

REGAINING CONTROL

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A Plan of Action Following a Fetal Diagnosis

*Tell your family (sometimes it is helpful to do this after you have gathered *some* information about the birth defect. Often times they will have questions and/or unfounded vision or fears concerning this diagnosis.)

*Begin immediately to gather as much information on the anomaly as you can.

(Information = Empowerment)

- Use the Internet looking up "keywords". For example: SPINA BIFIDA
- Go to the library
- Ask your OBGYN to refer you to respected neonatologist who will be involved in the care of your child after he/she is born.
- Arrange to have a face to face meeting with this neonatologist
- This is a special baby doctor whose job is providing care for these special babies. They are often witness to unexplained miracles.
- He will best be able to guide you to qualified medical specialists who will care for your child once he/she is born. (Cardiologist, neurosurgeon, etc...)
- Find other parents who have faced the same prenatal diagnosis.

*Take Care of Yourself:

- One of the most important things you can do beyond getting information and setting up a support system is to take good care of yourself. This entails getting adequate sleep, nutrition, fluids, exercise, and pleasure. While it may seem impossible to enjoy the things that pleased you perhaps as little as a week ago, it is important that you stay true to yourself. Often times, our attitudes will follow our actions. For example, If you derived enjoyment from scrapbooking with some friends before the diagnosis, though you may not feel up to it right now, if you continue with your typical routine and meet with these friends to scrapbook, you will probably find that the time spent on this activity is "therapeutic" for you.

- It is very important to your health and the health of your developing baby that you continue to do the things you get enjoyment and meaning from. There have been countless studies that suggest a developing baby in the womb can pick up on the emotions of the mother. Emotions create bio-chemicals called hormones. Feelings of fear or anxiety create the hormone adrenaline. Feelings of delight and peace foster the secretion of dopamine. Some have even suggested, if the mother was happy and peaceful during her pregnancy, the baby will more than likely be a happy and peaceful baby. If the mother was filled with

anxiety and hostility (thus excreting hormones associated with these emotions) the baby could have a tendency to be anxious. Do yourself and your baby a favor and treat yourself to the things that bring you pleasure. If you participate in these things, soon your attitude will catch up with your actions. Don't abandon yourself. Your baby needs you in top form.

*Nurture Your Baby:

- If you haven't done so already, develop a routine of lovingly communicating with your baby. This could come in a variety of forms.

For example:

-Sing lullabies softly as you are driving in the car. Once your baby is born, these gentle songs will go far to soothe your baby when he is upset. If you sing songs from the CD you've selected to take with you to the hospital, this same CD can be played in your absence by the NICU nurses to aide in comforting your baby.

-Read quality children's stories to your baby in the womb. You may wish to record these tender stories on tape so your baby can hear your soft and loving voice sounding a familiar tale during his time away from you.

Book Suggestions:

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| - | <i>The Carrot Seed</i> | by Ruth Krauss |
| - | <i>You're Just What I Need</i> | by Ruth Krauss |
| - | <i>God Gave Us You</i> | by Lisa Tawn Bergren |
| - | <i>Momma, If You Had a Wish</i> | by Jeanne Modesitt |
| - | <i>The Tale of Three Trees: A Traditional Folktale</i> | retold by Angela Elwell Hunt |
| - | <i>If You Were My Bunny</i> | by Kate McMullan |
| - | <i>Just In Case You Ever Wonder</i> | by Max Lucado |
| - | <i>You Are Special</i> | by Max Lucado |
| - | <i>The Oak Inside The Acorn</i> | by Max Lucado |
| - | <i>Guess How Much I Love You</i> | by Sam McBratney |
| - | <i>Goodnight Moon</i> | by Margaret Wise Brown |
| - | <i>The Runaway Bunny</i> | by Margaret Wise Brown |
| - | | |

*Begin working on your specific birthing plan.

- Remember, you are having a baby. Though there is heartache involved, the birth of this baby should be a joyous and memorable occasion. You should be in as much control as medically possible. Seek counsel from your neonatologist concerning specific requests like "rooming in" or "holding immediately after birth"; but you should feel free to create a beautiful and warm birthing experience for your baby AND for yourself. You both deserve it!

*Nurture your spirit:

- Whether or not you are a person of faith, you ARE a person who is multidimensional. You have a body. You have a mind. And you have a spirit. Your pregnant body continues to develop, your mind is swirling and problem solving, but it is your SPIRIT that is aching. There are things you can do to bolster and nurture your spirit.

-Read encouraging stories, poetry, and books. (This packet includes some powerful prose that has helped us connect and work our way through grief and anxiety.)

Book Suggestions:

- *YOU WILL DREAM NEW DREAMS: Inspiring Personal Stories by Parents of Children with Disabilities*
by Stanley D. Klein, Ph.D.
and Kim Schive
- *THE LANGUAGE OF COURAGE AND INNER STRENGTH*
edited by Douglas Pagels
- *EXPECTING ADAM*
by Martha Beck
- *CHICKEN SOUP FOR THE SOUL* (series of compiled stories)
- *SOMETIMES MIRACLES HIDE*
by Bob Carlisle
- *CHANGED BY A CHILD: Companion Notes for Parents of a Child with a Disability*
by Barbara Gill
- *A SPECIAL KIND OF LOVE*
by Susan Osborn and
Janet Mitchell
- *LIGHT FROM LUCAS: Lessons on Faith from a Fragile Life*
By Bob Vander Plaats

Devotionals and Bible Studies

- *GRIEVING THE LOSS OF A LOVED ONE: Devotions for comfort*
by Kathe Wunnenberg

-I have a personal relationship with this author. She lives in Phoenix, and she is a wonderful Christian woman. She has been instrumental in the vision and development of this project and has covered me with prayer many, many times. This devotional is perfect for parents who have experienced the death of the baby they were expecting to have at that moment of their prenatal diagnosis. Kathe knows this heartache.

