

A celebration of life — and love

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Danville woman throws reception for husband claimed by ALS

By Emily Stone
Free Press Staff Writer

DANVILLE — One Sunday morning last fall, Heidi and Curtis Vance sat beside each other in their new home and picked a date for their wedding. That same morning, they designed Curtis' gravestone.

He had a mask over his nose to help him breathe. A feeding tube into his stomach delivered the nourishment he could no longer swallow. He could move only his head.

For more than a year, Curtis' nerve cells had been dying. At 26, the formerly vigorous man was in the final stages of ALS, a fatal illness commonly known as Lou Gehrig's Disease.

"Here we are, two 20-something-year-olds planning a wedding and a funeral at the same time," said Heidi, now 25, thinking back to that day. "It was absolutely surreal."

Curtis died in December, three weeks after their wedding.

Their story, however sad, is also one of inspiration. Heidi and others talk about how much joy the couple had in their lives while Curtis was dying. They threw parties, from summer barbecues to a pumpkin-carving and Christmas tree-lighting celebrations.

People around them were struck by how they became complete partners. When Curtis lost his ability to speak clearly, Heidi talked for him. Sometimes, she could sense what he needed by looking into his hazel eyes.

"They could have just huddled together and kept out the world, and they opened up and let the world come in," said Curtis' mother, Linda

Vance. "Everybody was in love with them. It was like a fairy tale."

Now she has one more party to throw.

When they were planning their wedding, Curtis said he wanted it to be in the spring, when everything is in bloom. Heidi insisted they do it sooner, because otherwise, it might not happen at all.

Their compromise was to hold the wedding and a low-key reception in November, and the full-blown reception, complete with dancing, in the spring. Curtis was there in his tuxedo for the wedding, but he didn't survive for his party.

Tonight, Heidi is having the spring wedding reception. The party — and the planting of an apple orchard Sunday — kicks off the fund-raising for a charitable foundation Heidi set up in Curtis' memory.

"I see it," Heidi said, "as a celebration of Curt's life."

Longtime sweethearts

Heidi and Curtis knew each other for eight years before he became sick.

The summer Heidi was 15, she taught swimming at Joe's Pond in West Danville, where her family has a cottage. The two met, dated and remained good friends after Heidi went home to Connecticut.

They stayed close the following summers, and began dating seriously while Heidi was a student at Middlebury College. Curtis was splitting his time between working construction in Danville and staying with an uncle in South Burlington while working at IBM.

They knew they would eventually get married, but they took their time, determined first to find their own place in the world.

Then, in the summer of 1998, strange things started happening to Curtis. A workaholic who loved to be outside, he was used to being constantly on the go. Suddenly, he couldn't keep up with Heidi on bike rides. He



Heidi and Curtis Vance on their wedding day.

wanted to go to sleep at 7 p.m. One day, he walked out of the Danville General Store and fell flat on his face.

At the time, the couple didn't know what to make of it. Heidi laughs when she remembers how she thought she'd solved everything by sending Curtis off to work with a jug of water and a handful of vitamins.

In December 1998, Curtis was diagnosed with ALS. From one day to the next, he lost fundamental abilities. He couldn't press the clutch to drive a car with a manual transmission. Then he couldn't drive at all. Stairs were impossible. Eventually, so was standing up.

Early in 1999, the couple moved from their apartment in New Haven to a new house in Danville. The house had been built for Curtis' aunt and uncle, who didn't need it yet and were willing to let them stay there indefinitely. Curtis had been part of the construction crew that built the house.

As the spring and summer passed, the two learned to adapt. The small house quickly acquired a hospital bed, a wheelchair, a hydraulic lifting device, a special bathtub and the breathing machine. Creative thinking with the new gadgets allowed Heidi to rig up ways to care for Curtis virtually single-handedly.

Money was tight. Curtis' insurance from IBM helped, as did money Heidi earned from waitressing a few days a week in town. They also had substantial support from the community, which raised \$10,000 for them last spring.

Their house became a gathering place for friends and family. Curtis spent as much time as possible outside enjoying the mountains and their garden, cracking jokes all the while and cheering up those who came by to cheer him.

It was their natural instinct to make as much as they could out of every day together, Heidi said. They never thought about withdrawing or giving up. No matter how exhausted she became, Heidi said, there was never a single moment when she thought she would crack. Curtis' strength fed hers.

"I knew while he was alive I could do anything," she said.

