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Lost in a system

By Mary Ann Roser

They met when they were 14 at the Arkansas County Livestock Show Talent Contest in 1967. She asked the handsome guitar player to hold her cat-eye glasses while she danced. He told the willowy strawberry-blonde, who, at 5 feet 10 inches, was nearly a head taller, that he would under one condition: He wanted her phone number, too.

They lived in Arkansas towns 26 miles apart but became inseparable. Five years later, attending different colleges, they drifted apart. Ann Bosma married someone else, and so did Delbert Davis.

In May 2003, both single again and on the Internet, each wondered about the other. They connected on Classmates.com. Ann, still in Arkansas, and Delbert, in Austin since 1979, bridged a chasm of three decades with soulful phone calls and flurries of e-mails.

They reunited at the Austin airport in October 2003. Delbert whisked Ann away to Houston to see a show of 19th century masters, celebrating a love of art they had discovered as teenagers. Then off they drove to Galveston for a romantic weekend of strolls on the Strand. Ann, recovering from the death of a husband three years earlier, recalled thinking, "I didn't know a person could be this happy."

In January 2004, she moved to Delbert's Lakeway duplex. They were planning a wedding. "We just decided it was fate," Ann said.

Her sister, Jane Thyfault, said, "It was like watching someone . . . falling in love for the first time. They were 50 years old, and they were acting like they were 16."

Then Delbert got sick.

Neither Delbert nor Ann had any idea he was about to join an untold number of Americans suddenly caught without insurance and dependent on a procedure they could never afford.

Nor were they prepared to confront a medical system that could treat his symptoms but repeatedly turned him away from what he needed most: the chance to receive a new liver. In three years, the struggle would take nearly everything they had.

Delbert had been working as a printer for two decades when he and Ann married on March 17, 2004. He was the business partner of a woman who then owned a Lakeway printing company, and Delbert had been her romantic partner for seven years. The business relationship soured and, after employee cutbacks, Delbert lost his job — along with his health insurance — later that year.

Ann didn't have coverage with her new job, either. She was an adjunct history instructor at Austin Community College and had to wait three years for insurance, she said.

The lapse could not have come at a worse time.

Delbert, who was president of the Lakeway Rotary Club that year, fell ill on a Rotary outing to Fredericksburg in December 2004. He vomited blood — so much blood he went to the hospital.

The diagnosis was grim.

His liver was seriously damaged. He had cirrhosis. Dr. Stephen Utts advised Delbert, who drank heavily when he was younger, to stop the occasional drink and start eating better. Delbert never drank again and followed a strict diet.

"We were told it was possible his liver could regenerate, " Ann said. "We were told to wait and see."

As time wore on, Delbert had more gastrointestinal bleeding. Later, his belly stuck out from retaining fluid, as much as 16 liters at one point. Health insurance never seemed more urgent — or more elusive.

Ann continued teaching, and Delbert eventually found a part-time job at Target, but he didn't work enough to get insurance. Still, they were newlyweds, reveling in their love. "Every time I got around Delbert, he said, 'Do you know how much I love your sister?' " Thyfault recalled of visits from Mississippi.

They read to each other, loved music, laughed at all the same jokes. They cooked with herbs plucked from their garden. On a big chair at home, Ann knitted while Delbert, who loved the clackety-clack of Ann's needles, snuggled beside her, finishing a piece of cloth he had woven on a loom in the living room.

"He made me laugh, " said Ann, who had been heartbroken after her first husband of 12 years lost a 10-year cancer fight. "He made me young again."

But Delbert's failing liver was like a shadow over them. Stable periods were spliced with scary hospitalizations. With no insurance, the money Ann brought to the marriage, about \$10,000, evaporated, she said.

By October 2005, the couple was drowning in "upwards of \$200,000" in bills, Ann said. They declared bankruptcy, falling into a familiar pattern: More than half of all Americans who file for bankruptcy do so because of health-related financial woes.

"It's a place I never thought I would see myself ever in a million years, " Ann said. "I've always paid my bills, and I've always had adequate protection for life and health. . . . It was a very shameful moment for both of us."

The bankruptcy didn't wipe the slate clean for Delbert and Ann. For five years, \$1,875 a month will go to a long list of creditors, including doctors, hospitals, pathology labs and lawyers. Payments start next month, Ann said.

Meanwhile, Delbert was accumulating more bills, Ann said. She recently pulled the first one from a pile: \$38,544.68 for a hospitalization in April that included blood transfusions and intensive care.

Utts said then, more than a year after Delbert got sick, that his liver wasn't regenerating. In fact, it had quit working. Delbert had to have a transplant.

Without one, Utts said, he would be dead in a year.

Delbert, Ann and their loved ones were shaken. But they reasoned, if Delbert needed a liver, he should get on the transplant list. To their shock, they learned the system doesn't work that way.

"It was, 'Show me the money . . . and we'll get you on the list, ' " Ann said.

