

A Gentle Death

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At the far end of the end-of-life spectrum lies palliative care, a set of services created to benefit the chronically ill. In fact, it's so far from the end that, at times, it may not appear to classify as end-of-life at all. Patients receiving palliative care may simply be those with grave, life-limiting (but certainly not terminal) illnesses. Their care may consist of providing comfort, relieving symptoms, mitigating stress and pain. This may often exist hand-in-hand with curative treatment for disease.

This could include people such as polio survivors, perhaps struggling with pain, loss of function, chronic weakness, those who are ventilator users or those experiencing continually deteriorating muscle mass. Other people may be affected by serious complications of aging, cancer, heart or renal disease, stroke, Alzheimer's, Parkinson's or diabetes, for example, all longing for symptom relief, serenity, a better quality of life.

On the other hand, some patients may reach a point when their illnesses progress to the terminal stage, where palliative care merges into hospice care, and they are judged to have no more than six months left to live. Yet everyone seeks relief from pain and alleviation of distressing symptoms – the very definition of “palliative.”

How It Works

The concept is encouraging. Chronically or seriously ill individuals still living in their family homes (not necessarily bedridden), or even those in hospitals or other facilities, are eligible for palliative care, which brings physical, emotional and spiritual support into the picture wherever they are. Easing symptoms. Providing comfort. Patients are treated totally, not merely for their illnesses. Studies show significantly less depression and fewer emergency room visits among such patients.

Ideally, the focus is on the patient through what could be an extensive team approach according to need – this may include doctors, nurses, therapists, pharmacists, counselors, social workers; those addressing spiritual needs, psychological and emotional issues; holistic approach specialists, caregiver support and other members of a multi-disciplinary effort – all considerably enhancing the well-being of patients. In fact, patients themselves and sometimes family members may be an essential part of the team.

The idea is to bring palliative treatment to the patient. This is not about dying, but about living well, even at the end of life. And it fulfills the dream of a large percentage of the population who want to stay in their own homes until the end.

Patients sing the praises of palliative care. They feel safe and supported realizing they are being cared for by a full team who knows them personally and understands their wants and needs. Doctors can be more available, pain-relief honored upon request. They feel the freedom that empathy and hope engender.

Palliative care programs are a relatively new concept, still in various stages of development across the country. Doctors can be board certified in Hospice and Palliative Medicine, working with well-established programs, which themselves can be accredited by the Joint Commission on Accreditation of Healthcare Organizations.

Meeting Home-based Goals

Not all home-based programs have met their full potential. Some teams may consist of no more than a doctor and a nurse practitioner, far from satisfying all aspects of their palliative goals. There may be no counselor, no chaplain. These teams may still struggle to provide pain management through holistic methods

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This is the last of a three-part series by Nancy Baldwin Carter 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.

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such as massage therapy or acupuncture, or relaxation techniques such as yoga or even a pleasant drive through the countryside, for example. Home-based possibilities, the ideal for a large percent of end-of-life patients, may not yet exist.

Today our elderly population is growing rapidly. Estimates say that in the United States the number of people over the age of 65 will increase to 88.5 million by the year 2050. Many of these individuals will have serious illnesses. Chronically-ill patients are living longer. Home-based

palliative care is designed to answer the unique needs of such patients, providing an important measure of the highly-treasured independence most patients long for as a basic quality in their lives.

Funding

Finding financial solutions can be a challenge. Palliative care specialists are trained to discuss treatment preferences with their patients. Results show that patients are happier and even survive longer when their wishes are carefully followed. Being assured they will get exactly what they want brings them

peace. Patients who choose to cut short aggressive treatments that don't improve their conditions, avoiding the agony of the drawn-out inevitable, may also discover that a result of this decision is lower costs.

Additionally, because palliative care patients are not considered terminal, Medicare does not view that program in the same light as it does hospice care. The term "palliative" isn't used by Medicare. Although Standard Medicare Part B benefits may cover a small number of key elements of palliative care, such as certain physician, nurse practitioner or social worker visits in the home, this does not necessarily include paying the expenses that would bring in the rest of the team members, the very soul of any palliative care program.

Whoever offers the palliative care (a community-based organization, a

hospital, or some other provider) can bill Medicare, but the patient may be required to pay fees or other charges Medicare won't cover. Medicaid operates on the same standards in most states. Certain private health insurance plans cover palliative or chronic care costs, and other means of funding for the home-based option may be available.

