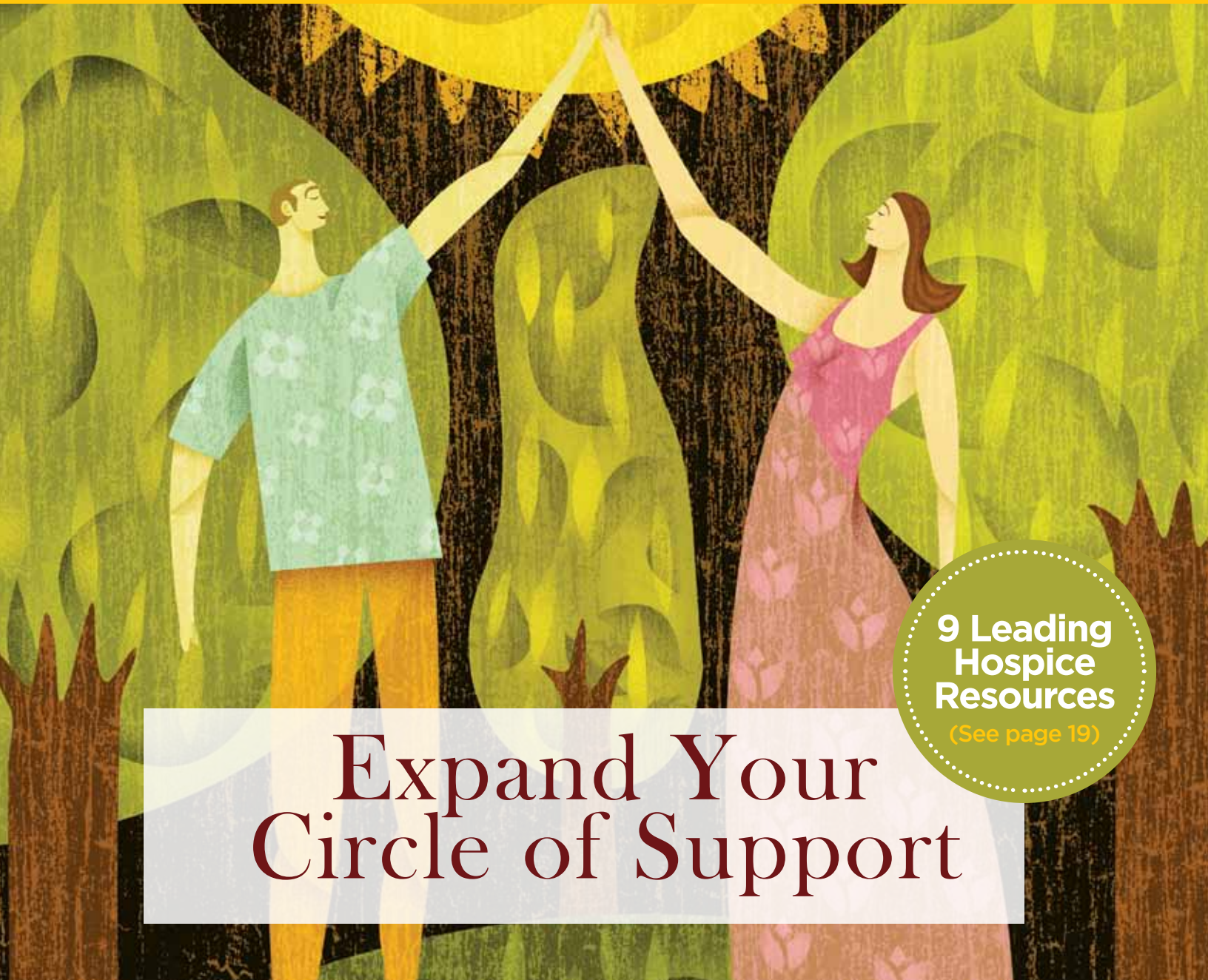


# heartnotes™

(A JOURNAL OF HOSPICE & PALLIATIVE CARE)



9 Leading  
Hospice  
Resources

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## Expand Your Circle of Support

Understanding Hospice  
and Palliative Care

Focus on  
Caregivers

## editor's note



When I signed on as editor of *Heartnotes*, I thought I had a pretty good idea of what this journal would be all about. I could see the pages unfold: clinical information for the nurses and docs, support and resources for families and patients, and lots of ongoing education about hospice and palliative care. Sure, we're talking about some challenging topics here, I figured, but it's just a magazine. I didn't expect many surprises.

Boy, was I ever wrong.

Throughout the editorial process, I have been flat-out awestruck by the richness of the hospice experience. I have heard the compelling experiences of hospice care providers who give selflessly to patients and families—kind souls who are eager to move mountains on behalf of someone in need. I have been honored to share in the stories of patients and families who are facing life-limiting conditions.

Perhaps more than anything, I have been completely taken aback by the limitless generosity of everyone I've met in the hospice field. From a local volunteer to the head of a premier hospice organization, each person has been more than willing to share their time and knowledge. These advocates have jumped at the chance to help build *Heartnotes*, and I'm deeply grateful for their contributions.

