

Project Sweet Peas'  
NICU Guide



For Parents

## **This NICU Guide is provided by Project Sweet Peas**

### **Our Mission:**

Project Sweet Peas is a nonprofit organization run by volunteers across the country, who through personal experience have become passionate about providing comfort to families with children in the intensive care units and to those who have experienced pregnancy and infant loss.

Our programs support the wellness of families by providing care packages and other services that offer comfort while furthering the bond between parent and child, and treasured keepsakes to families who have experienced a loss.

Through our services, we give from our heart, to inspire families with the hope of tomorrow.

To find out more about our organization and services offered:

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# Congratulations

The birth of your baby is a joyous occasion. However, the experience of being in the neonatal intensive care unit (NICU) can be very overwhelming. Concern and fear may take over the excitement surrounding the birth as you are now faced with a variety of different emotions. The range of emotions you are feeling are perfectly normal. Knowing what to expect can help you manage those emotions.

We want you to have this guide to help aid you through your NICU journey. It is our hope that this guide and the advice of your caregiver will provide encouragement and strength.

## Know the Rules

Each NICU is different; all rules will vary depending on the hospital's policy and the severity of your child's condition. Most NICU's will hand out guidelines, but if not, make sure you check on a few things the first day. For example: What are visiting hours? How many people are allowed at your child's side at a time? Are physical interactions such as bathing, diapering, feeding, and holding your child, limited? Can you bring items in from home such as a book to read to your child, or stuffed animals and pictures to leave in the isolette? What phone number can you use to check on your child?

## Know the Routine

A NICU has a specific routine in place. By knowing the routine you can be better prepared as to what to expect during your stay. Find out how long the shifts are, and what time shift change takes place. Ask what time rounds are made, and if you are allowed to be there during these times.

## Ask Questions. Take Notes.

No question is too small. This is your child, and staying informed is important. If no one is around, write down questions when they come up, to ask later. If you are even the slightest bit concerned about your child's condition, ask questions! The nurses and doctors are there to help you understand and make informed decisions on your child's care. To help you remember the answers to these questions, and jot down new ones, keep a journal and take notes. It can be a great tool to refer back to later on.

## Know Your Nurses

Every nurse is different with a unique personality, routine, and opinion. There may be times you disagree with an opinion or action. If you are uncomfortable with or not 'seeing eye to eye' with a nurse, take your concerns to another staff member that you do feel comfortable with. Remember, this is your child and you must be able to trust whoever is taking care of him/her. If you are unhappy at any time with the care of your child, take your concerns to the head nurse, social worker, or leading neonatologist.

## Make Sure Your Expectations are Understood

Most parents have a preference on the parenting style and care that they chose for their child. Breastfeeding vs. Bottle, the use of pacifiers, religious considerations, etc... are all topics that should be discussed. Keep an open mind, not every request may be able to be accommodated based on your child's condition. However, by informing the staff of your wishes, they can help you make the best decisions for your child.

# 1

## Celebrating Milestones

From the way they are fed to breathing on their own, milestones for NICU babies are reasons to celebrate. Each new step is one day closer to bringing your baby home.

Oxygen Saturation level will be one of the first things that you hear discussed in the NICU and keeping that level high is one of the first milestones your baby will reach. Many babies need some sort of respiratory support shortly after birth, and the length of time your baby needs this support depends on his/her condition. In some cases, oxygen may be needed even after they are ready to go home.

Apnea and Bradycardia, the A's and B's, is a common condition with NICU babies. While in the NICU the heart rate and breathing pattern of your baby will be monitored. Any issues are quickly caught and handled. While most outgrow the A's and B's around 35 weeks gestational age, an apnea monitor may be sent home for those that haven't.

If your baby does not have the strength to suck and swallow, or has another condition that makes him/her unable to eat by mouth, they may receive their nourishment through a feeding tube. Once they are strong enough to drink from the breast or bottle the tube will be removed. In most cases, before your baby can be discharged, they should be eating regularly and gaining weight at a steady pace.

An incubator is a scary sight for any new mom. However, this is the best way to keep your baby warm and safe. It's common for new babies to have trouble regulating their body temperature. If your baby is not in kangaroo care, then the incubator is the best place for them. Regulating their body temperature without the assistance of an incubator is an important milestone!

