Care Coordination in the NICU

Implementing Family-Centered Nursing Care for Optimal Outcomes

Sara L. Mosher, MHA, BSN, RN

Focuses on nurturing the emotional health of patients and families to ensure improved outcomes

This innovative clinical practice resource for neonatal nurses embodies family-centered care strategies for optimal outcomes through every phase of the NICU experience. While rigorous programs provide the knowledge and skills to care for the physical needs of high-risk mothers and neonates, NICU practitioners often find themselves unprepared to support the emotional health of these patients and their families. Care Coordination in the NICU provides the education, inspiration, and resources to NICU health professionals so they can learn how to be emotionally supportive to their patient’s entire family unit.

The book addresses a variety of challenging patient and family issues that occur in the NICU as they relate to care coordination throughout the process. Each chapter focuses on a particular area of the perinatal/neonatal family journey, and includes current medical research, clinical examples, and recommendations for best practice alongside case studies that depict families experiencing a perinatal challenge. Most valuable of all, each chapter also includes stories directly from the source, the families, who have experienced the fear, isolation, and uncertainty of a NICU experience and have greatly benefited from the emotional support of caring practitioners.

Key Features:

• Examines the gamut of challenging patient and family issues that occur in the NICU as they relate to care coordination throughout the process
• Helps practitioners to incorporate family-centered care into their daily practices
• Discusses effective listening and communication strategies for families in crisis
• Includes examples of practice improvement strategies to improve clinical outcome and reduce the risk of re-hospitalization
• Provides a Case-Based Learning section depicting real-world scenarios for discussion and problem-solving
• Includes links to abundant resources and educational material
• Contains chapters on palliative care and bereavement and supporting patients with special challenges

CARE COORDINATION IN THE NICU
Sara L. Mosher, MHA, BSN, RN, has been in nursing practice for more than 15 years. She received a bachelor’s degree from Linfield College and a master’s degree in healthcare administration from the University of Phoenix. Her career has been spent as a nurse in various roles such as neonatal bedside nurse, charge nurse, NICU clinical practice coordinator, critical care neonatal flight nurse, NICU family-support specialist, manager of NICU and pediatric departments, manager of nurse navigation and inpatient case management teams, and clinical nurse manager of population health.

Sara is driven by opportunities to improve the interaction between patient-centered practice and evidence-based healthcare, and has become a recognized leader in the field of NICU family support. Hospital executives, nursing staff, families, and other support organizations hold her in high regard, which was recognized when she received one of Oregon’s nurse of the year awards in both 2011 and 2014. Sara was nominated in 2012 for the Oregon Pediatric Nurse of the Year and in 2013 for the Elaine Whitelaw Service Award. She developed an original Support Program for Neonatal Transport Teams and received recognition for that work with a Best Practice Award from the March of Dimes in 2012. She was named a 2014 National Association of Professional Woman of the Year and received the 2015 Lloydena Grimes Award for Excellence in Nursing.
CARE COORDINATION IN THE NICU
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Sara L. Mosher, MHA, BSN, RN
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Printed in the United States of America.
This book is dedicated to the brave families who were courageous enough to share their private and intimate stories, to make this book so much more meaningful. Their personal accounts help make this book come to life!

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To Erika Bracken Probst and Cheryl Milford: two professionals with whom I have had the honor of working during my career and who were willing to share their stories as well for this text. Their expertise and experiences have enriched this content and bring a staff perspective to the material that will be of invaluable benefit to the reader.
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The question of nature versus nurture has been around for as long as the field of neonatology has been around, and maybe even longer. Steady gains have been made in the understanding of how the NICU environment interacts with genes to influence neurodevelopmental outcomes. Of critical import is what a big part that the family contributes to the NICU environment. This book illuminates some of the murky corners of collaborative neonatal and neuroprotective care and provides pearls of wisdom for support of the family experiencing a major life trauma—NICU admission.

The NICU of the 1970s and 1980s was a very different place than it is today. So much has changed—NICUs don’t look the same, sound the same, or even smell the same now that the impact of light, noise, and noxious stimuli on the neurodevelopment of the ill and/or preterm infant has been recognized. The list of therapeutic discoveries goes on ad infinitum. There have been subtle innovations such as removal of exposure to toxins (e.g., benzyl alcohol in intravenous [IV] flush solution) and preservatives (e.g., carcinogenic estrogen interrupters in plasticizers in IV tubing). In addition, there have been crucial advances in nutrition, allowing far smaller and sicker babies to survive and thrive. Moreover, there have been major breakthroughs in therapies for respiratory illness: artificial surfactant replacement, high-frequency ventilation, nitrous oxide, and extracorporeal membrane oxygenation. Gone are the dark NICU days of inadequate parenteral nutrition, lumbar puncture to confirm intraventricular hemorrhage, and denial (“newborns don’t feel pain”) of postoperative and procedural pain control during the multitude of invasive procedures. Noninvasive monitoring, fat emulsions, cranial imaging, and nonpharmacological analgesia were all lacking in the primordial NICU. Imagine life in the NICU without today’s technologies such as size-appropriate percutaneous catheters, telemedicine, immune therapies, and microsurgical interventions. Novel care modalities allow for the lower limits for perinatal viability to drop to a level beyond which anyone envisioned in the 1980s.

With improved survival comes the need for enhanced intact survival. As the late preterm infant demonstrates, every day in the uterus improves IQ and executive function. There are neonatal interventions galore to support the developing lungs; the current search is for the illusive answers to protecting the developing brain.

The benefits of the NICU providing care to the family while the family cares for their baby are clear. Improved clinical outcomes are gained by parental bonding and attachment, as well as full family participation as primary caregivers. Parents are central to the care of their baby, and steps are taken to avoid the historical negative effects the NICU can have on confidence and anxiety. The NICU is not a scary, forbidding place any longer—it is a home away from home. New NICU configuration and compassionate facility design allow for
24/7 family-integrated care that supports the caregivers (and others such as grandparents) during caregiving, allows for continuous kangaroo care, and improves communication.

Over the decades, neonatal care has come a very long way. As with all aspects of medical and nursing science, knowledge and technology have virtually (in all senses of the word) exploded in the last 30 years. From mapping of the human genome to babies with DNA contributed by three parents, it is impossible to know where we will be tomorrow. Will stem cell therapy allow regrowth of brain tissue damaged by hypoxic-ischemic encephalopathy or intraventricular hemorrhage? Will bionics or brain–computer interfaces improve the mobility of children with anomalous limbs? Will there even be anomalies? Until the future becomes the present, we still have work to do to improve the quality and quantity of life for preterm or ill newborns and their families. Read on to learn how to be part of this evolution.

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I still remember what it was like walking into the NICU for the very first time, and that day was over 15 years ago. I remember the sounds, the sights, the smells, and the feeling my heart felt when I saw the smallest and most fragile little babies lying there in their beds with countless wires and tubes connecting them to machines and pumps. I vividly remember standing beside a patient who was 26 weeks at birth, and I was awestruck at the translucency of her skin and couldn't fathom how a life so small and so delicate was able to survive in such a loud and invasive environment. What was more unbelievable to me, above all of the medical and technological advances that amazed me, was that there were families coming in and out of this place and calling these infants their babies. How did these parents have the strength to enter this foreign world and function? How did they push past the fear and the uncertainty they most certainly had to have and pour out enough love that these babies needed to grow and thrive?

As I began and continued on my career in nursing, these questions were answered. Parents, whose infants were in a high-risk situation, walked into that unit day after day. They came in blindly at the mercy of the staff and entrusted their precious children’s lives in the hands of complete strangers. Families relied on the doctors and nurses not only to care for their baby, but also to care for them as parents and to teach them how to parent in this new reality they were facing. They brought with them strength and courage in amounts I had never witnessed before in my life or in my nursing training. Later, when I became a parent myself, I realized that the way parents could come into this foreign world and pour out enough love to help their babies grow and thrive was because they were parents. They came into that frightening and overwhelming unit to protect and shield their child from everything they possibly could. Despite feeling scared, isolated, depressed, overwhelmed, exhausted, and hopeless, these parents showed up for their babies. I have always had the utmost respect for these parents and admire them in ways they will never fully understand.

My entire career, since 2001, has been dedicated to helping those brave families have a less stressful experience when they have to journey through the NICU with their child. The reality is that as nurses, we chose the profession we go into. I chose to walk into that NICU so many years ago; parents don't make that choice willingly. After seeing that very first family sit with their child, I knew I wanted nothing more than to help families in that
situation feel more supported, more educated, less isolated, and more empowered to be included in their child’s life so that the NICU wouldn’t seem so scary and overwhelming.

Over the years, I have been honored to receive some very humbling recognition; these recognitions have all stemmed from the work I have done supporting families and traveling the country speaking at conferences on family-centered care topics. My career has been incredibly rewarding, and although these recognitions have been gratifying, the most satisfying aspect of all of my work has been being trusted by the hundreds of families to care for their precious children and the countless incredible professionals I have worked with and met along the way.

The main goal of this text is to provide education, tools, and support for caregivers who care for high-risk maternal and neonatal patients so that they, too, can learn how to effectively and successfully provide high-quality care coordination and family-centered care to patients and families in their daily care practice. Each chapter is formatted in the following manner:

GENERAL INTRODUCTION
Each chapter starts with a general overview of the topic, including supporting data and information.

CHAPTER SECTIONS
The chapter has several sections that dive deeper into more information and more detailed descriptions about the topic at hand.

AUTHOR’S PERSONAL STORY
Throughout my entire 15+ year career as a nurse, no matter what role I was in, my goal and passion were always to find ways to improve the patient and family experience and to teach my colleagues how to better care for families through care coordination and family support. I share stories, some partially fictionalized, from the many families I have had the honor to walk alongside in their journey. The goal is to share these important topics from the care provider perspective.

FAMILY STORY
I feel that the real learning can happen from reading the stories from families that have lived the high-risk labor and delivery and/or NICU experience. Families are by far the real experts in this journey and are the one voice that tends to be left out when we should be asking to hear them first. Eighteen families have shared their very personal stories and experiences to increase the depth of this book, and their words have not been altered. You will read their very words directly from their hearts.
RECOMMENDATIONS/SUGGESTIONS FOR BEST PRACTICE

Within this section of each chapter, a summary of tips, strategies, and best practice recommendations are listed on how staff can support families when they encounter each particular situation. The list provides a glimpse into the main points covered in the introduction of each topic in a numbered-list format and is meant to act as a quick reference guide.

RECOMMENDED RESOURCES

A list of recommended resources is given within each chapter to provide further education and support, including, but not limited to:

- Books
- Journal articles
- Websites
- Apps
- Educational opportunities

CASE STUDIES

To further enhance the benefit of this text, the last section of each chapter contains a case scenario formulated by Pat Scheans, DNP, NNP-BC. Dr. Scheans has been practicing neonatal medicine for over 34 years. As a sought-after speaker by the Association of Women's Health, Obstetric and Neonatal Nurses, a worldwide neonatal resuscitation trainer, and a frequent author for Neonatal Network, Scheans is regarded as a leading expert in the field of neonatal practice. The Case-Based Learning section provides detailed case studies describing a typical real-world scenario and encourages readers to build their knowledge on how they would approach the situation. Several recommendations for this section of the text include:

- Use the case studies to foster group discussions in a classroom setting where students can begin to discuss the importance of family support concepts in the real-world setting.
- Use the case studies to promote discussion and policy change at the unit level in staff meetings, unit practice committee meetings, and/or quality meetings.
- Use the case studies to enhance personal growth by reflecting on how individuals would react; journaling thoughts, feelings, and even personal experiences for each situation; and examining how the reflection impacts future feelings and behaviors related to family-centered care.

This text looks at the high-risk antepartum patient stay, the high-risk delivery, the NICU admission, the NICU journey, the discharge home, special situations in the NICU, palliative
and bereavement in the perinatal and neonatal period, and caring for the caregiver. Each chapter focuses on one of these areas, and you will be provided real-world examples of care situations, positive care-coordination efforts, and exceptional psychosocial support provided to patients and families. You may even come across a few examples of where care coordination and psychosocial support did not go as well as it could have. The goal and main objective of this text are to present best practice recommendations in a way that is easy to read, is placed in the context of actual scenarios, brings a little humor in from time to time, and advocates for the interdisciplinary collaborative approach among teams.

This text is intended primarily for the nursing and nurse practitioner audience, yet that is not to say that it would not be a beneficial read for anyone who works with NICU families. The reality is that each and every discipline that partners with the NICU department has a very important role in impacting a patient's experience. Everyone who interacts with a NICU family or visitor in one way or another impacts the family’s perspective of the NICU journey. Everyone in the hospital that a family interacts with has the ability to positively impact a family’s experience and could benefit from reading these practice recommendations to reflect on how their own interactions with patients and visitors may influence a patient’s experience.

If each provider and individual who interacted with a NICU family adopted care-coordination and family-centered care practices into their daily routine, care would be revolutionized!

The hope is that this text, along with the additional resources included, will genuinely help the reader fully implement new practices into daily care of patients and families. There is no reason that patients and families should have a less than optimal experience in your care after you take the time to read, understand, implement, and support some key practice changes.

I hope you enjoy this text, and I also hope you will help me thank the many families who were courageous enough to share their personal experiences to help you have a firsthand glimpse into how our care directly impacts their lives forever.

Sara L. Mosher
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I would like to thank my husband, Christopher, who has been with me from the moment my career started, has supported me at home so that I could support families, and has never let me give up on my dreams of finding ways to stay connected to what I love.

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I want to thank the hundreds of families I have cared for, who have allowed me to walk beside them on their difficult journeys and have trusted me with the pieces of their broken hearts. To the angels who have left this earth far too soon, but whom I was blessed enough to know and care for during their short time here. You will never be forgotten.

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Share
Care Coordination in the NICU: Implementing Family-Centered Nursing Care for Optimal Outcomes
Balancing hospital life and home life can be a challenge, and when families find themselves having to learn to juggle those two lives for weeks or months when their baby is in the NICU, the balancing act can become a tremendous task. While part of the family’s life has stood still and their entire world revolves around their hospitalized child, they still have to somehow keep up with the responsibilities in their home life. They may have jobs to perform, bills to pay, laundry to do, housework and yard work to do, pets to take care of, other children to care for, vehicles to maintain, groceries to purchase, meals to make, events to attend, among other things. Let’s not forget they need to find time to take care of themselves too.