This special issue of *Heartnotes* recaps some of the key features we've run over the last three years. We've brought these articles together to provide a comprehensive overview of what hospice and palliative care are, and how patients and families can benefit.

I'd like to encourage you to add your voice to this publication, as well. Please, email me at [jgatti@uhc.com](mailto:jgatti@uhc.com) with your comments, stories and suggestions. And, to ensure you continue to receive *Heartnotes*, please complete and mail in the enclosed subscription card. Your input and perspectives will help us fulfill the *Heartnotes* mission and expand public understanding for the unique power of hospice. ❖❖

Sincerely yours,

Jennifer Gatti

### ABOUT HOSPICE

Hospice is a patient-centered, interdisciplinary approach to end-of-life care that respects the needs of terminally ill patients and helps them remain as comfortable as possible, with loved ones nearby. At the center of hospice care is the belief that every person has the right to die pain-free and with dignity, and that families will receive the necessary support to allow patients to do so.

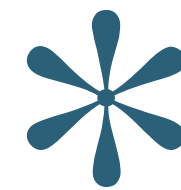
### ABOUT PALLIATIVE CARE

Palliative care is for those who have advanced illness but are continuing curative therapies. Care includes physician consultation and support services for the patient and family. This can be a time to learn about how an illness is likely to progress and plan for end-of-life care.

*Heartnotes* is published by Evercare™ Hospice and Palliative Care, 9701 Data Park Drive, Minnetonka, MN 55343. We provide compassionate care for those facing end-of-life issues and personal support to their families. We are proud to offer resources, education and advocacy on issues relating to long-term care, hospice and palliative care, and the needs of patients and caregivers. This information is not intended as medical advice. If you are concerned about your health or any symptoms you may be experiencing, please contact your primary care provider.

To learn more about Evercare™ Hospice and Palliative Care and the services we provide, please call 1-877-765-3917 or visit us online at [www.EvercareHospice.com](http://www.EvercareHospice.com).

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# PALLIATIVE CARE 101:

## COMFORT IN ALL PHASES OF ILLNESS

**IT IS A MEDICAL ILLUSION THAT** treating a disease can be separated from caring for the person who is suffering. When doctors and other clinicians focus only on curing an illness — instead of holistically responding to a patient’s pain, symptoms and personal needs — they miss the opportunity to provide the broadest spectrum of comfort and quality of life.

Palliative care is a powerful antidote to that disease-specific approach to care, providing specialized expertise in the relief of the pain, symptoms and stress of serious illness. The goal of palliative care is to anticipate, prevent and relieve suffering, creating the best possible quality of life at any stage of an illness. Palliative care is generally low-tech and high touch. It’s also a highly complementary approach to care provided at the same time as curative treatment.

Palliative care relieves symptoms such as pain, shortness of breath, fatigue, constipation, nausea, loss of appetite and difficulty sleeping. It helps patients gain the strength to carry on with daily life. It improves their ability to tolerate medical treatments and it helps them better understand their choices for care. It’s important to remember that palliative care is not the same as hospice. While hospice programs always provide palliative services, they focus on people who are no longer seeking curative treatments.

Palliative care is not a one-size-fits-all approach. Because patients have a range of diseases and respond differently to treatment options, a key benefit of palliative care is that it customizes treatment to meet individual needs. Palliative care can also provide an opportunity for family and friends to gather information about how an illness is likely to progress and to begin planning for long-term-care needs.

Doctors, nurses and social workers work with chaplains, therapists, pharmacists, nutritionists and others to create a palliative care team. Palliative care focuses on the entire person, not just his or her illness. The team members caring for you will address any social, psychological, emotional or spiritual needs you may have. Collaborating with your primary doctor, your palliative care team provides:

- » Expert treatment of pain and other symptoms
- » Close, clear communication
- » Help navigating the health care system
- » Guidance with difficult and complex treatment choices
- » Detailed practical information and assistance

*The goal of palliative care is to anticipate, prevent and relieve suffering, creating the best possible quality of life at any stage of an illness.*

» Emotional and spiritual support for you and your family

If you are suffering with pain and other symptoms, the first step is to talk to your own doctor about palliative care. Here are some tips on how to start that conversation:

» Tell your doctor you are considering palliative care and ask what palliative services are available in your area.

» Ask your doctor to explain your illness as well as past, current and future recommended treatments and procedures.

» Explain to your doctor what quality of life means to you. This may include being able to spend time with loved ones, aggressively treating pain and other distressing symptoms, the ability to make your own decisions for care and where you prefer to receive treatment.

» Be sure your doctor is aware of any personal, religious or cultural beliefs, values or practices that are important to consider in your care and treatment.

» Explain what curative treatments you may or may not want, such as resuscitation if your heart were to stop, being placed on a mechanical ventilator if your lungs were to fail, undergoing dialysis if your kidneys were to fail and artificial nutrition by a feeding tube if you were unable to eat.

