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Coping with the Transition from NICU to Home

By Sue L. Hall, M.D.

Every parent looks forward to the day their baby will be discharged from the NICU, but having the baby home is going to present a new set of challenges for you. The more you can be mentally prepared, the easier it should be. Some realities of what you might face once home with your baby:

- 1- You will be tired...even exhausted!
- 2- You may be stressed by responding to your baby's apnea alarms or providing other types of care that would normally be done in a hospital. Adapting to your new role of "nurse" may be a scary change.
- 3- Your baby may not eat very well. Even if baby was eating well enough in the NICU to be discharged, once home the baby may go "on strike." You may find yourself spending more time than you'd like trying to get baby to take enough calories to grow. In addition, baby may have troubling symptoms of reflux that may be difficult to relieve.
- 4- Your friends and family may not understand the level of your new responsibilities, why everything isn't instantly "all better" now that your baby is home, and why you aren't constantly overjoyed. They may not have any idea of the trauma you and your baby have experienced. They may not understand why you can't take baby out or have unlimited visitors.
- 5- You will be spending a lot of time inside your home; your activities outside the home will be greatly limited for a time. It may be difficult for you to arrange for a babysitter and/or day care for your child, and therefore to get much-needed "alone time" for yourself.
- 6- You will spend a lot of time arranging for therapists to visit your home and to take your baby to follow-up medical appointments. And then you will spend a lot of time at those appointments. Your stress level will probably increase the further away you live from your baby's healthcare providers.
- 7- You might have to arrange for medical supply deliveries.

- 8- Unfortunately, you may have to spend much more time than you would like dealing with your insurance company.
- 9- Hopefully these worries will be balanced by the joy of having your child at home with you—finally!

How you can prepare for baby's discharge:

- 1- Prepare your home. In addition to the usual tasks of setting up a crib for baby, also set up a cart with easy-to-reach supplies. Consider having your home inspected and if baby is coming home on equipment, make sure your electricity company, etc. is notified.
- 2- Take any classes your NICU has to offer. These might include classes on how to parent your preemie (and how they differ from full-term babies), how to administer medications, how to perform CPR, and how to correctly use a car seat.
- 3- Spend the night rooming in at the hospital if this is offered. Most NICUs will give you the opportunity to “room in” to give you a chance to take care of your baby all by yourself—with the nurses still available to you if you call them. This is especially recommended if you are first-time parents, if your baby is going home on any type of equipment such as an apnea monitor or home oxygen, or if you have twins or triplets. If you don't feel comfortable and confident after one night, you can probably ask to stay as many nights as is necessary for you to feel ready to take your baby home.
- 4- Accept home services if they are available. If your baby is going home with significant unresolved medical issues, she might be eligible for home nursing services, and all VLBW babies are eligible for Early Intervention developmental services. A therapist will come to your home to evaluate your baby and to work with him/her and with you to ensure the baby is gets all the help she needs to have the best chance to meet developmental milestones.
- 5- Anticipate and prepare for social isolation during the winter cold virus season, specifically the RSV (respiratory syncytial virus) season which typically runs from November 1st to April. It is not recommended to take your baby out or to have a lot of visitors during this time period if your baby is within the first 6-12 months of life, due to the risk of acquiring RSV from others. Contact with children less than 5 years old is to be particularly discouraged, since they are most likely to transmit this virus. If you have children of your own who are that age, be vigilant about monitoring them for signs of respiratory infections and limit their contact with baby if they have fever, cough, or runny nose. If parents or other caregivers come down with a virus, wear a mask while interacting with baby. Good hand hygiene is in order for all!
- 6- Be prepared for insensitive comments, even from family and friends. They don't know what you have gone through, and they don't understand the effects of prematurity on

your baby. Think ahead about how you might respond to questions or comments that upset you.

- 7- Try to prepare any siblings your new baby might have by giving them a tour of baby's room, and giving them a "job" in helping you care for baby. Try to carve out special time with your other children so they don't feel left out or resentful of your new baby.
- 8- Be proactive about your mental health. Learn about post-traumatic stress disorder, because if you are a NICU parent, you are at risk! Try to avoid any triggers that you may notice are disturbing to you, such as loud noises/alarms, etc. Be vigilant about postpartum depression and watchful for obsessive-compulsive behaviors. Of course, these are difficult to notice in yourself, so listen to friends, family, and professionals if they suggest you might need help for any psychological issues.
- 9- Acknowledge that coping is going to be a life-long process. Many parents believe that once they leave the NICU, life will get back to "normal," but it may never be what you thought or hoped would be normal. As your baby grows, if she doesn't catch up to her age peers developmentally, or if she has more trouble in school than you expect, you will have to process that and mourn the loss of the child you had envisioned you would raise.
- 10- Be mentally prepared for the possibility of your child's rehospitalization; about 30% of babies with chronic lung disease require hospitalization for respiratory issues during the first year of life. Just when you think things are going well, your child may end up back in the hospital. This would again cause considerable disruption in your day-to-day life, and it would also bring back all the memories and worries you had about your baby's health during her first hospitalization. Your risk of depression increases if baby is rehospitalized, so try to stay on top of your feelings if this occurs and get help if needed.
- 11- Don't lower your expectations for your child or limit her opportunities unnecessarily. Your baby's doctors may have indicated the baby is at risk for a poor developmental outcome, but don't let that limit how you interact with your child. Be sure you provide your baby with love and appropriate opportunities to grow and develop. Ask your baby's Early Intervention specialist what types of activities are best for your child's age and condition. It's natural to be protective of your child, since she may have had to fight for her life, but you can't let the past completely govern the future. Try to find a balance between protecting her health and giving her chances to do things other children do, especially as she grows older.
- 12- Schedule some time away from your child, either just for you or for you and your spouse. You need "mental health" time, and your relationship needs nurturing as well.

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