Heidi's younger sister, Tricia Erdmann, lived with them last summer. She said visitors were often surprised by how happy they were.

"It was really just the most amazing summer," she said. "They grasped this disease and used it in such a positive fashion. They took a lot of people with them on that positive journey."

Taking control

If they couldn't control what the disease was doing to Curtis physically, they were determined not to lose control of themselves emotionally. Creating joy in the face of such sadness was one of the few ways they could take charge of their lives, Heidi said.

While upbeat in public, Curtis sometimes lashed out in anger and frustration when alone with Heidi. One time, she remembers saying to him: "I can stand to watch you die, and I can stand to watch the disease eat you," but she would not "let the disease take who we are."

Nothing could stop the sickness, though. By August, Curtis was immobile except for his head.

With his nighttime breathing mask on, he couldn't talk, so if he woke up and needed Heidi, all he could do was nudge her with his head. She learned to sleep on top of him.

It wasn't until October that they decided to get married. When diagnosed, Curtis had said he did not want to marry Heidi and then die, but he changed his mind. His illness helped them both establish a relationship with God, Heidi said — not so much through religion as through spirituality. A wedding was a way to stand before God, family and friends and be united.

It also legally ensured that Heidi could take charge of Curtis' care.

In November, Heidi walked down the aisle at a St. Johnsbury church in her aunt's wedding dress, as Curtis sat in a special chair at the front, surrounded by his four brothers. He smiled as much as he was able to, letting the rest of his happiness come through in his eyes.

Although the day was beautiful, for many of the 500 guests the wedding seemed like a formality. "They were married a long time before that," Linda Vance said.

His last morning

Heidi's hand was on Curtis' heart when she felt it stop beating.

No one expected him to die quite so quickly. He was doing well, especially after starting morphine a few days earlier to help ease the sensation that he was choking. The night before he died, a Saturday, he went to a family Christmas party.

Sunday morning was awful. Curtis slept fitfully and kept shaking his head in his sleep. Then he stopped opening his eyes. At 10 a.m., Heidi noticed his ears were turning purple.

What is ALS?

■ **THE DISEASE:** Amyotrophic lateral sclerosis, or ALS, attacks nerve cells in the brain and spinal cord. It leaves them unable to send messages to the body's muscles, so movement is lost.

■ **SYMPTOMS:** Early symptoms include weakening muscles in the arms and legs, and trouble with speech, swallowing and breathing. Eventually, paralysis sets in. For most people, the mind is not affected.

■ **WHO GETS IT:** About 5,000 Americans are diagnosed each year.

His whole family soon gathered at the house. They told Curtis as each new person arrived. Heidi noticed that his chest was turning purple.

With his family around him, as his mother read aloud a letter about her love for him, Curtis died. Heidi, who knew first, crawled on top of him. At first she was trying to stop him from leaving. Later, she realized it was because she wanted to just crawl inside of him and leave, too.

'A real direction'

All the energy that went in to caring for and being with Curtis now needs somewhere to go, Heidi said.

The two worked on establishing a foundation for ALS research, but Curtis told her to wait until he died so she could give it her full attention. That's what she's doing. She is also working on a novel to tell their story. Though it will be fiction, it will include details of the trials in day-to-day life that are missing in other books on ALS, she said. She's still waitressing in town and

About 10 percent of cases are genetic, the rest are seemingly random. The average age for developing the disease is 55. It is more common in men than in women.

■ **TREATMENT:** There is no cure treatment to stop or reverse ALS. One drug modestly slows the disease's progression.

■ **SURVIVAL:** Half the people with ALS die within three years; 20 percent live five years or more; up to 10 percent live more than 10 years.

■ **INFORMATION:** Check the ALS Association Web site at www.als.org.

has been teaching and coaching tennis, something she did before Curtis became ill.

Two years ago, she said, her life lacked a focus. She spent months applying for jobs at even large companies in the area, thinking it was more important to make a lot of money than find something she loved. She was a young woman struggling to figure out who she was. Now she has many of her answers.

"I feel fortunate to be so young and have a real passion and a real direction," she said.

This weekend will be a happy occasion, but Heidi knows it will also be hard. Curtis had been intent on dancing with his wife at the reception.

Often, Heidi feels Curtis' presence, especially in dreams. Curtis stands out in particular. She is walking in the woods and comes into an apple orchard, something Curtis always wanted. Standing among the trees, she feels Curtis' spirit come embrace her. They dance.