



HAND to HOLD

NICU Milestone Beads

Implementation Guide



#H2Hmilestones

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Why NICU Milestone Beads?

When your baby is born early or with special healthcare concerns, milestones have a very different meaning.

Hand to Hold's NICU Milestone Beads celebrate each special step in a family's NICU journey. For NICU parents, the beads are more than just a piece of jewelry. They are a symbol of their baby's story.

Each necklace includes a NICU Milestone Bead Chart in which the family can record dates and make special notes as their baby reaches each milestone.

Hand to Hold also offers a special Love and Loss bead kit, a keepsake for families to memorialize their baby after enduring a devastating loss in the NICU.

In this guide, you will find suggested best practices, tips and ideas for administering NICU Milestone Beads at your facility.



A Note from Our CEO:

As a NICU medical professional, you're committed to the babies and families in your care. Hand to Hold wants to be your partner in providing family friendly support to the whole NICU family, from antepartum through the transition to home. From our in-hospital Ambassador Program to our podcasts to our online store, all Hand to Hold resources are based on the latest standards and incorporate the insights of families who've experienced a NICU stay or bereavement. To order resources for your NICU, please visit Hand to Hold's online store: handtohold.org/store.

Thank you for your dedication to supporting your NICU families.

— Kelli Kelley
Founder & CEO

What Parents Have to Say

“ My milestone beads are my most prized possessions. It’s a reflection of all the positive experiences we faced in the NICU as opposed to the surgeries he faced and still has to deal with. My favorite bead is when I first got to hold him. He was nine days old, and the moment he was placed on my chest there was an automatic stream of happy tears!” – Cece C.

“ That necklace became my talisman. It reminded me how far we had come and allowed me to take a piece of the hospital with me when I couldn’t be there.”
– Kheira A.

“ I have my son’s necklace hanging from my rearview mirror. Every time I look at it, I am reminded that if my little 23-weeker can make it through what he has gone through being so small, I can handle life every day.”
– Krissy B.

“ The “little” milestones to some people were so big to us, and this was such a wonderful way to recognize and celebrate every milestone we had been through. I will always cherish her necklace.”
– Kaleigh K.

“ Being a NICU mom is tough. But these beads help you focus on all the milestones your little one is hitting. Focusing on how far they’ve come and cherishing the smallest details is so consoling. Having the keepsake of those memories is so valuable. I remember starting out with a few beads and seeing all the other moms with so many, then I became one of the moms with all the beads. It’s nice to see someone who can say, “I’ve been there; keep your head up, Mama!”
– Danniela M.

“ My favorite bead is the going home bead, because I felt like it was going to take forever for my twins to come home after having them at 25 weeks. They are now eight months old, and we are so happy to have them home.” – Sabrina A.

Getting Started

The Welcome Kit

The Welcome Kit contains a necklace and a stork bead in a keepsake bag. Families should receive the Welcome Kit and the bead chart upon admission into the NICU or shortly thereafter.

Bead Distribution

Each hospital manages bead distribution differently according to their needs. Beads may be distributed by a single staff member or by a small group of staff working together. Typically bead distribution is handled by a member of the social work or child life staff, although some hospitals choose a department administrator or nurse to distribute the beads.

To make the process easier, we recommend picking a single day of the week as bead distribution day. Beads are delivered to each bedside, as indicated by each baby's progress. Ideally the beads are given directly to the parents; however, if the parent is unavailable beads may be left at the bedside in a small plastic bag in a designated location. Many hospitals distribute beads at a weekly support group or parent meeting which can encourage attendance. Finding the method that works best for your staff will ensure that both you and the families in your care receive the full benefit of the NICU Milestone Bead program.

Sample Distribution Process

- 1 Admission:** Nurse delivers Welcome Kit to family upon admission, along with any other NICU information regularly given.
 - 2 Weekly:** Designated staff member (child life, social worker, parent educator) delivers additional milestone beads on a set day each week (weekly support group, parent meeting or during rounds).
 - 3 Discharge:** Front desk administrator or discharge coordinator distributes the home bead to the family during the discharge process.
- * Tip:** Distribution of beads to families is a great way to engage volunteers and support NICU families at the same time.

“ I love the bead program because of how it evolves during the family's stay. It goes from something to look forward to with each bead, to a snapshot of baby's progress in the NICU, and then finally memorabilia of everything they overcame. Giving parents such a sweet keepsake that will grow with their baby is invaluable!”
Faith Wilson, NICU parent and Family Support Specialist

Bead Charting

We recommend families leave their copy of the bead chart at the bedside. Hospitals may choose to laminate a second copy of the bead chart to post by the bedside using Velcro or other means that works for your facility.

