

For Those Who Hold the Littlest Hands

Information & Support for
Parents of Babies in the NICU



Kirsti A. Dyer MD, MS, FT
Physician, Author, Educator & Former NICU Parent

For Those Who Hold the Littlest Hands



Information & Support for
NICU Parents & Their Families

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Contact Dr. Dyer at the NICU Parent Support Site, NICUParentsupport.org or nicuparentsupport@gmail.com

The information provided in this e-Book is based on sound medical knowledge, research and reasoning; it is designed to support, not replace, an existing physician-patient relationship. Please be sure to contact your physician, pediatrician or health care provider for professional care, if have any questions or concerns about yourself or your baby or need more follow up.

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Intro & Dedication

For Those Who Hold the Littlest Hands was written to inform, reassure, calm and comfort parents facing the admission of a newborn to the Neonatal Intensive Care Unit. The eBook is a freely available resource from the NICU Parent Support Site.

This eBook was written by a physician, health educator, author and former NICU Parent to share information, support and encouragement with current NICU Parents. It was created in response to our need at the time for a parent-friendly resource and the need discovered since of other NICU parents for more information.

Dedication

For Kristiina our Miracle & ICN Survivor - Life would be very, very different without you.



For Kaarina our Angel & constant source of Hope, Encouragement and Inspiration during our ICN time.

For other NICU and ICN Parents who currently face their own challenging times - a heartfelt wish of courage, hope & strength.

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Being the Parent of a NICU/ICN Baby

Each year in the United States, about 9 percent of all newborn babies require hospitalization in the Neonatal Intensive Care Units (NICU) or Intensive Care Nurseries (ICN). In 2006, nearly 380,000 infants were NICU admissions. [1] Some babies are admitted after premature deliveries (preemies), others due to congenital defects. Still others are hospitalized because they develop conditions and become sick newborns. The majority of these admissions are unplanned and are often quite traumatic events for the newborns and their parents.

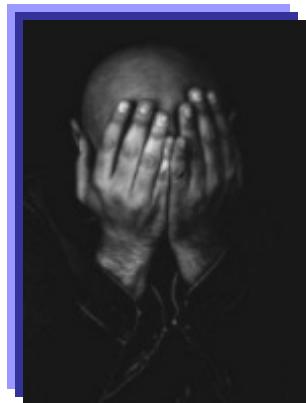


For most people, discovering you are the parent of a NICU baby comes as an unexpected shock; it is likely to be one of the most stressful & difficult life challenges ever faced. Finding ways to survive the first few hours and then the next few days, weeks or months can take all the strength, wherewithal and courage a new parent has.

1. National Center for Health Statistics. Births, Marriages, Divorces and Deaths: Provisional Data for September 2006. *National Vital Statistics Reports*. May 4, 2007; 55(16): 1 http://www.cdc.gov/nchs/data/nvsr/nvsr55/nvsr55_16.pdf

Being the Parent of a NICU/ICN Baby - Cont.

Parents of a NICU baby experience many different emotions during the intensive care admission of their baby. They must learn how to cope with an outcome very different than the original plan. Instead of celebrating the joyous birth of a new baby, parents must deal with a life-threatening situation with their baby in the NICU. The dreams of a normal pregnancy, delivery and soon after bringing home a happy, healthy newborn are over. NICU Parents may feel a great deal of sadness and sorrow over the change of events and the loss of their original dreams.



One way to adjust to this difficult, unexpected news is for parents to learn more about the strange, unfamiliar NICU environment; this can be invaluable and empowering. Knowing the common, normal physical and emotional reactions that a person might have to a stressful situation such as having a baby in intensive care can be helpful. Parents who understand the normal response to an unexpected life crisis can more effectively manage their own response. They are more capable of supporting their spouse, their family and their newborn through his or her own first life challenge.

Common Responses - Physical

*My grief lies all within,
And these external manners of lament
Are merely shadows to the unseen grief,
That swells with silence in the tortured soul.*

William Shakespeare

When faced with a major life challenge, a parent can experience a wide range of physical and emotional responses. These intense, overwhelming and unbearable responses often come in waves. A NICU Parent may feel fine one moment and then depressed, anxious, distressed or angry the next; this causes some parents to think that they are “going crazy.”

