

Your baby's medical care after the NICU

You've chosen your baby's provider, learned about her medicines and thought about using in-home nursing care. Now, it's time to take the next steps for your baby's health.

Follow up with your baby's health care provider.

Your baby will get several checkups with her provider during her first year. At each visit, talk to her provider to make sure your baby's developing in a healthy way. Is she rolling over, sitting up, crawling and walking when she should? These skills are called developmental milestones. You may need to remind the provider that your baby spent time in the NICU, because this may affect when she reaches the milestones.



Take your baby's medical file to your first visit with your baby's provider. This file includes her discharge summary and other information from the hospital. The provider needs to know what happened during and after your baby's birth. Hospital staff may send the summary directly to the provider.

Get your baby vaccinated.

All babies, including those who spend time in the NICU, need vaccinations to help protect them from serious diseases. Some babies start getting these shots while they're in the NICU. Check with your baby's provider about when she needs her vaccinations. Keep a record of your baby's vaccinations in your medical file for her.

If you have other children, they need their vaccinations, too. This helps keep them from passing infections to the baby. During flu season, everyone in the family, including parents, should get a flu shot. And, any adult who may have contact with your baby needs a Tdap vaccination to help prevent pertussis (also called whooping cough).

This resource includes some medical terms you may hear in the NICU. You can find out what they mean in the *Words to know* section at the end of this resource.

Protect your baby from RSV.

RSV (also called respiratory syncytial virus) is a common virus. It affects almost all children before they reach age 2. Most of the time, it causes a slight cold. But for babies who were born early, this virus can be more serious. Babies born prematurely or who have heart or lung problems may benefit from a medicine to keep them from getting RSV. Ask your baby's health care provider if your baby has gotten this medicine in the NICU or if he should get it now that he's at home.

See different health care providers.

If your baby has a medical condition, such as a birth defect, she may need ongoing care from different health care providers. Find a way to keep track of your baby's medical appointments. This may be on a calendar in your kitchen or on your phone with an alert to remind you. Think about if it will be easier to have a few appointments in one day or if it would be better to have them on separate days.

Ask your providers to keep your baby's main provider up to date about all visits and treatments. This helps make sure that all members of your baby's health care team have the same information. Keep your own record of any checkups, tests and treatments your baby has had. When your doctor makes a change to your baby's care or medication, make sure this is also shared with your baby's in-home nursing care agency and equipment company if you use these services.

Find out if your NICU has a developmental follow-up program. This program can help make sure your baby is meeting her milestones. If your NICU doesn't have one, check with your baby's provider about other programs that offer the same kind of help.

Watch for signs of illness.

All babies get sick from time to time. But babies who were in the NICU are more likely than other babies to get infections. Watch for signs that your baby may be sick so you can get medical help right away. See the list below for more information about when to call your baby's provider.

When to call your baby's health care provider:

Call the provider if your baby:

- Looks blue around the nose, lips or on the skin
- Is paler than usual
- Refuses to eat or doesn't eat enough
- Is more fussy than usual
- Is less active than usual
- Throws up (which is more serious than spitting up or reflux)
- Has trouble breathing or a change in his breathing pattern
- Has less than five wet diapers in a 24-hour period
- Has diarrhea for more than a day or has a change in bowel habits
- Has a temperature higher than 100.4 F or lower than 97 F
- Has apnea. This is when the baby stops breathing for 15 seconds or more.
- Just doesn't seem right or well to you

You know your baby best. If you think something is wrong with him, call your provider, call 911 or take him to the emergency room.

Manage medical equipment at home

If your baby has medical equipment at home, this can feel like a lot to manage. Staying organized and planning ahead can help.

Keep track of equipment and medical supplies

Keep a list of your baby's equipment and medical supplies, including order numbers, size and quantity. The equipment company can give you a checklist. Be sure to re-order supplies with enough time, as shipments can sometimes be delayed.

Always be prepared when you leave the house, make sure you have your baby's supplies even when you're just going to the park.

Plan for emergencies

Share information about your baby's medical condition with your local fire department and emergency or first responders so they know what to expect in case they're called to your home for an emergency. Invite them to come to your home to meet you and your baby.

Contact your utility companies to let them know your baby's health care needs. They may have a priority list for repairing power outages or plowing snow. Make a plan for if the power goes out. Have back-up batteries and know how long they will last.

Learn about early intervention programs.

These are programs that provide services for babies and children who have or who are likely to have developmental delays.

For example, a baby may have a developmental delay if he can't roll over or sit up by a certain age. Babies who were born early are more likely to have a developmental delay than a full-term baby.

Early intervention programs often include:

- physical therapy — A therapy that helps the baby improve her muscle strength and coordination.
- occupational therapy — A therapy that helps babies develop skills in moving their arms and legs, feeding and swallowing, and bonding. These skills will help the baby grow and develop in healthy ways.
- speech therapy — A therapy used to help the baby with speech and language problems. This is often used to help newborns with feeding problems.

You or your baby's doctor can request additional services to check for developmental delays.

If your baby can get these services, an Individual Family Service Plan, also called IFSP, is created. This plan is designed to meet the specific needs of your baby and family. Someone may come to your home or you may take your baby outside the home to get these services.

“Stephen was diagnosed with 17 conditions during his 2 months in the NICU. He had a lot of therapy in the NICU, and his health care team decided that he would need therapy after he went home.

Stephen has done really well in his development. This is thanks in large part to the physical, occupational and speech therapy he got. He's hit almost all his milestones.”

ERIN

MOM OF A PREMATURE BABY

Understand developmental milestones.

Developmental milestones are things that most babies and children can do by a certain age. Examples include smiling at people, making eye contact, rolling over and taking a first step. These milestones are skills that babies and children develop as they grow.

