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Nursing parents in their worst of times

BY KAREN M. THOMAS
The Dallas Morning News

The women file in slowly.

Dr. Elizabeth Purcell-Keith has invited them into a small conference room at Dallas' Medical City Children's Hospital for a parent support group. They are the mothers and grandmothers of extremely sick children. Some of their babies were born months prematurely. Other babies have undergone surgery to correct congenital heart defects. There are older children waging war with cancer and toddlers battling illnesses that doctors struggle to define.

The women are exhausted. Some have spent days, weeks and even months at their children's bedsides, their world shrunken to a hospital ward. But now they look confused. The conference table is covered with yarn. Someone has written on a dry erase board, "Welcome to Yarn Yoga."

"Oh, you came," Dr. Elizabeth says to one hesitant mother standing in the doorway. Dr. Elizabeth isn't like the other doctors in the building. She doesn't use her last name. She doesn't physically treat the children. She holds a doctorate in family therapy, not a medical degree, and is a registered nurse. She is there for the parents.

Under Dr. Elizabeth's gentle touch, parents find the strength and skills to wade through the medical decisions they must make. They learn to control the fear and stress that threaten to unravel them.

A medical family therapist, Dr. Elizabeth, 57, has worked at Medical City in Dallas since its neonatal intensive care unit opened nearly a quarter of a century ago. She says she is one of only a few such therapists who work full time in hospitals across the nation. Other hospitals offer similar services for families, but the care is often divided among several employees and agencies. Dr. Elizabeth has a rare combination of skills.

As a nurse, she says, she learned a lot about the disease process.

The babies she once cared for, she says, received excellent treatment. "But I found that we were leaving parents in the hall, crying."

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She went to graduate school and began to study crisis intervention so she could help parents. In 1983, Dr. Rachel Griffith and Dr. Eileen Milvenan, neonatologists at Medical City who believed in focusing on the family, offered Dr. Elizabeth a contract to work at the hospital.

Dr. Elizabeth conducts sessions for nurses and other hospital employees to help them understand the grief process. She serves on the hospital's ethics committee, helping the group to stay focused on resolving conflict. Doctors refer families to her to better treat the children.

Dr. Eric Mendeloff specializes in treating congenital heart defects. His patients are usually within the first two years of their lives and require surgery. He says that despite physicians' best efforts to explain, there are times when worried parents cannot absorb medical information.

"It's overwhelming for them. Dr. Elizabeth is there to keep them grounded and remind them of the realities of things. ... She provides the stability and support that a family needs, and she does it in a way that is very calming," he says.

Dr. Elizabeth's job isn't performed in one-hour sessions behind closed doors. One of her favorite quotes, she says, is from St. Augustine. It says in part, "Since you cannot do good to all, you are to pay special attention to those who, by the accidents of time, or place, or circumstances, are brought into closer connection with you."

So Dr. Elizabeth does her job in the hallways, over the telephone, in a hospital room and even at yarn yoga.

In the conference room, volunteers from Michaels arts-and-crafts stores teach the mothers to knit and weave. It's a brief escape for parents whose days and nights are spent bedside, a place where they can drop in for a moment's relaxation, and a place where Dr. Elizabeth can make a connection.

A mother across the table sits quietly. At the start of the session, when the mothers introduce themselves, she says that her 7-year-old son has a cancerous tumor. Her eyes fill with tears.

A volunteer shows her how to cast stitches onto a loom. Now she works, eyes cast downward.

Dr. Elizabeth greets other mothers and looks at the bags of yarn that the crafts-store employees have brought. While she encourages others to take blankets and booties from a side table, Dr. Elizabeth has been watching.

Without any fanfare, she makes her way around the table and sits next to the worried mother. As the mother's hands work, Dr. Elizabeth gently begins to ask. She wants to know what the woman is making. Then her voice becomes low and inaudible. These are personal questions that are softly plumbing the depth of the woman's sadness.

The mother talks while her hands cast stitch after stitch.

This is Dr. Elizabeth's way, meeting parents where they are, assessing how she can help and then going about the work of helping them.

It is difficult, emotional work. But Dr. Elizabeth says she is sustained by her faith. And her joy comes from knowing that she has helped nurture families and shored them up with practical skills that they can use for a lifetime.

Her ability to see hope for families during their darkest times comes in part from her own

experience, she says. Dr. Elizabeth grew up poor in the housing projects of New York City and put herself through school. When she took her children back to see her childhood home, "they got in the elevator and they were glued up against the wall and cried," she says.

But her past allows her to respect people from all walks of life, she says.

"I have great hopes for them. My folks were always, 'Read, read, read,' and everything was education. There was always a feeling that we could do what we set our heads to. It wasn't easy. But you just keep going," she says.

Families who have worked with Dr. Elizabeth describe her as a friend. But Dr. Elizabeth knows that even though she cares deeply for the families, she must draw professional boundaries. She doesn't go to dinner with the families. She doesn't attend church with them. She doesn't share too much personal information.

"I think one of the hardest things I ever did is I counseled a couple who was having really big, big problems," she says. "Some years later, they invited me to their 25th wedding anniversary, and as much as I wanted to go, I didn't. That is one of my personal rules for not crossing those boundaries."