These are just some of the wonderful milestones you will be able to celebrate. From small beginnings come great things!

There are many different ways to celebrate the milestones of your baby. From journaling and scrapbooking, to stickers and journey beads; you will want to capture the moments that bring your baby one step closer to home.

Don't forget to take pictures. Many parents are reluctant to take pictures of their critically ill newborns, but this is an important time in their life that you will want to document to see just how far they've come.

Keep in mind that all babies are different and your child's milestones may not follow the typical timeline. Discuss your concerns with your child's doctor and try to be patient; your little one is working hard to overcome the additional obstacles he/she faces to get there!

**NICU Journaling & Scrapbooking:**

[www.miraclebebe.com](http://www.miraclebebe.com)

[www.preemiestore.com/NICU-Diary\\_p\\_62.html](http://www.preemiestore.com/NICU-Diary_p_62.html)

[www.mykidsinspiration.com](http://www.mykidsinspiration.com)

**Journey Beads:**

[www.peekabooicu.org](http://www.peekabooicu.org)

# 2

## Glossary of Terms

### **Apgar Score**

The results of a test given to your baby to quickly evaluate the physical condition and need for immediate extra care.

### **Apnea**

The condition of not breathing.

### **Aspiration**

Inhalation of material (formula, meconium or stomach juice) into the trachea (windpipe) and lungs.

### **Attending Physician**

The physician in charge of your baby's care.

### **Bagging**

Pumping oxygen to your baby's lungs by squeezing a bag that covers your baby's mouth and nose.

### **Bilirubin**

A yellowish pigment that is produced when red blood cells break down. When the body can't dispose of bilirubin, jaundice can occur.

### **Bilevel Positive Airway Pressure (BPAP)**

A continuous positive airway pressure (CPAP) mode that is used during noninvasive positive pressure ventilation.

### **Blood Gases**

Laboratory test to determine the amount of acid, oxygen, carbon dioxide, and other gases in the blood.

### **Oxygen Saturation**

The percentage of oxygen bound to hemoglobin in the patient's blood.

### **Bradycardia**

A heart rate less than 100 beats per minute, slower than normal for an infant.

### **Catheter**

Tubing inserted into the body to allow the passage of fluids.

### **Central Venous Line**

A catheter that is placed into a vein in the neck, chest or groin to administer medications or fluids.

**Continuous Positive Airway Pressure (CPAP)**

A machine that pushes a continuous flow of air or oxygen through the airways to help keep the air passages open.

**Culture**

A propagation of microorganisms in a growth medium.

**Dextostix**

A special test strip used to determine how much sugar is present in a sample of blood.

**Echo-cardiogram (Echo)**

The use of ultrasound to view the structure and function of the heart.

**Edema**

Swelling caused by fluid retention.

**Electroencephalogram (EEG)**

The recording of the electrical activity of the brain.

**Endotracheal Tube (ET Tube)**

A breathing tube.

**Extracorporeal Membrane Oxygenation (ECMO)**

Providing respiratory support through an artificial lung

**Fellow**

A doctor training to be a physician in a given field of medicine.

**Fontanel**

An anatomical feature of an infant's skull referred to as the soft spot.

**Gastro-Esophageal Reflux**

Where food or liquid leaks backwards from the stomach into the trachea.

**Gavage feeding**

A feeding tube that is placed in a baby who has not learned to swallow.

**Gestational Age**

Age of baby in weeks from conception.

**Gram**

A metric unit for measuring weight. One gram equals 1/28 of an ounce.

**Hyaline membrane disease**

See Respiratory Distress Syndrome

**Hyperalimentation**

Administering nutrients by intravenous feeding

**Incubator/Isolette**

A heat-controlled crib used to maintain a baby's body temperature

**Intravenous(IV)**

A small tube inserted into a vein to deliver medicine, fluids into the blood.

**Intubation**

Insertion of tube through the nose/mouth into the trachea

**Intake and Output (I&O)**

Total amount of fluid taken in to the body (Input) VS. the fluid lost as urine, stool or perspiration (Output).