Common Physical Responses:

Some of the more common physical responses to life challenges or losses include:

- | | | | |
|----------------|--------------------|------------------|----------------------|
| • Fatigue | • Restlessness | • Abdominal pain | • Weight change |
| • Headache | • Crying, sighing | • Back pain | • Increased appetite |
| • Lightheaded | • Trouble sleeping | • Nausea | • Decreased appetite |
| • Dizziness | • Short of breath | • Diarrhea | • Chest heaviness |
| • Palpitations | • Empty Stomach | • Constipation | • Throat Tightness |

These responses, which can last for days to weeks, are not signs of being “crazy” they are normal reactions to an abnormal event—your baby being in the NICU.

Common Responses - Emotional

In addition to experiencing actual physical responses NICU parents can also go through confusing, fluctuating and conflicting emotions that range from joy to profound grief or distress. Strong emotions such as sorrow, sadness, fear, anger, terror, aching and guilt are among the very normal, common emotional responses for NICU Parents.

Emotional & Behavioral Responses

Some of the more common emotional and behavioral responses include:

- | | | | |
|----------------|------------|-----------------|----------------------------|
| • Anger | • Numbness | • Self Blame | • Meaninglessness |
| • Irritability | • Denial | • Disbelief | • Abandonment |
| • Panic | • Apathy | • Vulnerability | • Emotionally labile |
| • Anxiety | • Avoiding | • Longing | • Forgetfulness |
| • Fear | • Relief | • Helplessness | • Slowed thinking |
| • Guilt | • Sadness | • Loneliness | • Difficulty concentrating |

Many NICU parents feel stressed, anxious, nervous and afraid. On most days it takes great courage and inner strength for parents to walk into the hospital to visit; it takes even more to leave at the end of the day. With a NICU baby, phone calls can be terrifying for parents who fear getting bad news from the hospital. Finding ways to manage these intense responses is an important part of adjusting to the NICU challenge.

Focus on the Basics

*On life's most difficult days
all that we can do
is simply take things
Moment by Moment.*

Kirsti A. Dyer MD, MS

Effective Strategy for Coping - Focus on the Basics

During the first few hours, days & weeks following the admission of your baby it is helpful to just focus on the basics.

- Take it one hour at a time, one day at a time. If needed, just moment by moment.
- Try to maintain some type of a normal routine or develop a new normal one.
- Get enough sleep or at least enough rest.
- Participate in regular exercise to relieve stress and tension. Even walking helps.
- Eat a balanced diet. Limit high calorie and junk food. Drink plenty of water.
- Avoid using alcohol, medications or other drugs in excess or to mask the pain.
- Take time to do things and be with those people who comfort and recharge you.
- Talk to Nurses, Social Workers & other NICU Parents for advice. Those who care for babies and who lived through and survived similar events can offer valuable insights.
- Find creative ways to express intense feelings. Paint, photograph, build, draw, create, knit or collage something. There are even special journals for NICU babies.
- Remember coping skills you have used to survive past life challenges. Draw upon those inner strengths again for this current challenge.

Surviving Your NICU Experience

Knowledge can make the NICU experience a bit easier to manage. Whether learning how to get around the NICU setting or finding out more about your baby's diagnosis and treatment options, knowledge can be invaluable for helping parents regain a sense of control and be more capable of managing the challenge.

Coping and Self-Care

Coping involves realizing that others have experienced similar losses (or worse), have endured it & survived. Knowing this helps many parents feel less alone.

Although it may be difficult, NICU Parents need to remember to care for themselves and to keep from getting ill. Sick NICU Parents may be unable to visit in the NICU until they are no longer contagious leading to further stress.

Celebrating the Firsts



With a NICU baby, since many of their traditional firsts are postponed or may be even lost, many NICU parents decide to celebrate their NICU baby's special "firsts"—the first time being held, changing a diaper, feeding, bathing, nursing, coming off of the respirator, getting tubes out or gaining weight. Special diaries and journals can be purchased to keep track of the NICU baby's unique "first" experiences.