One doctor asks, "Why should Medicare fund only patients needing our help in the last six months of their lives? Patients who don't qualify for hospice because they are not yet at the final stage of life might still benefit greatly from palliative care."

Hospital-based Palliative Care

At the same time, hospital-based palliative care is on the rise. Surveys show that 63% of U.S. hospitals had palliative care teams in 2009, compared with only 24.5% in the year 2000. Clearly, hospitals are realizing the benefits palliative care brings to seriously ill patients at any point in their illness.

Doctors see this as a win-win situation. Not only do they get to supply significantly better quality and efficient personal care to their patients, but their patients recognize and appreciate receiving the extraordinary amount of empathy palliative care provides. Palliative teams bring an extra layer of expertise and efficiency to the hospital setting, easing the burden of care placed on physicians.

The presence of these teams lowers hospital costs through shortened stays, thus increasing capacity by working on care plans with those patients who hope to reduce unnecessary tests and treatments. Through it all, teams provide that special personal, compassionate, palliative care touch. Satisfied patients are good news to the hospital, which values being capable of delivering such excellent patient-centered care so cost-effectively.

Caregivers

In the meantime, caregivers reach out to provide help at home for longer periods of time. Family members and friends

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But plan for tomorrow.



▷ step in, devoting endless hours to the comfort and needs of loved ones. Over 43.5 million individuals care mainly for parents and spouses in this country every day. The effectiveness of the palliative program depends upon everyone's working together.

Much of the success of palliative care is generated at the communication level between team members and the family. Certain physicians have been reluctant to participate in end-of-life discussions. Team members, however, are specifically trained to help patients determine their treatment preferences, to explain recommendations, and to answer their questions.

Patients and families should be prepared to ask any questions they have about palliative care, such as:

- ◆ What is palliative care? How is this different from hospice? How serious is my problem?
- ◆ Can I get the care I need at home? How will this care be continued if I am moved from my home to a hospital or another location?
- ◆ How will you treat my pain?
- ◆ Will I have contact with my regular doctors?
- ◆ Who will be on my palliative care team?
- ◆ Will palliative care volunteers work with me? How are they trained? Does this include family members?
- ◆ What should I know about services involved?
- ◆ What fees and expenses will I be responsible for paying? Who will help me finance my care if Medicare won't?

In the End

Preparing for the end can be a long and involved process. It includes not only research, trying to find the path that suits us best, but also talking with loved ones about issues we hoped never to have to face. Following through, however, is what offers us that gentle death. Comfort rather than pain and suffering. Serenity rather than anxiety.

And so we search and discuss, examine possibilities like Death with Dignity and hospice and palliative care and others. We reveal our choices to our families and friends and those in the medical community who have us in their care. We make sure everyone understands this is how it must be for us. Our wishes must be carried out.

And then we turn to those we leave behind. We want our death to be as gentle for them as it can possibly be, as well. Some of us will say our goodbyes at special end-of-life get-togethers, others wait to express words of love and farewell until our final moments.

Some may plan the end with their loved ones over a long period of time: Mark, a practical and loving man, and Pat, his practical and loving wife, devoted eight years to fighting his cancer. They both wanted the best for him, worked together on every aspect of recovery. Yet they realized what the chances were and spent long hours talking about what she'd do when he passed on.

"He helped me make initial adjustments as a widow during that time – made lists of things for me to remember – property upkeep, taxes," Pat says. "He coached me on how to inflate the car tires with air, how to fill the sump pump battery with distilled water. He made a handy tool box for my personal use, saying 'Here's everything you should need for most small repairs.'"

He made death gentle – the final gift of a practical, loving man to his practical, loving wife. ■

Resources:

Palliative Care Services of Nebraska (www.palliativecarenebraska.com) is an excellent source for information on the topic. Created by Lisa I. Mansur, MD, FCCP, FACP, who is board certified in internal, pulmonary, critical care, sleep and palliative care medicine, the site is designed to educate people about what palliative care is and what it offers, as well as related issues such as advance directives and other practical matters. The site provides links to a wide array of articles, podcasts, videos, a glossary of terms and other resources for patients, families, caregivers and medical professionals. Dr. Mansur received the CHEST Foundation's 2012 Roger C. Bone Advances in End-of-Life Care Award for her work and that of her team in creating this site.