» If you have completed a living will or health care proxy, be sure to inform your doctor and provide him or her with a copy. ❖



## \* Expanding Palliative Services

The expansion of palliative medicine has been a critical step in addressing the unmet needs of patients with serious illness and their families. According to the *Journal of Palliative Medicine*, from 2001 to 2003 the number of hospital-based palliative care

programs grew by more than 60 percent. Now, one in four U.S. hospitals has a palliative care program, and all U.S. medical schools must provide training in palliative medicine.

*Explain to your doctor what quality of life means to you. This may include being able to spend time with loved ones, aggressively treating pain and other symptoms and where you prefer to receive treatment.*

## \* Get Informed: Five Questions to Ask about Serious Illness

No one likes to receive bad news, especially when it is about your health. Being diagnosed with a serious illness is one of the scariest and most upsetting things that can happen to you or a loved one. It is not uncommon to have a mixture of many emotions — fear, anger, sadness, anxiety, guilt. Also, if a person has had symptoms for a long period of time or has undergone many tests, finally “knowing the answer” to what is wrong may in some ways even be a relief.

Studies show that when given bad news about an illness, it is rare for patients and families to be able to remember everything they are told during the appointment. You may have to be told the information several times, and in different ways, before you are able to absorb or understand it. In addition, it can be very hard to think clearly in such a situation, so try not to be preoccupied with asking all of the “right” questions immediately. Below are some questions you should ask your physician when you or a loved one is diagnosed with a serious illness.

### **Can you tell me that again?**

When being told bad news, it is completely normal to not be able to take in everything that you are told. Whether it is at the same appointment or at the next one, it can be helpful to ask this question to make sure you understand what your doctor is telling you.

### **Can I say that back to you so I know that I correctly understand what you are telling me?**

Studies show that in many cases physicians believe they are clearly and fully explaining a diagnosis, while in reality the patient has left the discussion with only a partial or incorrect understanding of the information. Ask your physician if you can tell him/her your understanding of the conversation in

your own words to make sure you fully comprehend what has been said.

### **What do we do next?**

While it takes a while to adjust to bad news, knowing what comes next can often relieve anxiety and help focus your mind on positive activities. Work with your doctor to get a sense of the plan so you can better understand what comes next. When are you seeing the doctor next? Are there more tests that need to be done before the next visit?

### **How serious is this?**

This is probably the scariest question of all. Many times there are very good treatments that can cure your disease, and your doctor can tell you about them. Remember that not everyone wants to know the answer to this question — so doctors may not always tell you this without your asking. Also remember that if you are a family member who hears the diagnosis with a loved one, he or she may not want to know the answer (and vice-versa). So sometimes it is important to first ask your loved one, “How much more do you want to know now?”

### **What else should I be asking at this point?**

This kind of open-ended question allows your doctor to give you information that you might not think to ask. Many times the shock of hearing bad news makes it difficult to think, and so you may need help with asking the next question.

Once you understand your illness, the likely progression and potential treatments, you can consider all your options — including palliative care.

*From the Center to Advance Palliative Care at [www.getpalliativecare.org](http://www.getpalliativecare.org)*

## \* Palliative Care Questions and Answers

### **Is palliative care the same as hospice?**

No. While many palliative techniques are used in hospice care, palliative programs are in no way limited to people at the end-of-life. Palliative care empowers patients while they manage the course of any chronic illness, enhancing their quality of life by anticipating, preventing and treating their suffering.

### **So, how exactly are palliative and hospice programs different?**

Like hospice, palliative care addresses a person’s physical, social and spiritual needs and supports patient autonomy by strengthening access to information and respecting a patient’s choices and wishes. Unlike hospice, palliative care supports the patient’s and family’s goals for curative treatment or longevity and is not limited to the last phases of life.

### **How do I know if palliative care is right for me?**

Palliative care can be used at any stage of illness and along with curative treatments. It may be right for you if you suffer from pain and other symptoms due to a serious illness or injury.

### **What can I expect from palliative care?**

You can expect a comfortable and supportive atmosphere that reduces anxiety and stress. You can also expect relief from symptoms such as pain, shortness of breath, fatigue, constipation, nausea, loss of appetite and difficulty sleeping.

### **Does my insurance pay for palliative care?**

Most insurance plans cover all or part of the palliative care treatment you receive in the hospital, as with other hospital and medical services. This is also true of Medicare and Medicaid. Drugs, medical supplies and equipment may also be covered. If costs concern you, a social worker or financial consultant from the palliative care team can help you with payment options.

### **What role does my doctor play?**

The hallmark of palliative care is a team approach to patient care. Your primary doctor will continue to direct your care and play an active part in your treatment. The palliative care team provides support to and works in partnership with your primary doctor.

### **How do I start getting palliative care?**

Start by talking with your doctor or nurse, discussing your treatment plan and asking for a referral. Tell your family, friends and caregivers that you want palliative care and why it is important to you.