No hospitals do liver transplants in Austin, so patients typically go to San Antonio or Dallas, where the cost can vary from \$120,000 to \$500,000 depending on the patient's condition, said Leni Kirkman, a spokeswoman at University Hospital in San Antonio, a liver transplant center.

Right now, 1,380 Texans and 17,115 Americans are waiting for a liver, according to Annie Moore, a spokeswoman for the United Network for Organ Sharing, the Richmond, Va., nonprofit that oversees organ procurement and transplantation in the United States. Last year, 507 Texans received livers. Another 143 who were on the list died because organs are so scarce.

That doesn't include people like Delbert. He couldn't get that far.

He called two of the three liver transplant centers in San Antonio — the public University Hospital and the private Methodist Healthcare System. Both said he needed health insurance or government coverage — either Medicare, a program for the disabled or elderly, or Medicaid, which mainly covers poor women and children in Texas, Ann said. Because Delbert had none of those coverages, neither hospital would put him on the transplant list, Ann said.

"We can't. Safety net hospitals are forced to make very tough decisions," Kirkman said. "We wish we could provide every medical service, but it would be fiscally disastrous for us to do that."

For-profit hospitals are more able to provide free care, Kirkman said. But a procedure that costly is difficult, Methodist system representatives said.

"Unfortunately," said Marissa Alicea, a financial adviser at Methodist's Texas Transplant Institute, "if they don't have any coverage, the burden is too great" for the hospital. Methodist System spokeswoman Palmira Arellano said the institute actually has "a very good charity policy," and she didn't know why Delbert wasn't informed of it. She did not provide information about how many free liver transplants, if any, the hospital performed last year.

By the time Delbert knew he needed a transplant, Ann was teaching for ACC and St. Edward's University. In August, she took a third job at a bookstore. Delbert's full-time job was getting a liver. He focused on finding health coverage. But even that seemed impossible.

His doctor had seen it all before.

"What insurance company is going to insure someone staring down a half-million-dollar bill?" Utts said.

"There's a disdain for universal coverage, and it's tragic," he added. "In 20 years of practice, I've probably seen hundreds of patients" who died because they lacked coverage and couldn't get on the transplant list.

"This could happen to anyone," said Ann Kitchen, a former state representative and executive director of the Indigent Care Collaboration, a group of Central Texas safety net providers.

With one-fourth of Texans lacking health insurance and fewer businesses covering workers, "that's the kind of Catch-22 our chopped-up system results in," Kitchen said. "People don't realize that really happens . . . to average, working people . . . following the American dream."

Delbert's family and friends said they'd try to raise the money. Delbert mentioned that on his Web site, www.delbertspage.com, and wrote about what it was like to be told he had a year left. He said he was "too busy to wallow in self-pity."

Lyn Pierce, his ex-wife and a good friend, said, "I realize now it was a pipe dream to raise that much money. I went through a lot of anger at the system."

Delbert, who had a degree in social work from the University of Arkansas and volunteered with literacy and animal rescue groups, not to mention the Rotary, wasn't angry. He believed help was out there; he just had to find it.

But time was running out.

Delbert's trip to the Medical Assistance Program for needy people in Travis County left him in tears. He was turned down on the spot; he wasn't poor enough, Ann said.

So he asked about the state's Health Insurance Risk Pool. His premium would be \$850 a month, and a transplant could not be covered for a year.

Delbert and Ann couldn't afford the premium. And Delbert didn't have a year.

He applied for Social Security disability so he could qualify for Medicare but was rejected because he owned a residence and Ann had income from working.

Delbert asked his congressman, Rep. Lamar Smith, to intercede. An aide in Austin, Sheila Brown, jumped on the case, and Social Security quickly approved disability payments: \$1,200 a month. His first check came in September.

With that, he could qualify for Medicare. But not for two years.

Delbert couldn't wait two years.

The hurdles to get coverage seemed ridiculous to him, said his 22-year-old son, Daniel, who shared Delbert's passion for playing guitar, flying kites and fixing bicycles.

"He never appreciated the fact the government was going to let him die," he said. "Medicare makes you wait two years to get coverage hoping you'll die. Much to his credit, he avoided blaming anyone."

Medicare spokesman Don McLeod said, "Our hands are tied. It's in the statute."

Congress made exceptions to the 1972 law for people with Lou Gehrig's disease and for people with end-stage kidney disease, McLeod said. But not for people who need livers.

"My husband and I have worked hard all of our lives, " Ann said. "We had insurance up to a very brief window of time: three months that we didn't have coverage, and this happened. Just that little lapse of time . . . and we were trapped in a spiral that we couldn't get out of. "Had he been a homeless person on the street, he probably would immediately have been accepted for Medicaid, and he probably would have gotten on the list. That's the irony of the whole situation."

Delbert finally found hope at a support group for liver patients.

He met Kindell Badgley, who was diagnosed with end-stage liver disease in 2003. He was a former night club manager and lost coverage when he got a job at a small business.