In a perfect world, families who have a baby in the hospital would be surrounded by family and friends who would help them take care of all of life’s responsibilities so that they would have no additional worries and could focus solely on parenting their ill or premature child. Someone would take a lead role and figure out who would pick up older children and get them to school, help them with homework, shuttle them to after-school activities, make dinner, pack lunches, do the grocery shopping, do the laundry, clean the house, care for pets, and pay the bills. How nice would it be to have an entire community of support that would help care for families so that parents could care for themselves and their baby? I can’t even imagine what the immediate and long-term emotional and physical outcomes would be for infants and families if that were the case.

Sadly, not all parents of NICU babies have great support teams. Some NICU families have very little to no outside support at all and face the grueling NICU journey alone. For example, these families may be estranged from their families, may live far away from family, may be new to the area, may have been on vacation when they unexpectedly delivered early and away from their support network, might have been transported to a different city if their child required care at a higher-level facility, or may be recently separated from a spouse or significant other.
The one thing that all families have in common is they will need help from NICU staff to survive the NICU journey; they will need help psychosocially, and they will need help learning how to ask for help. So many individuals, fathers, and mothers want to appear strong and independent and feel it would be a sign of weakness if they relied on others for help. Staff need to highlight to families the importance of leaning on others during times of crisis and point out ways the unit and others can help make the juggling act a little less cumbersome. With any luck, so many balls won’t have to be in the air all at once.

BALANCING OLDER SIBLINGS

Some families experience the NICU with their very first child. Other families have other children and find themselves trying to balance time at the hospital and time at home. These “parents often struggle to manage their older children in addition to coping with their newborn, making this challenging time harder for the whole family” (Wainwright, 2017, “Abstract” section). These families struggle with guilt over where they spend their time; if they are at the hospital spending time with their new baby who needs them there for bonding, feeding, and growing, they feel guilty that the other children are at home alone or are being shuttled between other family and friends. If they are at home with older children, they feel guilty that their new baby is alone in a hospital. The reality is, they can’t be in two places at once, so NICU staff need to help them learn how to not only manage the guilt, but also spend time equally with each sibling, making time with both equally important. Staff caring for families who have other children need to pay particular attention to helping families include the siblings as important members of the family and should assist families in determining schedules to help create meaningful time and connections with all of their children.

In Chapter 6 of this text, we looked at supporting families in the NICU and discussed the importance of including siblings as equal and important members of the family. To elaborate on that message, encouraging sibling attendance and involvement in the unit allows families to be together and decreases the stress of separation. With encouraging sibling visitation and participation, parents are more able to be in the unit without the pressures of being separated; “the presence of parents in NICUs and their involvement caring [for] their babies, in a family centered care philosophy, is vital to improve the outcome of their infants and the relationships within each family” (Guimarães, 2015, “Abstract” section).

It is not realistic to expect that siblings can be in the unit around the clock; however, infection-control concerns need to always be kept in mind, as do the safety and health of neonates in the NICU. Although siblings of all ages should be allowed to visit at all times and studies have shown that “sibling visitations to the NICU [do] not result in an increase in the nosocomial viral infection rate” (Horikoshi et al., 2018, “Background” section), education and strict adherence to handwashing and limited visitation to those showing signs of illness should be followed. These strict guidelines also need to be enforced with siblings, and depending on the age and maturity level of siblings, visits may need to be limited to short periods so that they do not become disruptive to the healing environment.
Ideas to discuss with families for times when siblings cannot be in the unit or for supporting them in finding ways to balance time at home and at the hospital may include the following:

- If older children are in school, spend time at the hospital when they are in class and then spend evenings at home. This allows parents to spend quality time at the hospital while the other children are busy and already occupied, and then they can be available at home in the evening for dinner and homework help, keeping home routines as normal as possible.

- If children are not yet in school, find local family or friends who will watch them or take them to do fun things when parents visit the hospital without them. If they do not have family or friends in the area, assist them in finding respite nurseries or local resources that can provide low-cost childcare.

- If families live quite a distance from the hospital, assist in arranging a stay at a local Ronald McDonald House; encourage them to take advantage of the wonderful sibling activities sponsored by the House so that there is some time for family and fun outside of the hospital. If families are traveling to and from home to the hospital but live a distance, encourage an alternate schedule in which one parent stays longer at the hospital one day while the other parent is home with the siblings and then trade off the next day.

- If siblings are in school, encourage families to take time to visit the school for lunch or attend a school play, concert, or sporting event with them. As important as it is to be at the hospital with their baby, it is also important for them to remain active in their other children's life for events that are special to them.

- Facilitate activities for the families to do together that create a bond between siblings and the new baby. These may include participating in sibling support groups, asking big brothers and sisters to draw pictures to hang up at the baby's bedside, encouraging the family to bring in photos to hang up, and sending photos of the baby to the older siblings.

The important point is that even if they develop a schedule or routine that feels right for their family, they will never feel perfect! Parent guilt will be present no matter what. Staff should continually reassure them that everything will be okay and inspire them to have grace with themselves. Congratulate them on doing a great job and provide constant encouragement and positive reinforcement. They may have to change their plans several times to adapt to changing situations during the NICU journey, but with staff support, they will be able to better adapt and adjust.

**BALANCING PARENTING AND RELATIONSHIPS**

Mothers of preterm infants [tend] to report more health related difficulties, more depression, higher social isolation and role restriction, and less support from their spouses, than reported by fathers. Moreover, as time [goes] on, parents with preterm infants [continue] to
NICU care providers must understand these experiences and help design programs and interventions to help improve the parenting experience for families who have infants that start out life in the NICU. In the past, studies have reported that parents who have a child with a lifelong medical condition have a divorce rate of over 70%; that is just from statistics of married couples. Imagine if the data included the numbers of relationships that are not marriages that have also ended. At a time when a parent needs a support person (whether that be a spouse, boyfriend, or girlfriend) the most, these relationships historically have been falling apart. Talk about adding even more stress to an already stressful life event!

Facing the challenge of an unpredictable event and stressful start to an infant’s life can have a devastating impact on a parent’s life and a huge impact on the relationship with their parenting partner. “Men and women report different reactions to stress, both physically and mentally. They attempt to manage stress in very different ways and also perceive their ability to do so—and the things that stand in their way—in markedly different ways” (American Psychological Association, n.d.). Both mothers and fathers report experiences of trauma related to the hospitalization of their child so it’s not surprising that with such opposite coping mechanisms, they find themselves driving one another away and creating a distance between them that is sometimes difficult to navigate back from.

NICU staff are not marital or relationship counselors and should not claim to be. Nor should staff take on the responsibility of trying to fix relationships between parents. However, when looking at providing psychosocial support to families, if parents are struggling in their relationship with each other, that stress is certainly going to impact their stress level and, ultimately, their ability to bond with their baby and cope with the NICU journey. It is important for NICU staff to recognize signs of troubled relationships, know how to refer couples to support resources, and reassure families that stress on relationships during this tremendously stressful time of their life is normal. Staff should encourage couples to talk to each other, participate in peer-to-peer support activities, and recognize that professional support may be something they might want to consider.

Many couples do not want to admit that they may need professional support, but with the added stress of a NICU journey and potentially a life ahead of long-term health consequences due to their child’s prematurity, professional support may be the best thing to help them cope through the NICU journey and beyond. Kara Wahlin, a licensed marriage and family therapist, offers a list of really great questions that couples can ask themselves to determine whether professional support is the best choice for them. If a couple can relate to the following questions, seeking help may be a ticket to better communication, improved understanding, and better relationship with each other that may save their relationship and ultimately provide a stable and healthy environment for their child and family (Figure 10.1).

Kara Wahlin is not only a marriage and family therapist, but also a NICU graduate mother of twin boys of 26 and 6/7 weeks’ gestation. One boy survived and one passed away from complications of prematurity a week after birth. Kara knows firsthand what stressor parents face in the NICU and how difficult it can be to try to balance life at the
Kara Wahlin, NICU Healing

Have you and your partner experienced:

- Alienation from each other in trying to find your different parenting “roles” in this new and unpredictable experience?
- Difficulty communicating with each other after the baby is born?
- An avoidance of talking about the birth of the baby to protect your or your partner’s feelings?
- Concern about your partner’s level of depression and the ways that it may affect your relationship or their relationship with the baby?
- Physical distance in distinct contrast with what your physical relationship looked like before?
- Substance abuse and/or avoidance behaviors in one or the other partner in trying to “numb” memories of the experience?
- Very different ways of coping with the premature birth of your baby?
- Anxiety that is so extreme that it affects either the partnership relationship or one or the other’s attachment with the baby?
- Alienation from friends and family and an inability to feel motivated to do things together anymore?
- Feelings that you live a very distinct and separate life from your partner, and that you no longer “connect” in the ways you once did?

Figure 10.1 ▪ Partnership in the face of trauma.

hospital, parenthood, and a relationship. Kara has taken this experience and started an amazing organization called NICU Healing, a therapeutic program dedicated to the healing, education, and empowerment of parents and families facing the hospitalization of a premature or medically complex baby. Kara strives, with every client, to provide clinical resources that they can use to cope with the traumatic stress of the NICU environment and the parental stressors of having a premature or ill child; she also uncovers the hidden strengths of the families faced with incredible challenges. NICU Healing truly wants to help families find reprieve from the traumatic experiences they’ve had and to transform their trauma into powerful attachment with their child and solidarity as a family.

Parenting relationships are not the only relationships that NICU parents find themselves needing help balancing, however. All relationships are at risk of being compromised and take a toll when parents are stressed and spend time in the hospital with their child. Relationships with parents, grandparents, adult siblings, friends, coworkers, and others in their lives all are impacted. When individuals find themselves in episodes of stress or crisis, it can be very difficult to maintain relationships, which can be an additional cause of stress for parents. NICU staff can reassure families that this too is normal and recommend that communicating to family and friends through a letter or email may be beneficial, explaining what the family is going through and how their family and friends can help them through this difficult time (Figures 10.2 and 10.3).
Dear Family and Friends,
As you know, we have welcomed a new addition to our family! However, to get stronger and healthier, our baby needs a little extra help from the NICU. We have seen our child have great days and then some fairly rough days. Premature and sick infants apparently like a rush because they operate on this roller coaster, so we never know if it will be a good day or a rough day!

And what we are noticing is that we tend to have the same type of routine these days. Some mornings we can get up, feel like we can carry on a normal day, and get through all we have to do with little stress and worry. Unfortunately, other days we struggle to even get enough energy to just get out of bed and complete simple tasks. The emotions of being new parents, balancing the hospital with all of the other life responsibilities we have and trying to make sense of everything that is going on, can be a lot to deal with.

We want you to know that we will seem to go up and down, depending on the day. Please be patient with us! We need the love and support from our family and friends now more than ever, but we may also need space and time too. Do not take this personally. If you don’t hear from us for a while, it’s not because we are not thinking of you and not wanting to stay connected. It’s just that we have other competing priorities right now too.

Thank you so much for your understanding! We are just trying to figure this all out and we are so thankful for you to be by our side during this incredible journey!

With Love,

PATIENT + FAMILY CARE

2660 NE Hwy 20 Suite 610 #338 Bend, OR 97701

PHONE 541-410-1921
FAX 541-382-2145
WEB www.patientfamilycare.com

Figure 10.2 Sample letter to family and friends from NICU parent.

RETURNING TO WORK
Many parents face the unfortunate reality of having to return to work prior to their baby being discharged from the hospital. Depending on what maternal and/or paternal leave parents have and contingent on how long their baby will be in the hospital, many parents face the grueling decision of whether or not to take their leave after birth or after hospital discharge. Some families take partial leaves after birth and the remainder after discharge, some have one parent take leave after birth and the other take leave after discharge, others both take leave after discharge but not after birth, and others do not even have leave and must return to work shortly after delivery. Regardless of their situation, if a parent has to return to work while their child is in the hospital, the transition back to work is stress provoking for the family, and staff should be prepared to support them through this time.
When your friends or family members welcome a baby who requires time in a NICU, they experience great days and, unfortunately, difficult days. Babies can spend anywhere from hours, to days, to *months* in the hospital, so your patience and support for them will be greatly appreciated. Also, while many parents won’t ask others for help, we know that even the smallest things that others can help with will make a huge difference! Here are some ideas on how you can help:

- Prepare meals for them.
- Set up a meal train so that others can prepare meals too.
  - Visit https://www.mealtrain.com to set up a meal calendar and send it to other family and friends.
- If they have other children:
  - Find time to watch them and take them do something fun and special.
  - Help pick them up from school or daycare.
  - Help with homework and school projects.
  - Take them to their after-school or summer sports/activities.
- Help watch and take of their pets so that they can spend more time at the hospital.
- Spend an afternoon doing yard work for them.
- Ask if you can help wash and fold laundry for them.
- Spend an afternoon doing yard work for them.
- Offer to drive them to and from the hospital.
- Purchase gas gift cards to help lessen the cost of traveling back and forth.
- Go to the grocery store and get them basic things to make sure they have things at home:
  - Milk
  - Bread
  - Sandwich meat
  - Protein bars
  - Peanuts (if they are not allergic)
- Ask what would be helpful to them and have them create their own list of ways to help.

Figure 10.3 Ways that family and friends can help NICU parents.
Some important things to consider, and help prepare families for when returning to work, may be the following:

- If families have other children, time at the hospital and at home is even more challenging to split and balance because now their day is spent at work. Their free time is now much more limited and is divided between hospital, home, and other life responsibilities.

- If breastfeeding/pumping, mom needs to have a breast pump and the ability to pump while at work. Coordination with her employer ensures that she has a private space to pump several times a day, that there is a safe place to properly store the expressed milk, that she has a way to adequately transport the expressed milk from work to home or the hospital, and that her employer supports her breaks to pump.

- If both parents are working, they might visit the hospital together or take turns. Often, fathers visit the hospital on their way to work in the morning, and mothers visit on their way home in the evening, or vice versa.

- Depending on where their place of employment is located in relation to the hospital, traffic patterns or traffic times may impact their ability to visit the hospital or their visitation plans.

- When they are at work, the medical team needs to know the best way to reach them if there were an emergency and for daily updates.

The most important way that staff can support any parent having to return to work is finding techniques to help them feel connected to their baby, finding ways that they can stay involved in the care planning and decision making, performing care on the parents’ schedule, and being flexible to meet their needs.