**Jaundice (hyperbilirubinemia)**

A yellow discoloration of the skin and whites of the eyes that results from excess bilirubin.

**Kangaroo Care**

Holding a baby against one's naked chest, so there is skin-to- skin contact.

**Lung Hypoplasia**

Failure of one or both lungs to develop fully.

**Meconium**

A baby's first stool, which is greenish or black

**Nasal Cannula**

A special tubing that is used to give oxygen through the nose.

**Nasogastric Tube (NG Tube)**

A plastic tube inserted through the nose into the stomach or intestines to aid in digestion when the patient cannot eat by mouth.

**Necrotizing Enterocolitis (NEC)**

An intestinal infection that causes inflammation of the lining, and in rare cases necrosis (tissue death)

**Neonatal Intensive Care Unit (NICU) (3 levels)**

Intensive Care Unit specializing in the care of ill or premature newborn infants. There are three levels of care based on the complexity of care provided:

**Level 1 – Basic Care**

Provides routine medical care to healthy babies or those who may have mild illness expected to resolve quickly.

**Level 2 – Specialty Care**

Handles babies who need close monitoring or who have moderate illness or condition expected to resolve quickly

**Level 3 – Advanced Specialty Care**

Provides intensive care for babies born at all gestational ages. Handles babies who need respiratory support, and/or surgical care.

**Neonatologist**

A pediatric specialist that cares for newborn infants, especially very ill or premature infants.

**Nitric Oxide**

A gas that is used as an inhalant in order to try and enhance lung growth and recovery.

**Oximeter (Pulse Oximeter)**

A device worn on the finger, toe or earlobe that can measure levels of oxygen in the blood.

**Patent Ductus Arteriosus (PDA)**

A condition in which the ductus arteriosus (a blood vessel that allows blood to go around the baby's lungs before birth) does not close.

**Percutaneously Inserted Central Catheter (PICC Line)**

Also called a Percutaneous Line. This is a long catheter placed into a surface vein, with the catheter tip extending farther into the body into a large central vein.

**Phototherapy**

The process of using light to eliminate bilirubin in the blood.

**Pneumothrax**

The collection of air in the space around the lung.

**Pulmonary Hypertension**

High blood pressure in the pulmonary artery which conveys blood to and from the right ventricle of the heart, to the lungs.

**Respiratory Syncytial Virus (RSV)**

Infection of the lungs and breathing passages.

**Respirator**

Also known as a ventilator, is a machine that helps breathing by supplying and regulating a flow of air and oxygen.

**Retinopathy of Prematurity (ROP)**

A potentially blinding eye disorder that effects premature infants.

**Rounds**

The gathering of doctors, nurses or other health care professionals to discuss the condition and care of patients.

**Sepsis**

Infection that occurs in, or has spread to, the blood.

**Spinal tap**

A procedure that is done to collect a sample of spinal fluid for analysis.

**Step Down**

Decreasing in stages in the amount of care required.

**Suctions**

Removal of secretions from the nose or throat or from the endometrial tube using a small plastic tube connected to a vacuum outlet.

**Tachypnea**

Rapid breathing.

**Total Parenteral Nutrition (TPN)**

Supplying nutritional needs of the body through an IV, bypassing the digestive system.

**Transfusion**

The introduction of blood directly into an individual's blood circulation through a vein.

**Umbilical Arterial Catheter**

A line placed into the umbilical artery through the umbilical cord.

**Vital signs**

Temperature, heart rate, respiratory rate, blood pressure and pain level.

