



A Comprehensive Guide to NICU Bereavement Care



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You may add to your personal experiences, knowledge, and skills to the following suggestions that bereaved parents have found useful. This information is derived from current literature and qualitative interviews.

This program was created by Kimberly Valdez OTD, OTR/L with help from Dr. Kiley Hanish OTD, PMH-C, Dr. Kate Crowley OTD, OTR/L, bereaved parents, and NICU providers.
For more resources, visit www.rtzhope.org.



FOR PROVIDERS

General Recommendations

Improving hospital procedures in addition to training NICU staff can increase support and care for families during this difficult time.

- Provide bereavement training to staff members, which includes a parent panel.
- Offer support groups and NICU parent advocates to help families navigate a first time NICU experience.
- Give the option to pair parents with a bereavement mentor during their hospital stay.
- Deliver information in a private setting while using language that is culturally sensitive and appropriate to the family's education level; don't rush when explaining information. *Encourage the family to record the conversation or bring in a third party to take notes. You will need to repeat yourself.*
- Be aware of your body language and don't be afraid to be emotional with the family—they need to see that you are invested in their child.
- Make sure everyone on the team is informed and up to date on information, especially if the birthing parent is admitted as a patient in a different department.
- Give parents the option of joining rounds if possible.
- Be mindful of signs in front of the birthing parent's bed which could be triggering, such as "skin-to-skin."
- Place a picture of a white rose or green leaf outside of the room or by isolette to symbolize what is occurring and ensure sensitivity and privacy.
- Don't assume a parent needs anxiety medications or antidepressants, sometimes they just need a listening ear.
- Acknowledge that this is a loss for both parents.
- Make a bereavement room and support resources available for parents.
- Have a separate waiting room for family members and/or a separate exit for parents. Walk parents to their car to offer support.
- Consider consulting or having an occupational therapist or child life specialist as part of the bereavement care team. See the OT recommendations section in this document for further details.

Recommendations for NICU Nursing Staff

Nurses have the potential to be great liaisons for families and can support parental roles in the NICU.

- Try to always use the baby's name and talk about the baby as a person.
- Give parents opportunities to parent their child. They may be afraid or nervous and need encouragement and support to participate in their infant's care. Some ideas are diaper changes, oral care, gently brushing their hair, talking to them, reading to them, holding them if appropriate/possible, and taking pictures.
- Let parents know what's available and appropriate to do with their child.
- Ask if there are any meaningful cultural or religious traditions that they would like to consider for their baby. Offer chaplain services such as a blessing, baptism, or naming ceremony if appropriate.
- Take time to explain medical terminology, the process of when the baby dies, what happens to the body, and any other questions parents may have.
- Continue checking in with families regarding their wishes, especially towards the infant's end of life.
- When possible, try for staff consistency. Parents may have a hard time watching their infant rotate through various nurses who may do things differently.
- If the baby was transported to your NICU and birthing parent remains at the transferring hospital, use Facetime to communicate with her. If the baby's condition worsens or the baby dies, be sure to notify the birthing parent's nurse, so that the nurse knows to be supportive.

NURSES OFFER ADVICE

"Be compassionate and as caring as you can be."

"Be there for the parents. Hold their hands."

"You have to care for yourself. Talk to someone, ask for support."

"Walk in nature, if weather permits."

"Sometimes a good cry helps."

Recommendations for Social Workers & Case Managers

Offering families practical in-hospital and post-discharge support may improve NICU experiences and better help families navigate grief.

- Support families by
 - Setting up lactation consultations
 - Arranging any photography services (i.e. Now I Lay Me Down To Sleep)
 - Offering meal vouchers/parking validation/shuttle services
 - Connecting with the palliative care team or charities, such as the Ronald McDonald House (if available/appropriate)
- Provide families with updated, organized bereavement resources* when they're ready. This can include: Return to Zero: HOPE brochures, a list of funeral services for infants, information tailored for bereaved partners, coping with infant loss support resources, community support groups, and local therapists.
- Check in on partners by asking open-ended questions, such as "how are you doing," "how can I support you," or "is there anything you need right now." Their grief is just as important.
- Offer compassion carts that carry snacks and beverages.
- Have a social worker/case manager on call for the weekends.
- Ensure that NICU resources, such as a library, are open on weekends.