Author’s Personal Story

I met N.B. after a bedside nurse put in a referral for her to have a family-support specialist consult. Before our first meeting, I read her son’s NICU chart and learned that he was a 32 week and 4-day-old infant at birth and was now 2½ weeks old. Medically speaking, he was stable and was what we considered a feeder/grower and was doing well. N.B. was 39 years old and this was her fourth child. The other three children were 8 and 5 years old, respectively, with the 5-year-olds being a set of identical twin girls. The family lived in a town 45 minutes away, so N.B. was staying at the local Ronald McDonald House, and the father of the baby was staying at home with the older siblings so that there would be limited disruption to their school and extracurricular activities. N.B.’s husband worked from home, so he was able to see the children off to school and pick them up, and he would travel up to the hospital with the entire family on the weekends, when they would stay together at the Ronald McDonald House.

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I entered N.B.’s room and I found her tearful and facing away from her child, even though she was cradling him in her arms. I grabbed some tissue and asked if she would be okay if I came in and sat down with her for a little while. She agreed and I sat with her in silence after I introduced myself and allowed her the space to be with her emotions. After she collected herself and was able to stop crying, she apologized; I immediately told her that she should not apologize for being emotional, that being a new mother was stressful, exhausting, and emotional, and adding the NICU component on top of it all amplified all of those experiences. Her reaction was normal, and she was allowed to feel and be any way she needed to be.

I asked N.B. if there was anything in particular that was upsetting her or if she felt it was the hormonal and expected emotional reactions to motherhood. She opened up and shared the following things with me:

- She missed her older children terribly! Every time she held her son, she felt overwhelming guilt that she wasn’t at home with her other children. Her husband would come up on the weekends with the girls, but by the time they arrived on Saturday morning, visited at the hospital, went back to the Ronald McDonald House to spend time together as a family, she felt the weekend was already over and they were heading back again on Sunday.

- She hated missing everything at her children’s school. She was a dedicated volunteer and routinely spent every Tuesday and Thursday mornings in their classrooms and felt that she was letting not only the teacher, but also her girls, down. She had several big classroom projects that she had signed up to take on, and she was now falling behind on her work and she felt like she was failing.

- She felt like she and her husband were drifting apart. She was lonely and scared, and desperately wanted to talk to him. However, she felt like when they talked on the phone, he was short with her; when they saw each other on the weekend, he was distant; and they argued more now than they ever had before.

- She was missing her friends and didn’t know how to reach out to them. When she talked to them, she tried to tell them how she was feeling and what the NICU experience was like, but none of them seemed to understand, so she felt she almost scared them all off because they weren’t calling her, weren’t visiting, and weren’t including her in their weekly coffee book club meeting invites anymore.

N.B. was clearly struggling with many issues and there was no way we were going to be able to work through all of them in one sitting. I assured her that together we could work through all of her concerns and that she was not going to have to face any of her anxieties alone, but we would have to tackle them one at a time. It was almost time for her son’s care, so I tasked her with writing out all of her worries that night and then to prioritize them. We could then meet again the next morning and together create a plan. I also tasked her with (continued)
going back to the Ronald McDonald House early that evening to eat a warm, nutritious dinner and to get to bed at a decent hour. I educated her on the importance of sleep, and with her pumping around the clock, sleep was very important.

I met with N.B. the next morning and she looked like a different person. She looked rested and she had a big smile on her face. She came up to me with a journal and was proud to show me she took her assignment from the night before seriously. She wrote down all of her concerns in detail, ate a great dinner that had been prepared by a local Rotary Club, and after taking a nice hot shower, got to bed early and slept well between her scheduled pumping. Just journaling and writing down everything relieved her of a lot of her stress.

We sat down to go through her priorities and were able to easily work through almost all of her issues that one day at some level. When it came to her children, I asked her if their school district had early-release hours on Wednesday. She said they did, so I asked what she thought about being in the NICU Wednesday morning for her son and then heading home to pick up her girls when they got out of school at 2 p.m. She could then spend the afternoon with them and her husband, have a family evening, go to their school on Thursday morning to volunteer, and then come back to the hospital for Thursday afternoon care. That would give her another afternoon and night with her family, a night a week back at her own home, an additional night a week with her husband, and a day back in the classroom. She lit up and immediately crossed three things off her list at once. I told N.B. that while that idea sounded good at the time, that didn't mean it was a foolproof solution for all of those concerns. I recommend that she should trial it to see how it worked for her and her family and make adjustments as needed.

N.B.’s friendships was the next priority on her list and we spent time talking about how most people have no idea what it is like to be in the NICU. I asked her that before entering the NICU with her son, if she knew what it was like for a parent to be in the NICU with their child? She admitted she did not and seemed to instantly have a newfound sensitivity for what her friends were going through. I asked if she would leave the NICU to attend the book club if her friends invited her, and she said no. I asked her to consider that maybe her friends were respecting her time at the hospital and that is why they weren’t inviting her. I encouraged her to consider talking to them or sending them a letter if she didn’t feel like talking to them in person to let them know how she felt; I provided a sample letter of what other parents had provided to family and friends.

Last, we talked about her relationship with her husband. I disclosed to her that I was not at all skilled or trained to give her any advice at all, that staff in the NICU were there to provide support to her and her husband, but we were not trained counselors. I offered to provide her with resources within our community and online that might be beneficial. I encouraged N.B. to also continue meeting with our unit social worker and psychologist, with whom she had already been meeting and had established a trusting relationship. Before we wrapped up our conversation that day, she took me up on my offer of receiving

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a list of resources; I informed her that I would check in on how things were going for her in a few days in regard to her relationships.

I realized with N.B. that sometimes parents are so overwhelmed with all they are dealing with that they just need someone to sit down with them, encourage them to really think about what it is that is bothering them, and help troubleshoot ways to work through those issues. NICU staff have the luxury of seeing interventions that work or don't work for hundreds of families throughout their careers and can share those ideas with other families who have never been in that situation and just needed some creativity and inspiration. Thankfully for N.B., I was able to share some of those previous success tactics that seemed to work really well for her.

Family Story

Alex Ortega, a mom experienced at what it was like having premature deliveries, shares her courageous story about being admitted on antepartum bed rest and having to be separated from her husband and two older children while all she could do to maintain her pregnancy as long as possible to give her unborn son the best possible chance at survival. At first, she didn't realize that the struggle of balancing home life and hospital life would continue once she went home from the hospital and ended up realizing that, in fact, the balancing act became more difficult when she returned home.

“When they admitted us to the hospital for severe preeclampsia, I remember looking at the nurse with tears in my eyes, . . . but what about my family? Everything as we knew was going to change.

“Forget the fact that I was resigning from my full-time job immediately, or the fact that I was so sick. What about my family? How were they going to manage without me? What we didn't realize was that Mom being stuck in the hospital, for what we naively thought was going to be 15 weeks, was soon to become the least of our problems.

“Our son, our third beautiful preemie baby, Theodore Ronin Alexander, would enter the world a few short weeks later, at just 28 weeks’ gestation, changing our lives and our family dynamic forever.

“After having delivered our son prematurely and having had been admitted to the birth center for so long, I think that I was not only in shock from the recent events, but also so very homesick. I incredibly underestimated my readiness and my ability to manage my home life while attempting to be a parent to the NICU’s latest micropreemie admit.

“This naive, almost blissful, fog dissipated quickly once we were home. Once I returned home after being in the hospital for a month, the reality and the weight of the situation came to a head. I sat on my bed; my older kids climbing on me and loving me (they had missed me SO much), my husband pulling them off of me and turning on their new movie Moana. I sat there desperately trying to figure out how to get my breast pump to work, still sore and

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bleeding from the emergency delivery of Theo just 2 days prior. My womb and my heart aching to just have my child with me, as one, once again, and it hit me; How was I going to do this? How does anyone manage taking care of older children, a house, and a husband while they have a brand-new baby in critical condition in the hospital? That takes a supermom, and I felt far from it. I couldn't even figure out my breast pump, for crying out loud.

“Thus began my struggle with not only being a new preemie parent, but also a mom to my big kiddos and a wife to my husband. I had to learn how to balance everyone, and I had to learn fast. It felt like there was no right answer at all. I thought finding that sought-after balance would never happen. It felt like the balance of home–husband–NICU was most certainly unattainable after all. I thought I would never be able to get caught up on the laundry that I knew was piling up, nor the dishes that laid in my sink. I thought for sure my older kids were going to forget who I was, and if they didn’t, they would resent me for missing so much of this precious time with them, time I could never get back. I was afraid that I wasn't spending enough time with my newborn baby in the hospital and we wouldn't be able to create that special bond that mothers and their children had, and don't you dare forget the fear: the constant fear that something was going to happen to him while I wasn't there and I wouldn't be able to get to him on time, I wouldn't be there when he really needed me. The fear that I would, yet again, fail as his mother. I was convinced that if I did make it through this painful journey, my marriage most certainly wouldn't. I was afraid that this would all change and not for the better. The constant anxiety I had that I would become someone who was a stranger to my family and my husband was crippling. What if he can’t love me after this? What if I’m too broken? I had read all of the scary stories of marriages failing during or after a long-term NICU admission, and I had seen the less-than-pleasing statistics. I felt like it was inevitable that we were on our way to being one of those numbers or one of those sad stories. My heart was telling me that this wouldn't be the case for us, that we would beat the odds, but my mind was telling me something entirely different.

“This one particular night, I ended up just collapsing in the doorway of my extremely disheveled house, in absolute sorrow and hopelessness. Tears flowed from my eyes, but they were straight from my soul. (I had just returned home from seeing Theodore and received some rather saddening news. He was extremely sick and quickly worsening, so I'm sure that added to my distressed state of mind.) I sat on the floor in a mess of my kids' coats and shoes (that hadn’t been put away in Lord knows how long), and through the sobs and tears, I told my husband I couldn’t do it, that there simply wasn’t enough of me to go around. I remember telling him over and over again that I couldn't do it. That God had made a mistake when he chose me to be Theodore's mom; I wasn't strong enough. I was failing everyone. He just walked over to me and just sat on the floor of our entryway and held me as I bawled, not saying a word, but allowing my heart to get out what I needed to. I told him I was exhausted. I was so completely and absolutely drained to my core. I was emotionally and mentally depleted. We had two kids at home, my step-son on the weekends, and our poor 28-week preemie was fighting for his life in the hospital just down the street. He was so close, but he felt like he was half a world away. I was functioning in my daily life as a shell of my former self. I

(continued)
was so empty and felt so lost. I felt sad and guilty when I wasn’t with him but felt the same sadness and guilt when I was, because I was away from my family and my other children. In my mind, I was failing them too. I don’t know if I took it especially hard because of the type of person I am (I’m the type of person who feels like my true purpose in this world is to be a mother, it’s my everything, and my family is my entire world), but the pain I was feeling not being able to be there for ALL of my kids and my husband was crushing to my soul. I felt like I was dying from the inside out, and I knew then, I had to make a change.

“We had to make this work; we had no choice. The world didn’t stop just because we had our baby extremely premature. Our older children’s worlds didn’t stop just because they had a really sick baby brother. We had to learn how to function as a family again, in a world that never slowed down, that never missed a beat. I had to learn. I had to learn that the guilt I was feeling was okay and that the sadness and heartbreak was okay. I had to learn to allow myself to feel my emotions. Acting tough and keeping a smile on my face obviously wasn’t working anymore. I had to come to terms with the fact that I did miss out on enjoying the last half of my pregnancy and even grieve, if need be. I had to allow myself to heal and quit pushing myself too far and remind myself that this situation was only temporary and that one day, when I left those secured double doors, I would no longer be empty handed and my heart wouldn’t ache. I would be leaving with my son in my arms; we just had to get there. I forced myself to understand that my kids weren’t going to hate me, that my husband was still going to love me, and once we made it through this battle, we would be okay. Everything was going to be okay!

“I was now a mom of a micropreemie fighter, and a mom of two amazing preschoolers (one being special needs) and one awesome bonus kid from my husband, and I was a wife. It was time to step up . . . and be the warrior I needed to be and the warrior I knew deep down I could be, because this was our life for now. We didn’t know if it would ever go back to what we knew as ‘normal’ or what that normal would even look like once Theodore came home; however, I did know one thing, I was going to do it. I was going to make it work, and we would learn to adapt to our new world, as would my family, and in the end, my baby boy would come home.

“I just had to remember: It’s not forever, it’s just for right now.”

RECOMMENDATIONS/SUGGESTIONS FOR BEST PRACTICE

1. Assist families in finding ways to ask for help from others and provide resources in the community that can help meet any needs they may have.

2. Encourage and welcome sibling involvement in the NICU.

3. Assess the relationship status of parents and recommend professional support if relationships are struggling.

4. Provide support for parents in learning how to communicate with friends and family to help ease the stress of balancing relationships.

5. Provide families with journals and encourage them to write about their feelings throughout their NICU journey to help alleviate stress and decrease anxiety.
RECOMMENDED RESOURCES

Multiple resources are available to staff and families to help them learn to balance home and hospital life (Figure 10.4).

**Website Recommendations:**
5. https://www.mealtrain.com
15. http://micropreemie.net/blog/connect-siblings-nicu-babies
17. http://www.breastmilkcounts.com/working-moms/pumping-at-work

**Figure 10.4** Recommended resources for helping families balance home life and hospital life.

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Case-Based Learning

F.Y. is a 38-year-old mother of 6-day-old twins born at 29 weeks’ gestation. The twins were conceived with assisted reproductive technology after she experienced several pregnancy losses after the birth of her first child 10 years ago. She is hesitant to bring her 10-year-old to the hospital to see his siblings because of behavior that worries her. His soccer coach told her that he intentionally kicked a teammate and was unrepentant. In addition, he has been uncooperative at home and more aggressive with their dog than previously.

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QUESTIONS

1. What are the contextual elements that may be at play for the 10-year-old sibling?

2. What actions might you take to help support this family?

ANSWERS

The sibling may be feeling unattended to but cannot verbalize his emotions. He may be jealous of the attention that his tiny siblings are receiving. His mother is no longer home every afternoon to pick him up from school and take him to soccer practice. She is tired when she comes home from the hospital and may be spending less time with him due to stress and exhaustion.

Sibling rivalry is alive and well and lives in the NICU! However, many NICUs have programs to improve family dynamics. Childcare, family areas, and playrooms are wonderful additions to NICU design. Child life therapists offer activities such as drawing pictures and writing songs for the new baby. Role playing, diaper changing, and baby care with dolls empower the older sibling and allow them to practice until the time comes for them to participate in newborn care (Maree & Downes, 2016).