- *+LORD, I WANT TO KNOW YOU*
by Kay Arthur

- *+GOD'S NAME, GOD'S NATURE*
by Jill Briscoe

- *LORD, TEACH ME TO PRAY*
by Kay Arthur

(+) These are in-depth bible studies that help one to focus on the true character of God. The *best* advice I received when our baby was diagnosed at 19.5 weeks gestation was from my mom, "Jill, you can read up and network and learn everything there is to know about spina bifida and hydrocephalus - but *God is the one* who will determine *what* Nicholas will be able to do." With so many different notions floating around these days about who God is, it is critically important we go to the source - Holy Scripture - and see what God says about Himself! There are many false ideas about God. I am blessed to this day by that sage advice.

- HOLY BIBLE
 - Psalms 139: 1-16
 - Romans 8: 28-39
 - Psalms 46: 1-11
 - Using your concordance, do your own topical word study
 - prayer
 - promise
 - strength
 - healing
 - miracle
 - sovereign

Books on Pain and Suffering from a Biblical Worldview

- **HOW COULD A LOVING GOD?*
by Ken Ham
- ** WHERE IS GOD WHEN IT HURTS?*
by Philip Yancey
- *DISAPPOINTED WITH GOD*
by Philip Yancey
- *WHEN WE HURT: Prayer, Preparation, and Hope for Life's Pain*
by Philip Yancey
- **IN THE LIKENESS OF GOD*
by Philip Yancey and
Dr. Paul Brand
- *SUFFERING AND THE SOVEEIGNTY OF GOD*
by Dr. John Piper
- ** WHATEVER HAPPENED TO THE HUMAN RACE?*
by Francis Schaeffer and
C. Everett Koop, M.D.
- ** A CHRISTIAN MANIFESTO*
by Francis Schaeffer
- *THE GOD I LOVE: A Lifetime of Walking with Jesus*
by Joni Eareckson Tada

CREATING A BIRTHING PLAN

Birthing plans are ideas and desires for the birthing experience written by you for the obstetrician/perinatologist, head nurse, neonatologist, and birth assistant to read BEFORE the delivery date of your precious child. This will serve as a courtesy to these caring professionals as they are well versed in the joyous delivery of a healthy baby and may certainly feel at a loss as to how to best meet your unique needs. Creating a birthing plan will help them do their job better and afford you more control over the birthing environment and better memories beyond.

Your wishes should be reviewed and honored by the hospital you choose to deliver your baby. You may choose to mail a copy of your plan to everyone involved in the labor, delivery, and care of your child.

We found that brainstorming and writing our Birthing Plan helped us regain a sense of control over this facet of our lives we had lost at the prenatal diagnosis.

Areas to consider when creating an individualized Birthing Plan:

- 1.) What do we want for ourselves/our family this birthing experience?
- 2.) What are the most important details of our "ideal" that we do not want to sacrifice in the event of an emergency?
Example - husband present at all times
Example - holding the baby before being taken to NICU
- 3.) What do we want for our unborn baby?

BRAINSTORMING is quickly listing at random all the ideas and thoughts that come to mind when pondering the answers to these questions. Do not try to make rhyme or reason at this time. This random list can later be organized into a specific order Birthing Plan. Sometimes it may take several days to revisit this "list" before you feel your task is complete.

The following is the actual Birthing Plan for Kurt and Jill Grier who gave birth to a baby with spina bifida and hydrocephalus at Good Samaritan Hospital in Phoenix, Arizona in 1997.

Birth Plan/Final Draft

Induced labor anytime after 38 weeks gestation if pregnancy is going well and baby is "safe".

(We could not risk giving birth in a non-hospital environment - my second son was born in a mere 16 minutes start to finish at 36 weeks.)

Private LDR room (labor, delivery, and recovery room)

Church elder to start experience in prayer

Dim room lights/room door closed to chaos outside

Peaceful music playing (Enya, Yanni, Otmar Leibert, etc...)

I wear my own maternity gown. No tie up the back, bottom showing hospital gown for this girl! I want to feel pretty and comfortable. I'm okay with bloodstains, they will wash.

(Believe it or not, this was about the biggest "fight" I had during the actual labor experience. Our doctors didn't mind, but the nurse certainly did.)

Unlimited ice chips!

Epidural at onset of induced contractions just incase Nicholas becomes distressed during vaginal delivery and will require an emergency C-section. I do not want to miss this birth because I had to be put under general anesthesia in a flash.

(Most children with hydrocephalus and/or spina bifida are automatically delivered via Cesarean section. I wanted to attempt a vaginal delivery knowing I would have to "hit the ground running" as my baby would be in the NICU and facing several major surgeries his first days of life. I wanted to be in top form.)

I realize the very real potential for a failed vaginal turned C-section delivery. It goes without saying, but I must say, never put the well being of my child at risk for even a moment.

(Nicholas actually did become distressed and I required an emergency C-section.)

No forceps/no Vacuum cap - obvious with the birth of a child with hydrocephalus.

External fetal monitoring only.

Avoid episiotomy at ALL cost. Engage in vaginal massage to stretch and prepare for birth.