		Pounds										
		0	1	2	3	4	5	6	7	8	9	10
Ounces	0	0	454	907	1361	1814	2268	2722	3175	3629	4082	4536
	1	28	482	936	1389	1843	2296	2750	3203	3657	4111	4564
	2	57	510	964	1417	1871	2325	2778	3232	3685	4139	4593
	3	85	539	992	1446	1899	2353	2807	3260	3714	4167	4621
	4	113	567	1021	1474	1928	2381	2835	3289	3742	4196	4649
	5	142	595	1049	1503	1956	2410	2863	3317	3770	4224	4678
	6	170	624	1077	1531	1984	2438	2892	3345	3799	4252	4706
	7	198	652	1106	1559	2013	2466	2920	3374	3827	4281	4734
	8	227	680	1134	1588	2041	2495	2948	3402	3856	4309	4763
	9	255	709	1162	1616	2070	2523	2977	3430	3884	4337	4791
	10	283	737	1191	1644	2098	2551	3005	3459	3912	4366	4819
	11	312	765	1219	1673	2126	2580	3033	3487	3941	4394	4848
	12	340	794	1247	1701	2155	2608	3062	3515	3969	4423	4876
	13	369	822	1276	1729	2183	2637	3090	3544	3997	4451	4904
	14	397	850	1304	1758	2211	2665	3118	3572	4026	4479	4933
15	425	879	1332	1786	2240	2693	3147	3600	4054	4508	4961	

# 3

## Breastfeeding In The NICU

Discuss your breastfeeding intentions with the staff to be sure they know and understand your expectations, and can help you receive the information and assistance you need.

If you plan on breastfeeding, you will need to speak to a staff member about utilizing a breast pump within the first 24 hours after birth. Most hospitals will lend you a pump, if you do not already have one. They can also assist you with the purchase of a breast pump if covered by insurance. A lactation consultant will go over with you how often to pump and where you can pump in privacy in the NICU.

While you are pumping for your baby, the NICU should be able to supply storage bottles for your breast milk. Always clearly label your bottles with your child's name, date, and time. Find out where in the NICU the milk is stored and make sure they are being rotated properly to use the oldest milk first.

Try to keep to your pumping schedule in and outside the NICU. By pumping on schedule you can assure your milk supply stays strong and it will prepare you for the schedule of feedings when your child is discharged.

When the time comes to breastfeed your child, understand that there can be many challenges to breastfeeding a NICU baby. It's common for them to tire quickly, have trouble sucking, or become easily distracted. It can all be very frustrating for new moms. Request a lactation specialist to help you with any concerns or problems you are experiencing.

Breastfeeding and/or pumping can be a challenge, but it is the best thing you can do for your NICU baby. Remember to stay hydrated and take care of yourself as well. Your milk supply will rely on your well-being.

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## Dad's View

Dads have such an important role in the NICU, but at times it can seem as if your role is secondary, as everyone around focuses on Mom and her recovery, needs, and emotions. Don't let this discourage you. Your role and support is vital to your child's wellbeing.

You may find yourself feeling helpless and at a loss as to what to do. Strong and often contradictory emotions, such as anger and sadness, guilt and grief, helplessness and hope may be swirling through your head throughout the day. Stop and take a moment to acknowledge what you are feeling and just how difficult your situation is. Having a child in the NICU may be the hardest thing you ever face in your life, so now is not the time to play the hero and pretend you can do it all. Focus on what you can do to help yourself, your baby, and your spouse or partner.

### **Helping Yourself**

See if your NICU has a support group and consider attending. Most people you know have never experienced the NICU and they just can't relate to everything you are going through. Talking with others who are in the same situation as you can be very helpful. Be open and honest about your concerns and fears. If a support group isn't available, seek out a trusted friend or family member you can talk to.

Exercise can be a good way to release some tension and clear your head. Don't forget to get enough sleep, and eat as well. Your health is important too.

## **Helping your Baby**

Looking at your new baby hooked up to machines, looking so small and frail... this is not what you imagined fatherhood to be like. You may be extremely nervous about holding your baby, and participating in his/her care for fear of doing something wrong. Pay close attention to what the nurses are doing and ask lots of questions so you can feel confident about helping. They know that all parents are nervous about what to do, so no question will surprise them. Take notes if you need to or have them stay right there with you the first few times until you feel comfortable. The most important thing is not to let these opportunities pass you by. You will want to experience and remember these special moments.

## **Helping your Spouse or Partner**

You may find yourself wondering just how Mom is able to handle everything--and the secret is, she can't without a lot of help. Make sure you are helping take care of her so she is able to focus on your child as well. Some things that may help:

- If she is pumping breast milk for your baby, be supportive. Wash the pumping supplies and help label and store the milk .
- Keep track of the insurance information. Help make some of the necessary phone calls to insurance companies, specialists, etc.
- Make sure the house, diaper bag and her purse or bag is stocked with some quick, healthy snacks like granola bars, fruit, and nuts. Eating on the run will be commonplace now, so having some healthy options close at hand is important.
- Take over some of the household chores or enlist help to get them done. Laundry, cleaning, running errands—these still need to be done. By taking some of these items off her to-do list, you ease her stress and worry immensely.

