It is a happy time when you can finally take your baby home from the neonatal intensive care unit (NICU). For many parents, it may also be a stressful time with many questions. Like all new parents, you are about to begin a journey filled with many unknowns. Yet, if your baby has spent a few days or more in a NICU, you may have even more questions, such as:

What can I do to help my baby have a healthy future?
How will I know if my baby needs help?
Where can I find help for problems that may arise?

The purpose of this topic sheet is to give you a broad idea of issues you may encounter with your baby. It is based on what is currently known about babies who have been born early (premature) and/or with a low birth weight, and/or who have been ill. Keep in mind that this is only a guide to help you along the road ahead.

First: A good place to begin this journey with your baby is to make a list of your baby’s strengths and talents — to know what your baby can do. This can help you find ways to support your newborn’s unique strengths (such as feeding skills, speech and movement, etc.), as well as to find out in which areas your baby may need extra help. Use the box below to list the strengths you (and your baby’s nurses and doctors) observe in your infant.

My baby’s strengths are:

- ________________________________________________________________
- ________________________________________________________________
- ________________________________________________________________
- ________________________________________________________________
- ________________________________________________________________
- ________________________________________________________________

This topic sheet is simply a tool to help you address any issues that may arise along the road ahead. If problems are addressed early, it is often easier to limit their effect on your baby.
**Next: looking at the big picture.** Having spent time in a NICU, you are very aware that your baby began life in a way that is different from other newborns. You may already know if your baby has special needs, such as delayed growth, hearing or vision problems, or other health problems. Studies show that, along with these issues, infants born early and/or with a low birth weight also have a higher risk for learning or behavior problems that may affect their ability to progress at school. Although the impact of this decreases by 36 months for many children, it is vital for parents to be aware that problems may occur and to take their baby for all checkups or referrals to a specialist as advised by their baby’s doctor. Many of the problems affect learning, motor skills and language. These problems may appear around preschool or school age and can affect your child in ways you may not notice right away. With careful follow-up from your baby’s doctor, many problems can be decreased or avoided.

**How can I know if my baby may need special help?** Along with taking your baby for all checkups with health care providers, you can help track your baby’s progress by asking yourself these questions:*

- How does my baby respond to light, touch and sound?
- Is my baby losing weight and/or not eating?
- Is my baby sleeping well?
- Is my baby learning new skills (such as talking, walking, playing)?
- Has my baby stopped learning new skills?
- Has my baby lost skills he or she had learned earlier?

**What can parents do?** A key step for parents is being aware of problems and being prepared to address them. Take your baby for all checkups advised by doctors as this plays a key role in helping you keep track of his or her health needs throughout childhood.**

**Ask questions and more questions!** Talk to your baby’s doctors and NICU team about your questions. This is your first line of help for your baby. They can point you to other sources of help.

**Keep yourself up-to-date.** The more you can learn about your baby’s unique needs and how time in the NICU may affect him or her, the better you will be able to tackle any issues that arise later.

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*Massachusetts Family Voices. From www.massfamilyvoices.org


E3 - The road ahead: sources of help
Be prepared for visits to your baby’s doctor. Your baby’s feeding skills and sleep habits are vital factors that affect his or her health. Doctors will ask about these issues, among others, during your baby’s follow-up visits. It can be helpful for you to keep a written list of daily actions, such as how often your baby sleeps and for how long, how often your baby feeds and for how long*, as well as other things you notice about your baby and questions you may have. Take your list to your baby’s follow-up visits to help the doctor understand your baby’s health and address any problems at an early stage.

