

# *Transitional Infant Care (TIC®) Hospital*

## **A Family Centered Approach for Families of Medically Fragile Infants**

Imagine that your newborn baby girl, born prematurely, lies in the hospital and needs a ventilator to breathe. How will your family accommodate her and your needs when you take her home? Or consider that your baby boy has recently undergone surgery to repair part of his badly damaged intestine and he will need intravenous feeding for some time. How will you put a support network in place to help when he comes home to live with you?

"Situations like these can terrify parents whose infants have been born prematurely, are technology dependent or medically fragile and need around-the-clock attention and care

Our family-centered care helps them deal effectively with these circumstances," says Amy Medved, TIC's Nurse Manager.

According to Medved, TIC admits infants suffering from any number of medical conditions, including those awaiting organ transplants, those who have undergone tracheotomies, and those who suffer from respiratory disease because of prematurity, among others.

Medically fragile infants like these come to TIC when they have stabilized enough to move from a neonatal intensive care unit

(NICU) at a larger hospital.

Life has caught their parents unprepared for the circumstances of caring for them. Learning to care for a medically fragile infant requires parents to find reservoirs of personal strength and resilience they never could have imagined. When their infant is admitted to TIC, they enter a family-centered healing process that provides the knowledge, training and social support they need.

At TIC, parents undergo an intense program of education and support that raises their self-confidence as the primary caregivers for their medically fragile infants. Lucy Martha, TIC's clinical social worker assists every family through the process. She helps parents stabilize their lives so that they can re-connect and bond with their baby after he or she has spent so much time in the hospital.

Lucy enables parents to learn to integrate the medical aspects of their child's care into the context of their entire family. Many times, mothers and fathers have to incorporate caring for their medically fragile infant into their caring for their other children and into their home and work responsibilities.

Lucy recently helped Jonathan and



Sabrina Huston establish a family care plan that would effectively incorporated their son Zerick's medical care into their existing family. Zerick was transferred to TIC after an operation to repair his intestine.

"This planning was important for us," said Jonathan, "because we have three other children to care for besides Zerick -- our daughter, Selena who is nine years old, our son Jonathan who is four years old, and Zerick's twin brother, Eric."

Lucy also assisted the Flowers family in incorporating the ventilator-dependent care of their infant daughter, Monet, who was born prematurely at six and a half months and weighed only 15 ounces. She remains on a home ventilator to assist her with breathing.

Looking back on the experience, her mother, Tanya Rose Flowers said, "Lucy made sure to stop by our house on her way to TIC in the morning to pick up my 18-year-old son, so he could get the training he needed to help care for his sister once she came home."

"Besides that," Tanya added, "Lucy also notified our electric company to make our house a priority consideration in the event of an electricity failure. Though my daughter's ventilator comes with a battery, we couldn't go too long without electricity before it

cates, TIC's program further enables parents of medically fragile infants to make a transition from the hospital to home a little easier.

According to Lucy Martha, parents grow into the caregiving process by spending more and more private time with their infant. Before their infants come to TIC, health care professionals provide all the care for their baby. Making the transition to home, where there are no health care professionals, can prompt parents to feel overwhelmed.

At TIC, parents can nest with their baby and take on the greater responsibility of observing their infant and for monitoring the devices that they require, such as oxygen or cardiopulmonary monitors "Nesting helps parents to gradually take on increasing responsibility for the care of their children," says Martha, "at a pace they feel comfortable with and in ways that help them to become progres-

sively independent of the nurses at TIC."

Nesting gives families the opportunity to stay overnight and provide all of the care for their baby, knowing that the nurses are only a few steps away.

TIC continually strives to provide care for all its patients through a family centered approach.

"The most important component of this approach is the family and making sure that the whole TIC team --- from the attending physician and the nursing staff to the social worker, and the developmentalist -- look at the infant in the context of the whole family," Martha emphasizes.

She points out that one of TIC's main goals is to help empower parents to feel like parents.

"If parents can feel confident in their caregiving skills," she says, "so that they can be advocates for their child when the infant is discharged, then TIC has succeeded. One of the most rewarding parts of my job is to see a family gain confidence in caring for their child. TIC offers the place where parents can achieve that goal."

The rapidly changing healthcare environment will likely continue to change, but one thing will stay the same at TIC: Medically fragile infants and their families will have a place to be nurtured and cared for in a fami-