# 5

## Grandparents View

Congratulations on becoming a grandparent. Whether or not this is your first grandchild, having a grandchild in the NICU can bring its own set of challenges and worries. You may find yourself looking around the NICU, surprised at all the machinery, and overwhelmed with worry at the situation. Grandparents often experience their own unique set of feelings as you worry about your child and what they are dealing with, as well as your grandchild and the struggles they are facing. Whatever brought your grandchild to the NICU, it is important to take a step back from the situation and determine the best ways to care for you and your growing family.

Allow yourself to feel and express emotions. You may want to be strong for the sake of your child, and while that is admirable, it is not sustainable. Find a time and to express whatever emotions you are feeling. You may find journaling to be helpful, or talking to your spouse, partner or a trusted friend. It's important not to keep your feelings bottled up.

Find ways that you can help. In addition to visiting the NICU, you can prepare meals, offer to clean their house, pick up the mail, or run some errands. If there are other siblings, taking care of them will also relieve some of the stress.

If you don't live nearby but still want to help, sending the family gift cards to restaurants and gas stations near the hospital can help relieve some financial burden. You can also offer to be the contact person for extended family to return phone calls and give updates on the latest news regarding the new baby.

Whatever help you are able to offer, it will be greatly appreciated.

# 6

## Sibling Support

How do you inform your children that their new sibling may not be coming home from the hospital as quickly as you had thought? Take a bit of time to react to the diagnosis, and arm yourself with information and support to help share the news. Children are very intuitive, and also very resilient. Be as open and honest as you can possibly be, in simple, age appropriate language that they can understand.

Preparing how you explain it to your child(ren) is important. Choose your wording carefully to avoid confusion as children often take things very literally. Avoid making promises that you do not know you can provide to avoid future frustration and confusion. Allow them to express their feelings openly and let them know that you are always available to answer their questions, and provide the necessary comfort they may be seeking. Make time for the siblings, as they often become or feel like the "forgotten ones" while their new baby is in the hospital. It's important that in the chaos they still have some individual attention. Reach out to family and friends and request their assistance with the child-rearing responsibilities as well.

There will be times when your emotions may spill out in the presence of your children. This is normal and unavoidable at times. Be gentle with yourself as you comfort and reassure them that you're there for their needs, and that expressing emotions is "okay".

It's common for siblings to act out and have behavior issues during this time. Having a NICU baby affects the whole family. Seek outside assistance, if in doubt, through your local health provider or children's mental health services. Professionals will be able to recognize anything which may be concerning, and recommend/provide necessary supports and helpful resources.

# 7

## Taking Time For Yourself

Taking time for yourself while your baby is in the NICU may seem like the last thing on your mind. One of the most important aspects of caring for your new baby is also caring for yourself. You can become overwhelmed very quickly and need to express the stress that you are feeling.

Talking about your feelings is very healthy. Some may find writing in a journal therapeutic, or you may want to find a NICU support group or counselor to talk to.

Another way to express stress is to stay active, both physically and emotionally. You can take a walk or work on an art project. Even doing a crossword puzzle allows your mind to “get away.”

Eating healthy and often is important. It will keep your energy level up and provide you the nutrients needed to continue to heal after delivery. Pack a bag of fruits and vegetables to keep with you. Trail mix and nuts are very good snacks that travel easily.

Getting a massage or taking a nap are both perfectly acceptable ways to take time for yourself. Enlist support from your family and friends to ensure that you get the time you need. Be conscience of your own body’s signals for stress and find a way to manage it so that you can be relaxed and calm when you are with your baby.

# 8

## Getting Support From Others

You may be asked, several times, what people can do to help. This is the time to let others help you. Your job is to take care of yourself and your baby. There is nothing wrong with letting others take care of your house, the errands, the kids, etc...

