

Hospice: Why Family Members Wait Too Long to Call

By Anne-Marie Botek, August 30, 2012

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It can be difficult to admit that a senior's disease has progressed so much that additional treatment is impractical, but caregivers and their families can lose out on irrecoverable time with a dying loved one if they wait too long to seek hospice care.

More than 35 percent of people on hospice don't even receive one full week of care, while 50 percent receive care for less than three weeks, according to 2010 figures from the National Hospice and Palliative Care Organization.

"The full benefits of hospice care cannot be experienced in just a day or two," says **Myles Zuckerman, M.D., Chief Medical Officer of Family Hospice and Palliative Care**, "It makes me sad to get calls from family members who realize their loved one is dying within a few hours or days because they can't make the most of it."

Hospice in a nutshell

A person who reaches the point where more medical care is counterproductive is likely to be experiencing a significant amount of physical pain. One goal of hospice care is to enhance a dying senior's quality of life by alleviating as much of this pain as possible. The sooner they are called in to help, the sooner your loved one can get relief.

But hospice isn't just about alleviating a senior's physical symptoms.

A hospice care team consists of multiple professionals (including: physicians, nurses, social workers, psychologists, and spiritual counselors) that come together to help an elder and their family cope with the logistical, spiritual, emotional and mental facets of dying.

This holistic care focus can make it possible for a senior to have more pain-free time to spend with their loved ones.

Medicare offers up to six months of hospice care benefits for terminally ill seniors who decide to forgo further medical treatment.

Wishing to preserve hope

What makes a family caregiver so reluctant to call in the hospice care cavalry for an ailing loved one?

In some ways, it's all about perception.

Hospice has a potent stigma attached to it. Viewed as a last resort—something to try when all medical methods have been exhausted—hospice is often associated with giving up and giving in to the inevitability of death.

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Gail Gazelle, M.D., FACP, Assistant Clinical Professor of Medicine at Harvard Medical School, says that many families engage in "wishful thinking," believing that if they refuse to talk about the fact that a loved one is dying, then perhaps it won't actually happen.

She also mentions the common concern that broaching the topic of end-of-life care with an ill loved one may cause them to become depressed.

While both valid and understandable, these feelings can create unnecessary suffering for both a dying elder and their family if they cause a caregiver to delay calling hospice.

Medicine's fighter philosophy

A medical culture that makes doctors and family members reluctant to admit defeat further devalues the benefits of hospice, which is more focused on caring for a person rather than curing a disease.

Research has found that seniors often receive unnecessarily aggressive medical treatments in their last few weeks of life.

A recent Dartmouth investigation discovered that one-third of terminal cancer patients were subjected to costly, painful, and ultimately futile treatments in their last few weeks of life. Another study found that almost 80 percent of all seniors on dialysis were hospitalized at some point during their last month of life. During their stay, many of these patients were given feeding tubes, or had to be resuscitated.

Gazelle feels that efforts need to be made to educate physicians on the merits of hospice and how to approach the topic of end-of-life care with patients and their family members. She also acknowledges the vital role that caregivers play in these discussions, "It is critical that families begin to feel more empowered to name the truth and not wait for the physician to initiate the discussion," she says.

Knowing when to call

When should you call hospice for a loved one?

It can be hard for caregivers to pinpoint when further medical care would do a senior more harm than good.

"We're all guilty of having that Pollyanna view of things—no one wants to face the fact that there comes a point where there's nothing else medicine can do," **Zuckerman** says.

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One way to dispel the uncertainty is to seek outside advice:

- If your loved one is staying in the hospital, you may have access to the services of a palliative care professional. These individuals are tasked with relieving the physical and emotional pain associated with all types of diseases—curable, chronic, and terminal. A palliative care professional will be able to provide you with information and guidance regarding hospice care.
- If a senior is staying in an assisted living community or nursing home, **Zuckerman** suggests soliciting the advice and opinions of the staff that takes care of your loved one on a daily basis. They'll have the best idea of the status of an elder's physical condition and how it's affecting them.
- If you're caring for a loved one at home, their primary care doctor can be a source of information, but **Zuckerman** cautions against waiting for a loved one's physician to start a dialogue about end-of-life care. He says that doctors often lack the time necessary to sit down and address the issue appropriately.

Making the decision to pursue hospice for an elderly family member won't be easy, but it's important to acknowledge the potential benefits of this care option.

Zuckerman says that hospice can offer much-needed hope for people dealing with a terminal illness, "Even when there's no hope for a cure, there's still hope. There's hope for more pain-free days, and more time with family and loved ones."

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