Fast Track to Better Care for Your Baby + A More Satisfying Experience For Your Family

You will have many decisions to make as you navigate the NICU with your baby. A NICU Parenting plan will help you actively create a more satisfying parenting experience as you learn about your options, find clarity in your preferences, and clearly communicate your needs.

Like a birth plan, a NICU Parenting Plan is a tool for information gathering and communication. To get you started I've created a NICU Planning Worksheet in two parts: **Part 1: Your Options** introduces and encourages you to explore your NICU parenting options and identify your preferences; **Part 2: Getting to Know Us** offers a series of questions for you to consider and share with the team caring for your baby so they can better serve your whole family.

Your baby's unique medical needs and health status will be a starting point for what is possible—follow your baby's lead, partner with your baby's providers, and communicate your preferences to help guide decision-making and build a trusted relationship. Know that your preferences are an essential element of evidence-based care.

#### Why a NICU Parenting Plan?

A NICU Parenting Plan helps you find your voice as your baby's advocate, and creates opportunity to be the parent you want to be no matter what path your family's NICU journey takes.

#### A NICU Parenting Plan Will Help You

- Learn about your options
- Identify what you need as a parent and what you want for your baby from the moment they are born, admitted to the NICU, and for the duration of their hospitalization
- Begin and continue conversations about your family's needs,
   strengths, and challenges in the context of your baby's medical stay
   and the policies & procedures routine to your NICU
- Engage your baby's medical team to support and facilitate your parenting goals

Every NICU has its own policies, practices and culture. A thoughtfully drafted NICU Parenting Plan empowers you with a headstart for informed choice and shared decision-making.

#### **5 Steps** to a More Satisfying NICU Parenting Experience

Step 1: Gather your downloads Parts 1 & 2: Your Options + Getting To Know Us

Step 2: Read through the list of options in Part 1, and the questions in Part 2.

**Step 3:** Think about what feels important to you right now. Jot down any questions you may have. Do your own research online. Talk to your partner, and other people in your support circle: friends, family, your doula.

**Step 4:** Once you have a good idea for what your parenting goals are, prepare to have a discussion with relevant providers—your birth team, your baby's healthcare providers and specialists. Check the boxes of items you would like to incorporate into your parenting plan. Fill out the questions in Part 2. You can write notes about what you'd like to talk about, create a formal document to share, or use the worksheet on its own as a starting point in your discussion.

**Step 5:** Share your intentions and goals, and ask to learn more about what policies are in place at your hospital and what resources will be available to you. Use the information you have prepared to begin or continue a conversation about your parenting priorities, and help them partner with you in support of your parenting goals. Use this time to learn more about what benefits and potential risks may be relevant to your baby, based on their current or anticipated health status.

#### **A Reminder For Parents**

The NICU can be overwhelming! When having a discussion or making a decision about your baby and their care, here are five important questions to ask:

- 1. What are the benefits?
- 2. What are the potential risks?
- 3. What are the alternatives (and the benefits and risks of each alternative)
- 4. What does your intuition say?
- 5. How time sensitive is this decision? What if we do nothing, or wait-andsee for a specified amount of time?

As your baby's parent any discussion or decision made about your baby should include *your* preferences—consider what you are hearing and think about how you feel, what is important to you right now, what do you want to do, and what follow-up questions do you have? Learn more about the benefits and potential risks based on your baby's current health status. Once you've listened to the information received, and considered your own thoughts and feelings, you can do your own research and circle back with your baby's team to continue the discussion. Know that your baby's journey will not be linear and that conversations like these will be ongoing.

#### Remember to:

- Stay curious
- Communicate with your baby's doctors and nurses every day
- Learn the language and terminology
- Follow your baby's health status
- Ask questions, and share your perspective as your baby's parent
- Remember: you are an active **learner** and **teacher** in the NICU!



#### **Your NICU Parenting Plan**

This worksheet is designed to help you begin to consider your options for parenting in the NICU! This is not an exhaustive list, but instead a starting place. A NICU parenting plan is about setting and sharing your intentions and your goals with your baby's team. Read through the topics listed here to think through what you may need and want for yourself and for your baby during their hospitalization. If you have more than one baby you can fill out one form for each baby, or apply these ideas to all of your babies.