Sibling visitation in NICUs down to the age of 2 is not uncommon. However, tending to a curious, busy toddler while attending to a critically ill newborn is a parenting challenge unlike any other. Integrating the family does not stop at the parents; siblings and grandparents are also mentored by NICU RNs using this model of care. Older siblings can participate in supervised kangaroo care. They may bond and learn important lessons about their tiny siblings when they help diaper or help feed them. This can help them feel important, instead of left out (Kory & Fredian, 2017).

Sometimes, sibling visitation must be limited because of infectious diseases. Peluso, Harnish, Miller, Cooper, and Fujii (2015) concluded that the number of infants with respiratory syncytial virus (RSV) in the NICU can be reduced by excluding sibling visitors under 13 years of age during the RSV season. In these circumstances, school-age children may understand a clear explanation of the reasoning and benefit from praise for not giving germs to their sibling or other fragile babies. Booklets of photographs of their tiny sibling to share at school may be a way for them to feel special, too. Handwashing before touching the baby is a good thing to teach everyone who visits while in the hospital and at home.

REFERENCES


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REFERENCES


Perinatal and neonatal palliative care is a practice that has gained acceptance and recognition in recent years, primarily due to an increased need because technology has allowed for more infertility treatments, has led to more accurate diagnosis of nonviable conditions prenatally, and with the ability to care for infants at lower ages of viability. Despite these great technological advances in therapies and treatments, not all pregnancies and babies survive. “Palliative care should be offered to all parents who have been informed of a life-limiting fetal diagnosis, [and] end-of-life care should include individualized bereavement interventions for women with a high-level multiple gestation and their families when the pregnancy may need to be reduced or if there is an intrauterine fetal demise” (Catlin, Brandon, Wool, & Mendes, 2015, “Background and Significance” section). In the NICU, palliative care support should be offered to families whose babies are “diagnosed with life-limiting conditions at birth or who become critically ill during a NICU stay and are not responding to aggressive medical management” (Kenner, Press, & Ryan, 2015, “Abstract” section).

Palliative care, and end-of-life care decisions in the NICU, can be ethically and morally challenging. Yet “palliative care is an approach that improves the quality of life of patients facing life-limiting conditions, and their families, through the prevention and relief of suffering by means of early, impeccable assessment and treatment of pain and other physical, psychosocial and spiritual issues” (Kenner et al., 2015, “Core Concepts and Values” section). Palliative care truly focuses on and “emphasizes quality of life while alleviating the symptoms of medical conditions and their treatments” (Eden & Callister, 2010, para. 8) which can often be a welcoming decision for families and care providers who are looking for an alternative for continuing potentially futile ongoing care. In a unit where babies with complex medical needs are exposed to ongoing aggressive treatments, tracheal intubation, repetitive blood sampling, and invasive catheters are cared for daily and are being treated at younger and younger gestational ages, the uncertainty of immediate and long-term outcomes become a real issue. When infants do not seem to be responding positively to provided treatment, working with families to decide on palliative care can “enhance end-of-life care for newborns through better control of pain and other distressing symptoms and by avoiding futile treatments whose burdens outweigh benefits” (Dighe, Manerkar, Muckaden, & Duraisamy, 2011, p. 104).
PREPARING FOR PALLIATIVE CARE

When a healthcare team feels that palliative care would be warranted as the best care decision for an infant, there are careful considerations on how to approach the family. The provider must continue to have “ongoing assessment of care goals, parents, nurses, and other providers weigh the benefits of shifting the goals of care from focus on cure to provision of comfort for the infant and family” (Catlin et al., 2015, para. 1) and then determine who is the most appropriate person to first talk to the family. It is important to keep in mind that “family is defined as a constellation of people who are related by birth, adoption, marriage or those individuals the parents designate as part of their family unit” (Kenner et al., 2015, “Core Concepts and Values” section). Parents often lean on their extended family as their support network during this stressful time and may want them included in difficult discussions.

When deciding who should speak with the family and how the conversation should be approached, the team should delegate the person who has both the best relationship with the family and is the most comfortable with palliative care discussions. “Even though the neonatology team may have a good rapport with the family, members of the palliative care team may be able to provide additional psychological support to parents and families through these difficult times” (Dighe et al., 2011. p. 104). If a neonatal unit does not have an embedded palliative care team, it is essential that neonatal staff be well trained and comfortable having end-of-life discussions with families, which means that they know how to respectfully, compassionately, and honestly speak with families who are facing such an “immense, heartbreaking responsibility to decide to withdraw life-sustaining treatments for the infant” (Eden & Callister, 2010, “Parent Involvement in Decision Making” section).

Once a staff member is identified, families should be talked to in a private space so that there will be limited interruptions during the conversation. If possible, parents should be warned that the care team needs to have a difficult conversation with them, so if they would like to have anyone else present, they should be encouraged to invite them and schedule the meeting when all individuals can be present, if time allows. When the discussion occurs, parents need to then be given accurate, candid, direct, and thorough information about the condition of their child and the projected outcome of ongoing treatment. Some families decide that ongoing treatment is the best decision for their child, so healthcare teams need to continue caring for the infant and family while navigating the difficult task of either continuing with their wishes until the child can no longer maintain life and the discussion needs to occur again or to escalate the discussion to a hospital ethics committee—a topic for an entirely separate publication.

For families who do wish to proceed with palliative care, the care team in collaboration with the family, must “assist parents in making decisions about treatments their infant may receive” (Eden & Callister, 2010, “Palliative Care and Decision Making” section) as the family is an “integral part of the health-care team, and both work together to plan and implement palliative and/or bereavement care” (Kenner et al., 2015, “Core Concepts and Values” section). Families should be allowed to be involved in every aspect of the palliative care process as possible, including up to the time they choose to remove life support if time allows. This affords family time to invite other family, friends, or clergy members to be present for the passing of their child if they wish. Many units have visitation policies that limit the number of visitors that are allowed to be at a given bedside at a time, but in
times of palliative care, families should be allowed to have as many support individuals present that they desire to fully support the family-centered care philosophy.

It often can take families some time to process the news and reality of having to make such a definitive decision for their child, and if time allows, families should never be rushed into their decision and should be led with grace and patience by the care team in making the decisions they need to. Until that point, most parents were envisioning what it would be like to put their baby in their going-home outfit, to put them in a car seat and take them home to their nurseries, and to watch affectionately as they grow up and turn into their own little individuals. Now they are having to say goodbye to all of those dreams and have to picture bathing their baby for the last time, dressing them in a burial or cremation outfit, and knowing that after they leave that hospital, they will never be able to hold or see their precious child again. This is a realization that must be met with compassion, empathy, respect, and understanding.

When time is limited due to a rapidly declining status, care teams must express that time is restricted, that the staff wants the family to have every last minute with their child be as pain free and comfortable as possible, and that the staff wants the family to be as present and involved as they want to be. Yet staff must keep in mind that families may not be able to process everything that quickly and may not be capable of making many decisions in that moment. In these situations, staff need to assist the family in ways that support bonding and honoring the life of the child while being the primary decision makers; they must help walk the family through the process step by step.

Families need to be made aware of what to expect and how to prepare. For example, staff should inform all families of the following prior to removing life support or stopping lifesaving therapies:

- What will happen when respiratory support is removed
- How a baby typically responds during the transition from life to death
  - What respirations may look like
  - What color changes to anticipate
  - What body temperatures to expect
  - What secretions they may see
  - How long the transition may take
- What the team will do for the family during the time of transition
- How the team will be present to support the baby and family, to assess vital signs, and to determine an official time of death
- What will happen after the baby has passed away
  - What care the family can participate in
  - How long they can remain with their baby
  - How the unit will spend time helping collect keepsakes
  - What will happen with the baby’s body when families are ready to say goodbye and leave the hospital
- How social workers or other designated staff will help them with the resources they need to make arrangements with a funeral home
- How they will be given wraparound support services for grief and loss, and how they will not be leaving the hospital without the team continuing to support them
- How the option of bereavement photography is available and is highly encouraged

“Parents are often encouraged or expected to be at the bedside of their infant at the time of withdrawal of life-sustaining treatment” (Eden & Callister, 2010, “Palliative Care and Decision Making” section), and many families choose to hold their infant and be with them for the duration of the transition from life to death. However, some families do not feel that they can be witness to the event. Those families should be encouraged to make the decision that feels right for them and should not be shamed for choosing not to be involved. They do, however, need to also receive this information so that they can know what to anticipate for their child, if they wish to know. Parents should be assured that their infant will not be left alone during the transition, and a staff member should be assigned to care for their infant during the time from when the family leaves to when the baby passes. If at all possible, a staff member who has an established rapport and positive relationship with the family should be assigned this role to provide a layer of comfort for the family, who will know that someone they trust will be with their child during the difficult time when they could not be.

TRANSITION FROM LIFE TO DEATH

During the highly stressful and emotional period of transitioning from life to death, “it is important for health-care professionals and families to engage in effective communication and mutual respect” (Eden & Callister, 2010, para. 8) to ensure that families feel that they are being made aware of every new update on their child’s condition and current state. This transitional period is one that is foreign and completely devastating for families, and during this time, most parents feel out of control and powerless while they question whether or not they are making the best decision for their child. Staff have the significant responsibility of supporting families in finding ways that they can have control and to acknowledge their parenting abilities and decisions. One highly effective way to provide control is to allow families to be the decision makers and drive the majority of care during this time with the support of staff nearby. Families have “identified nurses as central figures in helping them assume parental roles” (Eden & Callister, 2010, “Parents’ Perceptions” section) during the time of transition, so nursing staff should remain present and available to families to help with education about the process, to help with any infant care, and to continuously reinforce the family’s positive interactions and actions.

As stated previously, parents should be allowed and encouraged to include other support individuals during this time. Healthcare professionals have become much better at ensuring parents are spending time with their infant, but the importance of including other family members is still less recognized. The grief of parents often is more “validated when their own parents, siblings, children and close friends can be with the baby, however briefly” (van Aerde, Gorodzinsky, Canadian Paediatric Society, & Fetus and Newborn Committee,
2001, “What to Do During the Dying Process” section). These individuals, who will be the ones to support the families after they leave the hospital, will be able to help continue the recognition of the child’s life if they are allowed to be a part of the transition process or are allowed to be present prior to the death, which will help them also acknowledge the child and the imprint of the child on the family’s life.

During the dying process, staff needs to prioritize respecting any cultural and/or religious rituals. If language barriers exist, all attempts to have an appropriate interpreter on site and in person should occur to truly foster a compassionate and more connected experience for the family. When an interpreter is available, staff may then directly ask families how they can best support any cultural or religious traditions that are important to them during the death and dying process. Not all families associate with a particular religion but may have feelings about how they want to respectfully deal with death and dying based on past experiences or familial traditions. Questions that staff may want to ask families might include the following:

- What are the family’s beliefs about what happens after death?
- What does the family consider to be the roles of each family member in handling the death?
- Who should the care team talk to about decisions that need to be made or to provide updates?
- Are baptisms or other religious ceremonies important to arrange prior to death that would be meaningful to the family?
- Are there prayers that can be said over the infant that would be significant?
- Are there treatments or particular cares that should be avoided?
- Are there specific oils or other ointments that they use during the dying process that they should be encouraged to bring in?

The overall importance is to ask questions that will encourage families to open up about what is important to them and how they want to honor the life, death, and dying of the child in relation to their culture, their religion, and their beliefs. In addition, the experience needs to be tailored to meet the needs of each family. When a plan is created, staff should always be flexible and realize that it may need to change as the parents experience various emotions and work through the emotions of the process.

FAMILY SUPPORT AFTER DEATH

Once death occurs, parents should be allowed to remain with their infant for as long as they would like and be given full privacy if they wish. Bereavement photography with the family should be offered during this time, and although many families initially decline because they cringe at the thought of ever wanting to see a photograph of their dead child, staff need to take the time to educate them that “remembrance photography is a very important step in the healing process. Photographs are one of the most precious and tangible mementos that parents can have, showing the love and bond that was given and shared with their baby” (Services for Families, n.d., para. 3). Professional organizations
are available in many areas and can be engaged ahead of time to be present if there is
time to prepare for the infant's death. In these situations, photography can even be taken
during the transition phase when the infant is still alive and spending time with the family.
Now I Lay Me Down to Sleep is one of the largest and most reputable organizations that
provide newborn bereavement photography. Volunteer photographers are trained at
being present in a very discrete and respectful manner so that they do not disrupt the
precious time families have with their child, yet can capture amazingly precious moments
for them in a photo that will last for generations. When a professional organization or
volunteer photographer is not available, staff must step in and fulfill the photographer
role. As mentioned numerous times in this text, a high-quality digital camera should be
available on the unit at all times so that staff has the ability to capture photographs for
families. Now I Lay Me Down to Sleep has a wonderful resource called a “posing guide
for hospitals,” which shows examples of various photos that are good to take of families,
of infants, of close-up features and even of keepsake memorabilia to assist staff who may
not have experience or ideas on how to capture bereavement photographs.

NICU staff should continue providing comprehensive psychosocial family support to
families as they provide postmortem care to their child. It is also highly encouraged that
words such as “postmortem,” “expired,” and “demise” not be used around families. Families
have shared that those terms feel extremely medical and feel harsh when used about their baby. Families want staff to continue “talking to parents about the infant as a person, not the
infant's medical condition” (Eden & Callister, 2010, “Parents’ Perceptions” section), which in
this case, would be expired or demise in medical terms. Talking to families as if the infant is still alive and treating the infant with as much respect is what families need after the time of death.

Families should be supported by staff to participate in all of the afterlife care that they
desire to participate in, including, but not limited to:

- Bathing
- Combing/brushing hair (even if there is just a little amount)
- Dressing the infant
- Participating in photography
- Obtaining a lock of hair
- Obtaining additional footprints/handprints
- Creating hand/foot molds

When families have spent time with their infant and are ready to say goodbye, staff
should reassure them that their baby will be cared for after they leave and that there will
be close collaboration between the hospital and the funeral home of their choice. Some families may ask details as to what will happen with their baby's body until the funeral home comes to pick them up, and staff should provide an honest answer about the
morgue and the process of safely and properly storing bodies. If possible, organizations
should use the infant Preshand system as a more respectful way to support the infant's body, rather than using a body bag or just wrapping the body in a blanket with a tag to be taken to the morgue. These beautiful and comfortable boxes provide a peaceful and
private place for the infant to lie, wrapped and secure, while being taken off the NICU or family birthing floor and while in the morgue waiting for the funeral home to come. For families who want to see what will happen with their baby, they can help tuck them into the comfortable bed and have a visual of exactly where their child will be after they are separated.

