not** put anything extra under, behind, or between your baby and the straps.

How to Place Your Baby in a Car Seat

Side rolls that go from head to bottom to help keep the baby upright for best breathing.

Rolls on both sides of the head provide extra head, neck, and airway support. These rolls sit right on top of baby's shoulders.

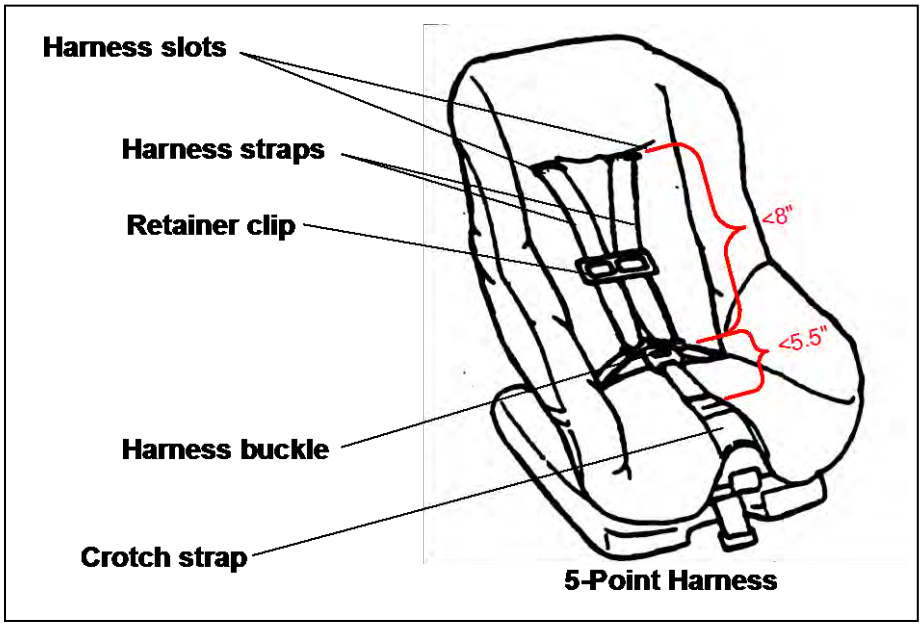
The baby's shoulders should be at or above the shoulder slots in the car seat. Straps should lie smooth and snug over the baby's shoulders. To test this, try pinching the straps over the baby's shoulders. You should not be able to pinch the strap between your fingers.



The harness clip should be at armpit level. If you put your finger on either side of the harness clip, your fingers should just touch the baby's armpits. If you touch the shoulder, the clip is too high. If you touch the tummy, the clip is too low.

The straps should lie flat and smooth over the baby's thighs.

If there is extra room between the baby's diaper and the crotch strap, roll up a cloth diaper and place it between the crotch and the strap. This helps secure the baby's bottom to the back of the car seat.



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Remember:

- Do not use any item that did not come in the box with your car seat. It is not safe.
- You may use a towel or cloth diaper to help position your baby, if you learned how to do this during your baby's car seat test in the NICU.
- Even if a product says it is "crash tested," it may not have been tested with your car seat. Be sure to read which car seat models it was tested with.
- The American Academy of Pediatrics advises that all babies ride rear-facing until they are at least 2 years old. The safest practice is for babies to stay rear-facing until they reach the weight limit of their car seat.

Learning More About Car Seat Safety

- If your car seat is not safe to use, UWMC sells car seats at an affordable price. Please ask your heathcare team if you have any questions.
- If you have questions about car seat safety, see the card from the Safety Restraint Coalition that is included in your NICU materials.
  - Get the most up-to-date information about car seats
  - Find out if your car seat has been recalled
  - Find the nearest place to have your car seat checked
- Take a baby safety class. UWMC offers a class called "Babysafe." To learn more about this class, call 206.789.0883 or visit *www.uwmedicine.org/ Patient-Care/Our-Services/Medical-Services/Obstetrics/ patient-education/Pages/classes.aspx*. The "Babysafe" class is listed near the bottom of the page.
- Visit the "Parents Central" page of the National Highway Traffic Safety Administration website at *www.nhtsa.gov.parent/index/htm*. The site gives current car seat information, installation tips, instructional videos, and more.
- Visit the Safe Kids Worldwide website at *www.safekids.org/car-seat*. In the "Safety Tips" column on the left, under "Risks," click on "Car Seats," "Boosters Seats," and "Seat Belts."

Use sunglasses to protect your child's eyes from bright sunlight.

Basic Car Safety

- On hot days, make sure that the car seat straps and buckles are not too hot before you place your child in the seat.
- Never leave your child alone in the car, not even for a minute.
- Use sunglasses to protect your child's eyes from bright sunlight.
- Don't forget that your child is in the car, especially on days when your routine is different than usual. Create a reminder by putting something in the back of the car next to your child, such as a briefcase, purse, or cell phone that you will need when you get out of the car.
- Toys, especially toys that are small or loose, can injure your child in a car crash:
  - Choose soft toys for your child to play with in the car.
  - Secure all loose objects and toys to protect everyone in the car.

Bike Safety

- Infants younger than 12 months are too young to sit in a rear bike seat, and should not be carried on a bicycle.
- Do not carry infants in backpacks or carriers while using a bike.