SOCIAL WORKERS OFFER ADVICE

"Approach with empathy and curiosity– don't make assumptions about their wishes and their process. Let the family take the lead."

"Attend to parents' feelings & listen to them. Every loss is different."

"Be okay with silence and know it's not always about making things better."

"Process a death—promote a ritual, light a candle, or rely on family and friends."

"Have boundaries—it's so important."

Recommendations for Occupational Therapy Involvement

In addition to the previous recommendations, occupational therapists can assist parents in developing the skills and mindset required for completion and success in activities of daily living, instrumental activities of daily living, creating new routines, and exploring new roles.

As part of the interdisciplinary team, OTs can:

- Support parents in maintaining parental roles with children and/or working roles.
- Identify strategies to manage transition between roles and responsibilities.
- Support the development of parental roles in the NICU by:
 - Enabling engagement in parenting occupations
 - Promoting positive parent-infant relationships
 - Encouraging families to personalize and decorate their baby's bedside space
- Provide long-term care in the form of in-hospital support groups to address daily occupations, habits, roles, and routines that impact overall health and wellbeing. Support groups can be activity-based, lifestyle redesign focused, or skill acquisition building.
- Advocate for parents, help them navigate a NICU experience, and empower them to foster meaningful relationships with providers and their child.
- Suggest modifications to NICU units and/or single family rooms, such as soft lighting, soft music, comfortable chairs, spaces to work virtually, access to fridge/cart with nutritious food, exercise or outdoor opportunities for parents, bookshelves, sensory products, puzzles/activities for children, and access to supplies for self-care tasks.

Memory Making & Memory Boxes

Helping parents to engage in memory making with their baby will be supportive in their healing process.

- Start memory making activities early on; parents will need support and guidance.
- Offer the family a private room if available.
- Memory making ideas can include:
 - Holding infant (swaddled or skin-to-skin), bathing infant, baptizing infant, reading to infant, or taking photographs. Now I Lay Me Down To Sleep (NILMDTS) offers free bereavement photography services
 - Some parents have found a seamstress to make an infant dress out of their wedding dress for a burial outfit or baptismal garment. (Kennedy's Angel Gowns or NICU Helping Hands Angel Gown Program, creates/donates free infant burial garments and keepsakes)
- Encourage parents to record siblings reading a book or singing songs, which they can play for the infant.
- Send parents home with a personalized memory box.
- Tangible items for a personalized memory box:
 - Footprints/handprints (i.e painted, clay, 3D), extra copies on cardstock for family members
 - Name card or name sign made from scrapbooking supplies or spelled with alphabet blocks
 - Clean diaper, infant's blood pressure cuff, pacifier
 - Knitted hat
 - Locket of hair (with parent's help or permission)
 - Ceramic heart necklace, *Beads of Courage*
 - Scrapbook with photos, birth certificate, birth statistics, locket of hair
 - Recordable heartbeat teddy bears, Molly Bears, or Comfort Cub (weighted teddy bears created for the loss of an infant)
 - Heartbeat tracing from monitor
 - Printed photos plus a camera SD card, holding all the the photos taken of this baby and family
 - Books related to infant loss

Follow Up Care

It is important to follow up with parents at various times after the death of their child.

- Follow up at least one month later, not sooner. It may take multiple contacts with the parents before they are ready for support. It is recommended to continue contacts for at least one year after the loss, calling and/or sending cards and information on anniversary dates and holidays.
- Keep in mind that a phone call from hospital staff may be triggering.
- Be aware of and respect the family's cultural, spiritual, and religious beliefs and practices regarding their infant's death and beyond.
- Ways to follow up:
 - Cards from NICU staff or palliative care team
 - Sending a card on infant's 1st birthday
 - Zoom or email check ins
 - Sending Father/Mother's Day cards
 - Cards around/regarding navigating the holidays

FOR PARENTS

The following information is intended to support and guide you through your NICU experience. Other parents in your situation have contributed to this guide and want you to know that **you are not alone**. As you adapt to your environment, please remember to be kind to yourself and give yourself permission to do what feels supportive for you and your family.