Ways of Interacting with Your Newborn



Sweet babe, in thy face

Soft desires I can trace,

Secret joys and secret smiles...

William Blake

Interacting with your Newborn

There are many special loving ways for NICU parents to start bonding with your baby and let him or her know you are there to care.

- Gently stroke or caress your baby. See how your baby responds. Be aware that some NICU babies do not like too much handling. You may just want to touch him or her.
- Lovingly hold your baby's foot or hand.
- Talk, read or sing quietly to your baby.
- Supply your baby with breast milk if possible.
- Write down your hopes as a poem or a blessing. Share your writings with your baby.

More Ways of Interacting with Your Newborn

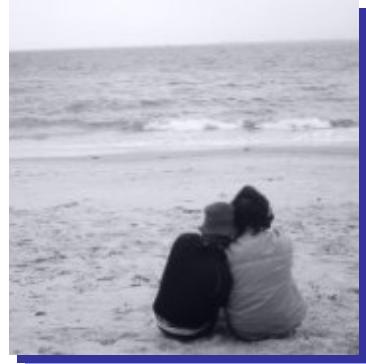
- Learn how music can calm your baby. Bring soothing and relaxing music to play for your baby on portable CD.
- Parents' and siblings' voices are familiar sounds for your NICU baby that can be very reassuring and comforting. Record your voice singing, reading stories or poems for the nurses to play to your baby when you are not around.
- Decorate your baby's incubator with washable toys, family pictures, cards, email messages & other special mementos. Make it a home away from home.
- Encourage your NICU baby to open his or her eyes by shielding your baby's face from the bright lights. This lets your baby look at you and around his or her environment.
- Once your baby is doing better and his or her condition has stabilized, learn how to hold and rock your baby out of the isolette.
- Kangaroo care (skin-to-skin) contact has been shown to help NICU babies thrive. Learn about this beneficial treatment. Check with the hospital's use of Kangaroo care.



Parents need to realize that while the NICU technology is a valuable tool, nothing replaces the love, care and touch of a parent. Parents are an important part of the NICU team. Since parents spend the most constant time with their NICU baby, as primary caregivers, they generally know their baby needs & can share these needs with the team.

Different People Different Reactions to the Same Event

People experience and respond to life challenges in many different ways. Some downplay the event and repress emotions. Some cope using angry verbal or physical outbursts. Others respond more emotionally by sighing, crying or sobbing. Still others cope physically with bodily complaints, pain and physical responses.



It may help NICU parents to know that people react very differently to challenges. Each person's reaction is unique, even if it is the same event. As a result, each parent may experience, react and respond differently when faced with the NICU admission of their newborn.

Knowing that there are different ways of coping with life's challenges can help parents understand each other's diverse responses. You can then look for ways to cope together.

Take some time to be with each other. Sit and hold hands during the difficult moments; this can help you make it through the NICU challenge together.

If need look for ways for each person to cope separately. This allows both parents to react in his or her own way and use his or her own unique coping strategies.

Creating a Circle of Healing

I have long believed that there is a healing power in holding a person in one's thoughts whether saying a prayer or blessing or lighting candles. These are the same beliefs echoed by Dr. Jim Reeves, the doctor who treated cancer survivor & seven-time Tour de France winner, Lance Armstrong, "*There is this ancient Chinese belief that when a person is held in the hearts and minds and souls of so many other people, they can do better.*"

Days after our daughter's unexpected intensive care hospitalization, I came up with the idea of creating a circle of positive thoughts and energies from family and friends around the world. Via phone calls and e-mail messages we formed a Circle of Healing. Friends and family were asked to hold Kristiina in their hearts, minds, thoughts and prayers to mentally aid in her healing process. We also shared her special Healing Blessing via email. The blessing on next page was written and used to decorate her hospital bed.



Creating a Circle of Healing to surround a person in loving, healing thoughts may help to empower family and friends during times of medical crisis by giving everyone something "to do" and overcome some of the tremendous feelings of frustration and helplessness.