### **Aren’t palliative programs an added expense to the health care system?**

Research consistently demonstrates that palliative programs can reduce costs without shortening life. In the largest study of its kind, the Center to Advance Palliative Care and the National Palliative Care Research Center examined expenses and quality of care for hospitalized patients with chronic conditions. According to this study of eight different hospitals with palliative care programs:

- » Hospitals saved from \$279 to \$374 per day per palliative care patient.
- » Hospitals saved \$1,700 to \$4,900 on each admission of a palliative care patient.
- » Savings included significant reductions in pharmacy, laboratory and intensive care costs. This meant savings of more than \$1.3 million for a 300-bed community hospital and more than \$2.5 million for the average academic medical center.

“Cost of Savings Associated with U.S. Hospital Palliative Care Consultation Programs.” *Archives of Internal Medicine*, Vol. 168, No. 16, September 8, 2008.



# HOSPICE 101:

## UNDERSTANDING END-OF-LIFE CARE

**H**OSPICE IS ONE OF THE MOST important advancements in how we approach end-of-life care; at the same time, it is often one of the most misunderstood. But, by empowering yourself with information, you can find a hospice program that fits your needs, understands your concerns and helps create a meaningful experience. With that comes dignity, compassion and respect. This section explains the philosophy of hospice, what to expect from it, how it serves patients and families and how to choose a hospice program.

### The Model for End-of-Life Care

Considered to be the model for quality, compassionate care for people facing a life-limiting illness or injury, hospice is a team-oriented approach to expert medical care, pain management and emotional and spiritual support. It focuses on caring, not curing, and is expressly tailored to the patient's needs and wishes. At the center of hospice is the belief that each person has the right to die pain-free and with dignity, and that our families will receive the necessary support to allow us to do so.

Typically, a hospice patient has a life expectancy of several months or less, rather than a few years. Hospice services are often

in the patient's home and are also provided in freestanding hospice centers, hospitals, nursing homes and other long-term care facilities. Hospice is available to patients of any age, religion, race or illness. It is covered under Medicare, Medicaid, most private insurance plans and managed care organizations.

Hospice is considered an appropriate care solution when:

- » A patient's general health continues to decline, in spite of the curative treatments he or she is receiving
- » A patient is in and out of the hospital frequently
- » Repeat or multiple infections are causing additional challenges to a patient's health
- » Increased or uncontrolled pain is impacting a patient's quality of life
- » Weakness, fatigue or shortness of breath is dramatically limiting a patient's mobility
- » A patient is unable to live independently or manage daily tasks on their own
- » A patient's changing mental awareness requires closer observation and support

*Hospice is a team-orientated approach to expert medical care, pain management and emotional and spiritual support.*

### How Hospice Works

Typically within the hospice model, a family member serves as the primary caregiver and, when appropriate, helps make decisions for the patient. Hospice staff members make regular patient visits and are on-call 24 hours a day, seven days a week.

The hospice team develops a care plan that meets each patient's individual needs for pain management and symptom control. The team usually consists of:

- » Hospice physicians or medical directors who work alongside a patient's regular doctor and consult on disease progression, pain management and symptom control
- » Nurses who monitor a patient's condition and have specialized training in pain and symptom management
- » Certified nursing assistants who help with a patient's care and support their comfort and safety
- » Social workers who provide counseling, grief support and assistance in accessing community resources
- » Chaplains who help patients explore spiritual questions. Hospice chaplains do not

represent a particular denomination or church and always respect personal beliefs

- » Trained volunteers who offer practical assistance, companionship and understanding to patients and families
- » Therapists who provide speech, physical, occupational and nutritional expertise

This interdisciplinary hospice team manages the patient's pain and symptoms, assists the patient with the emotional, psychosocial and spiritual aspects of dying and coaches the family on patient care. Hospices may also supply needed medications, supplies and equipment; provide short-term inpatient and respite care and offer bereavement care and counseling to family and friends after a loss.

Hospice's holistic philosophy extends to families and friends, as well as patients. Hospice provides a safe, comfortable place for families to ask questions about what to expect physically, emotionally and spiritually as the end-of-life approaches. Hospice also helps a patient's family members work through the anger, guilt, sadness and grief associated with illness and death, helping them affirm the life and the memory of their loved one during their bereavement process. ❖

## \* The History of Hospice

The term "hospice" can be traced back to medieval times, when it referred to a place of shelter and rest for weary or ill travelers on a long journey. The name was first applied to specialized care for dying patients in 1967 by physician Dame Cicely Saunders, who founded St. Christopher's Hospice in a residential suburb of London.

Dr. Saunders introduced the idea of specialized care for the dying to the United States during a visit

with Yale University. She spoke to medical students, nurses, social workers and chaplains about the concept of holistic hospice care and showed dramatic photos of terminally ill patients and their families before and after they received symptom and pain management. This lecture launched the U.S. hospice movement, which resulted in the development of hospice as we know it today. ❖

## \* Hospice Questions and Answers

### What is the right time to enter hospice?

It is appropriate at any time during a life-limiting illness to discuss all available care and treatment options, including hospice. Typically, patients enter hospice when they are no longer seeking curative treatment for their illness. A hospice patient generally has a life expectancy of several months or less, rather than a few years, and may receive care as long as their condition continues to decline. There is no time limitation on receiving hospice services.