This may be one of the hardest things that you have to do, especially if you like to be in control. Letting other's help you is one of the best things that you can do to give yourself the time you need to address important issues related to your new baby and your growing family.

Allow people to make you dinners and even come over and clean up your house. If you haven't had a chance to complete your nursery then let some closer friends come over and get it ready for you. Put a friend or family member in charge of arranging a meal schedule for your family, and in charge of returning calls or sending out updates. By delegating the daily tasks to others it will allow you time to rest, heal, and be there for your spouse and child(ren) when you need to be.

# 9

## Discharge and Beyond

### **Preparing for Discharge**

Since the time your baby was born you have been anticipating the day that you can all go home as a family. After your baby has completed the necessary milestones, he or she will be ready to go.

In preparing to take your baby home, the NICU staff will help you learn how to feed, bathe and dress your baby. They will also teach you how to give medications, take temperatures, and use any necessary medical equipment at home.

The more practice that you are able to get while in the NICU the more prepared you will be when arriving home. Check if your hospital offers infant cardiopulmonary resuscitation (CPR) classes and learn how to administer properly. If the hospital does not offer a class you can check with your local Red Cross or Fire Department.

If your hospital permits, take a chance to 'room in' with your baby prior to discharge. This gives you the opportunity to take charge of your baby's care but have access to nurses if questions arise.

### **Staying Organized**

Congratulations, you are now the parent of a NICU graduate! Right now you are focusing most all your energy on your new baby and trying to understand the overwhelming amount of information that you are being given. Staying organized is a great way for you to gain control in a situation where you may feel you don't have any.

Depending on your child's needs you may have several doctors' appointments to schedule, new medical equipment to learn how to use, and a wide variety of medicine to administer. You need to create a system that will work for you. One of the easiest things to manage is a binder system that is expandable, easy to follow and that you can carry with you.

Within the binder you should have a section for all contact information (a list can be found in our contact section), a medication schedule, a section for authorizations that are covered for when your infant has a doctor's appointments, and a place to store information that the doctors provide to you. Also save a place to store your receipts, co-pays, and mileage information as all of that is tax-deductible.

## **Developmental Delays**

Research shows that NICU babies are at risk for developmental delays in speech and language, cognitive skills, and motor skills. Getting these delays identified and treated early gives your child a better chance of reaching his or her full potential. Children that are at risk are often referred to an early intervention program. States are required to evaluate infants and toddlers who are at risk or have developmental delays and disabilities and provide support services to these children.

Your child will have a diagnostic evaluation to determine his or her strengths as well as areas that need improving. The evaluation may include health care providers from the following areas:

Early intervention programs are designed for families and service providers to work together to ensure the best possible scenario for your child.

Medical  
Nutrition  
Psychology

Education  
Hearing  
Vision

Speech/Language  
Physical Therapy  
Occupational Therapy

# Dealing with Insurance Companies

Having a child in the NICU brings with it so many emotions and realities, and often times one of the most stressful ones has to do with medical insurance. It won't be long before the bills and phone calls start pouring in, and while this is the last thing any new parent has time or energy to deal with, it's best to be prepared. Here are some tips that might be helpful:

- The first thing to do is to find your copy of your health benefits book from your insurance company and start reading it over. You most likely would have gotten this when you first enrolled in your insurance plan, and sometimes a new one is given each year with any updates and changes. Find it and start looking at the specific sections dealing with hospitalization charges, specialists, and in network versus out of network charges. You will also most likely have a short window to contact your insurance provider or employer to add your new baby as a dependent. This must be done to be sure they have coverage under your plan.
- Contact someone in the hospital's billing department. They can tell you if they accept your insurance and what your estimated co-pays or out of pocket costs might be for the first couple of days. Sometimes the NICU social worker also helps in this area—be sure to ask.
- Start a folder right away labeled with your child's name and birth date, and keep ALL receipts, notes, forms, and bills in this same folder. This keeps everything together in one place. As a new parent and a NICU parent, your stress level will be high. Don't add to it by misplacing important papers or forms. Make sure everyone dealing with the insurance knows that all forms go in the folder—it will save lots of headaches down the road.
- Keep detailed notes. Whenever you talk to someone about a bill or statement, write down a quick summary of what was discussed. You can do this right on the bill if there is room, or attach another sheet of paper if that works better. Include the name of the person you talked to, the date and time of your call, and a brief summary of what was discussed. This will be helpful if later on you have to talk to someone else about the same issue.