Intermittent catheterization after epidural has been administered.

My friend Joy to assist Kurt as my labor and delivery coach. Kurt needs to be with me.

(Joy can help us keep the tone light and cheery in the LDR room and fetch ice chips for me, snacks for Kurt, take pictures, and document events. Very helpful.)

I only want happy people in my room. No grumpy nurses, doctors allowed. We are excited to finally meet our baby...challenges and all.

"Power Verses" as focal points put up throughout room for all to see.

I sincerely wish our own neonatologist to be present at the actual delivery and neonatal examination of our baby.

(Our selected neonatologist - we interviewed for this role - had "guest" privileges at Good Samaritan as he primarily practices out of Desert Samaritan. It is not typical that doctors go out of their way like this - for some parents, it may be easier to go ahead and select a neonatologist who has his/her practice based at the delivering hospital.)

Once Nicholas is delivered, I wish to have him placed on my chest for his initial examination. If the sterile dressing must be placed on his back first, once it is placed, I wish to hold and kiss my son.

Father will cut the umbilical cord.

Nicholas will NOT be taken away without me first holding him unless he is in cardiac or respiratory failure.

I would like to put Nicholas to breast as soon as possible after his birth. I want him to know my scent. I want him to have a chance at nursing before he is rendered in a prone post-surgical position for many days.

If possible, once his sterile dressing is in place and if he is physically stable enough to do so; I would like to be able to "room in" with him until he is taken to the surgical suite for the closure of his back.

(This was NOT possible, but I wanted to make it known anyway.)

Nicholas will be fed breast milk, which I will pump on a two-hour schedule as if I was actually nursing my newborn.

We would both like to be present at his circumcision.

(This could not take place while he was in the NICU as he was recovering from three major surgeries and he had enough to deal with. We scheduled this to be done after his six-week check up. IF we had to do this over again, we would have a pediatric urologist do the circumcision. Your obstetrician performs most in-hospital circumcisions and they are swift and accurate. We had his circumcision performed by one of our pediatricians...they don't do circumcisions very often. Believe me, it will be much more pleasant if you go to someone who has abundant experience with this.)

We would like our children to be able to visit Nicholas in the NICU as soon as possible.

(This may or may not be possible if the hospital is under RSV precautions.)

Administer prescription for progesterone therapy in the management of postpartum depression should it occur.

(I suffered from postpartum depression with my previous births. They being healthy/normal births, I wanted to be sure I was prepared for postpartum depression with the more stressful birth of a baby with a serious problem. It should be noted however, I had no reason for using the progesterone after the birth of Nicholas but I'm glad I was prepared.)

I wish to stay in the hospital as long as my insurance will allow since my baby will undoubtedly have a more lengthy stay in the NICU.

- Items contained within the parenthesis (_____) are a postscript to explain and update this portion of the plan.

THINGS TO BRING WITH YOU FOR THE HOSPITAL STAY

Whether you are expecting the birth of a baby with special medical needs or your child has been born and you are planning on a stay in the hospital; there are things you need with you to make your stay - and your baby/child's stay more fluid, comfortable, and efficient.

- 1.) Your baby's health insurance cards or other documentation required for medical insurance.
- 2.) Latest films/scans and medical records.
- 3.) Listing of medical latex products to go over with all care personnel working with your child. (Don't assume anyone in the hospital knows what contains latex and what does not. Also, don't assume they know the severity of a sudden onset latex reaction. A hospital is the worst place to be for latex sensitive people.)
 - Poster's of LATEX ALLERGY to post on door and bed of hospital room.
- 4.) Baby's favorite toy, blanket, "stuffy".
- 5.) A small tape recorder/CD player to softly play soothing music during your child's hospital stay.
 - Research indicates that gentle, soothing music helps to regulate breathing and ease the way for a speedier recovery for infants.
 - Music suggestions:
 - Return to Pooh Corner* by Kenny Loggins
 - Sleep Sound in Jesus* by Michael Card
 - Hide 'Em In Your Heart LULLABIES*
by Becky Hernandez
- 6.) A collection of your baby's favorite stories to read during alert times.
 - You can also make a recording of yourself reading stories or singing lullabies for the times you are unable to be at the hospital.
- 7.) Photo's of your other children to place on crib/bed for your baby to see during alert times.
 - Even if your baby is too young to pay attention to these pictures, the hospital staff will get more of a feeling that your child is a valuable member of a loving family. It is important they 'see' your baby as a person.
- 8.) Your clothes and toiletries if you will be staying overnight.
- 9.) Ample supply of bottled water for you to keep hydrated during your stay.
- 10.) Any medications you or your baby are taking.
 - Don't forget to tell the doctor about medications or supplements your baby is taking and anything you are taking if you are breastfeeding.