### Is it true that hospice can extend a patient's life?

Hospice care may prolong the lives of some terminally ill patients. A 2007<sup>1</sup> study tracked 4,493 terminally ill patients who had either congestive heart failure or cancer of the breast, colon, lung, pancreas or prostate. Patients who chose hospice lived an average of one month longer than similar patients who did not choose hospice.

### Should I wait for my doctor to suggest hospice, or should I raise the issue first?

Patients and their families should feel comfortable discussing hospice care at any time with their physician, other health care professionals, clergy or friends. It's important that everyone, regardless of their age, share their end-of-life wishes and put them in writing with advance directives. Hospice programs can provide valuable information about advance care planning and how to discuss it with family members.

### Can a hospice patient return to regular medical care?

Absolutely. Any patient has the right to withdraw from hospice at any time for any reason. If your condition improves and you wish to pursue curative treatment, you would be discharged from hospice care. If needed, former patients can always return to hospice care.

### What happens if I lose my ability to make decisions or help direct my care?

All hospice patients designate an advocate who will serve as their medical durable power of attorney. This person should be aware of a patient's wishes and be able to consult with the care team. The team will follow the instructions dictated by a patient's advanced care plan to ensure the patient's wishes are respected, along with applying their professional expertise to help patients remain comfortable throughout the progression of their condition.

### Is there any special equipment or changes I will need to make in my home before hospice care begins?

Hospice teams try to minimize the disruption to your surroundings and encourage you to keep the furniture, mementos and other possessions that provide comfort and peace of mind. If a condition requires medical equipment, the team will make arrangements for its delivery and setup, continuing to be very respectful of your home and belongings. ❖❖

*It's important that everyone, regardless of their age, share their end-of-life wishes and put them in writing with advance directives.*

<sup>1</sup>Comparing Hospice and Nonhospice Patient Survival Among Patients Who Die Within a Three-Year Window. Journal of Pain and Symptom Management, Vol. 33 No. 3, March 2007.

## \* Choosing a hospice program

Entering hospice is a highly personal decision, and it's essential that a hospice program reflects a patient's needs and respects their wishes. The best way to decide whether a particular program is right for you is by interviewing hospice providers in your area. Begin by talking with people you trust who have experience with hospice, such as your doctor, clergy and other counselors. You can also contact your local or state Office on Aging or senior center.

There are some key topics to cover with any hospice. Bring this checklist to your interview and add any other questions you would like to review with a potential hospice provider.

- How are hospice costs covered, and will I have any copayments? \_\_\_\_\_
- How strong is your volunteer program, and how do you screen and select volunteers? \_\_\_\_\_
- How do you guarantee that volunteers are a good fit? Are they allowed to drive family members or patients? What other services do they provide? \_\_\_\_\_
- What homemaking services do you offer? \_\_\_\_\_
- What quality standards do you maintain? For example, how quickly do you return phone calls, and how do you measure the performance of your staff? \_\_\_\_\_
- How quickly can a nurse get to my home, if needed? Is response time the same at night as during the day? \_\_\_\_\_

- How and where does your hospice provide short-term inpatient care? \_\_\_\_\_
- Can hospice be brought into a nursing home or long-term care facility? \_\_\_\_\_
- Do you provide bereavement services in person, or just over the telephone? \_\_\_\_\_
- Do you have a medical director who makes house calls? How often does the medical director typically visit patients? \_\_\_\_\_
- What makes your program different from others? What do you do that goes beyond the standard hospice benefit? \_\_\_\_\_
- Why should I choose your program? \_\_\_\_\_
- Add other questions you may have: \_\_\_\_\_

Chaplain  
Anne Chida



## VOICES OF CARE: IN THEIR OWN WORDS

**OUR DEDICATED CARE TEAMS** are the heart of Evercare Hospice. Here are just a few examples of how these professionals remain so dedicated to the patients and families they serve.

### **Beth Martin, LPN, CHPLN**

To me, what makes a good hospice is a good team. If you need help from the other disciplines, it is imperative that everyone be responsive. Many times when we arrive at a patient's bedside, it is clear that they need more than nursing services at that time. I deeply appreciate the collaboration that I have with the chaplains, social workers, hospice aides and also the office staff that keep us all connected. It is amazing to be part of a team that works together for the benefit of the patient.

### **Gail Bekebrede, RN Case Manager**

I have been a nurse for almost 37 years. For the first time in my long nursing career I am doing something different and loving every minute of it! Like the motto of the U.S. Army, it is the hardest job you will ever love. I know I was always doing something important, but this brings important to a whole new level for me. I feel this is care on a more personal level. I get so much satisfaction from doing the most simple of tasks because my clients and their families really appreciate the work that I do.