At the Hospital



ADVOCATING FOR YOURSELF

- Don't be afraid to ask questions—it's okay to ask multiple times. *Record the conversation, take notes, or bring in a third party to take notes and explain.*
- Participate in rounds, if possible.
- Take pictures of your baby (if possible to do a family picture, do so, even if it is just the parents' fingers touching your baby).
- Speak with a peer mentor or a NICU parent advocate, if available, to help you navigate the experience and answer any questions.
- Connect with a lactation consultant to bring up any questions/concerns. If you are pumping, ask staff for supplies if you do not have your own.

PREPARING FOR A LOSS

- Ask the nurses to describe the protocols and procedures regarding your baby's passing so you know what to expect.
- If you want to baptize or participate in a religious ceremony while the baby is still alive, ask about providers available in the hospital or whether a provider is able to come into the hospital.
- Inform providers of final wishes you may have for your baby (i.e., funeral home, cremation).
- Connect with the palliative care team, a child life specialist, or an occupational therapist if available and as needed.
 - Palliative care team: help with transitioning a baby from life-saving interventions to providing "comfort care."
 - Child life specialist: provide families with education and emotional support in order to reduce fear and anxiety as they navigate the process of illness, injury, disability, trauma, or hospitalization.
 - Occupational therapist: assist parents in developing skills and the mindset required for completion and success in day-to-day activities, creating new routines, and exploring new roles as NICU parents.



SPENDING TIME WITH YOUR BABY AFTER PASSING

- Ask if a private room is available and if you are able to stay overnight.
- Engage in any memory making activities offered at your hospital. Incorporate siblings in whatever way feels right for your family. Some activities include:
 - Hold baby (swaddled or skin to skin), bathe baby, dress baby, read to baby, create handprints/footprints, take personal and professional photographs. Now I Lay Me Down To Sleep offers free bereavement photography services (ask staff to arrange this service).
 - Request a religious service or ceremony, if applicable.
 - Some parents have found a seamstress to make an infant dress out of their wedding dress for a burial outfit or baptismal garment. (Kennedy's Angel Gowns or NICU Helping Hands Angel Gown Program, creates/donates free infant burial garments and keepsakes). Some hospitals have these gowns available.
- Don't be afraid to ask for support on how to care for your baby.
- Bring to the hospital any personal blankets, accessories, or clothing items previously bought for your baby.
- Spend as much time as you'd like with your baby and hold your baby for as long as you want after they've passed. Other parents have reported cherishing these moments.

CARING FOR YOURSELF AND/OR YOUR FAMILY

- Utilize meal vouchers, parking validation, shuttle services, or charities such as the Ronald McDonald House if available/appropriate.
- Ask if there is a separate family waiting room in L&D.
- Attend in-hospital support groups during your NICU stay.
- Take as much time off from work as you need and are able to. You may qualify for family and medical leave (FMLA). Be aware that FMLA is often unpaid.
- Inquire if your employer offers an emergency assistance program (EAP), which assists employees who are experiencing a traumatic event.



- Try to spend a little time outside each day, such as taking walks outside the hospital.
- Eat nutritious food and try your best to maintain healthy sleep patterns.
 - Go home or to wherever you are staying to freshen up, take a nap, eat your meals, or spend time with children or pets.
- Reach out to family members/close friends for support by asking them to:
 - Visit your baby in the NICU so that you can take time to grieve
 - Set up a meal train or deliver meals
 - Assist with laundry or cleaning your house
 - Watch children at home
 - *If you prefer to be alone, ask that a close friend or family member checks in on you daily*
- Consider the effects of social media on your wellbeing. It may be helpful to take a break.
- Inquire if there is a different exit you can use when you leave the hospital.
- Ask for bereavement resources when you're ready (i.e. a list of funeral services for infants, coping with infant loss support resources, community support groups, and local therapists).
- Be patient with yourself and your partner.

