Baby's First 3 Months

Bringing your baby with Spina Bifida home from the hospital is exciting and a big relief! But it's also normal to feel nervous about taking care of your baby without nurses and doctors around all the time like in the NICU (neonatal intensive care unit). Don't worry– you're not alone! You have doctors, nurses, therapists, and the Spina Bifida community here to support you. Here are some important things to remember during your baby's first three months at home.

Follow-Up Appointments

In the first few weeks and months, you will take your baby to regular checkups with their pediatrician, just like you would for any baby. These visits are for things like making sure your baby is growing well, getting vaccinations, and treating common illnesses like colds. Your baby's pediatrician doesn't have to be an expert in Spina Bifida. What matters most is that you trust them and feel comfortable asking questions. A good pediatrician can help guide you through the healthcare world.

If follow-up appointments with your baby's specialists weren't set up before leaving the NICU, that should be one of the first things you do when you get home. Most babies with Spina Bifida need to see doctors like a neurosurgeon, urologist, and orthopedist within the first three months.

Some families visit each doctor on a different day or in different places, but many go to a special Spina Bifida clinic where the doctors work together in the same place, often on the same day, to see your baby. This can be easier for families and helps the doctors, nurses, social workers, and others work together as a team to care for your baby. These checkups are important to make sure your baby is growing and developing well, and to help you learn how to take good care of your baby and watch for any problems.

You'll have many appointments during the first year, but they usually become less often as your baby gets older.

Photo by Redefining Spina Bifida

Establishing Services

Every state has a program called Early Intervention that helps children under age 3 who may have delays in their development or were born with a disability like Spina Bifida. They often provide physical therapy and other services in your own home for free or low costs. Or your insurance may cover therapies at a clinic. In many states, babies born with Spina Bifida qualify for services right away, but it can take some time to get started. The earlier your baby can begin physical therapy and any other needed help, the better. Starting early can help your baby build new skills and reach their potential.

You might also be able to get help from programs like Medicaid, Supplemental Security Income (SSI), or other state and federal support. A NICU social worker, the Spina Bifida clinic, or the pediatrician's office can help you apply for any of these services.

Finding Support

The Spina Bifida Association is a great place to find information and support. You can visit ***spinabifidaassociation.org*** to learn about different topics related to Spina Bifida, find a list of clinics and local chapters, and get contact information for the SBA National Resource Center. There may be an SBA chapter or other support group near you, and you can also find online groups for parents. Talking with others can help you feel less alone and give you the chance to learn from their experiences. Over time, you may even be able to support other families too.

What to Watch For

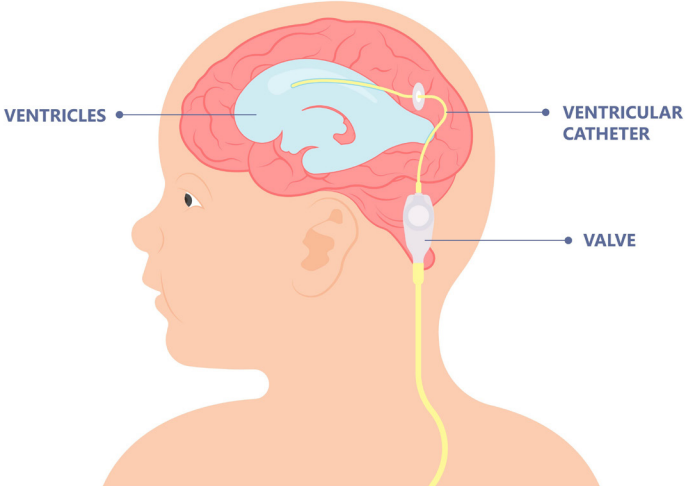
Hydrocephalus/Shunt Malfunction

Some babies get a shunt or ETV (endoscopic third ventriculostomy) before leaving the NICU. Others may need one weeks or months later as hydrocephalus symptoms appear, and some may never need one at all. Here are some signs that your baby might need treatment for hydrocephalus, or that the treatment isn't working well enough:

- Larger ventricles (seen on an ultrasound or CT scan)
- A bigger head size than expected
- Baby's soft spot begins to bulge
- Sleeping too much or having trouble staying awake, even for short times
- Strong or frequent vomiting
- "Sunsetting" eyes (when the baby looks like they are looking down, or you can see a lot of white above the pupil)
- Fluid leaking from the back incision
- High-pitched, noisy breathing (called stridor)
- Trouble swallowing/difficulty feeding

If you notice any of these signs, call the neurosurgery office right away. If it's after office hours, page the on-call doctor. Or, go to the Emergency Department (at a children's hospital, if possible) for help.

VENTRICULOPERITONEAL (VP) SHUNTS



Bladder Function

Most babies with Spina Bifida have a neurogenic bladder. This means the nerves to the bladder don't work as well as usual. One of the most important things you can do for your baby's long-term health is to keep their bladder and kidneys healthy. It's hard to know if a baby's urinary system is working well just by looking at wet diapers. That's why your baby's urologist will check the bladder and kidneys regularly. They may use ultrasounds and urodynamics, which are tests that show how the urinary tract is working.

