



Photos by Jeff Ruppenthal / Lancaster Newspapers

Elizabeth Stoltzfus' young life was cut short. "Throughout the multiple hospitalizations, we felt very alone," says Lisa Stoltzfus.

New Era, 12-13-05

# Stolen dreams

## When a child is terminally ill, family members and the health-care community struggle to cope

By SUSAN JURGELSKI  
New Era Staff Writer

**T**HERE WAS LITTLE time for celebrating first steps and first words.

Elizabeth Stoltzfus, who was born without a spleen, spent most of her short life battling to survive. She was in and out of the hospital 30 times before she died from complications of meningitis at the age of 2.

When Elizabeth's parents, Lisa and Dwight Stoltzfus of Manheim, learned the devastating extent of their daughter's illness shortly before her first birthday, they started grieving.

"It was like all of our dreams for her were just gone," says Mrs. Stoltzfus. "You don't dream about your daughter spending her life hooked up to feeding tubes. We began to mourn her loss long before we lost her physically (in 2002)."

The Stoltzfuses also longed for support.

"There just did not seem to be any 'so-your-child-is-neurologically-devastated' support groups out there," Mrs. Stoltzfus says.

Please see DREAMS page A7



"Elizabeth did not have a problem they could fix," says Lisa Stoltzfus, with husband Dwight.

## There is help for grieving parents

By SUSAN JURGELSKI  
New Era Staff Writer

**K**AREN NORTHEIMER-KITCH OF Brownstown tries to lighten grieving parents' darkness.

As volunteer facilitator of Loss of Child, one of several support groups Hospice of Lancaster County offers to help people grieving a loss, Northeimer powerfully connects with fellow parents.

Eight years ago, Northeimer-Kitch lost her 16-year-old daughter, Alex Weitzel, to colon cancer.

Northeimer-Kitch is continually amazed and gratified by her impact on members of the group.

Please see SUPPORT page A7

# Dreams

Continued from A6

Like many parents of terminally ill children, the Stoltzfuses weathered the prolonged stress of dealing with multiple members of the health-care community, who sometimes gave divergent advice about Elizabeth's care and prognosis.

The Stoltzfuses encountered both compassion and callousness.

"Elizabeth did not have a problem they could fix, so they were at a loss as to how to help us," Mrs. Stoltzfus says. "Because she was so neurologically devastated, people would act like she didn't feel pain, or maybe her pain wasn't valid."

The Stoltzfuses, who now have two sons, 2-year-old Brandon and 3-year-old Caleb — who ironically was born on Elizabeth's birthday — ultimately sought the help of Hospice of Lancaster County.

"We longed for professional advice," says Mrs. Stoltzfus. "But most of all, we longed to hear from parents who had walked the same pathways we were walking."

\*\*\*

A child's death is out of season.

No parent plans for a baby blanket to become a shroud.

Some 500,000 children cope with life-threatening conditions annually in the United States; more than 50,000 die.

Congenital and chromosomal defects most often lead to infant death.

According to the Pennsylvania Department of Health, the majority of state deaths in children between 1999 and 2003 occurred before age 5. In 2003, 39 Lancaster County children under age 5 died due to perinatal conditions or birth defects.

"In Lancaster County, where there is a high percentage of (seniors), we think about older people with serious illness, not children," says Dr. Joan Harrold, medical director and vice president of medical services with Hospice of Lancaster County. "It's not the numbers (of deaths) themselves. There are a larger number of children living with these illnesses."

The real challenge, says Harrold, is to provide effective care



After Elizabeth died, the Stoltzfuses longed for advice.

for ill children and their parents — and to cultivate a team approach in the professional caregiving community.

To further that goal, Hospice recently spearheaded and co-sponsored a community-wide educational program for professional caregivers and families of terminally ill children, called "Working Together When Children Need Help: Hospitals, Home and Hospice: A Conference on Pediatric Palliative Care."

"It's uncommon for all of these entities to be under the same umbrella," Harrold says. "But for the families, we are their one and only health-care system. We have to know each other, work with each other."

\*\*\*

Dealing with multiple members of the care-giving community can be a mixed bag for parents of terminally ill children.