Going Home



COMMON RESPONSES AFTER LOSS

- Depressed mood, irritability, or anger
- Feelings of insecurity, guilt, and low self-worth
- Anxiety
- Flashbacks to the loss
- Inability to remember moments around the loss experience
- Inability to concentrate, recurring thoughts, being in a mental fog, or feeling disconnected from reality
- Feeling lethargic, unable to move, moving slowly, or feeling “keyed” up or jumpy
- Sleeping too little (insomnia) or sleeping too much
- Significant weight loss or gain
- Avoiding people or places that might remind you of the loss
- Racing heart, rapid breathing, nausea, or diarrhea

CARING FOR YOUR BASIC NEEDS

- Utilize take-and-bake meals, meal delivery services, and cleaning services.
- Spend time outdoors.
- Focus on ways to prioritize your self-care (mentally, physically, emotionally, spiritually).
 - Exercise. While it can be so difficult to move, even a walk with a loved one or stretching at home can help release tension.
 - Sleep. Find a way to protect your sleep and talk to your physician if you aren’t able to sleep.
 - Nutrition. Be sure you are getting proper nutrition; sometimes a solid meal can help break up mental fog.

SUPPORTING YOURSELF

- Seek out mental health support. Use Return to Zero: HOPE’s Pregnancy & Infant Loss Directory (www.rtzhope.org/support) to find a mental health provider or support group in your area.
- Find the right people that will let you talk about your experience. You may lose relationships because not everyone will understand and support you, and that is okay.



- Connect with other people who have been through the same thing. Other parents have found a baby loss community using hashtags on Instagram.
- Consider creating an online memorial via Caring Bridge, Facebook, or Kudoboard to share your loss journey and create community.
- Rely on your support system for emotional and physical support.

PROCESSING AND GRIEVING

- Remember that grief is not linear, grief is nothing to be ashamed of, and there is no wrong way to grieve.
- You and your partner are likely to grieve differently.
- Find ways to connect with your partner (i.e. having date nights, attending couples counseling or a support group together).
- Create ways to memorialize and connect with your child.
- Write in a journal or on a blog.
- Ask someone to help you with the baby items you have at home. Do you want to keep, donate, or return?
- Allow children to grieve in their own way. Provide your child(ren) with opportunities to share their feelings.
 - Encourage children to ask questions and focus on answering the questions truthfully. Use concrete words like “died” and keep your answers in simple language. Answer questions in an age appropriate manner.
 - It may be helpful to find a grief counselor who works specifically with children.
 - Art and play therapy can be helpful in facilitating communication about their grief.
 - Pet therapy can be a soothing relief to your child(ren).

HOW OTHER PARENTS HAVE HONORED THEIR CHILD

- Participating in memorials such as A Walk to Remember, Celebration of Life, Wave of Light (if your hospital offers it)
- Releasing balloons/butterflies on birthdays
- Putting together donations for hospital/other organizations or donating items to hospital



- Starting a foundation
- Planting a tree
- Making and sending bereavement care packages for NICU families
- Attending/hosting a charity event
- Signing birthday cards every year
- Donating a book cart or starting a library outside the NICU
- Picking out ornaments for a Christmas tree dedicated to the child
- Starting a blanket drive

BEREAVED PARENTS OFFER ADVICE

“Reach out and find like minded people– it’s the most isolating thing you will ever go through. It’s the worst club but it has the best, most empathetic, and understanding members.”

“You are not alone and know that there’s no wrong way to grieve.”

“Talk about your child and find ways to remember your baby.”