### **Chauncya Lucas, Intake Coordinator**

One of my most rewarding hospice experiences was when one of our patients

was dying at the young age of 50. She was lonely because she was no longer able to get out the way she used to. She called the office and we sat and just chatted for about 20 minutes or so, not about her illness, but just about everyday things like movies and food. She told lots of jokes! It was very rewarding for me to fill her need of having someone to talk with. I feel that's what makes a good hospice: A compassionate and caring team.

### **Anne Chida, Hospice Chaplain**

My first experience with hospice happened when I worked in home health care in the early 1980s. It was fall, and our patient was a man dying of lung cancer. The one thing he wanted me to do for him was to plant tulip bulbs along his walkway. His wife of more than 50 years loved tulips, and he wanted her to know when she saw those tulips come up that he loved her even though by that time he would likely be gone. I shed a few tears while I was planting those bulbs.

When I hit middle age I decided to return to seminary and become a minister so that I could work as a hospice chaplain. I love being a hospice chaplain and feel that I get far more out of my job than I could ever give.

### **Dr. Rhonda Randall, Physician**

What makes a good hospice? One sentence: The expertise, commitment, compassion and availability of the staff to the patient and their caregivers. ❖

# GETTING THE FACTS

## 10 COMMON MYTHS ABOUT HOSPICE CARE.

### **MYTH #1: Hospice is a place.**

» Hospice care takes place wherever the need exists — usually the patient's home. About 80 percent of hospice care takes place at home.

### **MYTH # 2: Hospice is only for people with cancer.**

» Increasingly, hospices are serving patients and families coping with the end-stages of chronic diseases like emphysema, Alzheimer's, cardiovascular and neuromuscular diseases and HIV/AIDS.

### **MYTH #3: Hospice is only for old people.**

» Although the majority of hospice patients are older, hospices serve patients of all ages. Many hospices offer clinical staff with expertise in pediatric hospice care.

### **MYTH #4: Hospice is only for dying people.**

» As a family-centered concept of care, hospice focuses as much on the grieving family as on the dying patient. Most hospices make their grief services available to the community at large, serving schools, churches and the workplace.

### **MYTH #5: Hospice can only help when family members are available to provide care.**

» Recognizing that terminally ill people may live alone, or with family members unable to provide care, many hospices coordinate community resources to make home care possible. Or they help to find an alternative location where the patient can safely receive care.

### **MYTH #6: Hospice is for people who don't need a high level of care.**

» Hospice is serious medicine. Most hospices are Medicare-certified, requiring that they employ experienced medical and nursing personnel with skills in symptom control. Hospices offer state-of-the-art palliative care, using advanced technologies to prevent or alleviate distressing symptoms.

### **MYTH #7: Hospice is only for people who can accept death.**

» While those affected by terminal illness struggle to come to terms with death, hospices gently help them find their way at their own speed. Many hospices welcome inquiries from families who are unsure about their needs and preferences. Hospice staff are readily available to discuss all options and to facilitate family decisions.

### **MYTH # 8: Hospice care is expensive.**

» Most people who use hospice are over 65 and are entitled to the Medicare Hospice Benefit. This benefit covers virtually all hospice services and requires little, if any, out-of-pocket costs. This means that there are no financial burdens incurred by the family, in sharp contrast to the huge financial expenses at the end-of-life which are incurred when hospice is not used.

### **MYTH # 9: Hospice is not covered by managed care.**

» Medicare beneficiaries can use their Medicare Hospice Benefit anytime, anywhere they choose.

### **MYTH # 10: Hospice is for when there is no hope.**

» When death is in sight, there are two options: submit without hope or live life as fully as ever until the end. The gift of hospice is its capacity to help families see how much can be shared at the end-of-life through personal and spiritual connections often left behind. It is no wonder that many family members can look back upon their hospice experience with gratitude, and with the knowledge that everything possible was done towards a peaceful death.

"Hospice must be better understood if it is to reach all those who need it," Naierman emphasizes. "Increased visibility of hospice, locally and nationally, will result in more people becoming proactive advocates for themselves and their families." ❖

—"Debunking the Myths of Hospice" is reprinted with permission from the American Hospice Foundation.

*Hospice is not just  
a philosophy or  
service for me, it is  
a way of life.*

# EVERCARE HOSPICE SECTION:

## ABOUT EVERCARE HOSPICE

**A T EVERCARE™ HOSPICE AND** Palliative Care, we are committed to providing the best hospice and palliative care experience available. This can be a difficult time both physically and emotionally not just for patients, but for families as well. We strive to understand those needs and provide care for everyone involved, from preparing for an end-of-life experience with compassion and dignity through the entire bereavement process.