- 11.) Baby's silicone pacifier, if one is used.
- 12.) Baby's bottle with silicone nipple or toddler sippie cup (consider the dripless valve type in case your baby must stay in horizontal position for a while).
- 13.) Breast pumping equipment. Dish soap. Paper towels. Large ziplock baggie for storage.
 - Most hospitals will supply the on-site pump, but you must supply the tubing and breast attachments. Medela offers a wonderful dual system for efficiency.
- 14.) Clothing for the baby that is easy to slip into.
 - If your baby has had shunt surgery, make sure the opening for the head is large enough so not to tug against the shunt as it slips on.
 - If your baby has had myelomeningocile repair, make sure the clothing does not have snaps/buttons the repair site will rest upon in bed or the car seat.
- 15.) Socks, or something similar to cover baby's hands. The baby's face may be itchy due to swelling or morphine.
- 16.) A stroller or carriage, if your baby is soothed by a ride. You can pace the hospital corridors.
 - Some hospitals provide wagons to pull your child around in.
- 17.) Your pillow, blankets, etc. Not every hospital provides these comforts for parents.
- 18.) Your personal list of telephone numbers to keep family, friends, and church informed about your baby.
- 19.) A deck of cards, a novel, your bible, needlework, etc, to pass the time during surgery or when your baby is sleeping.
- 20.) The phone number of your child's primary care physician (pediatrician or family doctor) to keep him/her informed of your baby's status.
- 21.) Notebook for documentation of events during hospital stay.
 - Pediatric Intensivist name
 - Nurses names/shifts
 - Baby's length of sleep/wake states
 - Medications given/reactions to/effectiveness of
 - Baby's emotional state: Quiet alert, agitated,...
 - Baby's appetite/diaper changes

PARENTING YOUR BABY IN THE NICU

It may seem like you won't be able to be a parent to your baby until he leaves the NICU and you are able to take him home. This couldn't be further from the truth. You are this special baby's mother or father and he is depending on you to make sure he has the highest quality, and most attentive of care.

When you think about it, most NICU's are set up for efficiency for the health care providers. The babies in the NICU are the youngest, tiniest, weakest, and most medically fragile. What about harsh, blaring lights and loud alarms and constant noise...what about being thrust from a warm, enveloping, quiet environment (the womb) to such a stark, hostile environment is beneficial for the baby?

True, these bright lights enable nurses and doctors to accurately read charts and carry out their tasks. True, the monitor alarms are a necessary "evil" bringing to attention when your baby needs help. BUT, there are things you can - and *should* - do to help your baby have as peaceful a stay as possible.

The key to keep in mind is to do your best to mimic the womb. Roll up soft blankets and place them next to your baby. This will help produce the same affect as swaddling - providing a sense of security and closeness. Also, drape a thick blanket over your baby's isolette. This will help decrease both the exposure to harsh light, but also help insulate against the constant noise in the NICU.

You won't be able to watch your baby as you sit next to his bed, but you can know that at this particular time, what your baby needs most is a nurturing and peaceful environment. Harsh lights, bells and whistles, and the constant motion around your baby causes stress. Everyone knows stress is counterproductive to health and healing.

Never allow items to be placed on top of the isolette (except for that carefully draped blanket). Having a water bottle or a medical file set on this surface can cause a disturbingly loud noise within the isolette distressing your baby.

You might also keep note of how your baby reacts or responds to a particular assigned nurse. If you observe signs of distress with a particular nurse you can ask that she be removed from your child's care. This may seem uncomfortable to do, but you are the parent of a child who desperately needs your advocacy and protection. Also, don't hesitate to suggest another visiting parent to keep their voices down around your child.

PUMPING AND BREASTFEEDING IN THE NICU

Whether your baby was diagnosed in the womb and you had time to rent a hospital grade breast pump for your home, or you have just delivered a baby with a serious medical need, breastfeeding IS possible. Initially different than one expects, but worth the effort.

Hospitals will supply professional quality breast pumps for your use in your hospital room and within the NICU itself. If you do not already have a pump kit, a nurse will be able to locate one for you to purchase so you can begin to express and establish your milk supply.

Every mother will need her own kit to ensure a sterile collection environment.

Once you familiarize yourself with the "mechanics" of pumping, you will need to maintain a natural pumping schedule. Whether you subscribe to demand feeding philosophy or a scheduled baby philosophy; a newborn will need to nurse every 2 to 3 hours. Your breasts will need this stimulation to establish your supply. You can be sure, the NICU will be feeding on a set schedule and this is typically at 3-hour interval. A regular and systematic pumping of your breasts will ensure a mature and abundant supply of milk.

In the beginning, the expressed milk may seem too little to keep and freeze. The first secretions from the breast are the exact formula your baby needs for strong and healthy development. This is biologically "engineered" colostrum that should be given to your baby at his first actual feedings...the way nature designed. After a few regular expressions, you will notice your milk changing color and volume. Be sure to time and date each collection and storage container so they can be fed to your baby in order. Not only does this make sense concerning freshness, but also your body was created to produce "designer" milk for your baby. Your breastmilk is a living, dynamic food that is unique to both you and your baby.

For a time, this expressed milk will need to be safely stored at the NICU until your baby can receive feedings. Please know, sometimes these feedings are through nasal gastric tubes, but the colostrum and breastmilk is beneficial just the same. Once your baby is allowed to be held and can suckle, you will preferably nurse and save the expressed milk for feedings when you are away. Sometimes, babies in the NICU have an immature or weak suck and will require bottle feedings to get proper nutrition. Sucking is a reflex that is controlled by the brainstem and the cerebellum controls the fine motor coordination required. Children born with spina bifida (*and perhaps some other conditions*) may experience some difficulty developing an efficient "latch on" and suck to nurse the breast. This does not mean that you can't breastfeed. Breastfeeding for these mothers may require continued pumping of breasts and storage of milk for loving and nurturing bottle feedings or nursing using the Supplemental Nursing System (SNS) developed by Medela. When using a SNS, breastmilk or formula may be used.

It is absolutely possible to nurse a baby through a bottle. Nursing is an attitude of loving cuddling and interaction. A baby can be coldly and mechanically fed by breast just as a baby can be warmly and lovingly nursed by a bottle being held by a parent. Feeding is mechanical.

