

Final Decisions

Part Two

Financial Condition Critical

First, Ordeal of Liver Transplant, Then Blizzard of Bills

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TRINITY, Texas – After surviving cancer, a liver transplant and a grueling six-week hospital stay, Melanie Gentry-Tomme thought the worst was over. The 34-year-old mother of four couldn't wait to get home.

Then the bills started coming: the transplant itself, the hospitalization, her husband Robert's apartment near the hospital in Dallas, the house payment back home in Trinity and a small suitcase of medicine, including the miracle anti-rejection drug cyclosporine. They called it "liquid gold" -- \$900 a month to keep her body from fighting off her new liver.

All told, the debt was about a half-million dollars, some covered by insurance, some out of pocket.

"I thought that once I had the transplant, I was going to be fine," Tomme said. "I knew the medicine was going to cost a lot, but you have no choice so you don't really think that far ahead. You know you've got to take it."

It had taken everything her family had to make Tomme well. Her husband took five months off work to care for her. Her dad retired early from his job as a machinist in Houston so he and his wife could move to Trinity to look after their grandchildren, the youngest of whom was 18 months old.

Tomme's five brothers and sisters pitched in, too, pooling their money and time to keep the family afloat.

But almost immediately after Tomme's transplant in 1988, her insurance premiums started climbing. When they reached \$2,000 a month, she surrendered.

"We had gone through all of our savings. We finally threw our hands up," she said. "We dropped the insurance. We had to file for bankruptcy. We lost the house. We lost everything."

Tomme's situation is typical, according to the National Transplant Assistance Fund, a nonprofit group that helps patients with fund-raising. In fact, the organization urges all transplant patients to think long term, warning that even those with good insurance now may not have it in the future, especially if their policy has a lifetime coverage limit.

"If they are a liver patient who's been hospitalized 17 times before they get a transplant, they will reach that cap," said Dr. Pat Wood, who oversees Houston's liver transplant programs. "And there's a lot of people out there who work hard every day and make \$18,000 a year and have no insurance or inadequate insurance. How can they spend \$8,000 to \$10,000 a year on immunosuppression?"

Medicare will pay for three years of anti-rejection drugs for those who qualify. After that, patients are on their own, unless they can convince a drug company to provide the drugs for free or at low cost.

“That’s one of the stupidest things I’ve ever heard of,” Wood said of Medicare’s limit. “It’s illogical to say we’ll give you the transplant, but we will not pay for the drugs that will keep you alive. You either die or you pay for them yourself.”

Legislation is pending before Congress to extend Medicare benefits to cover the cost of anti-rejection drugs for life. If that bill were to pass, it would take away one worry for thousands of transplant patients. But it would not help those people who make too much money to qualify for government assistance, yet not enough to pay for anti-rejection drugs.

For the Tommes, things got so bad that their lawyer suggested they get a divorce so Melanie could qualify for Medicaid, a government health care program for the poor.

“At the time, we actually thought about it,” she said. “But we had four little kids, and I just didn’t think they could understand that. And Robert and I – after all we’d been through – we just couldn’t do it.”

Instead, Robert Tomme, a riverboat pilot working on the Mississippi, took a new job and began staying on the river three months at a time instead of just one. He slips back home to visit a few times a year.

To be covered by her husband’s insurance plan, Melanie Tomme had to go a full year without seeing a doctor or entering the hospital. In the meantime, her transplant support group, the Houston-based Lucky Livers, donated from their own cyclosporine stockpiles. The families of patients who died contributed their leftovers.

“I just depended on all these people to help me,” Tomme said. “If I didn’t have them, I don’t know what we would have done.”

Today, at 41, Melanie Tomme has decent insurance, but it has a \$1 million lifetime cap.

And now she has a new problem – a Catch-22 that many transplant patients face: The anti-rejection drugs that keep her immune system low so she won’t reject her transplanted liver have done tremendous damage to her kidneys, which could mean she is headed for dialysis or a kidney transplant.

The drug that keeps her alive day by day has other serious side effects in some patients, including high blood pressure, tremors, headaches and an increased risk for some types of cancer.

“When you look at the future, it’s hard,” Tomme said. “I try not to think about it. We have to live every day.”

“I still wouldn’t go back and change it,” she added. “It saved my life.”