Kirsti A. Dyer, MD, MS

A Special Healing Blessing

May you be surrounded in comfort.

May you be filled with love.

May you feel the healing presence of those who hold you in their thoughts and prayers.

May these positive thoughts and blessings provide you with strength.

May you be sustained in health as you continue your healing journey.

May you relax.

May you be calm.

May you be serene.

May you rest as your body heals in your safe cocoon of comfort, love and strength.

May your body be transformed into one filled with love, happiness, joy and health.

May you continue to heal

Moment by moment

Hour by hour

Day by day

May you feel loved.

May you be strong.

May you be healed.



Mommy, Daddy & Kaarina

This healing blessing was written our daughter, Kristiina during her ICN stay and placed over her bed where it remained until she was discharged. Copies were given to the ICN staff with our gratitude. A printable version, is available at <http://www.journeyofhearts.org/nps/blessing.pdf>

CarePages

Hold a Loved One in Your Heart, Soul & Mind

Simply by creating a webpage, CarePages is an easy way for family and friends to stay connected and provide needed emotional support when a loved one is hospitalized, facing a life-threatening illness or receiving specialized care. Creating a CarePage is an easy way to generate support, provide information and keep everyone updated with a few clicks of a mouse when a baby is admitted to the NICU.



We didn't know about CarePages at the time of my daughter's NICU admission, but their service would have been a great resource to use for enhancing the Circle of Healing we created for my daughter. (See page 13 for the Circle of Healing.)

One of the main benefits a family can receive from using CarePages may be the ability to hold the loved one in everyone's thoughts. I truly believe that having so many people hold our daughter in their hearts and minds, emotionally aided in her healing process until she was strong enough to be discharged from the hospital.

You can visit the Custom CarePage set up especially for the NICU Parent Support Site users <http://www.carepages.com/nicuparentsupport> to create your own page.

When to Seek More Support

Parents who take care of their own needs during a difficult time are better able to support their baby. Most parents are able to cope with having a NICU baby. However there are times when a parent should seek additional professional help. These occasions include any parent feeling or showing any of the following:



- Prolonged agitation or anxiety
- Depression or extreme hopelessness
- Impaired daily activities or job function
- Suicidal thoughts or ideation
- Prolonged, inhibited or absent grieving
- Extreme physiologic/psychological reactions
- Substantial guilt
- Substance Abuse - alcohol or drug use
- Psychotic states
- Uncontrolled rage

Some of the different supportive resources (professional & others) that can be helpful for parents to connect with include: physicians, nurses, healthcare professionals, clergy, counselors, social workers, therapists, support groups & leaders, mental health professionals, Internet sites, online forums & other NICU parents.

A Reminder to HAVE FAITH

Faith is believing in things...when common sense tells you not to.

George Seaton

One of the most difficult parts, but necessary, about a NICU experience is to "have faith" in your baby, in yourself, in the NICU staff & the healing process.

- Hope.
 - Accept that life is full of challenges & changes.
 - Verbalize questions, emotions and concerns.
 - Engage with supportive friends, family
- Empathize with other parents.
- Fortitude to endure the experience.
 - Adaptability. Being able to roll with the waves.
 - Incredible courage to survive day to day.
 - Trust your baby, yourself, your physicians & the rest of the NICU team.
 - Healing in whatever form it may take.



Without faith, nothing is possible.

With it, nothing is impossible.

Mary McLeod Bethune

Additional Helpful Resources

Selected Online Resources and Websites

March of Dimes. For NICU Families. http://www.marchofdimes.com/prematurity/index_nicu.asp

Preemie Health. 2007. Meriter Health Services and the University of Wisconsin.

<http://www.meriter.com/living/preemie/index.htm>

Sick Newborn Health. 2007. Meriter Health Services and the University of Wisconsin.

