



Advocacy Checklist

- Identify NICU social worker
- What time are rounds typically held? If you cannot attend, when is the best time to call for the outcome of rounds?
- What time are your baby's care times? In the early days and weeks, it is often best to leave the baby settled in isolette between care times. Diapering, vitals, feeds, opportunity for skin-to-skin or holding occur only at care times.
- Teach B.R.A.I.N. - **See Below**
- Most NICUs are 24/7 visiting hours. Are there any visiting restrictions? (e.g., shift change)
- Does your child have a primary nurse? If only a team approach, who is your best contact?
- Identify an insurance case manager and any NICU related programs with the insurance company.
- Obtain a hospital grade rental pump via insurance BEFORE discharge. Use a medical supply company if needed. The hospitalist OB/GYN, midwife, or private practice midwife or OB/GYN can provide the script. With script and NICU admission, this rental should be at no cost.
- Obtain contact information for hospital advocate. Not frequently needed, but good to have in case of concerns.
- Do not be afraid to speak up. Your child's care is not compromised by a proactive parent - advocacy is important.
- Does the NICU have a visitor or contact list of who can visit or call for information about your child? Be cautious about sharing your baby's band number.
- If the NICU stay is anticipated to be thirty or more days, or the baby has a qualifying diagnosis or weight, apply for SSI. Most teen parents should meet income qualifications even after discharge. Direct parents to their social worker for more assistance.
- Inquire about physical or occupational therapy for baby's positioning as needed.
- Inquire to Speech Therapy about any feeding questions/concerns
- Eye exam, head ultrasounds, etc., do you want to be informed ahead of time about these scheduled procedures? Ask for a note to be added to the chart.
- You can call the NICU 24/7 for information about your baby. What is the correct number? Are you easily reachable if they need to call back because the nurse is busy?
- Keep track of the baby's progress daily so you can see how the baby is progressing. There is no such thing as a small milestone in the NICU.



- Advocate for early and frequent skin-to-skin. Aside from umbilical artery lines, and a few other interventions, skin-to-skin is rarely contradicted. If you cannot hold baby, “hand hugs” are ideal (pressure not rubbing). Advocate for lots of positive early touch.
- What hospital based and community-based support groups can you join? Sign up!
- Set up a transportation plan. Seeing baby frequently is beneficial for both you and baby. If there are barriers to transportation, check with your social worker, local NICU support, and insurance to inquire about transportation assistance.
- Do you have a car seat designed for 4lbs in case of discharge before 5-6lbs? If not, what community resources can help you obtain one?
- What safe place do you have for baby to sleep? NICU babies are more vulnerable making safe sleep a MUST.
- Ask your team about Early Intervention and Early Intervention tracking programs.
- Attend a NICU follow-up clinic. They monitor for development far more than typical well visits.
- Prior to discharge, discuss with your rehab and medical team if outpatient therapy vs. Early Intervention is recommended (sometimes additional outpatient therapy supports are recommended for optimal discharge success). If outpatient therapy is recommended, ask the case management team for a list of providers in your area that accept your insurance.”

Use the BRAIN Acronym for informed choices

Benefit - What is the benefit of X?

Risk - What is the risk of X?

Alternatives - What alternatives exist?

Intuition - What is your gut feeling?

Nothing - What is the benefit/risk of waiting and doing nothing right now?