When parents leave the hospital, staff must recognize that they will experience a wide range of emotions. They will be leaving the intensive care unit for the last time, which compounds the intensity of their loss. NICU staff, for some families, has become an extension of their family and has been their support system for days, weeks, or even months. Walking out of the unit after the loss of their child means they are leaving their baby and their entire network of people who knew them as a family (a family they so desperately wanted to be) behind. Families find themselves leaving both an extremely intensive situation and a very intense environment only to enter silence and emptiness. Sending families’ home with mementos, photos, and a blanket that was wrapped around their baby can be ways to help them feel a little less empty. Furthermore, staff should tell parents that they will call within a few days to check in with them and see how they are doing. They also help staff anticipate future support, which can be a great comfort.

Having an infant loss in the NICU is a distressing event for both families and staff, so follow-up calls and sympathy cards can be extremely therapeutic for both parties. Often, staff also choose to attend memorial services of patients to help with closure and to also show ongoing support to families. Chapter 15 discusses the impact that loss has on caregivers and the ways that staff can support themselves and one another during tragedy. It is comforting to families to know that their baby’s care team truly cared for their child as an individual and not just as another patient on the unit.

Author’s Personal Story

I was greeted by Baby L.’s parents in the lobby of our NICU on the afternoon of his 22nd day of life. Each encounter I had with these parents was pleasant. Although baby L. had been through so much in his first 22 days out of the womb, his parents remained optimistic even in the most difficult moments.

L. had a very long journey ahead of him. He had been delivered emergently at 26 weeks’ gestation due to his mom’s worsening preeclampsia and was fighting the many challenges premature babies must fight to survive. By the radiance in his mother’s eyes, the almost giddy tone in her voice, and the ear-to-ear smile on his dad’s face, I instantly knew they were going to share a great success story with me that day in the lobby, a story that I was incredibly honored to have been invited to share with them and one that I will never forget.

As a nurse in the NICU, I am given a front row seat alongside families on the roller coaster ride each of them experiences during their NICU journey. I have to buckle up and ride the twists and turns that make me nervous and instill a great deal of fear, but I also get to soar through the easy parts and enjoy the fun and exciting milestones right along with them. L.’s roller coaster ride wasn’t much different than any other 26-week-old
neonate's. There were good days and there were difficult days. There were days when he was intubated, then days when he would stabilize on continuous positive airway pressure (CPAP). Yet L. ended up requiring oscillatory ventilation, and it became extremely difficult to wean him from this high level of respiratory support. L. was a very critical patient, no one would argue that. But above the diagnosis and above the many therapies L. was receiving, he was most importantly H.M. and M.M.'s son, their first and only child.

Being in the unique combined role of a neonatal nurse and family-support specialist, I got to share in the most intimate moments with families who were living through very traumatic and emotional birth crises. Whether their child was born at 24 weeks or if their term infant needed a few hours of NICU transition after birth, the stay in the NICU is a parent's worst nightmare.

In the case of H.M. and M.M., I initially met them on the 4th day of their son's life at his bedside. I remember entering the darkened room and seeing his parents visiting him. Both parents were standing at his Isolette staring in what looked like pure disbelief, at this incredibly small life in front of them. There was the traditional introduction of who I was and what I would be able to provide during their stay, and it seemed to be like any other first meeting. Little did I know that that moment was not only the start of an experience that I would never forget, but also was one that would turn into plans for great practice change in our department.

On Day 22 of baby L.'s life, when his parents found me in the NICU lobby, their excitement was contagious. His mother said that baby L. was doing so well that in 2 or 3 days, if he continued to improve, she would be able to hold him for the first time. My heart filled with joy for them. I anxiously watched L.'s progress the next few days right along with them. I frequently checked in with the medical care team and L.'s parents and received updates around the clock on his condition. I couldn't wait to hear when his parents would be able to hold him, and I planned on being present to capture that monumental moment for them with as many photos as our unit's digital camera would hold. Three days passed, and on Day 25 of life, I was there to capture pictures of baby L. in H.M.'s and M.M.'s arms for the first time, but tragically, it was also the last.

On the evening of Day 24, baby L. wasn't acting himself. His beautiful bright eyes didn't look the same; he was having more apnea and bradycardia, and after a septic workup, the providers found that he was very sick. L. was so small and had been so fragile that he didn't have much reserve and sadly continued to get increasingly ill as the hours passed.

As I walked into the unit early in the morning on Day 25, I saw extreme pain on the nurse's faces. As each nurse looked at me, I knew. I found both parents beside baby L. just waiting, praying. The care team frantically worked with baby L. trying to do whatever they could to improve his condition. One nurse had run to the blood bank and returned with blood and fresh frozen plasma, one nurse was administering his current dose of antibiotics, and another nurse was administering a fluid bolus. Baby L. was on 100% oxygen therapy with maximum ventilator support and maximal infusion of nitric oxide. Unfortunately, there was not much more that the care team could do, and L. was quickly slipping away.

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The neonatologist asked the family and I to step away into a private room for a few moments and told them that he thought it was time to have a very difficult conversation. I remember him sitting beside the family and so delicately explaining everything that had happened over the past 24 hours and what everything meant in very-easy-to-understand terminology. The parents sat there in disbelief, but the gentle hand that the provider placed on their shoulder and their knee comforted them. I offered tissue, and together the physician and I talked with the family about their two choices. They could either have us continue to provide therapies to see if baby L. would turn around, although all of the efforts up until this point made us believe that he would continue to decline and not respond favorably; he likely would not survive despite our very best efforts, yet this option would prolong how long he would be with them. They also could choose to stop the aggressive therapies and allow their son to be comforted and receive palliative care in his last hours of life; they could spend quality time with him and focus on holding him and loving him without the interruptions of invasive treatments, tubes, and wires. We recognized that the decision was extremely difficult to make, and either choice would be an okay choice to make, but it was up to them to look into their hearts and decide what was most important to them on how to parent and care for their son.

We allowed L.’s parents to have time alone and escorted them back to their son’s room where they could talk to one another and call family or friends if they wished. We knew this was an extremely difficult and painful decision and wanted them to have all the support they needed to make the decision that would impact them for their lifetime. Nurses continued to enter the room to provide treatment to baby L. as necessary until his parents had come to a decision; they wanted to end all of the aggressive treatment and allow their son to receive comfort care. The neonatologist acknowledged the parent’s difficult decision and their bravery in making such a big decision on behalf of their son, one that he felt was the right decision and one that would end a lot of pain for baby L. He then took the time to explain everything that the parents could anticipate, from how aspects of each care could be discontinued all the way up until the point of them placing baby L. into one of their arms and removing the intubation tube. He shared with them what the dying process in infants was like, so they knew what baby L. would look and feel like and offered to either allow them to be alone in the room or to have him or any one of the nurses stay with them. What was so special is that he said, “Getting to the point of where he passes away is difficult and is a lot to handle right now. Let’s just focus on getting from here to there, and then when we get to that point, we can talk about what the next phase of care looks like. Does that sound okay to you?” The parents both nodded yes, and I imagine they were happy with not having to be overloaded with more information at that moment but were relieved to know they would be given the information when they were ready.

The family was present and participated in deciding when the medications were slowly weaned and discontinued and was there when the monitors were removed. Slowly they were able to look down and see more and more of their child, who up until this point they had only seen covered in wires, tubes, and IV lines. As I was capturing some photos of

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baby L’s last few moments, the physician sat beside the parents and told them it was time. The nurses very compassionately removed the IV lines, assisted the parents in dressing baby L. in his first and only outfit, and then removed him from life support. Baby L. was gently picked up and placed into his mother’s arms.

The entire room filled with tears. As I watched H.M. and M.M., my heart ached. I kept reliving the moment 3 days ago when they shared their excitement at the thought of finally getting to hold their son. The pure delight and joy in their eyes were gone and were now replaced with hurt, confusion, sadness, emptiness, and uncertainty. Discretely, I continued to capture photos for the family of what would be their only family photos and hopefully be mementos that they would cherish later on.

Shortly after baby L. was removed from life support, both H.M.’s and M.M.’s parents arrived to not only say goodbye to their grandchild, but also to support and grieve with their children. Over the next several hours, other family members, friends, and church family arrived to also support the family. The social work team worked closely during this time with the father and mother to determine how they would like to proceed with arrangements, and I remember being in awe at the strength and bravery M.M. had in that time. He stepped up and really took on his caretaker role for his wife and his son and made really tough decisions with dignity and confidence.

After many hours and after the parents felt that all of their friends and family who were going to come pay their respects had been by to visit, they were ready to move to the next phase of care. In collaboration with another nurse, I walked H.M. through giving her son a bath, capturing moments of that in photographs as well. She then dried and dressed him, brushed his hair, and even helped clip a small amount to place in her memory box we were putting together for them. After all care was done and when the parents were finally feeling ready to leave, they were given privacy to say goodbye to their son.

Family Story

This first incredibly touching story comes from Megan Walker. Megan graciously shares about her experience with having both compassionate and less than compassionate care team members during their NICU journey when they were faced with the devastating reality of losing their son Simon.

“I remember clearly the moment when I knew Simon was dying. My husband was getting ready to leave the NICU; he was going to go home and try to sleep for a few hours. It was around 8 p.m., and we were standing above our Simon’s bed, quietly contemplating how life had brought us to this point in time. His little body was medically paralyzed as a last result to give his failing lungs rest to recover, he was on one hundred percent

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oxygen support, and there were cords and IVs surrounding him. We hovered there; it was as if our minds could not quite grasp what our eyes were seeing. Suddenly, the monitor beeped loudly beside us; Simon’s O₂ saturations were dropping low. Our nurse, and a resident from Simon’s first days who was working in a different section of the NICU that night, were there immediately beside us, watching with us and studying the monitors. Our doctors had exhausted every option for his care. We watched silently, helplessly to see what Simon would do. Would he recover? Or would he continue to decline? Simon’s saturations wavered, and I begged him to try harder, to keep going, to please not leave me. But then the moment came, one that many of my doctors had prepared me for, when Simon ‘told us’ he was done fighting. His saturations fell lower than they’d ever fallen, and my heart knew. I turned to the resident, and asked the hardest question I’ve ever had to ask, ‘Is he dying?’ Even though we’d only worked with this resident for the first week or so of Simon’s life, passed him in the halls on occasion, and spoken briefly with him, in this moment of our journey, he became a crucial person in our lives. His gentle answer, confirming what immediately became my reality, was exactly what I needed in that moment. Perhaps it is not common knowledge for all doctors, nurses, and caregivers, but this very important fact remains: Every working person in an intensive care unit is a key player to suffering families—his or her voice, smile, and the way in which he or she chooses to present himself with language and emotion, even how one handles stress or disappointment will influence lifelong memories for families like ours. Though our interactions with this resident were few considering the scale of our 5-month stay. I remember little details of our association that built the trust and friendship that I needed in that singular, critical moment of my life. I remember his genuine smile and concern with every mundane question I asked, and I remember one instance of passing him in a group in the hallway when he actually stopped to say hello despite his group continuing on. He was never angry, always kind, and he was genuine, confident, and encouraging at appropriate times. He didn’t have to be in Simon’s room that night. He was assigned in a completely different section of the NICU. But because he could, and because he cared, he was there with us. That, to me, is the epitome of an outstanding caregiver. This man is one of many we cherish in our NICU family. I remember fondly our receptionist too, a stickler to the rules, who kindly and patiently reminded me on countless occasions over 5 months to sign in before going back to Si’s room; our RT, who heard my seemingly crazy plea that something was wrong with Simon’s tubing and discovered holes twice during our stay; one of our nurses who spent extra time in our room to teach me how to care for a tiny human, who used clips to organize the cords around Simon, always making sure his bed was clean and clear; another nurse who kindly, but firmly, pushed me through my fear to hold Simon when he weighed just over a pound, who wiped down keyboards and tables at the beginning of every shift; yet another nurse, despite her own pain and devastation that last night, who gave me strength to cherish the moments and gave me a voice when I didn’t feel like I had one. All of these staff members were exceptional because they treated their jobs like they were truly members of our family.

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We were able to hold Simon all night that night, but we knew his lungs were failing him and that our time with him was now measured in moments. I had no idea what would happen next, what death looked like, or how to navigate through this process with Simon. Unbelievably, there were professionals at this point in our journey who failed to guide us. The fellow on call that night, I cannot even remember his name, who always seemed stern, rushed, and panicked, came to talk with us while we were holding Simon. He could barely look at us as he awkwardly explained, ‘It’s not looking good.’ My husband and I looked at each other, and the tender feelings in the room were exchanged with painful awkwardness and kindling anger at this oblivious man. ‘He’s dying,’ I said pointedly, crossly. The fellow seemed to let out a breath at my admission, his face immediately relaxing, and the nurse practitioner beside him loosened up as well. They proceeded to roughly explain that there were no further options to explore for Simon, and that we needed to decide if we wanted to ‘wait it out’ or pick a time to let him go. I felt dirty and disgusted at the way they treated my son’s life; his coming death felt like a business transaction, and I felt like I was negotiating the details with the Devil himself. They said things like, ‘I’m sorry this is happening,’ and ‘this must be hard for you,’ as plainly as though they’d read the lines from a book, but without any human feeling. Every kind phrase was followed by ‘but we need to know,’ or ‘let us know when you decide.’ The nurse practitioner was impatient, coming in to our room at several points in the evening, asking, ‘Have you thought about it? Have you made any decisions yet? We need to know in advance so that we can lift his paralysis. He shouldn’t feel anything, but if he does we’ll be ready with any medicine he might need. I’ll just wait outside; you just let me know.’ After three similar occurrences in this form, we felt horribly pressured. I told her that we were not ready, and we’d probably wait for the next shift to be with our doctor. I remember her face, always disappointed, always as if we’d inconvenienced her, like she had a plan already in her mind that was best, and we were doing something wrong. As the morning approached, we eventually made the impossible decision to remove care in the garden at the top floor of the hospital. I wanted my Simon to feel the sunshine that he’d gazed at so fondly through his window for 5 months. The morning was arriving, Simon was fading, and we called in the fellow and nurse practitioner to tell them our plan. They were immediately defensive, arguing that we couldn’t use the garden because it would be too complicated and that the time we’d chosen would overlap with shift change and would be too impossible for the staff. I was so angry and hurt; I felt like we’d been set up to fail and that after finally making the most difficult decision of my life and feeling like I had a voice and a plan to do something so completely against my heart and soul, I was rejected and tossed aside. We asked them to leave, without a further word and waited for our team to arrive. Our doctor came directly to us, she hugged us, gave us her deepest sympathies, and granted with ease our desires for Simon’s last hours. My broken heart was held together in that moment, my burdens carried a bit, by a capable friend. Two things I appreciated that morning in the garden were, first, having faces I loved surrounding us, and second, having a voice and being heard in every step. My team

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provided physical help by helping me find my shoes, walking beside me, squeezing my arm, providing tissues, and holding and organizing my things; they also offered emotional support by making eye contact, sharing in my pain, and allowing me moments to cry and express what I was feeling. Everything was made as simple and as straightforward and uncomplicated as it could be, with no judgment, only respect; we were presented with options as they were appropriate to the situation, and we were able to be in control of everything. Our night nurse stayed over and offered to take pictures for us; I am so grateful to have those reminders of how sick Simon was, to help me remember on hard days that I made the best choice for him.