The bead chart is intended to help families track the milestones their baby has reached. With each milestone, the parent or member of the care team marks the date for that milestone on the bead chart, and the parent receives the bead for that milestone on the next bead distribution day. A laminated bead chart at the bedside makes it easy for the staff distributing the beads to see which bead is needed. If a laminated bedside card is not being used, your staff will need to determine how best to communicate and facilitate the distribution of the appropriate bead.



Going Home

Since orders to go home are frequently given quickly, your designated bead distribution staff member should be someone who is available consistently. Some hospitals leave the home beads with the front desk staff to ensure the final bead makes it home with every family.

Love & Loss Bead Kit

When a family experiences a loss in the NICU, a member of your hospital's pediatric palliative care or bereavement team may deliver the Love and Loss necklace at the appropriate time, along with any additional bereavement materials provided by your hospital.

Recommended supplies—not included with your kit:

- Velcro dots or Command hooks to hang a laminated bead chart
- Plastic sleeve for families to leave their bead chart at the bedside
- Dry erase markers
- 2" x 3" plastic jewelry bags
- Bead storage system

Spotlight on NICU Heroes

Hospitals all over the country are using NICU Milestone Beads to support their families. Here is an example of a workflow from one hospital in Oregon:

"The Social Worker provides the necklace when they do their initial assessment with the family. At this time a bead chart with patient's name on it is also placed [at the bedside]. We also provide the "You Are Not Alone" brochure and discuss Hand to Hold support programs.



For bead distribution, babies born under 32 weeks get [Expanded] beads and over 32 weeks get [Essential] beads. We have bags filled with beads for each program in a drawer in the social work office. Once a necklace is given out, the patient's name is placed on a bag with all the beads, so we can keep track of beads distributed during the stay. We also place the family's name on a list, so we know a necklace was given.

Beads are handed out once a week on Wednesday, "Bead Day." We use bead charts at the bedside to track which beads need to be given. Some families do not use the charts, so if the parent is present, we ask them. We also

use this time to have a "warm check in" with all families that are present during bead distribution. If a family is discharging we make sure they have all the beads before they leave. We have also mailed beads if we miss a family. Usually the home bead is the only bead left. Our ward clerks have home beads they can give to families if a social worker is not present.

Our physical therapist hands out a bead to babies/families that participate in infant massage. Our spiritual care staff hands out the birth stone bead. A social worker hands out the rest of the beads on "Bead Day."

Our hospital has many high school and college age volunteers who help prepare the beads. We then store beads in a file cabinet, so they are ready to be assembled into the patient bags.

Families love this program and find it valuable. I cannot tell you how many parents show me their necklaces before they leave and take pride in the milestones they have achieved during their NICU stay."

Submitted by Michele Molony, Social Work Case Manager, Springfield, OR

Impact By the Numbers

In 2018, **312** families received free support and resources through our online request form, including a match with one of our trained NICU graduate peer mentors.

97% of nurses surveyed said parents who receive Hand to Hold support become more confident caregivers.

93% of respondents said Hand to Hold helped them navigate the NICU experience.*

87% of respondents said Hand to Hold helped to reduce the stress of having a baby in the NICU for their family.*

**Results from a third-party survey.*

Support Your Families with Hand to Hold Resources

Visit handtohold.org/store for detailed descriptions, images, and pricing.

NICU Milestone Beads

Celebrate each step in a family's NICU journey with our Welcome, Essential, or Expanded kits.

Handbooks

Support families during and after their NICU stay with our Navigating the NICU and NICU Graduate Handbooks.

Sibling Support

Our Sibling Sundaes Curriculum, NICU Tour DVD, and Siblings Are Special Activity Book extend support to the youngest members of the family.

Resource Articles

Hand to Hold offers support for the whole family, addressing topics such as Finding a Balance Between NICU and Home, Grieving Together as a Family, and more.

Free Resources

Hand to Hold is committed to providing support for every family. Visit our online store to order free brochures and posters for your NICU in English and Spanish—just pay shipping!

Hand to Hold's Mission

Hand to Hold helps families before, during and after NICU stays and infant loss by providing powerful resources for the whole family and most importantly, one-on-one mentoring from someone who has been there.

For Parents

Peer Mentor Program



Through our award-winning Peer Mentor Program, Hand to Hold carefully matches seasoned NICU parents with new parents in need of support. These relationships inspire hope and offer new parents the chance to ask personal questions and receive support from someone who is uniquely familiar with their experience. handtohold.org/support



NICU Now Podcast
A podcast for families on the NICU journey.

NICU Love & Loss Podcast
A podcast for bereaved families.



NICU Dad Discussions
A podcast for NICU dads, by NICU dads.



For NICU Professionals

NICU Heroes Podcast

A podcast for the NICU professional.
Each episode is worth one contact hour of nursing continuing education.



HAND to HOLD



Fragile Babies. **Family Support.**

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