To this end, we offer:

- » Home visits from an Evercare Hospice Physician who coordinates closely with a patient's primary physician.
- » Care provided wherever the patient resides — whether it's home, the home of a loved one, a hospital, nursing home or an assisted living community.
- » A comprehensive approach to pain management and symptom control.
- » The ability to admit all hospice eligible referrals the same day, unless otherwise requested.
- » On-call staff available 24 hours a day, 7 days a week, along with a commitment to return all patient-related calls within 15 minutes.
- » The services of an interdisciplinary team including the patient's personal physician, a hospice physician, nurses, clergy, social workers and trained volunteers.
- » An unrestricted options philosophy on admissions to help make hospice available to all who are eligible.
- » Bereavement support for up to thirteen months.

While most programs require a medical director as part of the hospice care team, many never see patients, and only a small percentage of programs include Medical Directors as part- or full-time employees. Our hospice physicians are deeply involved in the patient's care and are available to see patients on a regular basis.

We not only provide all of the basic hospice and palliative care services required by law, we offer many additional services that standard hospices do not. Evercare Hospice is Medicare-certified, which means that our services are covered by Medicare, Medicaid, military health plans and most private insurance companies. Any health care plan member is eligible; a patient does not have to be a member of a UnitedHealth Group or Evercare plan to qualify to receive our services. Our goal is to make hospice available to all who are eligible to receive this special care.

With Evercare Hospice's philosophy of fewer restrictions on admissions, we break down unnecessary barriers to care. For example, some hospice programs will not allow enrollment to patients receiving certain therapies such as IVs, radiation or chemotherapy, even though these types of treatments may be effective palliative strategies that can make patients more comfortable. We are open to these types of situations on a case by case basis.

Additionally, our palliative care program provides support for patients with advanced illnesses who may want to continue with aggressive, curative therapies. Palliative care specialists work alongside the patient, his or her family and the attending physician. The goals are to reduce the discomfort often accompanying the treatment or symptoms of advanced illness and to help develop a long-term plan of care. ❖

*We provide care for everyone involved, from preparing for an end-of-life experience through bereavement.*

## \* How to Refer a Patient to Evercare™ Hospice and Palliative Care

Call us at 1-877-273-5534 and we will walk you through the referral process. We strive to respond to all patient-related calls within 15 minutes—24 hours a day, 7 days a week. Unless requested otherwise, most eligible patients can begin receiving hospice or palliative care the same day you contact us.

### PREPARING TO REFER A PATIENT

We make it simple to refer a patient. There are just four main steps to complete:

#### 1. Gather documentation for the referral form:

- » Doctor's order for hospice or palliative care (required)
- » Legal documents (MDPOA or POA)
- » Living will

#### 2. Be prepared to answer these questions:

- » Is the attending physician the person who is requesting hospice?

- » Is the patient and/or family aware of the diagnosis and prognosis?
- » Do the patient and family desire hospice?
- » Can the word "hospice" be used?
- » Has the patient received hospice care previously? If yes, what dates of service?
- » Is the patient receiving skilled nursing services? With whom have you verified this?
- » Have you talked to the patient and/or family about the financial responsibility for room and board if the patient has no Medicaid?
- » Does the patient have a living will?

**3. Complete a referral form**, which is available online at [www.EvercareHospice.com](http://www.EvercareHospice.com).

**4. Fax the referral form** to the Evercare Hospice & Palliative Care office closest to you (fax numbers are listed on the referral form).

## \* When Families Need Extra Help

Evercare™ Solutions for Caregivers is a national care management service that provides advice and guides families through the complexity of choices to best manage their loved one's changing medical and non-medical needs. This innovative program helps family caregivers reduce their anxiety and become empowered to support their loved one, while also taking care of their own health and personal needs.

Services include:

- » An objective assessment conducted by a registered nurse.
- » A recommended course of action and potential services.
- » A family conference call to discuss recommendations and next steps.

- » An individualized care plan that addresses social, emotional, financial and safety issues and monitors medical and psychological conditions.
- » Coordination of community and in-home resources.
- » Referrals to other trusted professionals, including home health aides, nurses, lawyers and financial advisers.
- » Regular communication, ongoing monitoring and proactive planning.
- » 24/7 support and resources for caregivers and their families.

These services can make an important difference in the lives of patients and their families. To learn more, visit [www.evercarehealthplans.com/solutions\\_for\\_caregivers.jsp](http://www.evercarehealthplans.com/solutions_for_caregivers.jsp) or call 1-866-463-5337.



- » **Keep your doctor appointments.** Most caregivers ignore their own health needs. But if you get sick, who will care for your loved one?
- » **Keep a journal or diary.** By recording what you are going through and how you are feeling, you can better evaluate whether things are improving or worsening over time, and identify what other support you might need.
- » **Pursue hobbies.** Don't lose touch with the things that give you pleasure. Continue to do what brings you joy, even if it is less frequent than before.
- » **Blow off steam.** Go to the movies, go to dinner, have fun, see friends, play games. It's okay to escape and not focus all your energy on your loved one's illness.
- » **Accept the help others offer.** Trust in their willingness to help. Suggest specific things they can do.
- » **Tap into your support network.** Many people want to help, but don't know what to offer. Ask friends, relatives, neighbors, co-workers and people in your faith community to help you with tasks they feel best doing.
- » **Join a caregiver's support group.** There are many community resources that can offer you extra help and time away.
- » **Get professional help.** Care services can be provided in the home, in an adult day center or in a nursing home or assisted living facility.

