

Part II

A Gentle Death

Nancy Baldwin Carter, BA, MEd Psych, Omaha, Nebraska

Surely we don't need studies to prove that planning ahead is a good idea, yet plenty of them exist, even when it comes to end-of-life issues. The goal, of course, is to assure that a patient's medical care will ensure the greatest measure of comfort and serenity possible. This requires patient power – the promise that whatever medical plans dying patients choose will be carried out. Patients treated in this manner are known to experience a more positive frame of mind, less pain and even a longer life. Helping patients examine the details of possibilities such as Hospice, Palliative Care and Death with Dignity pays off.

Hospice

As a concept of providing comfort and peace at home for those at the end of life, hospice has progressed through several centuries. It wasn't until the 1970s in this country, however, that hospice was established as what is widely known today as the most recognized program offering compassionate relief from death's pain and agony.

Hospice is surprisingly multifaceted, operating with a large variety of designs. Many of us think of receiving hospice

care in our homes. Often a hospice doctor or medical director consults with the patient's personal doctor to develop a plan of action. Other professionals, such as nurses, aides, counselors, clergy and therapists may then enter the picture.

Family and patient work with everyone on the team: What kind of hospice support does the patient want? What equipment is needed? How should pain and other medical needs be dealt with? Care must be taken not to treat the patient more aggressively than wished, thus causing unintended pain and driving up costs unnecessarily. Does the patient have Medicare, Medicaid, private insurance or other financial resources? Has everyone

discussed what to expect from hospice and how the disease proceeds? Every aspect is covered.

In addition, trained volunteers as well as family members and friends bring a great deal of comfort to the terminally ill on their final journey. Studies show that hospice volunteers, family and friends make up around 90% of those caring for the dying at home. Because of this, hospices actively recruit volunteers and provide training sessions to prepare them to be the non-medical companions so necessary to the success of this challenge.

One Family's Experience

Here's how the hospice experience worked for Janice, a teacher in a small Nebraska town, and her mother: "When we learned my mother's struggle with cancer was coming to an end, I looked for hospice help. There was none available where we lived, but I located a hospital about 65 miles away whose hospice staff met with mother and me to discuss



Nancy Baldwin Carter, a Nebraska native, contracted polio in 1948 at age 11. With BA and MEd Psych degrees, she began her career as a high school English teacher and moved on to administering adult education programs in Missouri and Kentucky. Carter founded Nebraska Polio Survivors Association in 1984 and was its initial director.

She was a contributing author to Dr. Lauro S. Halstead's *Managing Polio: A Guide to Living Well with Post-Polio Syndrome* in 1998 as well as its second edition in 2006. Carter has written three series of columns for Post-Polio Health International – "Leadership," "Polio Survivors Ask ...," and "Post-Polio Thoughts."

▷ details. They told us a nurse would visit mother's home once a week to check her physical condition. As the family member on duty, I was introduced to good ways to care for mother's daily living needs such as bathing, feeding, toilet issues, turning her in bed, administering her medications. They also explained what to expect as mother's condition deteriorated.

"A volunteer came in for two hours once or twice a week. She tended to mother's needs and often also sat and chatted pleasantly with her. This gave me respite time, which I gratefully used to go grocery shopping or merely to enjoy a restful moment to put my feet up and have a cup of tea. Occasionally she would do small tasks around the house—sweeping or washing a few dishes, for instance. She was great help."

Hospice Situations Vary

However, not all hospice care occurs in the familiar surroundings of patients' homes. In some areas, patients or the family may choose, instead, a hospice house, created especially for those who want hospice care, but prefer not to remain at home. For others, hospice care is an institutional benefit. Many patients receive hospice care in nursing homes or in certain hospitals.

While not administered to "prolong life nor hasten death," specific medications are important to bringing comfort to hospice patients. Pain medication is, in fact, the prime source of such relief. The exact kind of medication and the extent to which it is used becomes a significant early discussion between hospice doctors and their patients in determining the care they desire.

Medicare and Hospice

In 1982, Medicare benefits became available to hospice patients expected to live no more than six months. If those terminally ill patients exceed that time limit, their physicians can re-certify to allow them to continue receiving hospice care.

Medicare pays 100% of hospice costs for terminally ill hospice patients who waive the right to curative care for that

illness. At the same time, these patients may be treated for non-terminal illnesses, though expenses for this are not covered by Medicare hospice. Medicaid is also available in a large number of, but not all, states. Statistics show that most hospice patients die within two to three weeks, confirming the public view of hospice as end-of-the-line care. In 2010 alone, an estimated 1.6 million patients received services from hospice. Some 30% of Medicare resources are expended on the 5% of beneficiaries who die each year and one-third of costs in life's last year is accounted for in life's last month.