Find out about local sources of help, such as:

<table>
<thead>
<tr>
<th>Breastfeeding support</th>
<th>Infant/child health assessment program</th>
<th>Language services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community health worker</td>
<td>Women, Infants and Children (WIC) program</td>
<td>Smoking cessation</td>
</tr>
<tr>
<td>Family planning</td>
<td>Mental health services</td>
<td>Social worker</td>
</tr>
<tr>
<td>Financial planning</td>
<td>Group shelter/housing authority</td>
<td>Unemployment office</td>
</tr>
<tr>
<td>Parent hotline/support group</td>
<td>Public health nurse home assessment</td>
<td>Genetic counseling</td>
</tr>
<tr>
<td>Medicaid program</td>
<td>Programs for children with disabilities</td>
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</tr>
</tbody>
</table>

Take care of yourself. Being a parent is hard work. Studies show that parents and family members of children with health problems may have increased stress as a result of these problems.** As a parent, it can sometimes be hard to talk to others about these issues. Keep in mind that your baby’s health care team knows that healthy parents are required in order to have a healthy baby. The health care staff can help put you in touch with many types of people to help with the following:

<table>
<thead>
<tr>
<th>Single mother</th>
<th>Disturbed mother/baby relationship</th>
<th>Employment problems</th>
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</thead>
<tbody>
<tr>
<td>Teen mother</td>
<td>Inadequate support system</td>
<td>Parent abused as a child</td>
</tr>
<tr>
<td>Crime and/or legal problems</td>
<td>Substance abuse</td>
<td>Abuse or violence in your home</td>
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<tr>
<td>Depression in either parent</td>
<td>Housing problems</td>
<td></td>
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<tr>
<td>Need for financial help (such as food stamps, WIC or Medicaid)</td>
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Farewell

You now are able to eat, breathe, sleep and grow without the help of the NICU, and it’s time to venture along the road ahead with your parents and family. You have been a bright star among us in the NICU and you have helped make our lives very special. We wish all of you a healthy and happy journey in life.

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Brought to you by Pediatrix Medical Group through The Center for Research, Education and Quality. To learn more, visit: pediatrix.com/forparents

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**Where can we find help for our baby and family?** You may find the following sources below helpful. Most of these sources can be accessed with a computer. If you do not have access to a computer, your local public library or your baby’s doctor’s office may be able to help you access these websites.

- **American Academy of Pediatrics** provides information about child health: [www.aap.org](http://www.aap.org).

- **The American College of Emergency Physicians** provides an *Emergency Information Form for Children with Special Needs*, a blank form for parents to complete and keep with their child’s health records: [www.aap.org/advocacy/blankform.pdf](http://www.aap.org/advocacy/blankform.pdf)

- **American Board of Internal Medicine Foundation** provides a list of support organizations for parents, families, and caregivers of children with health care needs: [www.abimfoundation.org](http://www.abimfoundation.org)

- **Centers for Disease Control and Prevention** provides information about child development through its program, “Learn the Signs: Act Early”: [www.cdc.gov/ncbddd/autism/actearly](http://www.cdc.gov/ncbddd/autism/actearly)

- **Early Childhood Learning & Knowledge Center**, operated by the U.S. Department of Health and Human Services, provides information and resources for parents about child health and development: [http://eclkc.ohs.acf.hhs.gov/hslc](http://eclkc.ohs.acf.hhs.gov/hslc)


- **Family Voices®**, a national organization that supports family-centered care for children with health care needs, provides information and support tools for parents, including a list of state health programs for parents: [www.familyvoices.org/toolbox](http://www.familyvoices.org/toolbox)

- **Healthy Steps for Young Children** is a national program designed to help children develop during the first three years of life. For more details and to find out if there is a program in your area, visit: [www.healthysteps.org](http://www.healthysteps.org)

- **The National Early Childhood Technical Assistance Center**, operated by the U.S. Department of Education, helps parents of infants, toddlers and pre-school children with special needs find early childhood services in their area: [www.nectac.org](http://www.nectac.org)

- **New Health Partnerships: Improving Care by Engaging Patients**, created by the Institute for Healthcare Improvement, provides resources and support for patients and their families to manage their own care within the health care system: [www.newhealthpartnerships.org](http://www.newhealthpartnerships.org)

- **Zero to Three®**, a national, non-profit organization that promotes the health and development of infants and toddlers and provides information about many topics for parents: [www.zerotothree.org](http://www.zerotothree.org)

*This information is for educational purposes only and is not intended to substitute for professional medical advice. Always consult with a health care professional if you have any questions about the health of your baby.*