

official site of NEWS 9 and The Oklahoman

Wed October 24, 2007

Cap on care puts hospice in financial dilemma

By Sara Ganus
Trade Talk

It was only three days before Christmas when my father's oncologist mentioned the word "hospice" to my mother, sister and me in the waiting area at the OU Medical Center.

The word felt strangely foreign to me.

Like most people, I knew what it was — I knew hospices helped people die with dignity — but I never thought I would need to explore the term any further. I don't think anyone really does unless they have to.

As we tried to process the word and what it would mean, we thought about my 70-year-old father, who had been diagnosed 10 months earlier with non-small cell lung carcinoma, or stage 4 lung cancer, and was lying in a hospital bed barely conscious in the intensive care unit after reacting badly to a new chemotherapy.

Along with the "hospice" word came a startling prognosis: Dad only had "days to weeks" to live.

The news was both heartbreaking and shocking. How did this happen? A few days ago, he was a little nauseous, but now, he's dying? It was our worst nightmare.

By then, we knew hospice was the only option. My dad had made it legal months earlier when he signed an advance directive with specific instructions: no tubes. He wanted to die at home.

With little to no knowledge of local hospices, we chose AutumnBridge Hospice in Oklahoma City, where my father's oncologist was a board member.

The first week of hospice care is a bit of a blur. Not only were we walking on pins and needles, but different people — nurses, aides, the prescription messengers and even masseuses — were in and out of the house daily. Was this hospice, I wondered?

I now know that hospice offers a comprehensive, team approach to care that addresses the physical, emotional and spiritual needs of individuals with terminal illnesses and their family members. Not to be confused with "giving up," hospice believes that each patient is entitled to live pain-free and with dignity — which is exactly what my dad wanted.

During our early weeks of hospice care, nurses delivered similar prognoses: He didn't have long to live and would never get out of bed again. We spent every waking hour by his side.

Soon those hours turned into days, and days turned into weeks until we were celebrating his 71st birthday on Feb. 4 — more than a month after he started hospice care.

It felt like a miracle at the time.

Sharon Steinman, president of AutumnBridge Hospice, calls it "the hospice magic," where patients do so well under hospice care that some eventually are able to leave the program. My dad never reached that point — but he



kept fighting for the next nine months.

It wasn't until close to the end when I learned that the payment for our hospice care was capped, and independently owned hospices, like our extended family AutumnBridge, were suffering because of it.

Next month is National Hospice Month and the 25th anniversary of the establishment of the Medicare hospice benefit.

When Congress created the hospice benefit to cover end-of-life services, it also created two caps: a lifetime cap that limits each beneficiary to a maximum of 210 days of hospice care and a cap that limits the amount each hospice could bill Medicare in a single year.

The cap is about \$20,000 per patient, and any payment in excess of that must be refunded to Medicare by the provider.

Here's the catch: When the hospice benefit was created, almost 95 percent of the people receiving hospice care were cancer patients, like my dad, and many did not exceed the cap. Then in 1998, Medicare expanded the criteria for hospice to patients with end-stage diseases, such as heart disease, dementia and Alzheimer's disease, but the cap on the hospice provider was never modified.

So how has this affected hospice providers?

In 2005, 41 percent of hospices in Oklahoma exceeded the cap; now they owe more than \$25 million to Medicare, according to the National Alliance for Hospice Access.

Recent improvements in cancer treatment have extended beneficiaries' life expectancies and significantly reduced cancer mortality rates. My dad was living proof of that. Most people diagnosed with stage 4 cancer at his age usually live between six and eight months.

Similarly, patients with end-stage diseases often do not die as quickly as cancer patients, so many hospice providers are increasingly exceeding Medicare's cap at a staggering rate. Many independent, mom-and-pop hospices are left wondering how they will foot the bill to refund Medicare without going bankrupt.

A few weeks ago, I asked Steinman how the cap was affecting AutumnBridge, which opened in 2004. With 60 current patients, she said AutumnBridge likely will owe more than \$750,000 to Medicare for 2006. The only option AutumnBridge has to survive under the current legislation is to agree to a payment plan with Medicare at a 12.5 percent interest rate.

"It's very scary," she said.

As I look back on the nine "extra" months my family got with my dad, there are very few memories that do not include hospice.

During that time, my dad reached dozens of milestones. With tumors that had spread to his brain, clavicle, right hip, groin and spine, he managed to get out of bed April 4, learned to maneuver a wheelchair and even gained enough strength to go out to eat. (Going to Cattlemen's for a beer and calf fries became a regular craving.)

These were all miracles to us, and I credit many of them to our hospice.

But as time wore on and the seven brain lesions took their toll on my father's once razor-sharp mind, we knew it wouldn't last forever.

Dad was on hospice 290 days — 129 days past the number Medicare will cover for patients in Oklahoma County. He died on Oct. 8 at home, just as he wanted.

Now our hospice likely will owe close to \$1 million to Medicare next year, partially because of my dad, and I can't help but feel some guilt.