BRIDGING THE GAP:  
LONG-DISTANCE CAREGIVING

Physical distance can further complicate the responsibilities of caregiving. About 7 million adults in the U.S. are caregivers for family members who live an hour or more away. Since

you can't often be there in person, this type of caregiving brings its own set of challenges. Here are some tips for long-distance caregivers.

**Get informed.** Learn as much as you can about your loved one's condition, including their medical, physical, financial, social, emotional and safety needs. This information can help you anticipate potential issues and prevent a crisis.

**Collect contact info.** Create a notebook or folder with all the vital information about your loved one's health care, social services, contact numbers, financial accounts, etc. Ask your loved one about giving you written permission to receive medical and financial information.

**Find trusted "eyes and ears."** Seek help from people in the immediate community: a next door neighbor, a friend, a doctor. Ask them to check in on your loved one and to be your eyes and ears. Encourage them to call if they see anything that concerns them.

**Make a medication list.** Include all prescriptions, over-the-counter medications, vitamins and supplements. Get doses and schedules. Update it regularly and keep a copy with you.

**Talk about the future.** Find out if your loved one has an advance directive with health care preferences, and if not, encourage them to document their wishes. Make sure you have a copy and you know where a copy is kept.

**Get in touch and stay in touch.** Schedule regular calls with doctors and other caregivers to get up-to-date information about your loved one's health and condition. Consider conference calls, so other relatives can participate in one conversation. ::

*Evercare™ Solutions for Caregivers can be an important link between you and your aging loved ones. Their Caregiver Coaches have the information, resources and expertise to support you and develop a customized care plan. For a free consultation, call 1-877-765-4473 or visit them online at [www.EvercareHealthPlans.com/Caregiver](http://www.EvercareHealthPlans.com/Caregiver).*

# RESOURCES

VISIT THESE WEBSITES FOR COMMUNITY SUPPORT AND VALUABLE INFORMATION ABOUT HOSPICE, PALLIATIVE AND LONG-TERM CARE.

» **EVERCARE™ HOSPICE & PALLIATIVE CARE** ([www.evercarehospice.com](http://www.evercarehospice.com) or 1-877-765-3917) offers education, resources and services for patients and families through its interactive website and 24-hour phone line.

» **CARING CONNECTIONS** ([www.caringinfo.org](http://www.caringinfo.org) or 1-800-658-8898) is a program of the National Hospice and Palliative Care Organization, providing extensive resources and support for patients and families who are coping with end-of-life issues.

» The **NATIONAL HOSPICE AND PALLIATIVE CARE ORGANIZATION** ([www.nhpco.org](http://www.nhpco.org)) is the largest nonprofit membership organization representing hospice and palliative care programs and professionals in the United States. It offers education and information for practitioners, patients and families.

Through the NHPCO website, you can search for a hospice or palliative care program in your community. Use the "Find a Provider" search page at [www.iweb.nhpco.org/iweb/Membership/MemberDirectorySearch.aspx](http://www.iweb.nhpco.org/iweb/Membership/MemberDirectorySearch.aspx).

» **MEDICARE** covers most hospice services for eligible beneficiaries. You can view a special publication online for more information about Medicare hospice benefits at <http://evercarehealthplans.com/pdf/MedicareHospice02154.pdf>.

» **AGING WITH DIGNITY** ([www.agingwithdignity.org](http://www.agingwithdignity.org)) provides practical information, advice and legal tools on end-of-life and long-term care issues, including the Five Wishes planning document ([www.agingwithdignity.org/5wishes.html](http://www.agingwithdignity.org/5wishes.html)).

» **CARINGBRIDGE** ([www.caringbridge.org/evercare](http://www.caringbridge.org/evercare)) helps you stay connected with friends and family during an illness through a free, personalized website.

» **LOTSA HELPING HANDS** ([www.caregiver.lotsahelpinghands.com](http://www.caregiver.lotsahelpinghands.com)) is a private, web-based tool that allows you to share your needs and let family, friends, neighbors and colleagues assist with daily caregiving tasks.

» The **WELL SPOUSE ASSOCIATION** ([www.wellspouse.org](http://www.wellspouse.org)) focuses on the needs of all spouses caring for a chronically ill or disabled husband, wife or partner.

» **CENTER FOR PRACTICAL BIOETHICS** ([www.practicalbioethics.org](http://www.practicalbioethics.org)) provides tools and resources about end-of-life decision making, including the Caring Conversations Series.

*It's okay to take a break and not focus all of your energy on your loved one's illness.*

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If you'd like to join the *Heartnotes* mailing list and receive each quarterly issue, please visit **[EvercareHospice.com/Subscribe](http://EvercareHospice.com/Subscribe)** to register for your free subscription.