NURSING YOUR BABY IS AN ATTITUDE.

If it is discovered that your baby has a weak, uncoordinated suck or has a prohibitive gag reflex and you wish to continue expressing milk for nursings, you will need to be sure to use a silicone bottle nipple to prevent latex exposure. Today, many manufacturers produce silicone bottle nipples. Advent is perhaps the largest supplier. Advent also sells sterile bags for milk collection and freezer storage. These bags can go on to be used in disposable nurser bottles. You will need to experiment with nipple flows. For example, perhaps a newborn flow will be too restrictive for a baby with a weak suck but a medium flow will allow too much milk and provoke choking. If you continue to experience feeding difficulties with your baby, be sure to contact a lactation consultant near you or call 1-800-LALECHE and asked to be put in touch with a nursing coach.

As mentioned before, the hospital will supply the onsite pump but you will need one for your home for once you get discharged. If you are discharged before your baby leaves the NICU, you will need to maintain the regular pumping schedule. Though you may be tempted to catch up on rest and sleep through the night; that will not benefit your developing milk supply. Use "middle of the night" pumpings to call the NICU and check up on your baby. The nurses will be more than happy to update you on your infant and you will be connecting with your baby while you pump.

Pumping your breastmilk has long-term benefits for your baby. Your efforts are not in vain. No matter how long your baby is in the hospital, no matter how long you continue to express so you can bottle-feed with breastmilk, you are affording your baby a natural and loving nourishment and start at life.

BREASTFEEDING 101

Congratulations! Breastfeeding your newborn for however long is an important and significant act of love. Breastfeeding is a beautiful time for both mother and baby.

In 1979, the American Academy of Pediatrics and the Canadian Pediatric Society issued a joint statement "strongly recommending breastfeeding." This statement is widely recognized as a sweeping endorsement of breastfeeding. The statement went on to say, "We believe human milk is nutritionally superior to formula," and concluded with "the overall nutritional superiority of human milk remains unchallenged."

When considering the benefits of breastfeeding, it should be known that there are benefits beyond the nutritional superiority provided to your baby.

Breastfeeding a healthy baby has many wonderful physical, emotional, social, mental, and economic benefits. Advantages to breastfeeding include superior nutrition, antibody protection for certain infections, and lower incidences of allergies, asthma, diabetes, pneumonia, respiratory infections, and ear infections. On top of all this, it is more convenient to breastfeed your baby (assuming your baby has an efficient latch-on and suck) and it certainly costs less than buying formula for the first 12 months of life. That said, breastfeeding a baby with health care needs is even more significant. Remember, even two weeks of breastmilk is better than nothing; a month of breastmilk is better than two weeks and a year is better than a month. Every precious drop counts.

Once you determine your baby can efficiently suckle at your breast and pumping may be abandoned, you may still run into nursing difficulties. As with any baby - healthy or not - nursing is a learning experience for both mother and baby. Even a veteran nursing mother has to adjust to the experience of nursing to meet her new baby's particular needs. All children are unique and within the same family diversity may be quite evident. The first baby may have been a voracious eater - demanding to nurse often and at lengthy, vigorous intervals. Perhaps the second baby was more placid and content to sleep longer periods of time - requiring the mother to wake the baby for feedings and stimulate him to stay alert and active to take in enough milk from both breasts. You will quickly learn what "kind" of baby you have been blessed with. (*See end or article for techniques for stimulating a docile, sleepy baby.)

You will need to determine if you subscribe to the "Demand Feeding" philosophy or if you subscribe to a "Scheduled Feeding" philosophy. Neither is right for every parent and child. Neither is wrong for every parent or child. You must determine which method works best for your baby and for YOU. For example, if this baby is your only child, perhaps it is reasonable to allow him to be demand fed throughout the day assuming he rouses when hungry and let's you know when he needs to nurse. The laundry can be interrupted. Cooking dinner can be put off for another feeding. However, if you have other children in the home, perhaps more will get accomplished in your day if your newborn is on a predictable feeding

schedule. Scheduled feedings do NOT mean you start off feeding at 4-hour intervals or you quickly abandon nighttime feedings. Scheduled feedings can certainly look like nursing every 2 to 3 hours

during the day and letting the baby wake up hungry for night time nursings. Having brought your baby home from the NICU, your baby has been accustomed to routine feedings. Keep in mind, rhythm and routine are both natural and comforting for people of all ages. There is a natural rhythm for the seasons of the year. There is a natural rhythm for the 24-hour cycle. Most people follow a predictable rhythm throughout their day. Even demand fed babies will develop their rhythm of feedings soon enough.

Breastfeeding can be a magical time of nurturing your baby. Whether you have just had your first child, or you have several, making the time to sit down and prop your feet up and snuggle with your nursing child can be a much needed time of bonding and closeness. Many breastfeeding mothers will lament that though nursing may have gotten off to a rocky start, when it was time to wean (mother led or child led) there was an element of sadness that this beautiful "mother-child" intimacy was coming to an end.

* Some Ways to Encourage a Sleepy Baby to Nurse *

Skin to Skin Contact: Remove all clothing from your baby except for his diaper. Having his smooth skin against your bare skin is a time-honored technique to stimulate a baby to nurse. You can gently and tenderly tickle or message your baby's feet, legs, and back further encouraging him to stay awake. Gently stroking your baby's cheek will cause a reflex sucking action, however stroking your baby's head will encourage him to fall back asleep.