Many parents learn how to catheterize ("cath") their baby while in the NICU. Some keep doing this at home, while others are told to wait until more testing is done. Parents who learn to cath early often feel less worried, because they see that it isn't as hard or scary as they first thought.

Watch for signs of a urinary tract infection (UTI). These can include:

- Cloudy urine
- Fussiness or irritability
- Fever
- Crying or seeming to be in pain while peeing
- Blood in the urine
- Other signs of being sick

If you notice these symptoms, call the urology office. If it's after hours, contact the on-call provider for advice. Pediatricians can test for UTI's, but it's a good idea to get input from the urologist because they often wait for higher levels of bacteria in the urine before starting antibiotics in babies who are cathed.

Photo by Redefining Spina Bifida

Diaper Rash

It is very common for babies with Spina Bifida to get diaper rashes in the first few months. This can happen because of antibiotic use, a loose anal sphincter muscle, and frequent bowel movements. The good news is diaper rash is often a temporary problem until they start solid food.

Keeping a barrier cream on your baby's skin at all times is often helpful—just make sure it doesn't get on the closure surgery site if it isn't healed yet. If regular diaper creams don't work, your doctor can recommend prescription creams. Ask your baby's pediatrician or urology team for advice on skin care. They may refer you to a wound care specialist. It may help to talk with other parents about what worked for their children.

Latex Precaution

People with Spina Bifida are more likely than other people to develop a latex allergy. It is important to prevent your baby from breathing in latex particles or letting latex touch their skin at medical visits, at home, and in the community.

Common items that may contain latex and should be avoided include:

- Red rubber catheters
- Latex surgical gloves
- Latex balloons
- Rubber toys
- Latex pacifiers, teethers, and bottle nipples

Make sure to tell your baby's pediatrician's office and other medical providers about the need to avoid latex. Choose silicone baby items–they are usually clear, and latex items are often yellowish-brown. You can use Mylar balloons instead of latex at parties. If you are unsure about an item, smell it—if it smells like a latex balloon, don't use it.

Constipation

Most babies with Spina Bifida have a neurogenic bowel. This means the nerves to the bowel don't work as well as usual, and stool often moves through them more slowly. Constipation may start early with certain baby formulas or iron supplements, but it's common when babies start solid food around six months old. Rice cereal is very constipating, so try to avoid that if possible. Your pediatrician will help you start solid foods.

Preventing and treating constipation quickly is very important. If the bowel gets stretched from constipation, it can lead to bigger problems like chronic constipation, UTI's and even shunt malfunctions because the shunt cannot drain as well. Talk with your baby's pediatrician or Spina Bifida clinic for advice. They may also refer you to a gastroenterologist (GI) or other specialist who knows about neurogenic bowel. Your baby may be given a stool softener or liquid glycerin suppositories to use regularly or as needed.

How To Contact Providers

Be sure to ask your baby's doctors which symptoms to watch for and what to do if they appear. Some may want you to send a message through the hospital's online patient portal, call their office to speak with the on-call doctor, or go straight to the Emergency Department. What you should do depends on how urgent the problem is.

How to Advocate

While your child is young, you are their voice. It's normal for parents to feel unsure about their baby's care or nervous around doctors. Trust your instincts. If you think something is wrong, speak up and keep asking questions until you feel your concerns are answered.

You may not get it right every time–sometimes you might be upset and too aggressive, and other times feel you weren't assertive enough. But that's part of learning how to stand up for your baby's needs. As your child grows, they will learn from you how to advocate for themselves.

Take Care of Yourself

Take good care of yourself so you can take the best care of your baby. Mothers should keep their own follow-up appointments to make sure they are healing after childbirth. Talk with your doctor about the signs of "baby blues" or postpartum depression and ask for help if you need it.

Many parents have trouble breastfeeding at first, and being in the NICU can make it even harder. Be patient with yourself, and ask to see a lactation consultant if you need support.

Be kind to yourself! Many parents go through a stressful experience—from the Spina Bifida diagnosis, to giving birth, to time in the NICU. Life with any newborn can be both magical and hard, and Spina Bifida adds a few more challenges. During the first months of feeding, changing diapers, washing bottles, and sleepless nights, accept help from others and take care of yourself as best you can.

You are already your baby's expert, biggest cheerleader, and strongest advocate. Enjoy and love your baby, and try to not worry about the future. As you bond, you will learn about your baby's unique personality and special qualities, and that he or she is not defined by Spina Bifida. You don't need to solve all the challenges of the next 18 years right now. Focus on what your baby needs in this moment. Most of the time, what they need most is you.

SPINA BIFIDA ASSOCIATION

Our mission is to build a better and brighter future for all those impacted by Spina Bifida.

Additional information

For more information and lifelong support, connect with the Spina Bifida Association at:

spinabifidaassociation.org, or by contacting the SBA National Resource Center at **(800) 621-3141, ext. 800** or *sbaa@sbaa.org*.

If you're an expectant parent, scan for more information and resources just for you.

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