



NICU Love & Loss: A Parent's Guide

Parents' Perspectives of Loss in the NICU and Beyond



A Message for the Bereaved Parent



When we go through the earth-shattering loss of a child, we often want and need immediate answers from others. How did our baby die? Why did they die? Did I do something wrong? Will we ever have another baby? Will this happen again?

It is natural to want to try to make sense of the many confusing and overwhelming reactions you are experiencing. You want to know how long your grief will last. You want to know whether you will ever feel "normal" or whether you will ever experience joy again. You want to know whether you will ever recover from the emptiness in your arms, heart and home.

Many people around you, including physicians, families, friends, spiritual guides, and others, will provide facts, information, words of comfort, ongoing support, and nurturing gestures. Some, if not all, of this support will help you as you go through your very personal grieving process.

You may hear the words, "I know how you feel." Others may share their own losses in the hope it will make you feel better. Although the storms we weather may have many similarities, none of us are in the same boat.

No one person or book has all the answers to your questions. No grief expert can provide a step-by-step guide through this process, even though many may inspire or calm you through some very difficult days. There is no finish line to cross.

We say all of this as your peers, as parents who have also had our hopes and dreams torn away from us by the loss of our own children. We know the pain you feel is just as excruciating, whether you spent days, weeks, or months at your child's side. Your dreams for your family may have started long before, and no matter how long your baby was in your life, the love for and connection to your baby is intense.

Our intention here is to share authentic and common emotions and reactions, which are often complex and chaotic. We will also share the words and reflections of other families who have been through their own devastating loss.

We want you to know that everything you feel is valid. Knowing you are not on your own will hopefully bring you strength to move through your difficult grief journey.

With love and understanding,
The Hand to Hold Team

Who We Are

Hand to Hold® is a national nonprofit 501(c)(3) that supports families whose baby(ies) spent time in the NICU, and that includes bereavement support.

Our Mission

Hand to Hold is dedicated to providing support before, during, and after a NICU stay. This includes our families who have endured the devastating loss of a child.

What We Offer

Hand to Hold provides support to parents at no cost to families. Our caring professional staff is made up of NICU graduate and bereaved parents. All support is designed with consideration to the emotional, physical, and social needs of the NICU and bereaved parent.



Find Hand to Hold's bereavement support and resources here.

Language Considerations

This guide uses many terms: mom, dad, partner, non-birthing parent, spouse. Mom and birthing parent are routinely used in particular sections. We acknowledge that these terms are not all encompassing, are not meant to exclude any parent or caregiver, and are not intended to diminish the importance of a person's identity and/or their relationship to their baby. We also use the word "baby," but understand that you may have lost more than one child. We use these terms for ease of reading.

If any member of your family needs support, is looking for further resources, or simply wants to talk to someone, please visit handtohold.org or call 1-855-424-6428.

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Parents' Perspectives of Loss in the NICU and Beyond

- 1 Navigating the Challenges After Loss
- 5 Physical Recovery
- 9 The Emotional Journey
- 17 Navigating Grief and Depression: Understanding the Difference and Finding Support
- 23 Mental Health During the Perinatal Period
- 29 Grieving Together
- 35 Self Care While Grieving
- 39 Your Support Systems
- 43 Your New Identity
- 47 Parenting Other Children After a Loss
- 53 The Loss of a Multiple
- 57 Pregnancy After Loss
- 63 Remembering Your Baby
- 69 Returning to Work After a Loss
- 75 Acknowledgments
- 79 Appendices
- 80 Theories of Grief
- 82 Glossary: Perinatal Mood and Anxiety Disorders
- 84 Mental Health Resources

Sometimes the healing hurts more than the wound.

— Unknown

"You never know how strong you are
until being strong is the only option."