Burp and Switch: Having nursed on the breast "left off with" last feeding, once your baby begins to doze off, gently sit him upright on your lap and pat his back to burp him. After he has burped, put him to nurse from the other breast until he is no longer interested in active nursing. (Remember to begin the next feeding with that breast to ensure equal milk production.)

THINGS WE WISH SOMEONE WOULD HAVE TOLD US

(So you don't have to reinvent the wheel!)

- 1.) Make sure the doctor informs his office staff if he asks you to call and have him paged. The staff's priority is to "protect" the doctors' valuable time. Typically, they will not page the doctor if there is not a medical emergency. Doctors typically don't have an awareness of how their own office is managed. Ask your doctor to communicate specifically with the office and/or answering service.
- 2.) You have a right to request and/or interview the pediatric anesthesiologist before the day of surgery. As this skilled doctor is balancing your child's life, it would be wise to make sure they know the specific precautions/allergies that will be required for your child's care. Don't assume they respect your child or his/her condition. Feel them out. You owe it to your child. The quality of their work is critical to the wellbeing of your loved one.
- 3.) Get copies of EVERYTHING. Films/CD's, office visit summaries, prescription information about medications, hospital records, surgical records, anesthesia records, primary care physician records, laboratory results. Everybody and everything counts. You will need your own copies of MRI, CT, X-ray, ultrasound films for when you travel and/or when you seek a second opinion. For films, be sure to inform the radiology technician BEFORE the image is taken. More than likely, they will simply tell the computer to develop two copies - one for hospital file, one for you. Be sure to indicate the date and the reason of the test. Once you know the results, that information should be listed on the film jacket also.
- 4.) It would be most helpful to keep medical paperwork and insurance summaries in chronological order in a large three ring durable binder. It would be wise to include a copy of your questions and concerns and file them along with the office visit summary. This will end up being a very comprehensive record of your child's progress and development.
- 5.) NEVER, NEVER, NEVER assume nurses and doctors know all the sources of latex exposure for your child. Merely telling a pediatric nurse (or pediatric intensivist or pediatric anesthesiologist) your child has a latex allergy doesn't adequately protect your child from latex exposure. For example, well-child vaccinations and other injectable medications must be drawn without the use of the rubber vial stopper. If your child is hooked up to an I.V. for fluids, injections must NOT be given through the I.V. port-hole. You may not know what this is, but do yourself and your child a favor and tell each nurse they can't give medication through the I.V. port.
- 6.) If you are spending the night with your child, require that you be awake prior to each administration of medication. Pretty much, everything concerning your child's
- 7.) Hospital care is on a schedule. Set your watch to his medication schedule so you can be sure to oversee the administration.

- 8.) After a surgical procedure, a routine of pain management will be implemented for your child. Sometimes, this will include narcotic medications. These will be administered routinely (for example, every 4 hours) to keep on top of the pain. Pain is much easier to control if it is never allowed to become intolerable. That said, the first reasonable opportunity your child is coping better, you might ask that his pain medication be switched over to non-narcotic form. Also, infants and children on narcotic pain medication tend to sleep "soundly" as they are doped up. If your child doesn't wake in discomfort at his scheduled 2:00 am administration, you have the right to refuse this dose. (Certainly it is not the case with every nurse working the night shift, but their job is much easier if the children under their care are sound asleep.) Just as you would not wish your child to be under-medicated for pain management; you should be just as vigilant about unnecessary medication.

- 9.) A treasure of pain management is Emula Cream. This special cream can be applied to the hand or foot (or wherever) prior to the insertion of the I.V. needle. For some reason, many facilities would rather sedate the entire child prior to this needle insertion, but truly the cream is adequate in tempering the child's anticipation of pain. A good idea as the needle is being inserted is to distract the child by looking away from the administration. With the Emula Cream, the insertion will not be detected.

DOCTOR APPOINTMENT WISDOM

Common sense will tell you that if you wish to have a good relationship with your child's doctor, you must exercise good social skills from the onset. First impressions count!

Basic social skills 101:

- eye contact
- firm handshake
- come prepared with films/questions
- listen attentively (eyes, ears, brain)
- speak calmly and clearly
- take notes
- ask questions if you don't understand something he/she says
- be considerate - don't be late/don't be a no show
- keep your appointments
- remember your manners; say "Please" and "Thank you"

Doctors like appreciation too. They work hard to care of your child. Writing a simple note of appreciation after an especially lengthy appointment or difficult hospital stay will encourage his/her heart. I guarantee, people take for granted that doctors know how much they are appreciated.

If your doctor is late to your appointment (especially if he/she is a surgeon) be thankful your child was not the reason for his/her tardiness. There may come a time in your future, when he will need to take care of your child and thus be late to another child's appointment.

Take key notes during office visits. Don't be rude however, and neglect to maintain eye contact with the doctor. If you have a difficult time remembering all that was said, ask to tape the appointment so you can go home and type/write up a summary.

Always ask the doctor to mail you an appointment summary. When dealing with team-approach care with medical specialists, they will send an appointment summary to your primary care physician (pediatrician or family physician). You need a copy of this for your records. I can't tell you how many times, I have been unaware of certain things only to read about them in the Doctor's summary.

Periodically update all your personal medical (inpatient/outpatient) records. There is typically a charge for this, but again, it is well worth it to have your child's complete medical file. You are your child's greatest asset as an effective "manager" of his condition. You are also your child's greatest liability if your management and knowledge of his condition is haphazard.