Stroller Safety

- Choose a stroller with a wide base so it won't tip over.
- To avoid tipping your stroller, do not hang anything from the handles.
- Always use the stroller seat belt and harness. Use rolled-up baby blankets on both sides of your child's head to add support, if needed.
- Before placing your child into the stroller:
  - Open the stroller all the way
  - Make sure the hinges are fully engaged
  - Make sure the wheels are locked
- If you string toys across the top of the stroller, make sure they cannot fall on top of your baby.
- **Always lock the stroller wheels when you stop.**

Safety When You Are Shopping

- It is best to use a front carrier or a stroller while you shop.
- It is best not to place your child in a shopping cart. If you have to place your child in the cart:
  - Make sure your child is securely positioned with the straps that come with the cart.
  - Check all straps and buckles. If they are broken, use another cart.

Wipe cart handles and surfaces with sanitizing cloths. These cloths are often provided by the store, or carry some with you, just in case.

Questions?

Your questions are important. Call your baby's doctor or nurse if you have questions or concerns.

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Safe Sleep

Protecting your baby during sleep

Sudden infant death syndrome (SIDS) and other sudden, unexpected infant deaths can occur in the first year of life. Follow these safe sleep rules to give your baby the best chance to stay safe during sleep.

"ABCs" of Safe Sleep

The "ABCs" of safe sleep are that babies should always sleep:

- **ALONE**
- On their **BACK**
- In a **CRIB**

Alone

- The safest place for your baby to sleep is **near** your bed, but in your baby's own "sleep space" (a crib or bassinet). Babies who share a bed with an adult or another child increase their risk of SIDS, suffocation, and accidental death.
- When you share a room with your baby, with your baby's sleep space near you, you can easily comfort or feed your baby as needed.
- It is dangerous to fall asleep with your baby on the couch or in an armchair. If you are sleepy, put your baby in a safe sleep space.

Back

- **Always** put your baby on their back to sleep, even for a short nap. Side and tummy positions are not safe. Your baby is **not** more likely to *aspirate* (suck fluid into their windpipe) lying on their back.

Crib

- Use a crib that meets safety standards. The mattress should be firm and fit snuggly in the crib. Use only a tight-fitting crib sheet.
- Do not use wedges or positioners to prop your baby.

Babies should always sleep alone, on their back, and in a crib.

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- Your baby should never sleep on top of a soft surface, such as an adult bed, sofa, pillow, or comforters. Car seats, swings, and baby carriers are **not** safe sleep spaces.
- Decorate your baby's room, but not your baby's crib. It is not safe to put anything soft, loose, or fluffy in your baby's crib. This includes stuffed toys, pillows, bumpers, loose blankets, quilts, hats, and bibs.
- Make sure your baby does not get too warm during sleep. Dress your baby in light sleep clothing, such as would be comfortable for a lightly-clothed adult.
- Consider using a wearable blanket sleeper instead of loose blankets. Loose blankets can cover a baby's face and cause problems with breathing.

More Important Safety Tips

- Teach everyone who cares for your baby about these safe sleep rules.
- Make sure no one smokes around your baby.
- Remember that:
  - Breastfeeding lowers your baby's risk for SIDS.
  - Immunizations may lower the risk of SIDS.
  - Giving your baby a pacifier at sleep times can lower the risk of SIDS. But, if you are nursing, wait until you and your baby have been breastfeeding well for about 1 month before giving your baby a pacifier.
- When your baby is awake and being watched, give lots of tummy time. This will help make your baby's arm muscles strong, and prevent flat spots on the back of the head.

Resources: NANN's "A Parent's Guide to a Safe Sleep Environment" and the First Candle website (*www.firstcandle.org*)

Questions?

Your questions are important. Talk with a member of your baby's healthcare team if you have questions or concerns.

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Safe Home

When you bring your baby home

We know you want your baby to be safe. This handout gives tips to help make sure your home is safe for your baby.

Your Baby's Security

- Only let people you know well into your home.
- If there is someone you don't know who needs to come to your house, such as a repair person or public health nurse:
  - Make sure you know the name of the agency and the person who is coming. When they arrive, ask to see their agency ID.
  - If you are at all unsure, call the agency or company to make sure they did send someone. Ask for the name of the person and what kind of ID they should have.

In the NICU, we do many things to keep your baby safe. When you take your baby home, be very cautious about who you let into your house.

- Only leave your baby with people you know well.
- If you put a birth notice in the newspaper, do not include your address.
- It is not safe to use outdoor decorations to announce your baby's arrival.

Basic Safety

- Do not leave your baby alone on a bed, sofa, or any raised surface that they could fall from.
- Never put the car seat on a high or unstable surface.
- Store all medicines and vitamins out of reach of infants and children.
- Close medicine caps tightly after use.

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- Avoid using cleaning products that contain harsh chemicals.
- It is unsafe to attach a pacifier to a string or chain.
- Keep your baby strapped in when using swings, strollers, or high chairs.
- Make sure toys do not have small parts or other pieces your baby could choke on.
- Remind smokers not to smoke around your baby. Chemicals from smoke stay on clothing and can harm your baby.
- Always supervise pets when they are near your baby.