"I went to work every day, and I struggled like every other middle-class American, " Badgley said. "I paid my bills every month. . . . I got sick, and my government said, 'You need to pack it in, put your affairs in order, suck it up.' It probably angered me enough I stayed alive to fight them."

Badgley, now 50, went to University Hospital with his close friend, Diana Soliz, a financial planner in Austin. While talking with a transplant counselor, Soliz said Badgley was trying to get Medicaid. The counselor's face fell when she told them that she couldn't help if Badgley didn't have health coverage, Soliz recalled.

"We kind of panicked, like, 'Oh, no.' We knew Kindell was dying."

Soliz said she went home and "hit the Internet with a vengeance."

Badgley was on Social Security, and Soliz discovered a program on the agency's Web site that might qualify him for Medicaid. Called the PASS program, or Plan to Achieve Self-Support, it requires making a plan for returning to work after a transplant.

Badgley would create an education account after his transplant and would have to set aside more than half of his disability check, putting him below the poverty level and qualifying him for Medicaid. His friends helped pay his living expenses so he wouldn't be homeless. Most Social Security workers Soliz encountered had never heard of PASS, she said.

"It's a shame people on their last legs, they have to go on this hunt-and-see to get help to stay alive, " she said.

Badgley was approved and moved to the top of the transplant list on March 26, 2004, when he was close to death. He was called to University Hospital for surgery April 1, and Soliz recalled a scary two hours when his coverage didn't show up in the computer and she scrambled to prove he was covered.

Badgley told Delbert about the PASS program, and Delbert called Soliz on Aug. 28 for help.

Ann couldn't understand why no one with any of the programs they had contacted had ever mentioned it.

"We had an almost childlike faith that there would be people there to help us, and these people are so overwhelmed that they don't even know what programs they have to offer," Ann said. "It's like a cattle call. You go to an office like this and there are haunted-eyed looking people sitting there, and the people who are processing them are just herding them through, and you just become a number."

Delbert went to work on the application in September. His plan was to be a public speaker, sharing the obstacles he faced in getting a transplant so he could help others.

August and September were rare months without any hospitalizations. "We almost fooled ourselves into thinking he was going to be OK," Ann said.

October would be the third anniversary of that blissful beach weekend, plus their 54th birthdays: Delbert's on Oct. 5, Ann's on Oct. 25. Delbert asked Ann what gift she wanted. "I said, 'I want you to get a liver. I want you to get your life back.' If somebody had told me we were going to be able to get him into surgery and get a liver for him, I could have cheerfully given up every birthday, every Christmas, every happy occasion for the rest my life."

At that point, divorce seemed more likely.

With Ann's income added to his disability payments, Delbert wouldn't qualify for PASS. "We were talking about seeing a lawyer" to discuss a divorce, Ann said. It was something neither wanted. But it never came to that.

Ann couldn't awaken Delbert on his birthday. His liver couldn't detoxify the ammonia in his blood, and he fell into a coma for 53 hours. When he regained consciousness at South Austin Hospital, he begged to come home Oct. 10 to celebrate his birthday. Friends came to the house that Saturday.

"That was the most amazing little party," Ann said. "He had the best time. He had cake." The next day, they went to Central Market for apple cider, and he insisted on picking up Halloween candy for the neighborhood children. On Oct. 17, he felt so sick he asked Ann to take him back to the hospital.

That week, Ann was exhausted from driving between her three jobs and the hospital. On Delbert's third day there, she told him over the phone that she'd see him Friday when she wasn't afraid of driving off the road.

The phone rang at 6 a.m. Friday. It was the hospital; Delbert was unconscious. Ann hurried to his side, but Delbert never knew it. He slipped away that afternoon.

"I didn't get to say goodbye, " said Ann, breaking down. "It haunts me."

Chip Kidd, who called Delbert "the brother I never had, " had a memorial service Oct. 28 in his family's backyard that drew 85 friends and family members. They recalled Delbert's humor, creativity and dignity facing death.

"All he wanted was to get to the list, and we couldn't get him there, " Ann said.

She said they would have done some things differently, such as written a will and started looking for a transplant sooner.

She fears losing the house. After the bankruptcy payments and a mortgage of \$1,100, she will have about \$660 left each month to cover the rest of her bills.

But she is determined not to be bitter, she said, because Delbert wasn't.

She wants to warn others: Get health insurance. Know the signs of liver disease. Be your own advocate.

She has a lot of unfinished business, especially her grief. Her love of teaching keeps her going, and she keeps reminding herself: "Do what Delbert would do, and you're going to be OK."

After losing her second husband in six years, the future is "like a black hole, " she said. But she doesn't regret reconnecting with her high school sweetheart, her soul mate.

"He was my lover, he was husband, and, most of all, he was my friend. My best friend, " she said.

"We had three years of amazing happiness. If I had known this was going to happen, I still would have married him."

The truth is, she said, she was lucky. Not everyone finds a love like that. She found him twice.