If a doctor instructs you to call his office and have him paged directly, make sure he knows he must inform his office/phone service of this or they will protect him from non-emergency pages. Also, if he were not on call that particular time, his office would page the on-call doctor NOT necessarily your doctor. It has been my experience that doctors rarely know or bother themselves with the management of their office. The job of the office staff is to guard the doctor's time and keep

things running smoothly. They need to be informed by the doctor if they are to do something out-of-their-ordinary. Doctors may think they are easily contacted - usually they are not.

THE VALUE OF LIFE

A well-known speaker started off his seminar holding up a crisp \$20 bill. In the room of 200, he asked, "Who would like this \$20 bill?". Hands started to shoot up. He said, "I'm going to give this money to one of you, but first let me do this....".

He proceeded to crumple the dollar bill up. He then asked, "Who still wants it?" Still hands were up in the air. "Well," he replied, "What if I did this?". And he dropped it on the ground and started to grind it into the floor with his shoe. He picked it up all crumpled and dirty and tore off a corner. "Now, who still wants it?" Still hands were up in the air.

"My friends, you have all learned an important lesson. No matter what happened to this money, you still wanted it because it did not lose its value. It is still worth \$20."

It is the same way with human life.

Whether we can walk or not, whether we can sing or not, whether we can create great works of art or simply manage play-dough, whether we can solve complicated mathematical equations or not, whether we can obtain our Ph. D., or merely complete vocational training **OUR VALUE IS STILL THE SAME**. Some babies will enter this world whole and healthy. Some babies will enter this world with obvious signs of crumpling. Be certain that in the eyes of our Maker, we are equally precious and valuable.

- Author Unknown

Power Verses

Philippians 4:13	I can do all things through Him who strengthens me.
I Peter 5:7	Cast all your anxiety upon Him because He cares for you.
Proverbs 16:1	The plans of the heart belong to man, but the answer of the tongue is from the Lord.
Ephesians 3:20	Now to Him who is able to do exceedingly abundantly above all that we ask or think, according to the power that works in us.
Ephesians 3:12	In Him and through faith in Him we may approach God with freedom and confidence.
Philippians 4:6-7	Be anxious for nothing, but in everything by prayer and supplication, with thanksgiving let your request be made known to God.
Proverbs 3:5-6	Trust in the Lord with all your heart and do not lean on your own understanding. In all your ways acknowledge Him and He will direct your paths.
Isaiah 41:10	Fear not, for I am with you. Be not dismayed, for I am your God. I will strengthen, yes I will help you. I will uphold you with my victorious right hand.
Hebrews 4:16	Come boldly to the throne of grace that we may obtain mercy and find grace to help in time of need.
Mark 11:24	Therefore I say to you, whatever things you ask, when you pray, believe that you receive them, and you will have them.
Mathew 7: 11	"If you then, being evil, know how to give good gifts to our children, how much more shall your Father who is in heaven give what is good to those who ask Him!"
Mark 9:24	Immediately the boy's father cried out and began saying, " I do believe; help my unbelief."

PATIENTS GLOSSARY OF TERMS/NEONATAL SPECIAL NURSERIES

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- Acidosis - Too much acid in the body.
- Anemia - Too few red blood cells in the blood.
- Antibiotics - Medications that kill bacteria or slow their growth; used for infections caused by bacteria.
- Apnea - Absence of breathing.
- Aspiration - Inhalation of material - formula, stomach juice or meconium [see definition below] - into the trachea (windpipe) or lungs.
- Bagging - Pumping air or oxygen into a baby's lungs by squeezing a bag into a mask placed over the baby's mouth.
- Bili-lights (phototherapy) - Fluorescent lights placed over the baby to help break down bilirubin and decrease jaundice [see definition below].
- Bilirubin - The product of the breakdown of red blood cells that causes jaundice [see definition below].
- Blood gas - A lab test used to measure the amounts of oxygen and carbon dioxide in the baby's blood.
- Blood pressure - The pressure of the blood in the arteries that makes the blood flow through the body.
- Bradycardia - Slowing of the heart rate.
- Cardiologist - A doctor who specializes in the treatment of the heart.
- Catheter - A tube for putting fluids into the body.
- Chest film - An X-ray picture of the chest showing the heart and lungs. Chest tube - A small plastic tube that is placed into the chest. This is used when a baby with breathing problems has a pneumothorax (air escaping the lungs into the chest cavity and pushing on the lungs). The tube removes the unwanted air and lets the lungs expand.
- Circumcision - Removal of the foreskin of the penis.
- CPT (chest physiotherapy) - A small vibrator is used on the chest to loosen fluids in the lungs. The fluids are then removed with a suction tube.
- Culture - A test done in the laboratory to find an infection. Cultures may be done on skin, spinal fluid, blood, urine or secretions.
- Cyanosis - Bluish color of the skin and lips caused by a low amount of oxygen in the blood.
- Dextrostix - A test done to determine how much glucose [see definition below] is in the blood.
- ECG or EKG (electrocardiogram) - A record of the electrical activity of the heart.
- Echocardiogram - A test that uses sound waves to produce a picture of the baby's heart.
- Edema - Swelling caused by extra fluid in the tissues of the body.
- EEG (electroencephalogram) - A record of the electrical activity in the brain.
- Electrode - A small patch that conducts the electrical signal from the heart to a monitor. Electrolytes - Certain body chemicals (such as sodium, potassium and chloride) that must be present in normal amounts for cells to function correctly.
- ET (endotracheal) tube - A tube used to provide a passageway for air through the trachea (windpipe) to the lungs.