Your Baby's Crib

- Your baby should sleep in a crib, bassinet, or baby "playard" (Pack 'n Play). Your baby should not sleep in a bed with anyone else. (See the handout "Safe Sleep" for more details.)
- If you are buying a crib, follow the assembly instructions and make sure every part is installed correctly. If you are buying or using a used crib, make sure that the mattress fits tightly, the hardware is intact, and nothing is broken or damaged.
- Make sure there are no gaps between the sides of the crib and the mattress.
- The distance between crib slats **must** be less than 2⅜ inches. (A soda can should not be able to fit between the slats.)
- Avoid using bumper pads in the crib. Tests show that they are not safe.
- Crib sheets should be tight-fitting and not get loose when your baby moves.
- Make sure the sides of your crib are raised when your baby is inside.
- Make sure your crib does not have any cracked or peeling paint your baby could swallow.
- Keep the crib away from windows. Keep drapery, blind cords, and baby monitor cords out of your baby's reach, both from the crib and from the changing table.

Air Safety

- Put a carbon monoxide detector on each floor of your house, near the bedrooms.
- The fumes from car exhaust are toxic, so make sure that you do not leave your car running while it is in the garage or other enclosed area.

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Your Baby's Bathtub

- Always keep an eye on your baby when they are in the bath or other water. It is not safe to use bathtub plastic rings, pool noodles, floaties, or other air-filled toys to keep your baby above water.
- See the handout "Basic Baby Care" for tips on giving a bath safely.
- Set your home water heater to no more than 120°F (48.8°C) to reduce the risk of scalding.

Your Kitchen

- Always put your baby where they are safe and protected before you do activities like cooking, drinking hot liquids, or eating hot food. It is not safe to hold your baby during these times.
- Keep hot items and sharp objects out of your baby's reach.
- Small magnets on the refrigerator are choking hazards. Avoid using them when there is a baby in the house.
- Make sure electrical cords are always well out of your baby's reach.
- Microwaves can heat milk unevenly, so use other ways to warm your baby's milk. You might place the bottle in a pot of warm tap water, or use a bottle warmer.

Fire Safety

- There should be a smoke alarm on every floor of the house, and one inside or near your baby's room. Test your alarms every month and replace their batteries once a year.
- Create a fire escape plan and practice it. If a door is blocked or on fire, is there another way out? Do you need a window ladder? Who will get the baby? Where do you meet outside?
- Make sure that your electrical outlets are not overloaded and that power cords are not under rugs.
- Keep space heaters away from anything that can catch on fire.
- Make sure to use your oven for cooking purposes only, not to heat your home.
- Grills, generators, and camp stoves are for outdoor use only. They are not safe to use indoors.
- Blow out candles before you leave the room.
- Keep a fire extinguisher in your kitchen, and know how to use it.

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- Post emergency numbers near your house phone, and program them into your cell phone.
- In case of a fire, take your baby to a neighbor's house and call 911.

Babysitters

- When you leave your baby with a babysitter, make sure the sitter knows how to reach you. Put a list of emergency phone numbers near the phone and show them to the sitter. Include:
  - Your cell phone number(s)
  - An emergency contact name and phone number if the babysitter cannot reach you
  - Emergency 911
  - Poison Control center number: 800.222.1222
  - Your baby's full name
  - Your full name
  - Your baby's primary care provider and phone number
  - Your baby's birth date
  - Your baby's health insurance information
  - Which hospital to go to if there is an emergency
  - Your written consent for your baby's emergency medical treatment if you are away overnight

References: NANN's Discharge Module: "*Baby's Steps to Home: A Guide to Prepare NICU Parents for Home*"

Questions?

Your questions are important. Talk with a member of your baby's healthcare team if you have questions or concerns.

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Basic Baby Care

Caring for your baby at home

This handout, written for parents of babies in the Neonatal Intensive Care Unit (NICU), explains the basics of caring for a new baby at home.

All new parents must learn how to care for their baby's basic needs. When you are the parent of a NICU baby, learning about these things while your baby is in the hospital will help you feel more confident about caring for your baby at home.

Learning about caring for your baby while you are in the hospital will help you feel more confident at home.

Diapers

- Diapers must be changed several times a day. Every time you feed your baby, check to see if the diaper needs changing.
- Make sure to wash your hands with soap and water after every diaper change.
- Your baby should have 6 to 8 wet diapers a day. This number means your baby is getting enough milk. If your baby has 3 dry diapers in a row after 3 feedings, call your baby's doctor.
- When you are changing a diaper, look closely at your baby's skin:
  - If your baby's bottom or groin is red, clean the area well with wipes or water. Apply an unscented cream or lotion to the area to protect it from moisture. Do **not** use products that contain alcohol.
  - If you see a raised, bumpy rash, your baby may have a yeast infection. Call your baby's doctor.

Stool

- Many babies have a bowel movement during or after every feeding. Others may go as little as once every 3 days.
- Breastfed babies' stools are often yellow or loose.

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- Bottle-fed babies usually have soft, slightly formed stools that are yellow, green, tan, or brown in color.
- If you are breastfeeding, changes in your diet can change the color or form of your baby's stools. This is normal.

Call your baby's primary care provider (PCP) if your baby's stool is:

- Hard or very dry, or your baby seems to be uncomfortable when having bowel movements (constipation)
- Watery or looser and more explosive than usual (diarrhea)
- White, red, or black

Using a Bulb Syringe

After using the bulb syringe, always clean it in hot, soapy water.

Clearing the Nose

A stuffy nose can make it hard for your baby to breathe. This can make your baby fussy, especially when trying to eat or sleep.

You can use a bulb syringe to clear mucous from your baby's mouth and nose. To do this:

- Gently squeeze the bulb to release the air.
- While still squeezing the bulb, place the tip at the base of your baby's nostril.
- Slowly release pressure on the bulb.
- If mucus or milk enters the syringe, squirt it into a cloth.
- Repeat until the nose is clear.