Finding Care

Hospice care is available to one degree or another in every state in our country, though it is carried out in a wide variety of ways. Knowing exactly what to expect when getting into hospice care can be quite an asset. Mayo Clinic and others provide a number of tips on what to look for when choosing a hospice program. Here are a few:

- ◆ If possible, use a Medicare-covered hospice program that, additionally, is licensed or certified by your state or is accredited by The Joint Commission, an independent evaluating organization known to inspire certain performance standards in health care organizations it certifies. Ask if hospice care teams are trained.
- ◆ Learn what services are offered and if they are available after hours.
- ◆ Find out how pain and other symptoms are managed.
- ◆ Check on which hospice services are available for family and other caregivers.
- ◆ Understand what Medicare hospice pays for and when private insurance or some other source is expected to pay.

Many Options to Consider

As it turns out, getting the medical issues settled in our thoughts may only be part of the task. Coming to terms with our intense inner feelings and the role our emotions play at this time in our lives also has much to do with the

continued on page 11

This is the second in a periodic series about end-of-life issues. While difficult to think about, avoiding the subject can result in last-minute decisions based on incomplete facts and misconceptions. Part III of this series will discuss Palliative Care.

continued from page 9

end-of-life process. Many of us take time to imagine those final days, dreaming of what we can do to bring about soft clouds of serenity to waft us peacefully on, for example.

We may rely on our deep faith, the divine gift that leads us to a glorious new tomorrow. Or on moments of laughter among the tears as memories of happiness crowd our minds, and loved ones find their way to say goodbye.

Others want no part of this. Their time is here, they say – let death design the stage and pull the curtain. Their plan is not to have a plan. So be it.

But no matter what, if we want to see our intentions carried out, active or passive as they may be, we are the ones who must steer ourselves to that outcome. We are in charge of this phase of life and death. It is we who examine our options, consider where they sometimes telescope into each other – Hospice merging into Death with Dignity? Palliative Care moving into Hospice? – and how this leads us to develop our plan. Whatever we decide, however we put it together, this is the message we send to those around us. ■

THANK YOU

For recognizing your friends and loved ones with contributions to support the unique mission of PHI and IVUN. PHI strives to publish an accurate list. Please contact us if we made an error.

Contributions to PHI's education, advocacy and networking activities ...

In Memory of

Louie Boitano	Elinor Natale
Charles P. Colby, Jr.	William G. Ohme, Jr.
Judith Horn	Jacquelin Perry, MD
Nora Leonetti	Desha N. Sanders, Jr.
Dellis S. Markowski	

In Honor of

Ellen Moats

Contributions to the Research Fund ...

In Memory of

Mary Ellen Kollodge	William G. Ohme, Jr.
Lillian Lindenauer	

Contributions to the Gilbert Goldenhersh Memorial Tribute Fund ...

John "Jack" Brogan
Irving Harris



continued from page 10

Dr. Maynard: In this case, I think the dilemma is deciding if the vertebral compression fractures were a result of violent trauma, or if they were a result of osteoporosis weakening the vertebrae sufficiently that minor trauma resulted in their fracturing.

I would favor recommending treatment with vitamin D and calcium, and then a repeat of the bone scan in one year before initiating IV bisphosphonates now, because violent bouncing in a car can result in fractures regardless of bone scan scores. ■

Not yet a Member?

Join PHI for just \$30 a year (Subscriber Membership) and receive your own copy of *Post-Polio Health* four times a year (February, May, August, November), plus eight *PHI Membership Memos* via email. For \$55 (Subscriber Plus Membership), join PHI and IVUN and also receive *Ventilator-Assisted Living* via email six times a year (February, April, June, August, October, December) and six *IVUN Membership Memos*.

You can join online at <http://shop.post-polio.org> or send (or fax, 314-534-5070) this form to: Post-Polio Health International, 4207 Lindell Blvd, #110, Saint Louis, MO 63108-2930 USA. Questions? 314-534-0475 .

\$30 Subscriber

Post-Polio Health (quarterly)

\$55 Subscriber Plus

Both *Post-Polio Health* (quarterly) AND *Ventilator-Assisted Living* (bi-monthly)

Name _____

Affiliation _____

Address _____

City _____ State/Province _____

Country _____ Zip/Postal Code _____

email _____

Phone (include area/country code) _____

I am enclosing a check for \$_____ made payable to "Post-Polio Health International." (USD only)

Please charge \$_____ to this credit card:

VISA MasterCard Discover

Card No. _____ Exp. Date _____

Name on Card _____

Signature _____