“Each situation is unique and it’s important for parents to know that. I feel like I’ve gone through so many ups and downs and changes since I lost her and still am, but I never thought I could ever be happy after I lost her and I truly am a happy person”

“Think of ways to include your child. If you have to cut people out of your life because they don't support what's going on, it's okay. It's okay to say no to things. Put yourself and your family's mental health first and speak your mind.”

“Take pictures and videos.”

“Dont stop asking questions, even if it’s the same question 150 times, don't stop. You're the only advocate for your child.”

“If you see something that reminds you of your child, don't be afraid to let your emotions come out. Don't be afraid to talk to someone. Be open about what you're feeling so someone can help you in a healthy way.”

“You just have to survive. You don't have to get better, just survive.”

Partners Grieve Too

Due to societal expectations and stigma, bereaved partners are often overlooked and feel alone after the death of their child. Some partners may consider themselves a “second class parent” due to the lack of acknowledgement of their grief and connection with the providers caring for their child.

Partners can experience delayed grief because, most of the time, the focus is on the birthing partner. During the grieving process, partners are almost always expected to play the role of the “strong supportive figure,” meaning it is their responsibility to comfort their spouse, family members, and friends, often at the expense of their own physical and psychological needs.

PARTNERS MAY EXPERIENCE THE FOLLOWING FEELINGS

- Denial
- Helplessness
- Overwhelm
- Disregard
- Worthlessness
- Powerlessness
- Stress
- Anxiety
- Frustration
- Anger
- Depression
- Isolation

PATERNAL MENTAL HEALTH FACTS

- As many as 1 in 10 male partners experience symptoms of depression and anxiety during the postpartum period.
- 24-50% of male partners of women with postpartum depression report depression themselves.
- Prior history of depression/anxiety puts partners at a higher risk of developing postpartum depression/anxiety.
- After birth loss or trauma, men have the same risk of developing PTSD as their partners.

*We note that this page occasionally uses the words “man,” “men,” or “father.” This is not intended to be exclusionary. We recognize that different categories of people, including cisgender men, transgender women, and people who are non-binary, will identify as “partner”. Accordingly, we have tried to limit the use of “man” or “men” to cited research and data.

Some partners may engage in risky behaviors or return to work too soon as a means to help suppress their emotions. In other cases, partners may develop unhealthy coping mechanisms such as substance abuse, gambling, or may even experience suicidal thoughts.

If you are thinking about suicide, please call or text the National Suicide Prevention Hotline at 988.

It is always helpful after the death of a child to seek out support. Utilize Return to Zero: HOPE's Pregnancy & Infant Loss Directory to find a local mental health provider or support group. (www.rtzhope.org/support)

WHAT OTHER BEREAVED PARTNERS HAVE FOUND HELPFUL

- Attending infant loss support groups
- Counseling—individual and/or couples counseling
- Leaning on trusted friends and family members
- Taking as much time off from work as you need
- Utilizing resources such as take-and-bake meals, food delivery services, or cleaning services
- Listening to podcasts or reading books on infant loss
- Visiting the burial site
- Exercising
- Getting a pet
- Turning to religion
- Being in nature; going camping
- Medication, such as antidepressants

SUGGESTED RESOURCES FOR PARTNERS & FATHERS

BOOKS

- A Guide for Fathers when a Baby Dies by Tim Nelson
- Fathers Feel Too: A Book for Men by Men on Coping with the Death of a Baby by Andrew Don
- From Father to Father: Letters from Loss Dad to Loss Dad by Emily R Long
- Grieving Dads: To the Brink and Back by Kelly Farley
- Strong and Tender: A Guide for the Father whose Baby has Died by Pat Schwiebert, RN

WEBSITES

- Partners Grieve, Too on Return to Zero: HOPE (<https://rtzhope.org/blog/2021/9/2/partners-grieve-too>)
 - Webinars on Return to Zero: HOPE's YouTube Page
 - Fathers Grieve, Too
 - A Conversation with Bereaved Fathers
- Grieving Dads (<https://grievingdads.com>)
- Love Comma Dad (<https://lovecommadad.com>)
- For Fathers on The Morning (<https://www.themorning.com/fathers>)

FACEBOOK GROUPS

- Men of M.E.N.D (Mommies Enduring Neonatal Death) (<https://www.facebook.com/groups/MENofMEND/?ref=share>)
- The Compassionate Friends: Men in Grief (<https://www.facebook.com/groups/tcfmeningrief>)

BEREAVED FATHERS OFFER ADVICE

"There is a lot of strength in being weak and vulnerable."