Clearing the Mouth

You can also use a bulb syringe to clear milk from your baby's mouth:

- Gently squeeze the bulb to release the air.
- While still squeezing the bulb, place the tip into the cheek pocket of one side of your baby's mouth.
- Slowly release pressure on the bulb.
- If saliva or milk enters the syringe, squirt i into a cloth.
- Repeat with the cheek pocket on the other side of your baby's mouth.
- **Important:** Do **not** put the syringe tip into the back of your baby's mouth. This can make your baby gag and choke.

Baths

Most babies do not need baths more than 3 times a week. Bathing more often than 3 times a week may dry your baby's skin and wash away the natural oils that keep the skin healthy.

Getting Ready

To get ready to give your baby a bath:

- Make sure the room where you will bathe your baby is warm and free of drafts.
- Gather the supplies you will need – mild soap, washcloth, and towels.
- Fill the tub with only about 3 inches of warm water.
- Check the water temperature with your wrist or elbow to make sure that it is lukewarm. It should be about 90°F (32°C).

Important Safety Tips

- Set your water heater to 120°F (48.8°C) to avoid scalding.
- **Never** place your baby in the tub while the water is running. The water may get too hot or too deep.
- **Always** keep one hand on your baby while in the bath. To do this, try:
  - Cradling your hand under your baby's head and shoulders as you wash.
  - Using blankets or towels underneath your baby to help hold the baby in position, then placing one hand around your baby's head.
- **Never** leave your baby alone in the tub or near water.

Washing

- First, wash your baby's face with just a wet washcloth. **Do not use soap to wash the face.** Wash the eyes from the inner edge of the eye (by the nose) to the outer edge. Use a different (clean) part of the washcloth for each eye. Then wash the rest of your baby's face with water only.
- Do **not** use cotton tipped swabs (Q-tips) to clean your baby's ears or nose. Swabs can cause injury.
- After washing the face, add soap to a washcloth and wash the body. Lift your baby's shoulders so that you can reach the back of the neck and clean between the skin folds.
- Next, lay your baby down on their back and lift their chin to expose the front of the neck. Gently clean between the skin folds.

- When you wash your baby's arms and legs, remember to clean between the fingers and toes as well.
- Wash the diaper area last. Be sure to clean between the skin folds. You may want to clean the folds after the baby comes out of the tub.
  - *For girls:* Always wipe her vaginal area from front to back. This can help prevent bladder infections.
  - *For boys:* If your baby's penis is not circumcised, do not pull the foreskin back when washing. This may cause damage. The foreskin will pull back on its own between 4 and 8 years of age. No special care is needed until then.

Important: Never leave your baby alone in the tub. If you must leave the room while you are giving a bath, wrap your baby in a towel and take them with you.

Cord Care

- The umbilical cord usually falls off between 10 to 14 days after birth.
- Your baby's cord will change from yellowish to brown or black as it dries out and then falls off.
- If the cord and base get dirty, clean with mild soap and water, then dry with a clean cloth.
- You may choose to do sponge baths and not put your baby in a tub until the cord falls off. When sponge bathing:
  - Swaddle your baby in a towel first. Uncover only the part of the body you are washing and keep the rest of the body covered.
  - Wash, rinse, and dry each part of the uncovered body before rewrapping it and washing the next part.
- Keep the front of your baby's diaper folded down under the cord so that the cord stays dry.
- Each time you change your baby's diaper, check the cord. Call your baby's doctor if you see any of these signs of infection:
  - Bad smell
  - Redness
  - Yellow pus or bleeding

Protect Your Baby's Skin and Eyes

Babies have sensitive skin and eyes. Also, skin conditions can be inherited. If you have sensitive skin, your baby might, too.

- If you are using lotions or creams on the diaper area, apply only lightly after bathing. If you apply lotion, use products that are unscented and do not contain any alcohol.
- To protect your baby's skin, wash new clothing and towels before using them on your baby. Use mild laundry detergents.
- If your baby gets a rash on areas that contact clothing, your detergent could be too harsh. Try switching to a milder baby detergent or one that does not have any dyes or scents.
- Bath soaps can irritate a baby's skin, especially if your baby tends to get rashes. Choose mild, scent-free products.
- Baby acne does not need special care. Just keep your baby's skin clean and dry. Do not squeeze pimples, as it could cause scars.
- A new baby's skin and eyes are sensitive to direct sunlight. Until your baby is at least 6 months old:
  - Keep your baby in the shade or put on protective clothing and a hat if you are taking them out in the sun.
  - Do not use sunscreen on your baby.
  - Put baby-sized sunglasses on your baby on bright, sunny days to protect sensitive young eyes.
- In the winter, keep your baby warm, but do not overbundle. If your baby is overheated, heat rash can occur. Dress your baby in layers and remove 1 layer at a time if you can tell your baby is getting too warm.
- Newborn fingernails and toenails are usually soft and flexible. It is safest to gently use a nail file or emery board to shorten and smooth your baby's nails.

If Your Baby Has Diaper Rash

- Change diapers as soon as they get wet or soiled.
- Use a soft cloth, water, and mild soap to clean the rash area. Do not use ready-made baby wipes. The perfume or alcohol in wipes may irritate and dry your baby's skin and make the rash worse.
- Pat your baby dry. Do not rub. Let the diaper area air-dry fully before putting on a fresh diaper.
- Apply a thick layer of ointment or cream.