- Bob Marley



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Navigating the Challenges After Loss



Navigating the Challenges After Loss

No parent ever dreams of saying farewell to their baby. In the agonizing blur after a loss, it is all the more painful when you have to make all the practical decisions to say goodbye – obtaining your baby's death certificate (sometimes at the same time as the birth certificate), deciding on a ceremony to say goodbye, possibly where to bury your child, and preparing an obituary or announcement. You do not need to do this alone. Your hospital will hopefully have guided you through these arrangements with sensitivity and kindness, recommending funeral homes and other organizations that may offer financial and other assistance if needed.

Involving Your Other Children in Saying Goodbye

If you have other children, depending upon their age, you might want them to be involved in your baby's end-of-life traditions. If possible, communicate with them to determine how they can or would like to be involved. It's important to note that not all children will want to be involved, and that is okay. You may want to share these desires with the trusted individuals supporting you through this process, so that your wishes and your children's are respected.

Expect and accept different reactions. Breaking the news to a child is never easy, whether they have met their baby sibling or not. You know your child best, and can decide how and when is best for all of you. You can decide whether to tell them yourself, or whether another family member, close friend, or professional (in the NICU or beyond) will help you. Every child and every family will experience varying grief patterns and reactions to their loss, whether visible and immediate, or longer term.

How to Share the News

It is hard to think about how you can even put into words that you have lost your baby. How do you share such devastating news with friends, acquaintances, or work colleagues? Saying the words, "My baby died," sometimes in response to someone asking how your pregnancy is going, how your baby is doing, or when your baby is coming home, may seem surreal or hard to voice, as it makes the loss a harsh reality.

Tips for Sharing

- Appoint a spokesperson at home or at work to shield you from direct questions if you are not ready to answer them.
- Some people may prefer to create a blanket announcement to multiple people (e.g., through a post on social media, a birth/death announcement or card).
- Prepare for difficult or awkward conversations. Play scenarios or responses in your mind so you can be ready. Sometimes a prepared or automatic response is easier than being caught off guard.
- **You owe nothing to no one.** There is no obligation to share unless you are ready to do so.

Keeping Belongings

It is hard to accept that you have to return to a home where you once believed that your child would grow up. Stillness and quiet may fill your home. Emptiness and shattered dreams may feel present in every room. It may be daunting coming face to face with all the items and belongings that you used, or thought you would use, for your baby. This can be a difficult reality to face; however, you may feel comfort in seeing your baby's crib, clothes, and toys. For others, those items can be unbearable to view.

While many people start sorting through belongings in the days after a death, some families choose to wait weeks, months, or even years before deciding what to do with their baby's belongings. If you feel like you are not able to go through your baby's belongings, find a family member or a close friend who can pack the items in boxes and store them in a safe place. There may come a day when you will be ready to go through these items, but it does not have to be today. There is no correct timeline. Take your time and be gentle on yourself.

I have packed away the sentimental items, like photo albums and her clothes. - Krista, Riley's mom

I removed baby items almost immediately. I did keep a couple of items that she used. - Crystal, Amoret's mama

Administrative Tasks

As your baby's next of kin, there is paperwork to be completed and decisions that only you can make. Some of this may need to be done before you leave the hospital, or at home following your loss. Medical and other bills, social security numbers, and other legal documents may not be processed until weeks after, and it may feel hurtful when you receive mail with your baby's name on it. Receiving results of a post-mortem or hospital review may reopen painful wounds. Other events may come much later, for example when filling out tax returns (some expenses may be tax-deductible).

It is undeniable that doing all of these practical and unavoidable tasks while reliving a traumatic loss seems unfair and hurtful.

So we went and did our taxes today. There is nothing like the sting and gut punch of taking your baby boy off of claiming as a dependent because he is deceased. It hit me once we got there that we would have to take him off. My heart wasn't ready, it never would be for something like that. But of course we had to. Later in the process she asked if we wanted to take him off the list to the side "because we will never add him again." After hesitation we agreed to take him off completely because it would be like ripping off the band-aid rather than seeing his name, unclaimed, on there every year. Our hearts hurt.

- Kayla, Ryan's mom

Physical Recovery

