

TODAY is a Good Day

ADVOCACY CHECKLIST

Advocating for You and Your Baby

The **BRAIN** acronym will help you gather information & make appropriate decisions about your baby's care.

BENEFIT - What is the benefit?

RISK - What is the risk?

ALTERNATIVES - What alternatives exist?

INTUITION - What is your gut feeling?

NOTHING- What is the benefit/risk of waiting & doing nothing right now?

INFORMATION TO REMEMBER

NICU Phone Number:

Primary Contact:

NICU Visiting Hours:

Time of NICU Rounds:

Baby's Care Times:

Social Worker Contact:

Hospital Advocate Contact:

Pediatrician Contact:

Notes:

FIRST STEPS

- Do not be afraid to speak up. **Your child's care is never compromised by a proactive parent. Advocacy is important.**
- 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!**
- Remember that you can call the NICU 24/7 for information about your baby.

- Set up a transportation plan so you can see your baby as often as possible. Ask about parking, public transportation, or other modes of travel.

Need help with transportation? Check with your social worker, local NICU support orgs., and insurance to inquire about assistance.

- Find out if the NICU has a visitor/contact list and appoint who can visit/call for information about your child.
- Sign-up for any hospital-based and community-based support groups, including Today is a Good Day.

INSURANCE

- Identify an insurance case manager and any NICU-related programs with the insurance company.
- If the NICU stay is anticipated to be 30+ days, or the baby has a qualifying diagnosis, apply for Social Security Insurance (SSI). *Your social worker will be able to assist you.*
- Breastfeeding/pumping moms should obtain a hospital grade rental pump via insurance BEFORE discharge. Your doctor can provide a script. *With a script and NICU admission, this rental should be covered at little or no cost. If you have no insurance there are community resources to help you obtain a pump.*

GENERAL

- Advocate for early and frequent skin-to-skin and lots of positive early touch. If you cannot hold baby, “hand hugs” are ideal.
- If you’d like to be informed in advance about your baby’s scheduled procedures, ask for your preference to be added to your baby’s chart.
- Inquire about physical or occupational therapy as needed.
- Inquire about speech therapy for any feeding questions or concerns.
- Inquire about lactation support services (breastfeeding, pumping, etc.), including access to the dedicated pumping rooms.

DISCHARGE

- Discuss with your medical team if outpatient therapy vs. early intervention is recommended. If outpatient therapy is recommended, ask your social worker for a list of providers in your area that accept your insurance.
- Be sure you have a car seat designed for 4lbs in case of discharge before 5lbs. If not, what community resources can help you obtain one?
- Prepare a safe space for your baby to sleep at home. Remember - back is best.
- Attend a NICU follow-up clinic in addition to your typical well-visits with your pediatrician.