- Do **not** use baby powder. Babies can inhale the powder into their lungs and have breathing problems.

Keep Your Baby at a Comfortable and Safe Temperature

At Home

- Keep the temperature in your house the same that adults are comfortable with.
- Keep your baby away from drafts and windows.
- Remove your baby's clothes when they get wet and put on dry clothes.
- If your baby's hands and feet are cool or look pale or blue:
  - Warm them with a blanket or cover them with mittens and booties.
  - If the color does not improve, call your baby's PCP.

For Outings

- Dress your baby as you dress yourself, based on the weather. Or, dress your baby with one more layer of clothing than you are wearing.
- Do not overdress your baby or cover with too many blankets, especially when sleeping.
- Put a hat on your baby when you go outside, year-round. Babies can get too hot from the sun if their heads are not covered in hot weather. Babies also easily lose heat from their heads in cold weather. (Be sure to cover your baby's feet, too.)

Fever or Low Temperature

- Call your baby's PCP if your baby has a fever higher than 100.4°F (38°C).
- If your baby's temperature is lower than 97°F (36°C):
  - Undress your baby and place skin-to-skin on your chest. Wrap yourselves with blankets.
  - Call your baby's PCP if the baby does not warm up after 1 hour.

Questions?

Your questions are important. Talk with a member of your baby's healthcare team if you have questions or concerns.

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Signs of Infection

Caring for your premature baby

Premature babies have a higher risk of getting an infection. We want to teach you about the signs of infection so that you know when to call your baby's primary care provider (PCP).

Warning Signs

Watch for sudden changes in your baby's usual:

- Feeding habits, such as:
  - Throwing up
  - Changes in eating patterns – not wanting to eat as much as usual or demanding to eat more often than usual
- Sleep patterns, such as:
  - Being very fussy
  - Suddenly having lower energy level (*lethargy*) than usual
  - Being very sleepy and hard to wake up
  - Being very weak

Signs of Infection

Signs of infection may include:

- Diarrhea (watery stools).
- Eye drainage.
- Fever higher than 100.4°F (38°C).
- Body temperature lower than 97°F (36°C) even when wearing extra clothes and wrapped in a blanket.
- Cough, stuffy nose, or nasal discharge.
- Poor feeding (see "Warning Signs," above).
- Fussiness or lethargy (see "Warning Signs," above).

You know your baby better than anyone. Trust yourself if you think your baby may have an infection.

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- Urine smells bad or is a dark color.
- No wet diapers in past 8 hours.
- Rapid breathing or having a hard time breathing.
- Pale or grayish skin.
- Thick, white patches on gums, inside cheeks, on tongue and/or roof of mouth (thrush). Your baby may have a hard time feeding and need medicine to help clear the area.
- Rash on your baby's bottom, groin, or skin folds. This rash may look like shiny, red bumps and increased redness. It may be tender to touch and may need ointment medicine.

What to Do

If you think your baby may have an infection, call your baby's PCP right away. You know your baby better than anyone. Trust yourself, if you are concerned.

Before calling your baby's PCP, have this information ready:

- Your baby's temperature
- How many diapers your baby has had in the past 12 to 24 hours
- How much more or less your baby is eating, and if your baby is throwing up or has a tender stomach

Before Discharge

Before your baby leaves the hospital:

- Talk with your nurse about signs of infection so you will be able to recognize them at home.
- Post your PCP's phone number where you and others can find it quickly.
- Know what number to call after hours and on weekends and holidays.
- Know when to:
  - Call your baby's doctor
  - Go to the emergency room
  - Call 911

Questions?

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Protecting Your Baby from Infections

Caring for your premature baby at home

Premature babies are at a higher risk of getting an infection and needing to return to the hospital after discharge. As a parent, there are many things you can do to lessen your baby's infection risk.

Basic Care

The basics of good baby care are your baby's first defense against infection. Make sure your baby:

- Gets plenty of rest
- Eats well
- Has regular checkups
- Receives all recommended immunization (vaccines)

Hand Washing

The most important thing to remember is to wash your hands. Just like when you were in the NICU, wash your hands:

- Before touching your baby
- After touching your baby
- Between diaper changes

Remember to have soap or hand gel by all your sinks. It is a good idea to have hand gel in your baby's room, in your purse, and in your baby's diaper bag.

Hand washing is the most important thing you can do to protect your baby against infection.

Breast Milk Can Offer Infection Protection

Breast milk is considered the best food for your baby for the first 6 months of life. Mother's milk can help your baby's immune system fight lung and stomach infections.

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Screen and Limit Visitors

- **Do not let anyone who is sick be near your baby.** Just like when your baby was in the NICU, if someone has any signs of a cough or flu, they should wait to visit until they are completely well.
- **Limit how long your guests stay.** This will lessen the amount of time your baby may be exposed to an infection.
- **Do not let your baby be near anyone who smokes.** Secondhand smoke can harm your baby's lungs and increase their chances of getting an infection.

Avoid Public Places

For several weeks after you bring your baby home, do not take your baby to crowded areas, such as a mall or a church. This is extra important during colder months of the year, when viruses that affect breathing are more common.

Preventing Respiratory Syncytial Virus

Respiratory syncytial virus (RSV) is a virus that spreads easily when someone with RSV coughs or sneezes. The virus can live on countertops, doorknobs, hands, and clothing for up to 7 hours.

