

Getting Ready for Discharge from the NICU:

(content may also be helpful for children or youth being discharged from the PICU (Pediatric ICU) or MICU (Medical ICU))

Before you know it, hopefully it will be time to bring your baby home. There are usually three routes to discharge in the NICU: (1) going directly home, (2) going to a floor within the hospital for additional training and (3) going to a sub-acute facility for further rehabilitation and additional training. If your child is being transferred to another floor in the hospital or to a sub-acute facility, ask the staff to explain the differences. Transition out of the NICU can be difficult. Many times it is hard for families to leave the NICU where the baby was under constant watch. But as the baby becomes more stable and the families become more comfortable with their child's care many times NICU care is no longer needed. Before discharge, family members should make sure they are comfortable with all aspects of care and spend time caring for their baby on their own. Families should also be comfortable knowing what can happen if they go home and then need to be readmitted. Will the baby need to go through the ER? Will they be admitted back to the NICU or will they have to go to the PICU (Pediatric Intensive Care Unit)? What are the differences between the NICU and the PICU?

Most NICUs are only for babies who have never been discharged. However, some NICUs will readmit but require the infant to be in an isolation room so that outside germs are not brought into the NICU. If the hospital's policy is not to readmit into the NICU, the baby will go to the PICU. PICUs care for children from birth until age 22. Some hospitals may also have a separate Cardiac ICU for infants and children with heart conditions.

The following is a checklist that will help in the discharge process. As the discharge nears, the NICU team (doctors, nurses, social worker, discharge planner etc.) will help to ensure that everything is in place.

- Do you know what your insurance coverage is for nursing, durable medical equipment etc.?
- Has the discharge planner contacted your insurance company for pre-approval for equipment and nursing care that will be needed at home?
- Has the discharge planner or the social worker explained supplemental insurance programs in the state where you are located? In Massachusetts this falls under MassHealth. Common Health and Kaleigh Mulligan can help pay for co-pays and equipment/nursing if your primary insurance doesn't cover these items. See the agency section for more information.
- If your child doesn't have insurance, ask the social worker if your state has programs that you may be eligible for? In Massachusetts, the program is MassHealth. See the agency section for more information.
- Have you and the discharge planner contacted the Early Intervention (EI) program in your area (assessments must be within 45 days of referral). Early intervention will provide Physical Therapy, Occupational Therapy and other services if your child is found eligible. EI Programs encourage families to call and self-refer. To find out what program serves the town that you live in call 1-800-905-TIES, the central directory number for EI in Massachusetts or check the website at www.massfamilyties.org and see the link Early Intervention Directory.
- If your child is medically complex, once they are enrolled in Early Intervention, ask about the Regional Consultation Program in your area and have your EI case manager refer your child to this program. Please see agency section for further details of this program, which can help with respite, equipment etc.
- Ask the hospital and Early Intervention if they are aware of support groups, Internet resources, books etc. that might help to understand your child's condition. If your child is undiagnosed, ask if there is any condition that is similar with the same issues that you are dealing with.
- If the NICU team has determined that nursing is needed for your child to be cared for at home, has the discharge planner contacted MassHealth Community Case Management who will assist in determining your nursing eligibility?
- Have you contacted nursing agencies directly (this can help in the process)?

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- Have other agencies been identified as potential help (Department of Developmental Disabilities, Department of Public Health, Mass Commission for the Blind, Mass Commission for the Deaf and Hard of Hearing etc.) and have they been contacted? See agency section.
 - Has the family been trained in CPR?
 - Has an emergency plan been established at home?
 - Do you have a “To Go” bag with all the essential trach supplies you would need in an emergency?
 - Is it necessary to contact local Fire/Police Departments to inform them about your child’s condition so that they will be prepared to attend to your child according to your wishes in the event of an emergency? What will happen if you call 911? How long will it take? What hospital will they bring your child to? Are there any exceptions? You may want to have your doctors contact the local hospital so that they are aware of the situation.
 - What equipment is needed at home (ex. Apnea monitor, heart monitor, oximeter, oxygen etc.)? Has the equipment been ordered?
 - How will you transport your child? Do they need a special car seat or a car bed? Where can you find those?
 - Do you feel comfortable with all aspects of your child’s care? What training do you need to go home (g-tube feedings, tracheostomy care, wound care etc)?
 - What follow up appointments are needed? How do you make appointments? How do you find specialists? When should you make these appointments for (1 week, 1 month etc.)? Is there a service in the hospital like Coordinated Care that helps with medically involved children? Are there special neonatal follow-up clinics?
 - What should you watch for? What are the guidelines for returning to the hospital Emergency Room (limits on oxygen levels or heart rates might be established as benchmarks)?
 - If your child is going to need future surgeries, at about what age might those occur and who will perform the surgeries?
 - Has the community pediatrician been notified about discharge? If you don’t have a pediatrician yet, ask if anyone has recommendations. Some practices specialize in children and youth with special need

Steps to Take if Nursing Is Needed

As you approach discharge from the hospital, the NICU or ICU team (doctors, nurses, social worker, discharge planner, etc.) will determine what will be necessary for your child to go home. In some cases where a child has complex medical needs (tracheostomy, g-tube, seizures, ventilator, TPN etc.) nursing is needed. The following may help you to secure nursing for your child.

- **Determine Coverage:** Find out what insurance coverage you have (visiting nursing visits, skilled nursing visits or block nursing and if there are yearly or lifetime caps). All policies are different and many of the private insurers have limited home nursing available.
- **Apply for Supplemental Coverage:** If your insurance has limited nursing coverage, in Massachusetts, MassHealth will cover nursing if medically necessary. It can take up to 90 days to process a MassHealth application so apply as soon as it is determined that your child will need it. Depending on your situation, you may qualify for various MassHealth programs. Common Health is a supplemental insurance program for individuals with special needs (a premium is paid based on income). Kaleigh Mulligan Home Care is a waiver program for children with complex medical needs who either require technology and/or skilled nursing care in order to live at home. This program is called a waiver program because family income is not used to determine eligibility. Please see other sections in this packet for more details on MassHealth.
- **MassHealth Community Case Management:** If home nursing is approved by MassHealth, you will be assigned a MassHealth Community Case Manager who will do a nursing assessment, help determine hours of eligibility, and will assist in providing information about possible nursing resources. You can read more about this Community Case Management program for complex health needs at: <http://commed.umassmed.edu/services/care-management/case-management> .

Call Nursing Agencies in Your Area: Talk to the hospital discharge planner and your Community Case Manager through MassHealth to find out what agencies cover your area and ask them to call the agencies early in the process. In addition, it can help if you call directly and explain your situation. The sooner you start looking, the sooner you will find help. Be flexible. If they can't fill the exact hours that you would like, try what they can offer and work into what you would like down the road. Be persistent. With a nursing shortage, it is hard to fill hours but it can be done and many nurses enjoy working with infants and children at home