

# Prenatal hospice program helps family to cope

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Greg and Allison Wert found comfort in their deepest hour of grief. It was their faith in God and the support they received while their son, Jonathan, was a patient of the Angela Hospice Prenatal Hospice Program that helped them cope with his premature death.

"The Werts, along with their daughter, Caroline, now 5, celebrated the news in February 1999 that Allison was expecting their second child, due in the fall. Approximately 4 1/2 months into the pregnancy the Werts were scheduled for a routine ultrasound. They were looking forward to learning whether Caroline would have a brother or sister.

"We were not prepared for the news we received," said Greg.

The ultrasound revealed their son had hyposplastic left heart syndrome and hydrocephalus.

"We consulted with specialists at Beaumont Hospital, a social worker, our OB/GYN and a cardiology specialist," said Allison. "They told us his heart would get worse without intervention. The condition meant the left side of heart was significantly smaller than the right."

The Werts were devastated but quickly turned to their doctors and their bishop for guidance. After numerous visits with specialists and participation in a multi-disciplinary conference at Beaumont, the Farmington Hills couple learned the combination of defects was not encouraging.

"Either taken separately could be dealt with. Together they caused extreme complications that precluded surgery," wrote Greg in a journal he compiled titled "Jonathan - Our Precious Gift."

The medical options included surgery almost immediately after birth, a heart transplant (eventually ruled out), terminate the pregnancy or continue it.

"They told us without any intervention Jonathan probably wouldn't live long past his birth," said Greg. "Maybe two days."

Heavy-hearted the Werts turned to prayer. "Abortion was not an option. We felt the surgery would be too painful and risky for the baby so we chose to go ahead and pray for a miracle," said Allison.

To reduce further risk to the baby or mother, Allison's labor was induced, and Jonathan was born Sept. 16, 1999.

"Allison delivered Jonathan naturally and he was blue for about 10 minutes," said Greg. "The doctors confirmed their original diagnosis and told us he would probably live for 48 hours."

## Preparation

Through much conversation and prayer the Werts prepared their three-year-old daughter Caroline for Jonathan's birth and anticipated death.

"We talked about Jonathan a

great deal and told Caroline we would love him as much as we possibly could for as long as possible but that he might not be with us very long. We also told her he would not be able to live with us, and for the little while he was here we'd enjoy it."

Their decision to continue the pregnancy was not accepted by all. Greg said some members of his immediate family believed they made the wrong choice.

Greg recalls in his journal that family members asked whether he and Allison were being "martyrs." If the baby did live by some miracle, what kind of quality of life would he have, they wondered. And if they didn't ter-

minate, "why not force the doctors to go ahead with the high-risk surgery?"

In the end, some family members distanced themselves.

Hours after Jonathan's birth the Werts were put in touch with care providers at Angela Hospice in Livonia. They began to find closure.

"It's a hard stress going through a pregnancy knowing the baby is seriously ill," said Wendy Winkler, pediatric nurse manager, Angela Hospice.

"There are so many family pressures. 'Why didn't you get an abortion' or 'We're glad you didn't get an abortion.' And then there are religious differences in

the family. All those issues we're so good at."

## Prenatal hospice

Since Jonathan's birth Angela Hospice has initiated the first hospice program in the Midwest to offer support to families of seriously ill infants starting in the prenatal stage. Hospice staff felt the program, one of only two in the United States, should allow parents the choice of receiving counseling and support before the birth of their baby.

The Werts connected with Angela Hospice after Jonathan's birth; however, had the program been instituted at the time, they said it would have been equally, if not more valuable, than the support they received after his birth.

"I can think of nothing but positive outcomes that would come from having support before Jonathan was born," said Allison. "The people we came to know and befriend through Angela Hospice were there when we needed them and gave us the support to make the choices and decisions that were necessary."

In 1999 Angela Hospice only had the My Nest in Best program for parents and families of terminally ill children, but they intended to extend that support to before birth. Earlier this year, under the leadership of Angela Hospice Medical Director, Dr. Jim Boal, Pediatric Manager Wendy Winkler, and Pediatric Social Worker Leslie Feret, the Prenatal Hospice Program came to fruition.

Hospice support should begin as soon as possible to achieve the greatest benefit, say organizers. Prenatal hospice care should be initiated at the time a mother is referred to a high-risk obstetrician, during the birth process or shortly thereafter.

"The goal of hospice is to get the baby home soon with less invasive treatments," said Boal. "Nobody wants to be in the hospital. The slogan of My Nest is Best is that children be treated in the home."

"Caring for the child at home enhances parents' sense of achievement ... it might just be one little thing ... we got our

babies home," said Winkler.

The Werts thought Jonathan would die in the hospital. However, their "little miracle," as Allison and Greg call him, surprised everyone.

The hours turned into 20 and then two days, and before we knew it the nurse in NICU was getting the paperwork ready for us to check out and send Jonathan home," said Greg.

Strong-willed, alert and smiling, Jonathan became acclimated to his parents, his big sister and his surroundings. Although he didn't grow much physically he was conscious, responded to the world around him and went everywhere with the family including a Christmas vacation in December 1999.

Greg wrote, "I especially remember him sleeping on my chest on the sofa as if our hearts were working together. Our miracle was that we were able to know him and love him for the seven months he lived. Every day was precious."

Although a nurse and social worker didn't visit the Werts everyday, Allison and Greg knew if they needed them they would be there without question. The nurses and social workers provided assistance with feeding, medications and oxygen, as well as counseling and emotional support. Caroline was included in everything. The staff from Angela Hospice became like family.

## Saying good-bye

The last month of Jonathan's life the Werts say he didn't smile as much. His energy level started winding down and required an increase in his medications to make his breathing easier.

"He died in his sleep," said Allison.

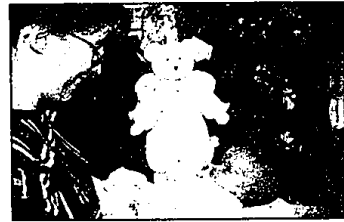
A memorial service was held two days later at The Church of Jesus Christ of Latter-day Saints in Farmington Hills. Allison's father delivered the eulogy.

The Werts involvement with Angela Hospice and their staff hasn't ended. They attended a special annual memorial service offered by Angela Hospice, group therapy and other support-based activities.

"(They) helped us to understand that just because Jonathan isn't here anymore doesn't mean he's not still a part of our family. We don't mind sharing Jonathan's story and we want to tell people what hospice has done for us," said Greg.

"We made the right decision for our family."

The Prenatal Hospice program will help families who experience a miscarriage, premature birth or stillborn. Parents may have to contact Angela Hospice regarding the prenatal program directly. To learn more, call Wendy Winkler, (734) 953-6013.



Celebration: Allison Wert plays with her three-month-old son Jonathan at Christmas in December 1999.



Family Portrait: Greg and Allison Wert of Farmington Hills with their two children Caroline and Jonathan in December 1999.

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