During RSV season (October through March in Washington state):

- Wash your hands often.
- Avoid crowded places and areas where school-age children gather.
- Talk with your baby's primary care provider about your day care plans. Your baby may qualify for Synagis, a medicine that can help lower your baby's risk of getting RSV. Ask your NICU care team if your baby qualifies for Synagis.

Questions?

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Signs of Breathing Problems

Caring for your infant at home

Before you take your baby home from the hospital, we want you to know what it might look like if your baby starts to have breathing problems (*respiratory distress*). The first step is to know how your baby's normal breathing looks, so that you will notice if there is a problem. Ask your nurse if you have questions about your baby's normal breathing pattern.

Warning Signs

Here are some signs that something may be wrong:

- **Your baby is taking too many breaths.** Ask your baby's nurse how many breaths your baby normally takes in a minute. This number may be different for your baby than for other babies. In general, if your baby is breathing over 70 times a minute, that is too fast.
- **Your baby is working harder than usual to breathe.** You may notice these symptoms:
  - *Retractions:* You can see the muscles in your baby's chest (under the ribs and maybe below the neck) going in and out much more deeply than usual.
  - *Nasal flaring:* Your baby's nostrils flare out while breathing in. This means your baby is working harder to breathe.
  - *Grunting:* You hear a grunting noise at the end of your baby's breath. This could mean your baby is trying to open a blocked airway.
  - *Wheezing:* You hear a whistling sound when your baby breathes out. This may mean there is a blockage in the small airways in your baby's lungs.
  - *Hoarse, barking cough:* This may be a sign of an infection in your baby's windpipe and bronchial tubes (*croup*).

Ask your NICU nurse about your baby's normal breathing pattern.

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  - *Cyanosis:* The skin looks blue. A grayish-blue color appears around the lips, eyes, under nails.
  - *Congestion:* Your baby's chest feels crackly, nose sounds stuffy.
- **Your baby isn't feeding well.** Feeding intolerance and breathing problems often happen together.
- **It is hard to wake your baby up to feed, or your baby's energy level seems to have rapidly declined.** These are symptoms of *lethargy*.
- **Your baby has a fever higher than 100.4°F (38°C).** Lung infections often cause a fever.

What to Do

- **Call 911 right away if your baby is blue or not breathing.**
- If you are think your baby may be in respiratory distress, call your baby's primary care provider (PCP) **right away**. Trust yourself. You know your baby better than anyone.

Before calling your baby's PCP, have this information ready:

- How your baby's breathing is different than usual
- Your baby's temperature
- How your baby is eating

Before Discharge

Before your baby leaves the hospital:

- Talk with your nurse about signs of breathing problems so you will be able to recognize them at home.
- Post your PCP's phone number where you and others can find it quickly.
- Know what number to call after hours and on weekends and holidays.
- Know when to:
  - Call your baby's doctor
  - Go to the emergency room
  - Call 911

Questions?

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When to Call Your Baby's Primary Care Provider

A quick guide

This handout is a quick guide to use when you are concerned and wondering if you should call your baby's primary care provider (PCP). Remember to post the phone number for your baby's PCP where you can find it quickly and easily!

For more details, please see these sections in your *Caring for Your Baby in the NICU* booklet:

- "Basic Baby Care"
- "Signs of Infection"
- "Signs of Breathing Problems"

It may help to write down your baby's temperature and other symptoms before you call the PCP.

Before Calling

Before you call your baby's PCP for any reason, have this information ready:

- Your baby's temperature
- How many wet diapers your baby has had in the past 12 to 24 hours
- How much more or less your baby is eating
- If your baby is throwing up or has a tender stomach
- If your baby's breathing is different than usual (be ready to explain how)

When Changing Diapers

Call your baby's PCP if you are changing your baby's diaper and:

- You see a raised bumpy rash. This rash could be on your baby's bottom, groin, or in skin folds.

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- Your baby's stool is hard or very dry. If your baby has constipation (hard stool), they may seem to strain when having bowel movements.
- Your baby's stool is loose or watery and comes out more quickly than usual (*diarrhea*).
- Your baby's stool is white, red, or black.
- The urine smells bad or is a dark color.
- Your baby has not had any wet diapers in the past 8 hours.

Umbilical Cord

Call your baby's PCP if your baby still has an umbilical cord and it:

- Has a bad smell
- Is red
- Is bleeding or oozing yellow pus

Fever

Call your baby's PCP if your baby:

- Has a fever higher than 100.4°F (38°C)
- Has a temperature lower than 97°F (36°C) and has not warmed up after 1 hour of skin-to-skin contact

Infection

Call your baby's PCP if your baby has any of these signs of infection:

- Eye drainage
- Cough, stuffy nose, or discharge from the nose
- Unusual fussiness or suddenly having lower energy level (*lethargy*)
- Poor feeding
- Thick, white patches on gums, inside cheeks, on tongue or roof of mouth (*thrush*)

Breathing Problems

Call your baby's PCP if:

- Your baby is working harder than usual to breathe.
- You see retractions, nasal flaring, grunting, wheezing, hoarse barking cough, cyanosis, or congestion (see "Signs of Breathing Problems").

Questions?

Your questions are important. Call your baby's healthcare provider if you have questions or concerns.