Every baby is different, and babies may reach the milestones at different ages. For example, about half of babies can walk by their first birthday. But some

babies may walk as early as 9 months or as late as 16 months. All these ages for walking are normal.

The milestones below and on the following page are only guidelines. If your baby was born prematurely or with a serious illness, he may not reach these milestones at the ages listed in the timeline. Your baby's health care provider checks your baby's development at each check-up.

You know your baby best. Talk to your baby's health care provider if you're worried about your baby's development.

By the end of their **first month** (adjusted age), most babies can do the following things*:

Moving

- Move arms in jerky ways
- Bring hands near face
- Keep hands in tight fists
- Move head from side to side while lying on tummy

Seeing and hearing

- Focus on objects 8 to 12 inches away
- Like human faces over other shapes
- Respond to some sounds, including parents' voices
- May turn toward sounds they know well

Smelling and touching

- Like sweet smells
- Know the smell of their mother's breast milk
- Like to touch soft things instead of rough things

By the end of their **third month** (adjusted age), most babies can do the following things*:

Moving

- Raise head and chest when lying on tummy
- Support head well
- Kick when lying on tummy or back
- Push down on legs when feet put on hard surface
- Open and shut hands
- Bring hands to mouth
- Grab and shake hand toys

Seeing, hearing and talking

- Follow moving object with eyes
- Smile at faces and voices that they know well
- Begin to coo
- Enjoy playing with other people
- Start using hands and eyes in coordination

Social and emotional

- Begin to develop a social smile — this is when your baby smiles in response to something, such as when they're hugged or smiled at
- Enjoy playing with other people and may cry when playing stops

* Adapted from American Academy of Pediatrics. "Caring for Your Baby and Young Child: Birth to Age 5" (Bantam Books, 2009).

By the end of their **seventh month** (adjusted age), most babies can do the following things*:

Moving

- Roll over both ways (tummy to back and back to tummy)
- Sit up using hands and without using hands
- Reach for an object with hand and use hands like a rake
- Move objects from one hand to the other
- Support whole weight on legs when held up

Seeing, hearing and talking

- Respond to own name
- Babble sounds (ba-ba-ba-ba-ba)
- Tell different emotions by tone of voice

Social and emotional

- Like seeing themselves in a mirror
- Respond to how people show emotion
- Often seem happy

Thinking

- Find hidden objects (playing peek-a-boo)
- Explore objects with hands and mouth

By the end of their **twelfth month** (adjusted age), most babies can do the following things*:

Moving

- Sit without help
- Get into hands-and-knees position
- Crawl
- Pull self up to stand
- Walk holding onto furniture and possibly a few steps without support
- Use thumb and forefinger to hold something

Seeing, hearing and talking

- Say “dada” and “mama”
- Say things like “uh-oh!”
- Try to say words they hear
- Respond to “no”
- Use simple gestures, such as shaking head “no”
- Babble, sounding like speech, but not real words

Social and emotional

- Find hidden objects easily
- Look at the right picture when the content of the picture is named

Thinking

- Explore objects in many ways, such as shaking, banging, throwing and dropping them
- Begin to use objects correctly, such as drinking from a cup or brushing hair

* Adapted from American Academy of Pediatrics. “Caring for Your Baby and Young Child: Birth to Age 5” (Bantam Books, 2009).

Words to know

adjusted age (uh-JUHS-ted age) — The age of the baby based on his due date. It's the date that health care providers may use to decide if the baby is growing and developing in a healthy way.

developmental delay — A serious delay in a baby or child's physical, mental, behavioral or social development. For example, a baby may have a developmental delay if he's unable to roll over or sit up at a certain age.

developmental follow-up program — A team of health care providers who make sure babies are meeting milestones.

developmental milestones — A skill or activity that most children can do at a certain age. Milestones include sitting, walking, talking, having social skills and having thinking skills.

discharge — When a baby leaves the NICU and goes home or to a step-down unit.

discharge summary — A report prepared by a health care provider that states what happened in the NICU and what treatment the baby may need after the NICU.

early intervention programs — Programs that provide services for babies and children who have developmental delays and/or more chance of having developmental delays than other babies.

full-term baby — A baby born between 39 weeks and 40 weeks, 6 days of pregnancy.

health care provider — Also called provider. The person who gives medical care.

health care team — A group of health care providers who work together to care for a baby.

IFSP — See Individual Family Service Plan.

Individual Family Service Plan — Also called IFSP. This is a plan for special services for babies and young children with developmental delays.

infection — An illness caused by some viruses, bacteria or other germs.

in-home nursing care — When a nurse comes to a family's home and provides medical care to the baby.

NICU — Also called the neonatal or newborn intensive care unit. The place in the hospital where newborns go for special care.

pertussis (pur-TUSS-iss) — See whooping cough.

premature birth — When a baby is born before 37 weeks of pregnancy.

provider — See health care provider.

reflux (REE-fluks) — Also called GER or gastroesophageal reflux. A feeding problem that happens when food in the baby's stomach comes back up during or after a feeding.

respiratory syncytial virus (ress-puh-rah-TOR-ee SIN-sish-uhl VYE-ruhss) — Also called RSV. A common virus that most children have before the age of 2. It can cause a serious illness for babies born too early or who have heart or lung problems.

RSV — See respiratory syncytial virus.

social smile — When the baby smiles in response to something, such as when she's hugged or someone smiles at her.

Tdap vaccine — A vaccine which offers protection from three serious diseases including pertussis (also called whooping cough).

vaccination (vak-suh-NAY-shuhn) — A shot that contains a vaccine that helps protect against certain diseases.

whooping cough — Also called pertussis. An infection that spreads easily and is very harmful to a baby. Babies and adults can get a vaccine to protect them from pertussis and prevent spreading it to others.