Directing your Care- Hospice at the Road's End

This week Lathrop Easthampton says good-bye to Herb Steeper whose wife Nancy shared with me her appreciation for the support and care both Herb and she received from a local Hospice Agency. I came to know this family well before my arrival at Lathrop while providing VNA home care services. I offer this as tribute to their journey and share this last topic in our series with you this week.-RO

For millennia most of the ill and infirm ended their days at home, in their own beds. But increasingly through the last century hospitals became the place where families said good bye to loved ones. Sadly, in many cases this moment was burdened with obstructions of technology and institutional need. For the most part, our community is committed to fighting this trend and many are clarifying their intentions to take advantage of at-home hospice care, an important Medicare benefit. Many of you have already had experience with hospice care through the death of a parent or spouse. Your experience may be invaluable for neighbors and friends as they or a loved one consider how best to seek care at road's end.

For those new to the topic, let me first address the confusion between the terms palliative care and hospice. Palliation is the general idea of an intervention that supports function or comfort but does not seek cure of a disease or condition. A palliative care program in a hospital or home care setting primarily addresses symptom management and comfort, as patients continue to seek life supporting treatment like chemo therapy or cardiac surgery. This is provided under standard Medicare and insurance coverage.

At some point in the arc of illness or aging, it becomes clear to an individual, and hopefully the treating physician that further treatment is not beneficial or effective. The decision is made to forgo hospital treatment. At this point the priority becomes insuring the comfort and dignity of the patient as the body surrenders to the impact of the disease or aging process. Thankfully, in part due to the growing demand of patients, spurred by numerous activists and authors such as Atul Gawande, as well as to the reality of the societal costs posed by questionable end of life hospital care, physicians are increasingly directing their patients to seek the support of hospice.

Like so much in health care, access to hospice is mostly determined by the rules of Medicare. This benefit is available to patients identified by a physician as having 6 months or less of life. (It is possible to recertify the benefit beyond 6mo if patients continue to qualify.) Studies have shown that most physicians overestimate life expectancy and most hospice programs will suggest that for this reason as well as general reluctance to pursue hospice care, most people sign up for hospice too near the end to make the most of the care. Despite many patients fears that hospice means surrender, studies show that good hospice care can actually extend the last

months of life and certainly make those months more easeful, comfortable and calm for patients and their caregivers.

A hospice program must be certified by Medicare to qualify for coverage, which in part means operating under the direction of an MD. Most hospices operate as part of home care agencies, though many are stand alone, and in some case are residential. In the latter case Medicare is reimbursing them for the mandated services including nursing, some limited home health aides for direct physical care, medical social work and bereavement support. In residential programs, families (and potentially secondary insurers) cover the cost of room and board. In the home, hospice benefits cover all costs of necessary durable medical equipment including hospital beds and commodes etc., as well as all medications.

Once under hospice, the teams operate from medical protocols that treat pain, agitation and breathing difficulties. Patients are helped to eat and drink as they may wish. Nurses make themselves available to assess, respond to concerns and help adjust medications. Health aides are scheduled for daily personal care and bathing as needed. Social workers and numerous volunteers work with patients and caregivers to help ease the strain with talk, touch and often music. Families who have traveled the hospice journey will tell you that at some point caregiving can be a full time process, so families must be available and willing. There are many private duty resources that can be tapped to provide respite care and attendance where needed.

Lathrop care coordination can help you consider decisions around hospice care, as well as help connect you with a local agency. (Medicare is only now mandating creating an on-line Hospice compare website as is done with nursing homes and home care.) Hospice is often referred from decisions made during a hospitalization but can be arranged anytime by your physician when the time seems right. While hospice assumes that hospitalizations will be avoided, challenging symptoms and issues may arise and hospice care can be briefly provided in a hospital setting. Further, a patient or proxy can choose to rescind the benefit and seek treatment outside of hospice care. If you have further questions about Hospice care I'd be happy to share what I know. The best people to speak to of course are the community members who have ridden alongside.