"It's ok to ask for help. Actually, it's good to ask for help."

"Lean into the grief because if you try to fight it, it makes it harder."

"Let the tears flow. There are no emotions that are wrong, even if there are joyful days."

Suggested Resources*

BOOKS

For Parents

- At a Loss: Finding your way after miscarriage, stillbirth, and infant death by Donna Rothert
- Bearing the Unbearable: Love, Loss, and the Heartbreaking Path of Grief by Joanne Cacciatore
- Empty Cradle, Broken Heart by Deborah L. Davis
- It's OK That You're Not OK: Meeting Grief and Loss in a Culture That Doesn't Understand by Megan Devine
- Navigating the Unknown: An Immediate Guide When Experiencing the Loss of Your Baby by Amie Lands

For Children

- Invisible Strings by Patrice Karst
- The Memory Box: A Book About Grief by Joanna Rowland

BLOGS

- Glow in the Woods (<http://www.glowinthewoods.com>)
- Still Standing Magazine (<https://stillstandingmag.com>)

NONPROFITS

Financial Assistance

- Kennedy's Angel Gowns (<https://www.kennedysangelgowns.org>)
 - Provides free infant burial gowns made from donated wedding dresses as well as emotional and financial support.
- The TEARS Foundation (<https://thetearsfoundation.org>)
 - Seeks to compassionately assist bereaved parents with the financial expenses they face in making final arrangements for their precious baby who has died. TEARS also offers support groups and peer companion program in select states.
- The Colette Louise Tisdahl Foundation (<https://colettelouise.com>)
 - Provides financial assistance to families in crisis due to high-risk and complicated pregnancies, premature birth and NICU stays, and loss.
- The Unforgettables Foundations (<https://unforgettables.org>)
 - Assists low income families provide a dignified, appropriate burial for their children who have passed away.



Social Support

- NICU Helping Hands (<https://nicuhelpinghands.org>)
 - Serves families who are looking for education and support through 5 unique programs: Project NICU, One-on-One Mentoring Program, Family Assistance Program, NICU Mom Connect, Angel Gown Program.
- Return to Zero: H.O.P.E (<https://rtzhope.org>)
 - Provides holistic support, resources, and community for all people who have experienced unimaginable loss during the journey to parenthood.
- Share Pregnancy & Infant Loss (<https://nationalshare.org>)
 - Offers support services to families after the loss of a baby in 29 states. Services include bed-side companions, phone support, face-to-face support group meetings, resource packets, private online communities, and memorial events.

PODCASTS

- Hand to Hold's NICU Love & Loss
(<https://handtohold.org/resources/podcasts/nicu-love-and-loss/>)
- Hope After Loss (<https://www.hopeafterloss.org/hope-after-loss-podcast>)
- Sisters in Loss (<https://sistersinloss.com>)
- Still a Part of Us (<https://stillapartofus.com>)

For additional resources please visit <https://rtzhope.org/support>



In Honor of

Andrew Sebastian Boge

Dylan Marie Feller

Colden & Xavier Foltz

Lucy Rae Gaudet

Torvi Ann Gundersen

Hope Margaret

Alexander Thomas Kerr

Caleb Alan Kotarek

Fiona Claire Kaye

Mya Josephine

Patrick Palin

Mila Grace Quinn

Hazel Rae

Ruby Robinson

Vanellope Sky Roco

Isaac William Schreiner

Colette Louise Tisdahl

Claire Elizabeth Tobin

Ella Grace & Ryleigh Annabelle Whittle