



### *Parenting Your NICU Baby*

We recognize that each family is unique and it is the goal of the Holden NICU to help families cope with their specific challenges and go home united as a family.

The birth of a baby is both an exciting and scary time. Have a baby admitted to the NICU because he or she has been born early or has special needs adds layers of fear, anger, and disappointment for parents and family.

### *What are Some Common Parent Feelings?*

There is no right or wrong way to feel or act as a parent. Some cry a lot, some focus on the monitors, others come all the time, and some make short visits. Each parent has a unique response to his or her baby. Here are some of the feelings that families share:

- Anger at everyone and everything especially the staff because they have the role you want — primary care of your baby. One new mother shared how furious she was at seeing staff look more comfortable holding her baby than she did!
- Worrying about becoming “too attached” — in case something should go wrong.
- Avoiding coming to the NICU, because it is too overwhelming.
- Feeling guilty for not doing something to prevent the hospitalization or feeling responsible for causing the early birth or birth defect.
- In the case where a parent did do something that contributed to the early birth or a birth defect, feeling overwhelming guilt and anger.
- Panic when leaving the hospital, especially the first time, because of intense fear that something may happen to the baby and you won't be there.
- Powerlessness to do anything to protect the baby from feeling pain or having this experience.
- Grief over the loss of the normal pregnancy, delivery, and birth of a healthy child.
- Intense feelings of anger that this is not fair and “why me?”
- Fear that the baby will not bond with you as his or her parent.
- Self-consciousness for asking questions over and over because something doesn't make sense or you have forgotten the answer - or feeling “stupid” and not asking any questions at all.
- Fear of saying something that will upset the staff because you do not “want to rock the boat” and have staff angry with you, or worse — your baby.
- Concern over lasting emotional effects of hospitalization and it's effects on older siblings. “Will our family life ever be normal again?”
- Exhaustion from emotional drain and physical recovery from the pregnancy and birth.
- For the baby's father, exhaustion from trying to support mom and cover all of the necessary tasks of daily living as she recuperates and focuses on the baby. (Dads typically have less support and few outlets for their frustration).
- Grandparents who are trying to support their son or daughter as well as a grandchild may feel frustrated. The grandparent may feel less ability to control the situation or support the family.
- Anger at seeing other newborn babies leave the hospital with their parents.
- Frustrated that the only real answer is time for the baby to grow and develop.
- Hope that today is the day you will be able to take your baby home.

These emotions come and go, vary in intensity, or may not appear at all - all of which is OK. Slowly, families begin to adjust and settle into a routine, and eventually move towards accepting their value and role as a parent of an infant in the NICU.

### *Support Along the Way*

As the parent, you are the consistent caregiver who brings comfort and consistency to your baby when the staff changes at each shift. Recognizing, appreciating, and believing in the essential function of your role as a parent will help your baby bond, grow and eventually go home with you. To do this, whether you are here for a week or for months, you will need support along the way.

### *Individual Needs*

Throughout this time, it is important to eat, rest, get fresh air, and communicate your needs with your partner, family, friends, and medical staff. Remember that by taking care of yourself, you are taking care of your baby. It is important to give yourself time and space to work through the natural grief associated with a stay in the NICU. It is also important to take care of the details of your life — children, pets, work, activities, home — that need your attention.

### *Family and Friends*

It is also important to use the help your friends and neighbors offer or to ask them for help. They are very concerned, but are equally frustrated in not knowing what to do or even what to say. People usually want to be supportive, but don't know how. You might have to be specific about what would be helpful to you: please prepare a meal, baby-sit the older kids, or get the dog out of the house for a walk. There is a printed card available that you can hand to your friends and family that lists a number of possibilities for them to help. The clerks at the front desk can help you find that.

It is also OK to say no when friends and family want to visit the baby. It is up to you who are allowed to come to the bedside.

### *Important Points to Remember*

Most parents of previously admitted NICU infants agree on several fundamental points and offer some advice for successful parenting of an NICU infant. These include:

- Believe you have the most essential role. This is your baby and you are your baby's most consistent caregiver. Your touch and loving presence are key factors in your baby's growth and development.
- Adopt, along with staff, the philosophy of family-centered care and become as involved as you can with your baby's care and growth.
- Understand your preemie or special needs baby by asking questions, reading, talking with staff, and getting outside resources.
- Learn about developmental care. Advocate and ensure that your baby is getting it. The NICU has three developmental therapists to work with you and your baby.
- Learn what you can do to help your baby develop and grow by participating in a care plan and creating an environment that modifies light, sound, handling/touch, and positioning.
- Get the support you need to be 100% available for your baby. Eat, sleep, and use the Parent Host or staff as a sounding board for concerns and ideas.
- Give yourself permission to feel overwhelmed. There will be days that you will feel disappointed, helpless, or incompetent. Reward yourself as you begin to understand your baby and his or her cues.

And most of all, congratulations on your baby's arrival!

*Note: We would like to thank the Children's Hospital at Providence in Anchorage, Alaska for the opportunity to adapt this document for our use.*