My Communication Style
☐ I like a little information
☐ I like a lot of information
Tell me everything
Before Baby Is Born
I would like an antenatal consultation with a Neonatalogist, NICU Nurse, Lactation Consultant (IBCLC), other specialist:
☐ I would like to tour the NICU
My baby/babies will be born preterm, and/or will be born with the following known health conditions or diagnoses:
☐ I have questions about/would like to discuss the following:

At Birth
☐ I want my baby to receive the benefits of delayed cord clamping
I want my baby placed-skin-to skin on my belly or chest, and/or to touch or hold my baby during delayed cord clamping for as long as my baby will tolerate
If/When NICU Services are Needed
■ Non-birthing parent will go with baby to NICU
■ Non-birthing parent will stay with birthing parent
<ul> <li>Non-birthing parent will go to NICU to orient, and then return to support birthing parent</li> </ul>
During this time our doula or other chosen support person will:
First Meeting
☐ Please reunite me with my baby as soon as possible
☐ I want to provide my baby with the benefits of kangaroo care
☐ I want to offer my baby to nuzzle, lick, and latch at the breast/chest
<ul> <li>I want my baby's feeding tube to be placed in their nose, if possible (so they have mouth free to suckle and body feed)</li> </ul>
☐ Twins and multiples: I would like my babies to share a private room, or if in an open bay design be placed next to each other
I want to learn more about and be shown right away how I can bond with and comfort my baby
Kangaroo Care
I want to learn more about the benefits of kangaroo care for babies and parents, and the proper way to do it
I want to provide kangaroo care for my baby every time I visit, and for as long as possible

#### **Part 1: YOUR OPTIONS**

#### **Your NICU Parenting Plan**

#### Feeding I want my baby's first food to be colostrum ☐ I want to speak with a Lactation Consultant (IBCLC) as soon after birth as possible I want to have a discussion about feeding options if my milk hasn't come in yet and my baby needs to be fed I want to learn more about donor milk ☐ I plan to breast/bodyfeed; I do not plan to breast/bodyfeed ☐ I want to learn more about human milk fortifiers (HMF): bovine milkbased HMF vs. human milk-based HMF ☐ I want to learn more about human milk feeding vs. bovine milk products and the risk of Necrotizing Enterocolitis (NEC) Donor Milk: I do want my baby fed donor milk; I do not want my baby fed donor milk Formula: I do want my baby fed formula, I do not want my baby fed formula Combo Feeding: I want to combo feed human milk (breastmilk, donor milk) and formula ☐ I want to learn more about how my baby will progress from IV or tube feeds to bottle or breast feeds (feeding progressions) in the NICU and learn more about how my personal feeding goals will be supported in that process I want to learn more about feeding supplements (vitamins, fortifiers, and NeoSure) in the NICU and after graduation **Pumping** ☐ I plan to pump and hand express colostrum ☐ I want help to learn how to use a breast pump I want help to learn about breast massage and hand expression ☐ I want to rent a hospital grade pump, and would like information about how and where to get one

### **Your NICU Parenting Plan**

#### Daily Care

When I am with my baby in the NICU I want to:
change diapers
☐ take temperature
give bath
provide oral/mouthcare
<ul><li>feed my baby with my body or bottle, skin-to-skin during tube feeds</li><li>pump for my baby</li></ul>
provide kangaroo care for at least one hour and as long as possible
<ul><li>help manage my baby's pain during painful procedures</li><li>read, sing, or play an instrument for my baby</li></ul>
get an update on my baby's health status and progress
■ be present at morning rounds
I want to spend the night with my baby in the NICU
☐ I want 24hr/unlimited access to my baby for both parents
☐ I want to call for updates on my baby when I am away from the NICU
Comfort Measures and Pain Management
☐ I want to learn about my baby's signs of stress and discomfort
I want to learn more about how nurses and doctors prevent, assess, and manage my baby's pain in the NICU, especially in my absence
I want to learn more about what I can do to help relieve my baby's pain during procedures when I am present
I want to learn more about the pain relieving benefits of:
sucrose, breastfeeding, and skin-to-skin
<ul><li>swaddling, containment, nesting, and facilitated tucking</li></ul>
pacifiers and non-nutritive sucking
music, talking, singing