<http://www.meriter.com/living/sicknewborn/index.htm>

NICU Parent Support Site - <http://www.NICUParentSupport.org>

NICU Parent Support Blog - <http://nicuparentsupport.blogspot.com>

Neonatal Intensive Care Unit Booklet. Carl R. Darnall Army Medical Center

<http://www.hood-meddac.army.mil/default.asp?page=nicu&vi=n&mn=4>

Regional Neonatal Intensive Care Unit. Marquette General Hospital. Parents' Guide: Specialized

Hospital Care for Your Baby. <http://www.mgh.org/wcc/guide.html>

Common Diagnoses in the NICU. 2005. KidsHealth for Parents.

http://www.kidshealth.org/parent/system/ill/nicu_diagnoses.html

NICU Equipment. The Hospital for Sick Children in Toronto, Canada

<http://www.aboutkidshealth.ca/Redirect.aspx?ArticleID=9429>

The Neonatal Intensive Care Unit (NICU). From Stanford's Lucile Packard Children's Hospital.

<http://www.lpch.org/DiseaseHealthInfo/HealthLibrary/hrnewborn/nicuinr.html>

Selected Online Forums

Share Your Story. Community Center, March of Dimes.

<http://www.shareyourstory.org/webx/Share%20Home/Community%20Center/>

NICU Forum - NICU 101. <http://www.nicu101.com/phpbb2/>

Preemie Community Forum. <https://preemie.clinicahealth.com/index.pl>

Our Story



I faced a major life crisis soon after the birth my youngest daughter.

I was still in the recovery room after delivering my daughter by C-section when my husband came in and told me the doctors were taking X-rays of her lungs. She was barely an hour old.

As a physician, I knew that "taking X-rays of her lungs" wasn't routine so it wasn't good. As a mother, I was anxious because the doctors and nurses weren't telling me what was going on. I was so frustrated because I couldn't move and go find out myself because I was still recovering from the spinal block anesthesia.

Even though I was a physician used to being in the hospital setting, I was also a mother with a sick newborn unable to help my daughter. I was concerned about her health, her condition and her well being. My head was filled with questions that I wanted answered. "What is happening to my daughter?" "Where was she?" "Why was she having an x-ray?" "What could I do to help?" "When would I get a chance to hold her?" "Was she going to make it?"

It was several fearful hours before I was reunited with my daughter, now in the Neonatal Intensive Care Unit. For reasons that were *never determined*, my daughter developed PPHN or Persistent Pulmonary Hypertension of the Newborn. Thankfully her condition stabilized within a few days of intensive care support. Within a few weeks we were able to take her home.

We were blessed with the ending of our NICU experience. She is now a healthy, active 5-year-old, a walking poster-child for positive outcomes that can result from supporting babies in the NICU.

About the Author

Kirsti A. Dyer MD, MS, FT is a respected physician, life challenges, grief and bereavement expert, professional health educator, professor, college instructor, lecturer and published author. Dr. Dyer received her Medical and Master's Degrees from the University of California, Davis and completed her residency training in Internal medicine. She pursued advanced post-doctorate training in grief, loss and bereavement.

Dr. Dyer is a recognized Fellow in Thanatology: Death, Dying and Bereavement from the Association for Death Education and Counseling, a Fellow of the American College of Wellness, a Fellow of the American Academy of Experts in Traumatic Stress, a Board Certified Expert in Bereavement Trauma and in Traumatic Stress and a Nationally Certified Bereavement Facilitator.

Dr. Dyer has published professional and educational articles and created continuing education course based on her NICU experiences and research. Dr. Dyer was a featured speaker at the First Annual Perinatal Conference hosted by the March of Dimes, Kaiser Permanente and Blue Cross speaking about "Identifying, Understanding and Working with Grieving Parents in the NICU." Her NICU experiences also were an important part of a professional presentation that she delivered to Kaiser Permanente Physicians on "Grief and Loss in the Medical Setting."

Since having her second NICU daughter in March 2002, Dr. Dyer has been on hiatus from practicing clinical medicine. She viewed the NICU experience as a wake-up call to reassess her personal and professional priorities so has been the primary caregiver for her two young daughters. During this time her career emphasis has shifted to teaching. In 2004 she was recruited to teach Nutrition and Wellness at Columbia College and joined as an Adjunct Instructor in the Biological Sciences Department. In November 2006 Dr. Dyer joined the College of Nursing and Health at Madonna University as an Associate Adjunct Professor where she teaches online Bereavement Courses as part of the Hospice Graduate Education program.