Sometimes, her work starts before an infant is born.

For the past two months, Dr. Elizabeth has spent time with Lucy, 18, of Aubrey. (Lucy and her mother, Sheree, have asked to be identified only by first names for the family's privacy.) They arrive at the end of the yarn yoga session, and Lucy looks through blankets brought by volunteers. She selects a soft pink one for her newborn daughter.

On Jan. 24, after spending two weeks in the hospital trying to control high blood pressure, Lucy gave birth to Jadyn. The baby was born more than three months early and weighed about 15.5 ounces, or the size of a can of soda.

But Lucy was prepared. Dr. Elizabeth had explained to her exactly how tiny her baby would be, bringing in a Beanie Baby stuffed toy as an example. And she told her what to expect medically. The baby already has had heart surgery.

"Dr. Elizabeth was definitely walking the walk with us," says Sheree, Lucy's mother. "She helped Lucy a ton."

While mostly women have shown up for yarn yoga, Dr. Elizabeth assists other family members, too. She teaches communication skills that help keep marriages and relationships intact.

Many couples with sick children end up divorcing, she says. "Supporting them in their relationships is real important."

Coleen Hallmark, 35, sits at the opposite end of the conference table, knitting an intricate burgundy scarf. She has brought her own materials, having been taught to knit months ago by Dr. Elizabeth.

Knitting, she says, keeps her empty hands busy. Her 18-month-old, Patrick, died in August. He survived for just weeks after being diagnosed with a rare cancer. Dr. Elizabeth and Coleen knew each other well by then. Their bond grew over the six months Patrick spent at the hospital after his premature birth in February 2004.

"Being in NICU is so terrifying," Coleen says. "You have this little baby that needs you to take care of him, and you can't. You are a useless parent. But Dr. Elizabeth makes you feel like you are a mom all the time. She's a shoulder to cry on."

When Coleen and her husband needed to talk to Patrick's doctors, Dr. Elizabeth assembled them. And when the worst news of all came, that Patrick was sick and wouldn't get better, Dr. Elizabeth helped the family arrange hospice care for Patrick. Now she stays connected to Coleen, calling every few weeks to check on her.

"When there is bad news, always it's been, 'Here comes Dr. Elizabeth around the corner to help,'" Coleen says. "I think the difference is that she has the therapy background, and her medical knowledge is so good."

The professional relationship Dr. Elizabeth forges with families can spill out of the hospital and last for years.

Frank and Robin Cornish have a decade-long connection with Dr. Elizabeth. She has helped them through difficult medical times with five of their six children, with the relationship beginning shortly after the premature births of their twin girls. One of those girls, Danielle, didn't survive.

"I was a little standoffish at first," says Robin, 36. With a degree in psychology and personal experience with family therapy after a sibling's death during childhood, Robin thought, "Oh, no, here she comes asking me, 'How do you feel?'" she says. "But she never did that. She gently chipped away at my shell.

"She has this touch and these words. She has a way of giving you things that you need, but not shoving them down your throat. She gives you energy and peace so that even at the worst moment, you know it will be OK."

When Robin was placed on bed rest while expecting a second set of twins nearly a year later, Dr. Elizabeth came to her hospital room each day, and their relationship blossomed. And when the couple learned that Blake, the youngest of their five children, had a heart defect before he was born, Dr. Elizabeth held Robin's hand during the delivery.

Blake required a heart transplant, and the family traveled to California for surgery, spending four months there. Robin frequently called Dr. Elizabeth for support.

The five surviving Cornish children - Frank, 11, Gabrielle, 10, Sydney and Sarah, 9, and Blake, 5 - are doing well. But Dr. Elizabeth taught Robin one lesson that she wants to share with others:

When a parent loses a child, Dr. Elizabeth suggests that families consider using their love for that child to help others. It keeps the love alive and allows the families to heal.

It's why Coleen has begun to knit blankets and scarves for others.

It's why the women from Michaels have donated their time and supplies for yarn yoga. And it's why Robin has enrolled in nursing school.

She wants to become a labor and delivery nurse, taking her medical and personal knowledge to help others, just like Dr. Elizabeth.

"She taught me to use what I have here," Robin says, pointing to her heart. "She is my role model. I never met anyone like her. This is truly her gift."

WHERE TO FIND HELP

Dr. Elizabeth says that families seeking professional services can turn to the American Association of Marriage and Family Therapists. They can also look for those with three types of credentials: licensed marriage and family therapists, licensed professional counselors or social workers who are accredited as advanced clinical practitioners

She advises families to ask several questions. They include asking a potential therapist about his/her experience with hospitalized patients and whether they have a specialty in end of life issues or any other topic the family is interested in exploring.

Families should also inquire how much a practice is based in that specialty. Obviously someone who only sees two families a year with end of life issues is probably not as well versed as someone who sees others more often.

She also says that therapy work should be consumer driven. If a family feels they cannot connect to a therapist, it's perfectly ok to seek out someone else.

American Association of Marriage and Family Therapists: [http://www.aamft.org/index\(UNDERSCORE\)nm.asp](http://www.aamft.org/index(UNDERSCORE)nm.asp)

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