Firsts
☐ I want to give my baby their first bath
☐ I want to dress my baby the first time they wear clothes
☐ I want to give my baby their first bottle
Other:
Personalizing Our NICU Space
I want to decorate and personalize my baby's NICU space, please tell me what items are not allowed.
Bereavement Care
I want to learn more about the resources and options offered here for palliative and bereavement care:
education about the grieving process
ways to connect with my baby before, during, and after their passing
ways to memorialize my baby
peer support
community resources
counseling
Mental Health
☐ I want to speak with a therapist, counselor, or psychologist
☐ I want to speak with a chaplain
■ I want to connect with other NICU parents on the floor
☐ I want to participate in a virtual peer-support group
☐ I want to learn more about local community mental health resources and support groups

### **Your NICU Parenting Plan**

#### **NICU Resources**

Please tell me about resources available through the NICU:
parking vouchers or validation
meal vouchers
provided meals or snack on the NICU floor
☐ Ronald McDonald House
gas or transportation vouchers
computer and internet access
resource library
showers
kitchen facilities and food storage
□ breastpump access and/or rentals
pumped milk supplies and storage
sibling play room or on site childcare
Outro and Decouvered
Support Resources
<ul> <li>I would like to speak with the NICU social worker or case worker about financial aid, baby's SSI and medicaid eligibility</li> </ul>
I need financial or logistical help with the following:
parking
mental health
<pre>food</pre>
housing
gas
transportation
employment/employment leave
hospital bills
sibling care
other:

#### **Your NICU Parenting Plan**

#### **Routine Newborn Immunizations** ☐ I want my baby to be immunized in the NICU ☐ I want to delay immunizations until my baby graduates the NICU—my baby will be immunized by their pediatrician My baby will not be immunized I want to learn more about the process to qualify for Synagis Circumcision ■ I want my baby circumcised in the NICU ☐ I want to delay circumcision—my baby will be circumcised by their pediatrician or mohel My baby will not be circumcised **NICU Graduation** I want to learn more about: How to estimate when my baby will be discharged from the NICU The milestones my baby will need to meet in order to graduate The checklist for discharge planning: what to expect and things to do to prepare (choosing a pediatrician, feeding plans, critical congenital heart defect screening, hearing screening, oxygen and medications, CPR, feeding, car seat challenge, and more) The transition home: what it may look like, and what hospital or community resources will be available to my baby and our family after graduation

# **PART 1: Your Options**

#### Notes

#### **Your NICU Parenting Plan**

You have the power to drive your baby's healthcare team to deliver better and more personalized care to your family during this time.

Knowing your options, having clarity for your preferences, asking questions, and engaging in discussion to share your ideas and parenting perspective are all very important ways you can cultivate a better experience parenting your baby in the NICU.

Another important opportunity is to connect! One of the best ways to connect with your baby's providers is to share important information they should know about who you are and what your family brings to your NICU parenting journey.

This worksheet is designed to get you thinking about topics that will help your healthcare team—nurses, doctors, and other specialists, including your NICU social worker or case worker—get to know you better and in turn provide the kind of information, education, and resources you need most. This will help you better meet your NICU parenting goals and ensure the best possible outcomes for your baby.

Birthing parent:
Partner:
Personal pronouns:
Our baby has older siblings (names, ages):
Our parenting style & philosophy:
Our communication style:
NICU Parenting options that are very important to me:
NICU Parenting options that are very important to my partner:

Our family STRENGTHS include (We are really good at THIS!):
Our family is currently facing the following CHALLENGES (THIS part is really hard!):
Our family is in NEED of (We could really use THIS right now!):
Our Circle of Support includes (Family, friends, community):

We would like you to know this about us:
We have specific concerns or questions about:
We would appreciate the following kinds of emotional support:
My ideal day at the NICU looks like this:

#### Notes


## To Learn More

#### **About Empowered NICU Parenting**

NICU parents need more connection, and less trauma.

<u>Empowered NICU Parenting</u> is an online resource with a mission to give back the power to parents with informational support delivered through original research-based content. Let Empowered NICU Parenting show you what's possible!

For more please visit

Website www.empowerednicuparenting.org

Instagram @EmpoweredNICUParenting

Facebook @EmpoweredNICUParenting