"At best, these professionals will exemplify 'medicine with a heart,'" says a 2003 Institute of Medicine report. "At worst, families' encounters with the health-care system will leave them with enduring painful memories, anger and regrets."

"Throughout the multiple hospitalizations, we felt very alone," says Mrs. Stoltzfus. "We had the support of family and friends, but the medical professionals were unable to give us the comfort we needed."

Through Hospice, the Stoltzfuses were able to deal with their guilt and conflicting emotions.

"The decision to allow our daughter to die is not a decision any parent should have to make," says Mrs. Stoltzfus. "The guilt you can feel as a parent who 'allows' your child to die can be overwhelming."

Patti Homan, program director for Hospice's Pathways Center for Grief and Loss, says losing a child results in a long, complicated grief process, whether the loss is of an infant or an adult.

To help them deal with their grief, the Stoltzfuses were referred to Hospice's Caregivers and Loss of Child support groups.

"As we listen to the grief of others, we have been able to move our grief from the forefront of our lives to the shadows," Mrs. Stoltzfus says. "It is always present, but it is no longer an overwhelming darkness."

"Now we have sunshine with shadows of grief."

\*\*\*

As a physician and a parent, Harrold believes in putting herself in the shoes of parents coping with a terminally ill child.

"I would want my child to be well cared for," she says.

She recalls taking care of a terminally ill 3-week-old baby who had an extra finger on one of his hands.

His five brothers and sisters came to visit him in the hospital. The parents nervously tried to prepare them for their first look at their brother and explained about his six fingers.

"The (children's) eyes got big, and they said, 'Cool!'" Harrold recalls. "It was a real warm lesson about the power of other children to love and to accept a younger child who was not going to live."

A visit from a young member of the family's church Sunday school also impressed Harrold.

"One of the girls touched him and talked to him, and she looked at me with big, sad eyes and said, 'I don't want him to die.'"

"There was a purity in that moment. I told her I didn't either. She just needed to know she wasn't by herself in that wish."

"I think that's really the way it is for anyone in this situation. They just don't want to go through it alone."

# Support

Continued from A6

"I'm often surprised at the end of group, when someone comes up and thanks me for something I said," says Northeimer-Kitch, who has a 16-year-old son, Derringer Kitch, and a 13-year-old daughter, Sarah Kitch. "I never felt like the group was something I would ever be involved in. I'm a very private person.

"I guess you can say, in a spiritual sense, I was led to help."

It was actually Alex who led her to volunteer at Hospice.

During her illness, Alex chose to develop her own support system rather than attend a support group at Hershey Medical Center, where she received treatment.

"Alex was a little firecracker from the day she was born," Northeimer-Kitch says. "She had a will of steel. She always knew what she wanted to do."

Alex believed that her friends were her main support, so with the help of a school guidance counselor, she spearheaded Hospice's Soulmates, which pairs volunteer teens with kids who are chronically ill or experiencing a loss.

Northeimer-Kitch first helped with Soulmates and then was invited to help lead the Loss of Child group.

The group, which meets the last Tuesday of the month, has an



**"Alex was a little firecracker from the day she was born," says mother Karen Northeimer-Kitch. "She had a will of steel. She always knew what she wanted to do."**

outline as a guide but often sets its own agenda, Northeimer-Kitch says.

"The holidays and special occasions are often difficult times, so we talk about how to get through them," she says. "We tell (parents) you need to create a new normal; the old normal is gone."

Parents who lose a child have a secondary loss, she says.

"You are losing not only your child but the dream of what that child could have accomplished.

"You are losing that future."

## HOSPICE SUPPORT GROUPS FOR PARENTS

### All Loss

12:30 to 2 p.m. the second Tuesday of the month at Hospice of Lancaster County's Pathways Center for Grief and Loss, 685 Good Drive, and 7 to 8:30 p.m. the first Thursday of the month at The Ephrata Cancer Center, 460 N. Reading Road, Ephrata

### Loss of Child

7 to 8:30 p.m. the fourth Tuesday of the month at the Pathways Center

### Caregivers

6:30 to 8 p.m. the last Wednesday of every other month for families receiving care at Hospice. The meeting is held at the Pathways Center. In 2006, Hospice will offer a series of educational forums for all caregivers.

For details, call the Pathways Center, 391-2413.