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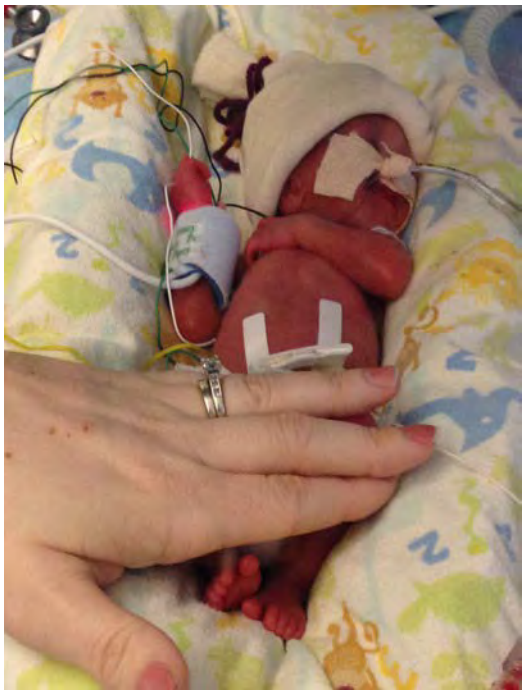
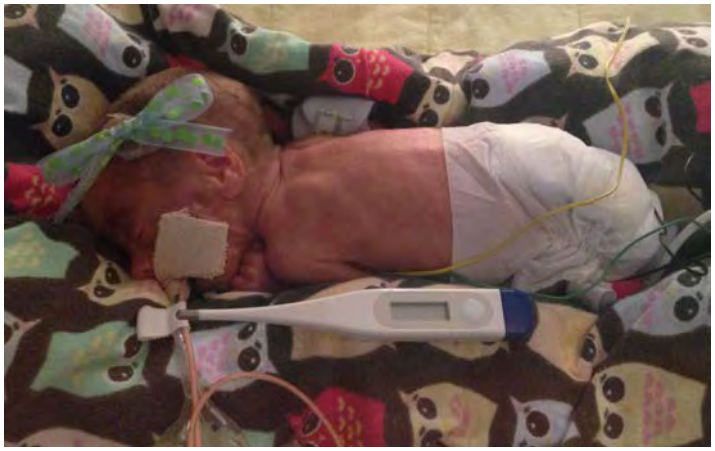
NICU Alumni: Timmy and Tessie

If you would like to read more about these alumni journeys, please visit Health Online at *https://healthonline.washington.edu* and click on "Neonatal Intensive Care Unit" in the Departments drop-down box.



Timmy in the NICU



Tessie in the NICU

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Tessie and Timmy at 1 year

Questions?

Your questions are important. Talk with your NICU doctor or nurse if you have questions or concerns.

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Taking Your Baby Home

When it's time to leave the NICU

It's time! Congratulations on taking your baby home!

You may have waited days, weeks, or even months for this day, and it is finally here.

A NICU nurse will call you during your first week at home with your baby. The nurse will ask how you and your baby are doing and will answer any questions you may have.

Remember, you can call your baby's primary care provider (PCP) at any time if you have concerns or questions.

Congratulations – it is finally time to take your baby home!

UWMC Resources and Support

Infant Development Follow-up Clinic..... 206.598.9348

Lactation Services..... 206.598.4628

Neonatal Intensive Care Unit (NICU)..... 206.598.4606

NICU alumni page..... *https://facebook.com/groups/uwmcnicu*

NICU Physical Therapy.....206 598.1251 or 206.598.9184

NICU Online Patient Education.....*http://healthonline.washington.edu*
Click on "Neonatal Intensive Care Unit (NICU)" under "Departments."

Other Community Resources

Preemie Parents Meetup Groups .....*www.meetup.com/PreemieParent*

Program for Early Parent Support (PEPS).....*www.peps.org*
206.547.8570

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"Trust yourself. Hold on to the confident feeling you have as a parent. Your child is thriving and ready to go home because of you and the love you are providing when you feed your child, change your child, or hold your child. It's easy to lose confidence without the medical team and monitors, but you can do it!"

-- Kylie's Mom

Seattle Children's Hospital ..... *www.seattlechildrens.org/safety-wellness*

Seattle Parents of Preemies ..... *www.seattlepreemies.com*

Within Reach ..... *www.withinreachwa.org*
206.284.2465

Questions?

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Emotions After Discharge

When you bring your baby home

When your baby is finally ready to leave the NICU and go home with you, it is a very exciting time. But, many parents find that their baby's homecoming is bittersweet. They feel relief and joy, but they also feel many difficult emotions, some of which are a surprise.

It is normal to feel a wide range of emotions when you finally have your baby home with you. This handout describes the feelings that many NICU parents report having after they brought their baby home. You may feel all, some, or none of these feelings.

Unexpected Feelings

The depth and range of your feelings during your baby's first weeks at home may surprise you. You might find yourself reliving the events of your child's birth and hospital stay, and wonder if there was anything you did or didn't do that made a difference.

Most parents are also surprised to find that they actually miss the NICU! While your baby is in the hospital, NICU staff become a part of your life. The nurses, doctors, and other staff share a life experience with you that others may not fully understand. And, you probably planned your days around the NICU routines. Your time in the NICU may have been stressful, but it also provided structure and support.

Many parents feel this "post-NICU letdown" during their first few weeks at home with their baby. Without the daily support provided by the NICU staff and unit, you may feel lonely and isolated. But over time, you will set up new support systems and routines at home.

If you are feeling a letdown after you take your baby home, try to ease your feelings of isolation. Ask trusted friends to visit or schedule some time for yourself away from your baby, if you can.

