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When birth ends in loss: Medical Center's new hospice program helps parents cope with grief

By **DEBBIE GILBERT**
The Times
GAINESVILLE

Imagine being pregnant with a baby who may not survive long after birth. What would you do? It's a dilemma that didn't exist before the advent of prenatal testing. But with modern diagnostic techniques, doctors can determine early if the fetus has a condition that is incompatible with life outside the womb.

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In such cases, patients are usually advised to undergo an abortion. But some women refuse that option and are determined to continue the pregnancy as far as they can, even though they know the baby is going to die.

"I just couldn't have an abortion," said Sicili Millsap of Gainesville, whose unborn son, Elias, was diagnosed with a serious brain defect in early 2005. "He was already moving and growing."

To help these women and their families endure this experience, Hospice of Northeast Georgia Medical Center has started an innovative "perinatal hospice" program.

Traditional hospice takes care of patients who have been given less than six months to live. Rhonda Rogers, social services coordinator for the Hospice of Northeast Georgia, said the perinatal program turns that concept upside down.

"Right now, this prebirth program is not covered by insurance, because hospice is set up to cover a (dying) patient, and in this case, the patient is not born yet," she said.

"If there is a live birth, we may be able to admit the baby into the regular hospice program. Otherwise, if the baby is born dead or dies a few hours after birth, we continue with the bereavement program."

The service is free to families and is supported by donations to the hospice, including the annual Love Light Tree program.

Rogers calls perinatal hospice "a beautiful concept."

"It allows the family to engage in a relationship with that unborn child, yet they're grieving at the same time," she said.

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Rogers said the program helps the family make decisions about how they want to handle the situation, usually through home visits from a counselor.

"Together, we write a birthing plan and present that to the hospital. For example, we ask if they want heroic (life support) measures taken if the baby is born alive," she said.

"We also discuss funeral arrangements, and even birth announcements, if that's something the family wants to do."

The counseling sessions include all members of the family, Rogers said.

"If there are other children, we do art activities with them, and we draw a family tree that includes the name of the baby. We help them create some memories to acknowledge and celebrate the child."

Millsap said the counseling was beneficial for her two older children, who were then ages 8 and 9. "It helped them to understand what was happening," she said.

After the birth, the perinatal program is similar in some respects to Resolve Through Sharing, a program the medical center has for mothers whose babies unexpectedly die shortly after birth.

"In both cases, we can take pictures of the baby and make a print of the baby's foot," said Pat Allen, director of women's services. "But the beauty of the perinatal program is that the woman can enter it during the pregnancy and also receive services after."

Allen said the hospital tries to give families as much privacy as they need, knowing how difficult it can be for grieving parents to be in a maternity ward surrounded by mothers of healthy babies.

"Moms have the option of being moved off the OB floor, but some choose to stay," she said.

In Millsap's case, her baby defied expectations. Elias was born in September 2005 and was enrolled in the regular hospice program because he wasn't expected to live long.

"After a while I took him out of hospice, because he was thriving and developing," Millsap said. "But Rhonda was always there for me. When Elias did pass away, in June 2006, she came to the funeral."

It was Millsap who provided the impetus for the local perinatal hospice program.

Not knowing where to turn after she heard her baby's diagnosis, she called the Gainesville Care Center, a nonprofit organization that encourages women not to choose abortion.

"She was looking for advice," said Mitzi Williams, a nurse who works part time at the center and part time at the hospital.

"Her doctor had told her that her baby probably wasn't going to live and told her she should terminate the pregnancy. She was adamantly opposed to that and asked us if there was anything we could do to help.

"At that point, all we could do was pray for her."

But shortly after that conversation, Williams and center director Ann Gainey attended a conference where they heard a speaker talk about perinatal hospice.

"I got in touch with Rhonda (Rogers), and she presented the idea to the hospice

directors," Williams said. "We talked to some other perinatal hospice programs around the country to see how they do things.

"And though we didn't have an official program yet, we improvised and did what we could to help this client."

Later, Williams went through hospice volunteer training, specifically so she'd be able to work as a perinatal counselor.

"When I first sit down with a client, I ask, 'What are you hoping to get out of this (program)?'" she said.

"One client asked us to be present at the delivery so we could make sure things were done the way she wanted. And we were there for her."

The perinatal program has only served a few women so far, Rogers said, but that's partly because hardly anyone knows it exists.

"We've made presentations to the obstetricians and pediatricians, and we are working on a brochure to get the word out about this resource," she said.

Williams said it's impossible to guess how many women might need the program, because no one has ever quantified how many pregnancies end up in this unusual circumstance.

"I've been working with Gainesville Care Center since 2000, and I know that for years there have been women who refuse to terminate their pregnancies and have been dealing with the grief themselves," she said.

"It's hard for their doctors to address the emotional aspects of this, so I hope they will present their patients with the hospice option."

Williams said sometimes it's difficult for friends and relatives to understand why a woman would choose to possibly risk her own health on a pregnancy that is not viable.

"You might think that women do this because of strong religious beliefs, but that's not always the main reason," she said. "Some women just want their child to be recognized as a person."

As a hospice social worker, Rogers has helped many patients and families work through their end-of-life issues. In most cases, they can look back at all they've accomplished and the experiences they've shared.

But with perinatal hospice, there is no context. Clients are dealing with a baby who will have little or no opportunity to live in the world outside the womb, yet will always be part of their family history.

"The mothers I've worked with are intensely sad and disappointed, but they want to celebrate the life of this child," Rogers said.

"It's one of the most humbling things I've seen. These women know that they can't plan for their child's future, yet there is hope and joy just in the fact that the baby is alive inside them at this moment."

Millsap said even though her story took an unexpected turn and she found herself caring for a very sick child for eight months, she has no regrets.

"God let me get pregnant with him for a reason," she said. "That was the life he was meant to have."

In August 2006, just a few months after Elias died, Millsap gave birth to a healthy baby girl, Brianna.

"She looks just like her brother," Millsap said. "Sometimes it seems like she's trying to talk to someone who's not there, and I believe Elias is with her. I think he's her guardian angel."

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