

For More Information Contact:

Mickey Key RN at Compassionate Care Hospice
Telephone 405-948-4357
www.compassionatecarehospice.org

For Information on the

National Alliance for Hospice Access Contact:

Lois Armstrong, President
Telephone: (480)-452-2497
www.hospiceaccess.org

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Compassionate Care Hospice, one of Oklahoma City's most well known and loved hospices is proud of the role they have played in the lives of hundreds of Oklahoma families. That role includes many facets of care-giving: nurses, certified home health aides, social workers, volunteers, chaplains, bereavement counselors and physicians. Each is an integral part of the hospice concept, allowing patients and families to spend quality time at home with those they love.

Having started Compassionate Care Hospice in 2001 after devastating cancer nearly took Mickey Key's life, she and her husband Mike Harvey have strived to provide the best care possible to those in need in spite of their ability to pay. But, now Compassionate Care Hospice is one of the hundreds of Hospices across Oklahoma and the nation hit by "THE CAP", a devastating consequence which is the result of an obscure rule in the Medicare hospice benefit. Hospices in at least 25 states are being asked to refund hundreds of millions of Medicare dollars they were paid to care for hospice patients that are **taking too long to die**, according to the Centers for Medicare and Medicaid Services.

Hospices are hitting the CAP at an escalating rate. In 2004, hospices in 15 states were asked to pay back about \$100 million. In 2005, estimates suggest that hundreds of hospices in at least 25 states will be asked to repay hundreds of millions of dollars. In Jan, 2007 we received our Cap notice for 2005, almost \$400,000! Of course, we don't have this kind of money lying around! We spent it providing hospice care to our patients who were eligible to receive the services we gave them". Some hospices were hit with \$800,000, others \$2.2 MILLION! If they were not able to borrow the money, Medicare simply cut off their funds, making it impossible to carry on business as usual. Sadly, many hospices have been forced to close their doors.

We at Compassionate Care Hospice are determined to do what ever it takes, we have paid the CAP, but we need the public to be aware of the hardships this has caused not only to our hospice, but many others. Many hospices have had to cut back on the number of pro bono cases and discharge many who continue to need care. We urge you to speak to your congressmen and senators about this very urgent issue

After reading a recent article in the *Daily Oklahoman*, our phones began to ring. Patients were concerned that they were "taking too long to die". One asked, "Am I supposed to go out behind the shed and just die?" We have assured our patients that we will continue to be there for them for as long as necessary.

How can the cap affect patient care? Here's an example: after being discharged by another hospice on 9/4/07, the patient's family called asking us to assume care. Although, he had been on hospice six

months, our medical director felt he continued to be very hospice appropriate. We admitted him and he died a month later. How sad that he might have missed having the care, love and support both he and his family needed in those last days just because of a money issue!

The Medicare program pays a daily rate to hospices to care for dying patients whether in a private home, nursing home, or assisted living facility. Patients must meet Medicare's eligibility standards and be certified by a doctor as terminally ill with six months or less to live if their condition declines at its current rate. Hospice provides nurses, medication, incontinent supplies, medical equipment, chaplains, and social workers along with bereavement counseling for family members.

From 1982, when the hospice legislation was passed, until 1998, few hospices hit the Cap; most hospice patients had cancer and stayed a relatively short time in the benefit. In 1998, Congress changed the law so that terminally ill non cancer patients, who have somewhat unpredictable periods of decline, could take advantage of hospice care. Under current regulations, the Hospice benefit is comprised of two 90 day periods, followed by **unlimited** 60 day periods as long as they can be certified to be terminally ill by their physician and/or the hospice medical director.

No one can be certain the NUMBER OF DAYS our lives contain. Oftentimes a physician is reluctant to say a pt's condition is "terminal", because of the impact of those words on the patient and their family. Also, they are afraid of being "wrong".

I know very well the impact a life-limiting or terminal illness has on families. I also know that we are able to lessen that impact. Patients who had numerous ER visits and hospitalizations stopped going to the hospital because their hospice was providing care for them at home. Studies have shown that people on hospice "live longer", which is true. We improve their nutrition, and manage their pain, we love and care for them, giving them a better quality of life. My belief is: 'Hospice is not about dying, but about living the best you can till God calls us home.'

In a September, 2000 letter to hospices, Nancy-Ann DeParle, then Administrator of the Health Care Financing Administration (HCFA) wrote, "There is a disturbing misconception that hospices and beneficiaries will be penalized if a patient lives longer than six months. Nothing could be further from the truth." She continued, "Let me be clear. In no way are hospices beneficiaries restricted to six months of coverage. There is no limit on how long an individual beneficiary can receive hospice services, as long as they meet the eligibility criteria."

Medicare caps average per-patient benefits for each hospice at about \$20,000 which covers approximately 120 days. Hospices that exceed the average are required to repay the difference to Medicare. Does that sound like **unlimited care**?

Recently, Compassionate Care Hospice joined other hospice providers in the National Alliance for Hospice Access, (NAHA) a coalition of independent hospices who are interested in ensuring that hospice services remain available to those who are entitled to receive Medicare covered end-of-life care.

NAHA was founded by Lois Armstrong and David Daucher, partners in Sojourn Care, an Oklahoma hospice that first hit the Cap in 2005. "Hospices cannot 'manage the Cap' without rationing access to care," said Armstrong, who serves as President of NAHA. "Good hospices care for all eligible patients

who elect the hospice benefit for however long they remain eligible. The Cap means that these providers face devastating consequences, even bankruptcy.”

NAHA has a single goal, a legislative correction to the flawed law. “Providers feel forced to make terrible choices such as limiting the admission of non cancer patients or discharging patients who “live too long” whether they remain medically eligible for hospice or not,” Daucher said. “Such choices deny patients the access to hospice care that Congress specifically intended. NAHA hospices are working with Congress now to find a legislative solution to this problem that is hurting patient access to hospice care.”

Numerous illnesses are covered under the Medicare Hospice Benefit: heart disease, lung disease, renal or liver failure, stroke, coma, neurological diseases, Alzheimer’s and cancer, Failure to Thrive is another category. We sometimes admit a patient for “Failure to Thrive”, due to advanced age, a number of chronic disease processes, weight loss and increasing dependence on others for their care. Infections, numerous trips to the hospital or ER can also be a “predictor” of severe decline.

Some families cannot handle the burden of taking care of a loved one alone. Medicines are so expensive, caregivers are hard to find, even getting them to and from doctors appointments is nearly impossible. Hospice is a Godsend for them. Help us continue to provide the care they need. Help us change the law. For more information call Compassionate Care Hospice at 948-4357.

Local Resources

Compassionate Care Hospice can provide interview opportunities with:

- A patient with a non cancer diagnosis and his/her family members who will invite you into their hospice experience and describe the devastating hardship they would face if deprived of the Medicare hospice services they are eligible to receive.
- Dr. Wallace McLeod, medical director of Compassionate Care Hospice, who will discuss the difficulty of predicting prognosis in non cancer diagnoses, even when patient meet the requirements of objective eligibility standards.
- Micheal Harvey, CEO of Compassionate Care Hospice who can describe the significant negative business outcomes the hospice will face if forced to repay the CAP.