- Once the bills start really coming in—don't stress yourself out by looking them over every day. Just open them, put them in your folder, and designate one day a week to look over them. Nothing is going to change in a week's time, and by setting aside that specific time each week, you spare yourself a lot of worry and anxiety over each day's mail.
- If you are having trouble paying the bills or not getting what you need, see if your hospital or insurance provider has a medical billing advocate that you can talk to. Medical billing advocates are sort of like a middleman between you and the hospital to help everyone come to a resolution regarding bills and payments. While they are not found everywhere, you should definitely look to see if one is available in your area.
- Know your insurance company's appeal process. Sometimes this information is printed right on the bottom or back of bills, if not; check your health benefits book again. If you think a charge is denied and it shouldn't be, you will have to file an appeal. Often time these are a lot of work—but it is necessary if you think something isn't being paid that should be. You may also need to get detailed medical records on certain conditions or letters from healthcare professionals like doctors—don't be shy about asking for these. In this day and age, doctors are well aware of the difficulties found in some insurance policies and most likely will work with you to try and get any issue you may have resolved.
- Lastly, find out if you qualify for any state or federal programs. Often, the NCU social worker or discharge planner can handle this. Each state has different criteria and regulations, but you should check to see if your child is eligible for Social Security Income, Medicaid/Medicare, WIC, or any other programs.

Hang in there. No one likes dealing with paperwork and forms. If this is a task that can be delegated, perhaps to a spouse, do so. Insurance paperwork is time-consuming and draining, but it is usually short lived.

## Expecting The Worst

Not something you would like to think about, but in some extreme circumstances, it may be something you are faced with. If you are told it is unlikely your child will make it, there may be some things you should consider doing before your child dies. Take time with your child. These memories will be important to you. Bathe, dress, and hold your child. Take foot and hand prints and/or molds and make sure to cut and save a lock of hair. Do not feel "rushed" while holding your child. Take as long as you need. Have someone take pictures of your child and this time together. These pictures and keepsakes may be something you find hard to look at first, but it is better to have them, then to regret not having them.

Talk to your social worker, Chaplin, and nurses about what services are available. Can they provide a memory box and tools to collect these precious mementos? There are free services for parents to help get through this time. Take the time to ask what ones are available in your area. A few national resources:

### Now I Lay Me Down to Sleep

[nilmdts.org](http://nilmdts.org)

Provides free memorial photos to families which have received a poor prenatal diagnosis or poor prognosis at birth.

### The Compassionate Friends

[www.compassionatefriends.org](http://www.compassionatefriends.org)

Offering support to families following the loss of a child

### Virtual Memorials

[www.virtualmemorials.com](http://www.virtualmemorials.com)

An Online Memorial Website that celebrates the personal life story of your loved one.

For a complete list of resources visit our "Sweet Links" page under the Resources tab on our website at [www.projectsweetpeas.com](http://www.projectsweetpeas.com)

## **Additional Resources**

### Supplemental Security Income (SSI)

This program provides benefits to disabled children who have limited income and resources. To see if you qualify you can take the benefit eligibility screening tool found on the SSI web site. <http://www.ssa.gov/ssi/>

### Early Intervention

Early intervention services are designed to meet the needs of infants and toddlers who have a developmental delay or disability. <http://nichcy.org/babies/overview>

### WIC

Supplements foods, provides health care referrals, and offers nutritional education for low-income pregnant, nursing or non-nursing postpartum woman and infants and children up to age five. <http://www.fns.usda.gov/wic/>

For a complete list of resources visit our "Sweet Links" page under the Resources tab on our website at [www.projectsweetpeas.com](http://www.projectsweetpeas.com)

# 10

## Contacts

Pediatrician

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NICU Nurses Station

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Nursing Director

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Social Worker

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Hospital Main Line

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ER Line

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Lactation Consultant

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Medical Supplies

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Insurance Company

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Family Doctor

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Other

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