“When the time came, I’m grateful in that experience to have had intelligent and compassionate individuals to explain those hard things to us. One of them looked us in the eyes as he spoke to us, although I know it was terribly painful for him, too. As we gave Simon back to his Father in Heaven, we felt broken in a way no one in this earthly life should have to feel. It is inconceivable. I had no idea; I could not have even remotely fathomed that the pain I felt then and continue to feel now was humanly possible. No description can justify the feeling of once bearing life and then holding that life as it leaves. It was the hardest moment I will ever witness, and if I could take this pain away from any other human being, I would. But on the same token, it was also the most sacred, spiritual experience of my life, and I am equally grateful for the reverence and respect given to us by our team. The staff stayed close to us through it all, and I know we were surrounded by both heavenly and earthly angels that morning.

“The nurse helped me wrap him in a blanket and cover his sweet face, and I carried him back to our room. She guided us to bathe and dress Simon’s body. She provided us with every necessity, stayed close, but gave us space. Loving staff members aided her in making gifts with his handprints and footprints. Every single previous doctor of Simon’s came to see us. One gave me paperwork to guide me through drying up my breast milk, with information on donating my remaining bottles. After the family had packed up our room, we again said goodbye to our Simon, King of the NICU. The nurse hugged me and cried with me and told me that she would personally make sure Si’s body was kept safe.

“Since then, a dozen or so of Simon’s nurses and staff came to his funeral nearly 3 hours away. Some sent me gifts soon after and even Christmas cards this past year. They are forever my family. I can never thank them enough for what they’ve given me—for sharing their intelligence and education to allow my family 5 months with the strongest, most beautiful little spirit I have ever met. It has been 7 months since my last moments with Simon, but I relive that final night, see the faces of every person who surrounded us in those precious last hours, every single day.”

This second story is shared by Sherry Graf, who openly shares her experience of having premature triplets in the NICU and having to go through saying goodbye to one of the three, after one became too ill from an infection to survive.

“On February 9, 1997, I gave birth to triplets at 28 weeks. It was an exciting yet scary time for my husband and me. The weights of my three babies were 2 lb 11oz, 2 lb 12 oz,
and 2 lb 13 oz. I thought that was good since that seemed to be the focus on my doctors at the time. When one of the doctors told us this would be an emotional roller coaster ride, they weren’t kidding. Naturally, because they were born premature, all of them were on a ventilator. Every hour, it seemed like there was a change in one of the babies’ care, whether they were off the ventilator or put back on to something as simple as one needing a blood transfusion. I kept daily logs on all three. Through this experience we dealt with many doctors and nurses. Overall, most were great. When dealing with such high emotions and uncertainty, it is helpful to have people taking care of your, not one baby, but three babies, who have compassion. I understand they deal with so much and see so much; however, in my experience, the ones who showed compassion are the ones that I shall remember and be thankful for. Some of the neonatal doctors talked to my husband and I as if we had gone to medical school. We needed to understand everything that was happening, and yet we felt like some were just reading a textbook to us. I worked in a hospital setting and thankfully understood most, but I needed to feel connected to these people I entrusted to take care of my children.

“The nurses were amazing. For all that they do in taking care of our babies, I was quite amazed. It made it so much more tolerable for when I had to leave the hospital to go home and take care of my 4-year-old. I knew they were in good hands. I always called to get updates, and not once did any of them make me feel like I was bothering them.

“After 5 weeks, one of my triplets caught an infection. Despite all the days that we scrubbed our arms and hands, there is never a guarantee that anything can be 100% sterile. Giving antibiotics to a preemie is the only hope we had. In this case, it wasn't enough. The infection attacked my baby viciously and he became septic. His kidneys shut down, and we helplessly watched him deteriorate slowly. The doctor in charge at that time was wonderful. On March 13, 1997, I lost my precious baby. I watched him fight for his life, and in the end, he lost. The hospital we were at during that time had no privacy around each baby. The whole room watched as we suffered our loss. I am a very private person, and that was very difficult to deal with. I tried to be strong, yet I saw everyone around watching and crying with us. When we lost our baby, we knew that he had the best care and that the doctor did everything he could to try and save him. I am thankful for that because I didn't become angry at my loss and want to blame anyone for it. To me, that is huge in the healing process. We all want to blame something or someone when something goes wrong, and we did not. My only challenge was that I did not have time to grieve for my loss because I had two other babies and a 4-year-old who needed me. After the nurses cleaned and dressed my baby, they then did give us a private room where we could hold our baby and spend some time alone with him. I can't tell you how important that time was to us. There were many times I did not hold my baby and I needed to. I took pictures as well and I am so glad I did. I wanted everything I could so that my heart could heal from this loss. It was in fact very difficult giving him back because I knew it would be the last time I would ever see him again, but I did.

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“The hospital took pictures as well. Those pictures did not turn out good at all and I think I can definitely say they were awful. The mistake the hospital made was, they put my baby in the same position you would see a deceased person in a coffin. Although it is great to have pictures, I think they should have swaddled my baby instead. I offered my opinion to them in hopes that they would change that for the next parent who had to suffer a loss.

“The loss of a baby is traumatic and one a parent will never forget. And like everything, in time it gets easier to cope with but the pain never goes away. My children may never have met their brother, but they know of him. In fact, two of them have tattoos of his name on them in remembrance. The outcomes may not have been what I wanted, but I will always cherish and celebrate his birth.”

The final story comes from Sophie Fauveau, who bravely shares her story about losing both of her twin boys—one very shortly after birth and one unexpectedly more than 2 months into his NICU journey and just after they began to anticipate preparations for discharge home.

“I am Sophie, the happiest, saddest mom at the playground. I have been excited to be a mom from as young as I can remember. Daydreaming about my future family, pregnancy, and sometimes even daring to stretch my dreams to a vision of raising twins. After a grueling 7-year battle with infertility and a scorecard boasting six miscarriages, countless infertility procedures, injections, and insemination, my husband Mark and I decided to put the ‘US’ back in ‘uterUS’ and adopt.

“We naively thought adoption would be an easier road. Instead, what followed was a 3-year trek with many setbacks, false hopes, and crushing disappointments. But, in the midst of our storm, came our rainbow. We were blessed with the privilege to adopt a newborn little girl in Oregon. We named her Zoélie Estrella.

“Shocked, though pleasantly surprised, within a few months we were referred a second little girl in Ethiopia who had a rough start in life and needed parents. She was just 5 months younger than Zoélie. The stars were aligning. Several months and mountains of paperwork later, we flew to Ethiopia to adopt our new daughter and named her Azalea Mitike. Life got busy, happy, smelly, and exhausting. With our girls holding hands, strapped in their double stroller, we could see a twin-like bond blossoming. It was perfection. Zoélie and Azalea are 8 years old today and best friends.

“When our ‘twins’ turned two, life surprised us with a biological son! My belly and my heart grew bigger but unbeknownst to me, Windsor’s heart grew weaker. Windsor was born at 35 weeks, with holes in his heart. A large ventricular septal defect and small atrial septal defect. At 3 months old and barely 9 pounds, he underwent open heart surgery and I learned what it really feels like when the heart of a mother is put to the test. It was a traumatic time. Windsor flat-lined when he got extubated postsurgery but was successfully resuscitated, giving me just enough time to know what losing a child would feel like. Complications continued with pneumonia and respiratory syncytial virus, which sent him back in the ICU for weeks, but Windsor is a healthy, thriving 6-year old today.
Two years later I became unexpectedly pregnant with identical twin boys. I was 39. I knew they were twins from the minute I peed on that stick in the bathroom at work. The stick lit up with shiny blue lines in less than a second and the nausea was so severe that I just knew it. I did the math: 5 kids under 5 years old!! And mentally curled in the fetal position. That would scare even the most ambitious of moms! But I felt giddy.

The first ultrasound was memorable. The OB/GYN only saw one baby and I asked her to look more, it took her 30 seconds but she said ‘Oh, yes! Oh, yes!! There is another one!’ I cried in disbelief that my intuition was right, I cried out of joy. And out of fear. I was monitored very closely because the boys were identical and because I was well, you know, geriatric! The pregnancy was hard with three little kids and a home undergoing a massive remodel, but we were literally ‘making rooms’ to accommodate a family of 7.

At my 20-week anatomical scan, everything looked perfect! The boys were so healthy! Because I had a 2-year-old son with coronary heart disease (CHD), I was told that the twins needed an echocardiogram. I was confident that life could only be trending up now. Our suffering bank was full. At 23 weeks, I went in for the echo. Alone—I was confident. The technician was serious, concentrated and not engaging with me despite my attempts. She left the room a few times, came back, and kept taking pictures. I was petrified and freezing cold, but it was not a regular surface cold; it was a ‘core cold,’ a feeling that everything was about to turn.

“It did.”

“The doctor walked in and told me she was sorry. This word ‘sorry’ never quite fits in the mouth of a doctor. It is way too small and just falls out pathetically. There should be a word solely for doctors and nurses to express how sympathetic and horrified they are to deliver bad news. She told me that Baby A (whom we later named Cyprien) only had half a heart. Half A. Heart. His condition was called hypoplastic right heart syndrome. I wrote ‘HPRHS’ down to Google later. Our family could handle CHDs and open-heart surgeries, we had been there. I immediately tried to be positive. The doctor crushed my hopes with 3 simple words: ‘Unfit for life.’

“Armand (Baby B) had a perfectly formed heart, but because I also had the beginning of a placenta abruption and was showing signs of twin-to-twin transfusion syndrome (TTTS), Armand was not getting enough amniotic fluid or blood—and was in utter distress in my uterus. My brain froze. I was getting this news all at once. Alone. In a cold room, dimly lit by neon fluorescents. It was like getting a death sentence. I don’t know how else to describe it. I was a deer in headlights that felt shot in the heart.

“I was then walked out and left (once again) alone to check myself into the maternity ward for observation. Once in my room, I called my husband, Mark. Words failed me. Everything failed me. The neonatologist came to my room and showed me a statistic chart with what it meant to have a baby at 23 weeks, 24, 25, 26 weeks, and so on. He gave me a cold, dry, and matter-of-fact speech and showed very little compassion or emotion. I was still alone, as Mark was stuck in traffic. The conversation with the neonatologist left me to feel that I too should not have feelings about the decision. I stayed a night in the hospital

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attached to two fetal monitors. I was bleeding internally but was offered to go home on modified bed rest. I decided to leave because I desperately needed warmth. I needed my children and my husband to warm my soul and tell me we would be OK.

“My body was covered in red blotches. My belly was visually growing by the day. I was bigger at 23 weeks than I was at delivery with my last pregnancy. I had no room for my lungs or my stomach to function. I was gasping for air and hope; for nutrition and nurturing. I was at the end. I felt I was going to die, but nevertheless I went ‘home.’ They let me walk out. We were not in our house anymore, as the construction prevented us from living in it. We were in a borrowed place living out of a suitcase.

“With the chart of statistics in hand and the neonatologist still talking in my head, we decided that we would not resuscitate any babies prior to 25 weeks. We decided that we would not try to resuscitate Cyprien because he was ‘unfit for life.’ Oh, how I felt ‘unfit for life’ too. And surely ‘unfit to decide about life and death’ for Armand. It was awful. I felt very lonely and broken. By that point, the hemorrhage inside my uterus had created a clot the size of a third baby. My stomach was enormously distended. Both babies were fighting for their lives inside and I, their vessel, was out of fuel. It felt to me that cabin and cargo were headed for a fatal crash and all I could do was sit in a recliner. ‘Sit back, relax and enjoy the crash.’ It (I, we) felt like a ticking time bomb.

‘At 24 weeks and 3 days, on Labor Day of all days, I went into labor at home. Everything happened extremely fast and in the middle of the night. Our three kids were sleeping, and we had no family around, so my best friend Sue took me to the emergency room. There started a whirlwind of misinformation, rapid contractions, confused diagnoses, magnesium infusion, steroid injections, poor communication, projectile vomiting, debilitating headaches, and utter confusion. In the middle of that walks in our doctor. I liked her, despite the sad little ‘sorry’ she had to deliver earlier. She greeted me at the head and the tail and said, ‘Girl you are 9 cm dilated, we need to make a decision as to how you want to deliver. You have about 5 minutes to decide.’

“She said I could deliver the babies vaginally but that neither baby would survive given their positions. Baby A was breech, and Baby B, transverse. I was informed that a vaginal delivery would be a safer option for me (they were very concerned I might hemorrhage as I had low platelets due to the giant clot). She said a C-section would give us options to save the babies, but the risks for me should not be ignored. She had papers in hand for me to sign.

“Mark and I had already decided not to resuscitate the babies less than 25 weeks, as it was the neonatologist’s cold-headed recommendation, so a vaginal delivery would be the proper answer to give them right now. Yet, in that moment, my motherly instincts burst out and took over. I could not follow-through, I had to give Armand a chance. From my bed, which felt like a death bed, I chose a C-section. I didn’t weigh the consequences. I was not mentally or physically able too. I chose their life over mine because the promise of hope is far greater than the grip of fear. ‘C-section,’ I said. I chose the C-section. I was not even done saying the word ‘section’ when I was handed those papers to sign and got

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wheeled to the OR—numb, scared, and crying for my babies. Crying in fear and disbelief. I wanted to resist, to scream, to go back, yet I was so docile. I felt like a restrained mental patient who is taken away against her will to a mysterious torture chamber. I was lost but had no more fight in me.