It is normal to feel lonely and isolated after you leave the NICU.

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"Not being able to see her monitors was scary at first. Trying to make sure she took enough milk was scary, too. All of her care was up to us – it was no longer back-stopped by round-the-clock medical care. But, we finally found our routine and settled into it. And because of our NICU stay, we knew a ton about how to take care of Lucy."

-- Lucy's Dad

Anxiety

While in the NICU, your baby is always monitored and cared for by nurses and other medical staff. You and your baby suddenly lose these comforts when you leave the hospital, and it can be scary. Some NICU parents say that once they take their baby home, they lose their confidence and start to second-guess whether they can keep their baby safe.

One way to ease this normal anxiety is to stay overnight in the NICU for long stretches before your discharge date, if you can. This way, you can become very familiar with your baby's unique behavior and patterns.

Also, remember that our first priority in the NICU is the safety of your baby. We would not send your baby home if we were not 100% confident that your baby is ready and that you are able to care for them on your own.

Friends and Family

In the NICU, we teach how important it is to wash your hands often, since your baby is at high risk for infections. Once your baby is home, your friends and family may not understand why it is so important to always wash their hands before they touch your baby.

Some parents feel distant from family and friends who do not understand or respect their unique needs. They also become closer to those people who do understand.

Parents may also be worried exposing their baby to germs when they leave the house or have a visitor. These are normal feelings. But, friends and family may question why you don't want to go to public places or be around many other people during the winter months.

Try to remind yourself that you are doing the best you can, and that it is OK to have visitors and to leave the house. You just need to take the precautions that you learned while in the NICU. Try to educate your family and friends as best you can, and know that you are doing everything you can to keep your baby safe.

Bonding and Attachment

When a baby is born early, bonding and attachment do not occur as easily as with a full-term birth. Your baby may have arrived before you were prepared. And, while your baby is in the NICU, you may not be able to have much close contact at first. This lack of contact may be due to your baby's medical needs, a lack of privacy, or not being able visit the NICU as much as you would like.

"An anxiety developed within me after he came home – a hypervigilance and an over- protection. I wish someone had told me you could develop post-traumatic stress disorder after your child comes home from the NICU."

-- Layne's Mom

Even if they spent a lot of time with their child in the NICU, many parents feel like their baby never was truly *theirs*. They were always sharing their baby with the nurses and other care providers. When you get home with your baby, you may still feel some detachment, as if your baby is still not fully yours. This is normal.

The time you were able to spend with your baby in the NICU may have helped you to start to bond with your baby. But true attachment grows slowly. After you bring your baby home, give yourself plenty of time to get to know your child, gain confidence in your parenting skills, and recover from the emotional rollercoaster you have been riding. With time and patience, the bond between you and your baby will grow and strengthen.

Chronic Sorrow

"Chronic sorrow" is sadness that lingers even after the source of pain has eased. After your time in the NICU, events that once didn't bother you can now bring feelings of deep loss.

NICU parents often feel very helpless while their tiny baby is in the hospital. They can still feel this insecurity even after their baby is safely at home. The effect of painful times can stay with families for many years, and may forever change their lives.

These are some symptoms of chronic sorrow:

- Recurring dreams
- Strong reactions to certain sounds
- Seeing images and smelling odors that remind you of the NICU
- The return of pain and fear when your children are sick, even with common illnesses like colds

Chronic sorrow may last months to years, since many preemies are still fragile and may have health and developmental problems after they leave the NICU. During this time, old anxiety and sorrow can return if there is another need to go to the hospital, if your baby needs to be assessed for any reason, or even if you attend a happy event such as a baby shower or a child's birthday party.

Post-Traumatic Stress Disorder (PTSD)

Some experts compare the reactions of NICU parents after discharge to *post-traumatic stress disorder* (PTSD). PTSD is an anxiety disorder that is triggered by witnessing a terrifying event. Symptoms include flashbacks, nightmares, severe anxiety, and not being able to stop thinking about the event.

Many NICU parents have symptoms of PTSD. They may have nightmares, or have flashbacks when the phone rings unexpectedly.

"Coming home felt liberating, but I'll admit it was a much harder transition than I had anticipated. I suddenly lost all confidence in my ability to be a mother because I no longer had nurses there to validate me. Over time, I regained trust in myself. As I look back, I just wish I hadn't been so hard on myself."

-- Kylie's Mom

Parents with this type of anxiety may clean every surface of their house or wake up to check on their baby many times a night.

The symptoms of PTSD are the same as those for chronic sorrow. It can be a serious problem, so please talk with your primary care provider or mental health professional if you:

- Have a hard time falling asleep or staying asleep
- Are very jumpy or irritable
- Have problems concentrating on anything

Taking Care of Yourself

- Remember that you are a good parent.
- Stay connected to loved ones and talk often with trusted friends.
- Think about talking with a counselor if you are struggling with your feelings after you go home with your baby.

References:

The Preemie Parents' Companion: The Essential Guide to Caring for Your Premature Baby in the Hospital, at Home, and Through the First Years by Susan L. Madden, M.S.

Preemies - 2nd Edition: The Essential Guide for Parents of Premature Babies by Dana Wechsler Linden, Emma Trenti Paroli, and Mia Wechsler Doron

Questions?

Your questions are important. Talk with a member of your baby's healthcare team if you have questions or concerns.

Neonatal Intensive Care Unit: 206.598.4606

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