About the NICU Parent Support Site



NICU Parent Support Site - <http://www.NICUParentSupport.org>

The NICU Parent Support Site and Blog were created as complementary websites to provide information, encouragement and resources to reassure and support NICU Parents and NICU Families during the challenge of having a NICU baby.

NICU Parent Support on Squidoo - <http://www.squidoo.com/nicuparentsupport>

In addition, the NICU Parent Support Site also has a series of webpages (lenses) for NICU Parents on Squidoo, one of the new innovative websites to watch. The lenses include:

- *NICU Parent Support Site Lens* - <http://www.squidoo.com/nicuparentsupport/>
- *My Baby's in the NICU: Now What?*
<http://www.squidoo.com/marchofdimes/mybabysinthenicu>
- *How Will I Survive the NICU? Advice for NICU Parents and Families*
<http://www.squidoo.com/marchofdimes/surviving-in-the-nicu>

NICU Parent Support for the NICU Baby that is Dying

Finally there are two lenses that we hope no NICU parent needs to use. These resources for parents facing the end of their baby's life & then going on once that life is over.

- *My NICU Baby is Dying: Now What?*
<http://www.squidoo.com/marchofdimes/mynicubabyisdying>
- *My NICU Baby has Died: Now What? -* <http://www.squidoo.com/mynicubabydied/>

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PSSST - Our Secret Message of Support

You received this complimentary (free of charge) eBook by either downloading a copy from our website, <http://www.NICUParentsupport.org> or receiving a gift from a friend, a NICU Parent or a NICU staff member.

After reading this eBook, if you have found it to be beneficial, encouraging or comforting to you during this challenging time dealing with your NICU Journey, please take a moment to pass on the word about this complimentary eBook to others.

Our Secret Message to Share the Support...PSSST

PSSST

Print a Copy to
Share with
Someone
Soon,
Thank You



Sugestions for Spreading the Word

You can share the support and spread the word in one of three ways:

1. Share a printed copy with someone else - another NICU parent or NICU staff.
2. Email the info about this eBook (website at <http://www.nicuparentsupport.org>) to someone who may benefit, so they can download a copy themselves.
3. Post a comment (hopefully positive) or review on the "For Those Who Hold the Littlest Hands" website: <http://www.squidoo.com/free-nicu-ebook>

We are grateful to you for passing on the secret message of support.

About the eBook

The materials developed by the NICU Parent Support Site were created in response to our own need for parent-friendly resources and the need of other NICU parents for more information.

My Baby's in the NICU: Now What?

The eBook, *My Baby's in the NICU: Now What?* is a lengthier downloadable eBook to support NICU Parents and Families. The longer eBook complements this eBook, *For Those Who Hold the Littlest Hands*, by covering more topics and more in depth information. In the eBook NICU parents can find information, encouragement and resources and strategies for getting themselves and their family through this challenging time and support their newborn. Information on purchasing the book is found at: <http://www.nicuparentsupport.org>

How to Survive Your NICU Experience - Advice from a Former NICU Parent

Based on the success of the Squidoo lenses, *How to Survive Your NICU Experience* was started as an Online Book. Proceeds from this book site benefit the Room to Read Organization, an organization created to educate children around the world. You can find the Online Book at <http://www.squidoo.com/roomtoread/surviving-in-the-nicu>

My NICU Baby is Dying: Now What?

The eBook, *My NICU Baby is Dying: Now What?* is being developed based on the need for information and resources for the thousands of NICU parents whose children die each year and unexpected response of the My NICU Baby is Dying and My NICU Baby has Died lenses on Squidoo.com This eBook is scheduled to be published in the Fall of 2007.

*Hope is important because it can make
the present moment less difficult to bear
If we believe that tomorrow will be better,
We can bear a hardship today*

Thich Nhat Hanh



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