“The OR was jammed with people ready to operate. I was praying that the spinal tap would be put in between contractions and not during. I was 10 cm dilated, and contractions were 2 minutes or less apart. I sat on the edge of the operating table and hugged my labor and delivery nurse, Brandy. I hugged her and hung on to her body like a barnacle on a rock holding on as furious waves crash and attempt to make it lose its suction. As the anesthesiologist pierced my skin, Brandy hugged me calmly with a motherly strength. The pain was uncontrollable, and I was wondering if that would be my last memory of being alive.

“I was now lying on my bed, crying, and silently holding my friend’s hand. Sue had appeared all suited up in a sterile gown. She looked scared. Sue never looked scared. Tears were streaming down my face, and the warmth of them was the only thing I could feel now; everything else was numb. I was so sad, so lost. An island of stillness and silence among the hustle and bustle. I put 100% of my faith in God that He would work through these strangers’ hands. From my vantage point, I looked up at faces to try to connect and be a little present. I could see the kind eyes of the young anesthesiologist and knew she cared. I could see that Nurse Brandy was concealing her worries like a family member would. There was a solemn atmosphere of urgency and sorrow in the operating room.

“I was strapped-in in a cross position and thought of Jesus. No one was going to put nails in my palms and feet, but I was about to be cut open and witness my child dying. Maybe I would die too and meet Jesus or I would go crazy. My babies, my precious babies, what would happen to them? Would we all enter Heaven together? Those were the thoughts going through my head. Sue’s firm grip on my hand brought me back to earth. The babies’ heart rates were going down; everyone panicked. I was calm while shoved, cut open, tugged, and pulled. Sue’s gown and shoes were splattered with blood. I could hear the squishy sound of rubber soles walking in my blood on the floor. Babies were out, I heard ‘he is beautiful,’ then I heard nothing. There were no baby sounds, there were no cries, no signs of any infant, no noise anywhere. I saw that Mark had appeared, Sue had disappeared. I cried for my babies. For Mark. For me.

“Once sewn back up and wheeled to my room, it all got blurry. Within some time, we got an internal call from the NICU to tell us that ‘Baby A’ was not doing well. Our sweet Cyprien’s heart was failing. We were asked what we wanted to do, and we both said we didn’t want him to suffer and that we wanted to let him to go. We didn’t confer, but we both talked in unison. Minutes later, we were in the NICU to meet our son who was alive. Living! It was the first time I saw him.

“Numb from the chest down, in my giant bed on wheels, I entered the NICU. I have no recollection until I saw Cyprien as he was being unhooked, unplugged, and carried to my chest. We lay there in my bed, just him and me, then Mark leaned over and stayed

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with us very close. Brandy had brought her big camera and took a picture that I cherish today. I am so thankful that they wheeled me in before unplugging. I am so thankful our nurse was prepared. So thankful she took that photo of Cyprien alive.

“Cyprien died on my chest, peacefully. I was kissing his head, telling him how I loved him. I felt at peace. Finally, the dreaded moment had come and gone; it was over. I was alive, he was in Heaven, yet I felt that we were still together and would always be.

“For the next 8 hours he stayed with us in the room. After a while, Brandy took him, washed him, got him little clothes, and dressed him. He looked so beautiful. So peaceful. She took his hand and footprint, busied herself with him like a nurse would with any ‘live’ newborn. She had a gentle touch and a caring voice. From my bed, I watched her caring for our son, and it looked like any scene in any postpartum room. I am grateful she gave me that moment. Despite the fact that there were no cooing and cries, seeing her with him was healing.

“A couple of close friends came and loved on Cyprien. I felt at peace. I could not think of anything besides being here in the moment. I did not think about Armand, our other kids, or anyone else. Just us now, in that room. This day is all we would ever get, and we had to make it count by being present. Mark held him and cried, quietly. I could not cry anymore. I went into a zone, a place where all of this was not sad, and a place of peace. I enjoyed my 8 hours with Cyprien. I didn't want to be a sad, sobbing mom. I do not know what superpower allowed me to have a good day with my son. All my preconceived ideas of ‘acceptable,’ ‘normal’ behavior for a mom holding her dead child was challenged. I will never judge how someone acts when they are shocked out of their body by trauma, grief, and pain.

“I cuddled Cyprien in bed for 6 hours. All sadness was repressed and thoughts of death kept at bay. My brain was doing a great job protecting my heart, but I could not ignore what my hands were now starting to feel. Cold. His body was getting cold. Time was up. From that point on, I could no longer look at his face. I had to hold him wrapped up a little more, with the blanket covering almost all of his face. He was starting to change physically and I was starting to change emotionally. For the first time, I saw myself as a mom holding a dead baby. I didn't want to remember him not looking alive and I didn't want to remember me feeling that way.

“Mark felt like he was ready to say goodbye. I held Cyprien in his blue blanket and, after Mark had said his goodbyes and left to go back home to care for the kids, I stayed a couple more hours with him but didn't look at him straight on. When it was time for me to say my final goodbyes, I told the nurse (a new one) that I was ready. She called the morgue and someone came up with a body bag. I heard the ruffle of plastic and the sound of a zipper. I froze, felt anger, and said I did not want this in our room. The person and their horrid piece of plastic of death swiftly disappeared.

“Even if my son had been dead for hours he was not ‘that dead’ to me. Body bags are for other people, for movies, not for precious babies whose souls were still way too close to their bodies. That moment made me have visions of suffocation in a bag. It is something

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I still have nightmares over. Cyprien went to the morgue and I never saw him again. The only comforting thought was that my 2 babies and I were all still in the same building. I asked my brain to not think of the morgue or of anything related to what happens after death. My brain listened. Our nurse printed the photos she had taken during the day and put them in a beautiful keepsake box with other memorabilia.

“..."The next day I had a friend help me build a ‘shrine’ in my room. I was never a ‘shrine person,’ but in this moment, I had the urge to express my pain, and a shrine in my room was helpful. As someone who had zero experience with grief, I had always thought that shrines were ‘creepy’ and that they kept people ‘stuck.’ Now, I understand the power they have. They provide a place to pray, to meditate and to focus our grief so it doesn't suck all the oxygen out of life. I put pictures up, flowers, an old Bible, a precious rosary, and a statue of the Virgin Mary that various friends had brought over. I do not consider myself religious, but my Catholic upbringing and convent-school education provided an anchor in the storm.

“With Cyprien now ‘safe,’ I needed to see Armand. I wanted to go to the NICU but could not sit in a wheelchair yet. I was severely anemic due to the blood loss and needed a transfusion. Mark went to see Armand, but words failed him, and he could not report back on what he saw or felt. He kept saying, ‘You will see; he is small, but he is strong.’ The 6-hour transfusion literally pumped life back into my veins and put me in an unexpected state of euphoria. I am not sure whose blood I got, but that was some amazing blood! I am thankful to all the blood donors, especially those who share their ‘happy blood.’ I had oodles of energy and the giggles, which was hurting so bad in my stitched and stapled lower abdomen. Finally, like a reinflated balloon, I felt good enough to move and was told I could be transferred to a wheelchair and go to the NICU.

“..."As I was ‘refueling’ at the blood station, Mark was asked to sign lots of paper, pick a funeral home, and make impossible final arrangements for Cyprien’s transport and cremation. I could not help emotionally, as I had to focus solely on life. I wish that there had been a person dedicated to handle such things. ‘Paperwork of death’ is a horrible thing to ask a parent to do right after they said goodbye to their child. Mark handled it all through many tears, but he did it without asking me to be much involved. It was hard to see him cry, but I was so relieved not to have to look at those papers. Cyprien’s soul felt present, very present to me. I am immensely thankful that Mark took care of the sad and ‘down-to-earth’ realities of dealing with bodies after death.

“Now, in my wheelchair, ready to head to the NICU, I felt terrified. I feared I would find Armand in a state that my heart would not be able to handle. I was afraid that seeing him would send me into a panic attack with uncontrollable anxiety and spasms. With the wound on my abdomen and the one in my heart, I was not sure I could take either. But nevertheless, I went in.

“Entering the NICU felt like entering a high-security sci-fi research lab. Special badges, special access. The light, the smells, the noises. Nothing felt familiar. It is a world within a world, with its own staff, its own hours, its own culture and language. Time doesn't exist.
There are no windows, no reference to anything that the outside world is busying itself with. The earth keeps turning, the world keeps churning, but the NICU stands as its own ecosystem. I felt like I was sucked into a vortex every time I entered. I learned to love that vortex. Over time, it became a cocoon. A warm and safe cocoon where everyone knew what we were going through. A cocoon full of superheroes cut away from daylight, time, and distraction.

“I was wheeled to Armand’s area. I approached carefully, feeling so sorry that I did this to him. Everything looked foreign. The plastic incubators felt like no match for a womb. I felt so sorry that I subjected him to this. I felt broken and responsible for my broken womb that had forced him out and into this. I remember thinking that it would be better if the incubators were filled with warm water. At least it would make me feel better.

“Then I met him. My little man. Smaller than a baby cat, with all his tubes and lines, all wired. I saw him, and as hard as I tried not to fall in love, I did. Wholeheartedly. Desperately. Right there and then, the minute I laid my worried eyes on his 575 g of strength and perfection. Armand’s size scared me because he had a lot to accomplish in this body to remain alive. Cyprien was the same size, but nothing was required of him. He was not asked to live in that size of a body. I felt immeasurably helpless but unconditionally in love.

“I wish someone had prepared me for what I was going to see though. I wish there had been a movie in my room like the one in the plane. ‘Buckle up, you are about to enter a new universe, you will see things that will change you forever, you will be pushed to your limits but always remember that you are not alone, meet the friendly crew with decades of experience, meet the passengers, many are feeling just like you, review the safety procedures, map of the facility, blah blah.’

“What I mean is that I wish someone had gone over the unique language of the NICU, explaining the pumps and PICC lines and blood gases and what each number on each monitor was indicating. I really wish someone had walked me through the setups and what a typical day would look like. I would have wanted a tutorial about all the alarms and learn what they really meant. To this day I have an inner fear every time I hear the ‘ping’ of an elevator because it sounds so much like one of the alarms. In the first few days, I craved stats and success stories. Even just realistic stories. I wanted context, a roadmap for my brain to not feel so lost and for my body to not feel so inadequate. I wish there had been a nurse, a therapist, or social worker with me to check on my emotional health and detected signs in me indicating I needed help when I could not recognize or express it. I had millions of questions that I didn't dare to ask. I felt like all the babies in the other incubators were huge, but when I asked if they had started as small as mine, I was given vague answers.

“Mothers on recliners were holding babies or pumping; grandmas were smiling and cooing. It seemed that all the fully grown humans I could see were acclimatized and comfortable. No one was in the same state of stress, despair, and shock that I was in. I felt like an unassimilated alien, and surrounded by all the Isolettes, I was the one feeling utterly isolated. By Day 4, it was apparent that Armand was a special kind of preemie. He

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hit many milestones early. He was strong. Our strong, tiny, baby miracle. I was so proud of him and would allow myself to catch glimpse of hope that he would make it and come home. We named him 'Armand Cyprien Williams.' This way, he would know his guardian angel by name.

“I poured all my positive energy into my little warrior. I loved him so ferociously. Cyprien's ashes were in a heart-shaped urn inside Armand's incubator. It made me feel good to see my boys together, and I believed it gave Armand strength. I needed to believe a lot of things to survive. I didn't care if it was real or not. I taped a picture of our family in Armand's area. I wanted him to feel that he was part of our strong tribe, but most of all, I wanted the nurses and doctors to see him as a member of a family. That was so important for me to know that those who cared for him saw him as a full-fledged human being with parents and siblings rather than just as a patient on a shift. I felt that seeing us all would make them remember him more easily, relate to our family—trauma and dreams—and with that, maybe they would grow to love him.

“I was on unpaid extended maternity leave and spent 8 hours a day in the NICU. I was dropping our three kids off at day care and spending the day with Armand. Life was entirely scheduled and all consuming. I lived hour by hour in the NICU as a caretaker and in a construction site back in our home with no gas or water. I didn't care. I lived for kangaroo care.

“Milk did not come easy; I pumped for hours on end. My lactation consultant Kathy was a godsend. I really struggled with my pumping schedule on top of everything else. She had seen me with breasts bigger than my head when I was engorged, brought me cabbage leaves, and helped me through mastitis day after day. I could share everything with her. She was my lactation confidante.

“There was absolutely zero time for self-care for me, and if I did take 30 minutes to eat in the cafeteria, I felt guilty. All my time was spent caring for my children. I desperately needed to feel that everyone loved my son and would care for him like I would if I could. I wanted him to be surrounded by love, and until I felt that, I couldn't leave his side and feel at peace. My nurses Ruby, Audrey, Rachel, Jenni, and Joy took turns caring for and loving on him.

“Each time a new nurse was a bit rough (or perceived rough), I felt like they were hitting me. I felt every discomfort as if it was done to my body. I tried not to comment or ask for anything as I didn't want to be the annoying mom and aggravate them. I cried every night but in the NICU, I was strong. I was Armand's advocate, and advocates don't cry. Soldiers don't cry.

“Here I was, day in and day out, with all the ups and downs other parents have described in the other stories, the roller coaster of bad blood gases, surgeries, coding, resuscitations, and so on. There were the good days where I felt almost high on hope—and bad days when I was in despair, gasping for air. Hyperventilating happened a few times. We had some big scares.

“By Day 74, we finally started talking about ‘when Armand goes home.’ The delicious word home. I had never heard that word in one sentence with ‘Armand’ before and that was

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music to my ears. It gave me so much hope. Two days after that, at 76 days old, Armand took an unexpected turn for the worse. All his levels were out of whack. Everything that needed to rise, dropped, and everything that needed to drop, rose. All attempts to stabilize him failed. He was given blood, platelets, blood pressure medication, insulin, morphine, and 100% oxygen. We could not support him enough. Armand's spirit was still strong but his body was failing. Mark and I held his hand on both sides of the bed. He was showing us he wanted us right there by refusing to close his eyes and doing slightly better when we were around, so we stood by his side every minute. We sang, hummed, and talked to him out loud while praying in our heads. He was incredibly alert for being on so many drugs. I started to sing religious hymns through my tears. The nuns of my youth would be proud.