- Exchange transfusion - May be necessary when a baby has a high level of bilirubin [see definition above]. The baby's blood is exchanged with blood containing normal levels of bilirubin. At the end of the procedure, the bilirubin level is lower.
- Geneticist - A doctor who specializes in the study of heredity (inherited traits). Gestational age - The length of time from conception to delivery. Full-term babies are born at a gestational age of 40 weeks.
- Glucose - A sugar that is a principal source of energy for all living organisms.
- Gram - A unit of weight in the metric system; there are 28 grams in an ounce (a nickel weighs five grams).
- Hematocrit - A test that measures the concentration of red blood cells in the blood.
- Hypocalcemia - A low calcium level in the blood.
- Hypotension - Low blood pressure.
- IM (intramuscular) - Within the muscle - a way to give medications.
- Intubation - Insertion of an ET (endotracheal) tube [see definition above] through the baby's mouth into the trachea (windpipe). While the tube is in place, your baby will not make crying sounds.
- Isolette - An enclosed bed that keeps baby's temperature under control.
- IV (intravenous) - Introduction of fluids or medication into a vein, usually through a hollow needle or a catheter.
- Jaundice - The yellow color of the skin caused by a high bilirubin [see definition above] level.
- Kilo (kilogram) - A unit of weight in the metric system. One kilo is equal to 2.2 pounds.
- Lumbar puncture (spinal tap) - Insertion of a small needle through the back to obtain a sample of spinal fluid.
- Meconium - A dark green stool in the baby's bowel at birth. The first stool the baby passes.
- Milligram - A unit of weight in the metric system. There are 1,000 milligrams in one gram.
- Monitor - A machine that measures the heart rate or breathing rate. Should the rate become too slow or too fast, an alarm will sound and alert the nurse.
- NCPAP (nasal continuous positive airway pressure) - With the use of small prongs placed in the baby's nose, a small amount of air can be kept in the baby's lungs at the end of a breath. This keeps the tiny air sacs at the bottom of the lungs from collapsing.
- Neonatologist - A doctor who cares for sick newborns.
- Neurologist - A doctor who specializes in diseases of the nervous system.
- NG (nasal-gastric) tube - A tube that is passed through the nose into the stomach and is used for giving food or medication.
- NPO - An order that means the baby cannot be fed anything.
- NICU - Neonatal Intensive Care Unit.
- NSCU - Neonatal Special Care Unit.
- PCO₂ - A measurement of the carbon dioxide in the blood.
- Phototherapy - See "bili-lights." For jaundice.
- Pneumothorax - A condition in which air escapes from the lungs into the chest cavity and pushes on the lungs.
- Potassium - One of the body's electrolytes [see definition below].
- PO₂ - A measurement of the amount of oxygen in the blood.

- Premature - A baby who is born before 37 weeks of gestation.
- Public health nurse - A specially trained nurse who visits parents and their baby at home after the baby is dismissed from the hospital.
- Red blood cells - The cells in the blood that contain hemoglobin (the blood's iron-containing pigment) and carry oxygen.
- Resident - A doctor in training who will help the neonatologist take care of your baby.
- Respirator (ventilator) - A machine used to help breathing problems. It works by filling the lungs with air or oxygen. This air or oxygen is given through an ET tube [see definition above].
- Respiratory distress syndrome (hyaline membrane disease) - A condition most often seen in premature infants. The tiny air sacs of the lungs tend to collapse as the baby breathes out.
- Retractions - The pulling in of a baby's chest when the baby takes a breath; a common symptom of respiratory distress.
- Room air - The normal air we all breathe. It has an oxygen concentration of 21 percent. The most oxygen that a baby can be given is 100 percent.
- ROP (retinopathy of prematurity) - A disease of the eye some premature babies develop.
- Rounds - The gathering of doctors, nurses and other hospital personnel to discuss the condition and treatment of the babies.
- Saturation monitor - A small cuff wrapped around the baby's foot or hand that measures the oxygen level in the blood.
- Sepsis - An infection in the blood or other tissues.
- Social worker - A licensed professional who provides services that include emotional support, help in adjusting to hospitalization, information and planning for dismissal, and referral to community resources. Social work services are available to all families with babies in the NICU or NSCU.
- Sodium - One of the body's electrolytes (see definition below).
- Spinal tap - See "lumbar puncture."
- Suctioning - Removing mucus from the nose and throat or from the ET tube (see definition above] using a plastic tube attached to a suction device.
- Surfactant - A natural substance produced by the lung that helps keep the small air sacs of the lung open.
- TCPO₂ / CO₂ (transcutaneous oxygen/carbon dioxide monitor) - A small black electrode attached to the baby's skin to help monitor the amounts of oxygen and carbon dioxide in the blood.
- Temperature patch - The small patch on the baby's skin that sends a message about the baby's temperature to a sensor in the bed. The sensor keeps the bed at a proper temperature so the baby will not get too warm or too cold.
- Trachea - Windpipe.
- Transfusion - Giving extra blood to the baby through an IV.
- UAC (umbilical artery catheter) - A small plastic tube put in one of the arteries of the umbilical cord. It can be used to take blood samples and to give sugar solution and medications.
- Urinalysis - A laboratory examination of the urine.
- Ventilator - See "respirator."
- Ventricular sonogram - A test that uses sound waves to produce a picture of the ventricles (cavities) of the brain.
- Warmer - A special open bed with an overhead heating device to keep the baby warm.