"Both Mark and I were dropping big tears all over his bed. He didn't want to go to sleep. The doctors and nurses were puzzled as to how he could still have his eyes open and connect. His stare was very intense. We didn't know what to do for him. The priest and chaplain came, and I prayed with them. I was begging God to intervene. The harpist who had been part of our 77-day stay also came to play for him. Armand loved it when she played, but this time, over the loud noises of his oscillator, he could not hear her. We conferred with all the professionals around us, trying to figure out how best to care for him, how best to help him. We talked to the doctors and surgeon, the nurses, and therapist. We reached out to anyone for input/advice/guidance—anything, from anyone. It was utter desperation.

“We were seeing more pain on his face, and he was maxed out on morphine as it was, lowering his blood pressure too much. We understood that there was really nothing medically that could be done, so we decided to ask Armand to help us help him. He had given us such strong responses and eye contact for the entire day. He had even reached for Mark's face with pleading eyes. We knew he could talk to us. We knew he had a say in this. So we asked him.

“We told him we were so proud of him and that we loved him beyond this body, beyond life. I asked him to open his eyes really big if he needed us to take him off all the support and let him rest. He opened his eyes really big. Maybe a burst of pain, maybe a response, but he did, and we felt we knew what to do.

“The doctors and nurses were still trying to do things to help him and support him. It was so busy around his bed. More drugs were being ordered, blood was ready to be drawn, and someone was preparing to add more things to the IV in his head. I felt like we had instructed them to stop, but I guess it was not official enough, so I gathered the last bit of strength I had in me and said: 'We want to discontinue support.' It took everything out of me to say those words. My last heroic act as his mother. And with these words, my world collapsed.

“The privacy screen showed up and surrounded us immediately, leaving a 2-foot radius around his bed. The world was shrinking, the walls were literally closing in. I was suffocating and started to have a panic attack. By the grace of God (and cell phones), Nurse Ruby and Kathy magically appeared and joined Audrey who was our nurse on this
final shift. Audrey and Ruby really had been part of ‘Armand’s Army’ and supported him for 77 days. Now they were the ones disconnecting him from life support. I felt that even though the machine stopped, the love and respect was continuing to flow from them to him. That was so important for me to feel.

“First the monitor went dark, then the humming of the ventilator stopped, and all went silent. Until I heard this primal and cavernous sound. I didn't understand immediately what it was and that it was coming out of me. I was wailing in a way I had never heard myself or anyone before. It came from the pit of my stomach. It was controlled by instinct. It was the sound of despair. I collapsed and was lifted to a chair. It was like the floor opened up to swallow me whole. All the adrenaline that had held me up for 77 days vanished, and I became a shell. I was empty. I had no strength and temporarily no purpose. I picked myself up because I wanted to be present for Armand while he was still alive and give him the mom he deserved. Once again, I feel like I was spiritually lifted to be able to be present.

“Armand was free; they wrapped him and handed him to Mark. We were ushered in hush-hush ways to a little private room out of the way. I felt so bad for any families in the NICU who witnessed us that day and accidentally got a vision of the dreaded nightmare scenario.

“Once in the room, I rested Armand’s head on my bare skin. He felt so good and finally closed his eyes. I swear he smiled a bit. After a few minutes, Audrey listened to his heart. It was still beating. I asked to listen for it with the stethoscope and heard a sad slow, peaceful beautiful and barely audible beat. ‘Pom … pom … pom … pom.’ I sensed an irrational hope building up and imagined that it would turn into a ‘pom-pom’ … ‘pom-pom’ … ‘pom-pom’ … ‘pom-pom’ … ‘pom-pom’ … ‘pom-pom’.

“I had fantasies that the heartbeat would be back, strong, that Armand would suddenly move and start crying. He was so perfect. How could he be dying?

“After 10 minutes, Audrey listened again and declared time of death. I continued to bargain with God for several minutes, asking for the ultimate miracle. I felt guilty for bargaining, seeing the disapproving faces of nuns. I couldn't stop squeezing his body and kissing him. I was making up for lost time. I rocked him, talked to him. I kissed his head over and over again. Mark and I cried over him, told him everything we wanted to tell him. It was sad but peaceful. We felt we had followed through and honored him. I even felt proud that we did that.

“Audrey took pictures of us. We brought a heater so his body would not get cold so fast because I now knew I could not handle that. I bathed him. It was excruciatingly painful. Mark wanted him to have a bath but didn't feel strong enough to do it himself. I did it for him but made it short because it was beyond my capabilities too. I then dressed my clean baby in the same rocket ship striped outfit he was in when he was healthy. He looked so gorgeous and perfect. He looked like Mark, a lot. He was perfect. He is perfect.

“Our NICU team of nurses came in the room. Audrey, Ruby, and Kathy were surrounding us. Others had come in with tears in their eyes and wide-open arms. Everyone was very
supportive. I ran my fingers on Armand’s skin, his perfect face. So soft, so peaceful, and his eyes so firmly shut. With our team in the room, Mark and I decided it was time to let him go. We handed him over and thought he would be taken straight out of the NICU and to this place I didn’t want to think about.

“We went by his bedside to collect our belonging and stopped. Armand was still there, laying in his bed with the privacy screen around it, all dark, all quiet. So much more dead than 5 minutes before. I wish I had not seen him again like that. When a parent has said goodbye in their own term, they cannot have a surprise sighting.

“All of our stuff was there by his bedside. All the pictures and cool scrapbook pages that the nurse made that had accumulated for two and a half months. All taken down and piled up with everything else . . . all there, with our dead baby, it was the saddest sight. I cry every time I think of it. I wrapped Armand in his quilt, gave him a last kiss, and walked away. I never saw him again but in my dreams.

“I felt evicted. Nicely evicted by a landlord who deeply cares but still needs to kick you out, because you no longer belong or qualify.

“We left the unit walking by busy, crying nurses and others oblivious to the tragedy. We hugged, we kissed. It was horribly sad yet comforting to see so much sadness. At least it matched how we felt. Our cocoon was feeling with us. Our tribe was vibing with us. My legs were shaking. Mark held me in his strong arms. I could not believe how sad it was that this was our last walk out of there.

“No balloons or ceremony for those who leave without a baby. All I had was a baby in the morgue and Cyprien’s ashes in my pocket. That is as close to ‘walking out with a baby’ as it got. How sad can this be? Why? Why us? Why me? I wish a nurse had walked out with us all the way to the car. Going through these doors for the last time was simply the hardest walk out of anything and anywhere ever.

“Two days later I asked if I could come back to the NICU with a big basket of treats for the nurses. I got invited back in. Now it was by invitation only. I wanted to thank everyone but mostly I needed to go back so I could walk out again. I didn’t want that last walk out to be my last memory of this ‘temple.’ The NICU had shifted from feeling like a cocoon to being a temple. A temple erected in the place where my baby lived his entire life. I have gone back many times since with treats and hugs. I beat the sadness with gratitude and kindness.

“Within days, I also picked up my frozen milk and donated it to a friend who had just adopted a baby boy. It felt good to donate it, yet quite painful, as I was very attached to it. It represented my love and my hopes. Hours and hours and hours of hard work had been ‘poured’ into those tiny bottles. Literally. Donating my milk was in a desire to make good come out of pain. Within a few weeks, I had partnered with an NGO [nongovernmental organization] and was fundraising to build a NICU in a children’s hospital in Ethiopia. I devoted my energy to the cause of helping other babies. I felt that if my sons could not have a legacy, then I needed to be that legacy for them.

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“Eleven months after Armand died, a little NICU opened in rural Ethiopia with a sign that says, ‘In Loving memory of Armand and Cyprien Williams.’ I was able to share this with some nurses in the NICU when I went back for the remembrance ceremony. A ceremony held yearly in the basement of the hospital for all the babies who had died that year. It was healing to tell them, and when I registered for my badge at the ceremony, I was handed a card from Nurse Brandy. This was 11 months after that fateful day when I delivered my sons, and she had been my labor and delivery nurse. Rock star Brandy, pillar of strength. I do not know how she knew I would be there that day as we had not kept in touch, but her card meant the world to me.

“I am now 4 years into this grief journey, and my days are mostly joyous. I feel our sons all around us. I cherish memories of my time in the NICU because I choose to focus on remembering the love and the good times more than the pain and trauma. Post-traumatic stress is rearing its ugly face from time to time, but it is manageable.

“There is one more twist to our family story that I want to close with. In January 2016, we found out that our daughter Azalea is a twin!! She was separated from her brother at birth, and he remained in Ethiopia with his grandparents. In January 2018, we headed to Ethiopia to meet him in his village. We hope to have an ongoing relationship and help him thrive and go to school.

“So in the end, miracles do happen. They happened with our adoptions, with Windsor’s resuscitation, with the inspiration brought to us by Armand and Cyprien and with this newfound twin brother for Azalea. Miracles are not always what we pray for, but I do get to be a mom of twins in so many ways today. A piece of my heart is in Heaven, but I have learned to live in the present. A sign hangs near our bed, under a shrine I made for Armand and Cyprien, and it says: ‘Cherish yesterday, dream tomorrow, live today.’ I do all 3.

“Losing a child who never got to meet the outside world and never got to be met by the outside world is a unique loss experience. It is a hidden and invisible kind of loss. There are few pictures parents can share and almost no shared memories to remember fondly with friends and family. It is a very complicated kind of grief and so isolating.

“Because I felt that none of the bereavement support groups locally or online were a good fit for this unique loss, I got inspired to create my own group. First it was for myself, and then it became a healing way to offer a helping hand to other bereaved parents. The group is called Bereaved Mothers of NICU Angels, but we do have a few dads, a few grandmothers, and even a few NICU nurses in it! We are now hundreds from many parts of the United States and abroad. I personally talk to each mom. Every one of them is where I used to be at some point, and some are where I am now (or beyond) and help out. I email, phone, message, or meet with mothers to offer a listening ear and a shoulder to cry on, on a daily basis. At times it feels more like a suicide-prevention helpline, and at other times, we are just proud mothers sharing stories and pictures. The biggest reward is to hear that I eased their isolation and loneliness.

“I have immense gratitude for compassionate medical personnel around the world. “For all that you are to so many people, Thank you.”
RECOMMENDATIONS/SUGGESTIONS FOR BEST PRACTICE

1. Include families as equal members of the care team and allow them to be highly involved in the palliative care decision-making process.

2. Allow families to have as many support people present at the same time during the last hours/minutes of life and at the time that life support is withdrawn.

3. Use in-person and on-site interpreters at all times possible when language barriers exist.

4. Respected and honored religious and cultural rituals.

5. Have a private space for families in the NICU to be with their child as their child passes, or offer to allow them to take their infant to a place where they feel comfortable.

6. Empower families to be the primary care providers during the time of transition from life to death and during the bereavement care process.

7. Staff needs to provide encouraging words to families highlighting their positive parenting skills and decisions.

8. Highly encourage bereavement photography, which should be available to all families.

9. Have a high-quality digital camera on the unit so that photographs can be captured at any time and in the event a professional service cannot be present.

10. Have a comprehensive bereavement program that all neonatal staff are competent and comfortable following.

11. Use the Preshand boxes to transport and store infant bodies.

12. Never leave the deceased infant alone.

13. Prepare families for what to expect after the death of an infant.

14. Have layered levels of psychosocial support available for families. This may include bedside nursing, social work, and chaplain support, as well as unit staff psychologists.

15. Have resources, such as social workers, available to assist families with funeral home arrangements.

16. Provide grief and loss resources, both locally and online, for families.

17. Provide keepsake items and mementos for families.

18. Provide lactation support to mothers who are breastfeeding and/or pumping to assist with lactation weaning or breast milk donation.

19. Send a condolence card, signed by all the care team members who cared for the family during their child's life, to the family 1 to 2 weeks after the patient's death.

RECOMMENDED RESOURCES

Remarkable resources are available to both staff and families to help support the process of loss during the neonatal period (Figure 14.1).
Figure 14.1  Recommended resources for supporting families that experience loss in the neonatal period.

Case-Based Learning

S.P. is a 32-year-old primigravida whose fetus has been diagnosed with trisomy 13. In preparation for the birth of her child with a limited life span, she and her partner have met with the genetic counselor, perinatal clinical specialist, and palliative care team to prepare a care plan for their son, whom they have chosen to name Carter.

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QUESTION

1. What are some of the components that you might expect in this family’s care plan?

ANSWER

The goal of palliative care is to prevent, treat (as much as possible), and provide support for (as early as possible) the pain, symptoms, and incumbent emotional distress related to life-limiting conditions. Palliative care is about putting quality into the time one has left. A palliative care team provides an extra layer of support to the family and the bedside care team by drawing on the evidence for best practices in this arena. Unfortunately, death sometimes arrives in close proximity to birth. Fortunately, there is a rapidly developing body of knowledge on this topic.

The care plan for a baby with trisomy 13 can be difficult because the immediate outcome is unknown. Perinatal demise is not uncommon, and there is unpredictability about the length of the expected lifetime.

Often, palliative care is involved to help bridge the unknown in preparation for the potential outcomes. One of the most important things that a palliative care consult can provide is a plan for the care of the baby and family. It is important for all team members to be on the same page to provide a consistent approach to care. A documented care plan goes a long way toward this end. Integration with bereavement and grief support is also a benefit of palliative care (Kenner et al., 2015; Parravicini, 2017).

This family will need ongoing information, privacy, unobtrusive emotional support, and possibly, home hospice care. The planning should encompass siblings, grandparents, and other people the parents designate.

Since this family will experience an unexpected loss, anticipatory guidance regarding the care and grieving process can be provided. Planning will likely include the following:

1. Labor and delivery planning such as whether there will be fetal monitoring of the fetus or C-section for fetal distress
2. The baby’s expected appearance and experience
3. Comfort measures and the family’s desires for participation in care
4. Identified psychosocial support systems (including peer-to-peer)
5. Bereavement rituals—their own, as well as the NICU’s
6. Home follow-up: hospice as needed, NICU staff contact
7. Clinical follow-up such as autopsy results

REFERENCES

Palliative care team members have an amazing skill set. It is likely that we could all benefit from a rotation with the palliative care team, as suggested by Henner and Boss (2017).


REFERENCES


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