

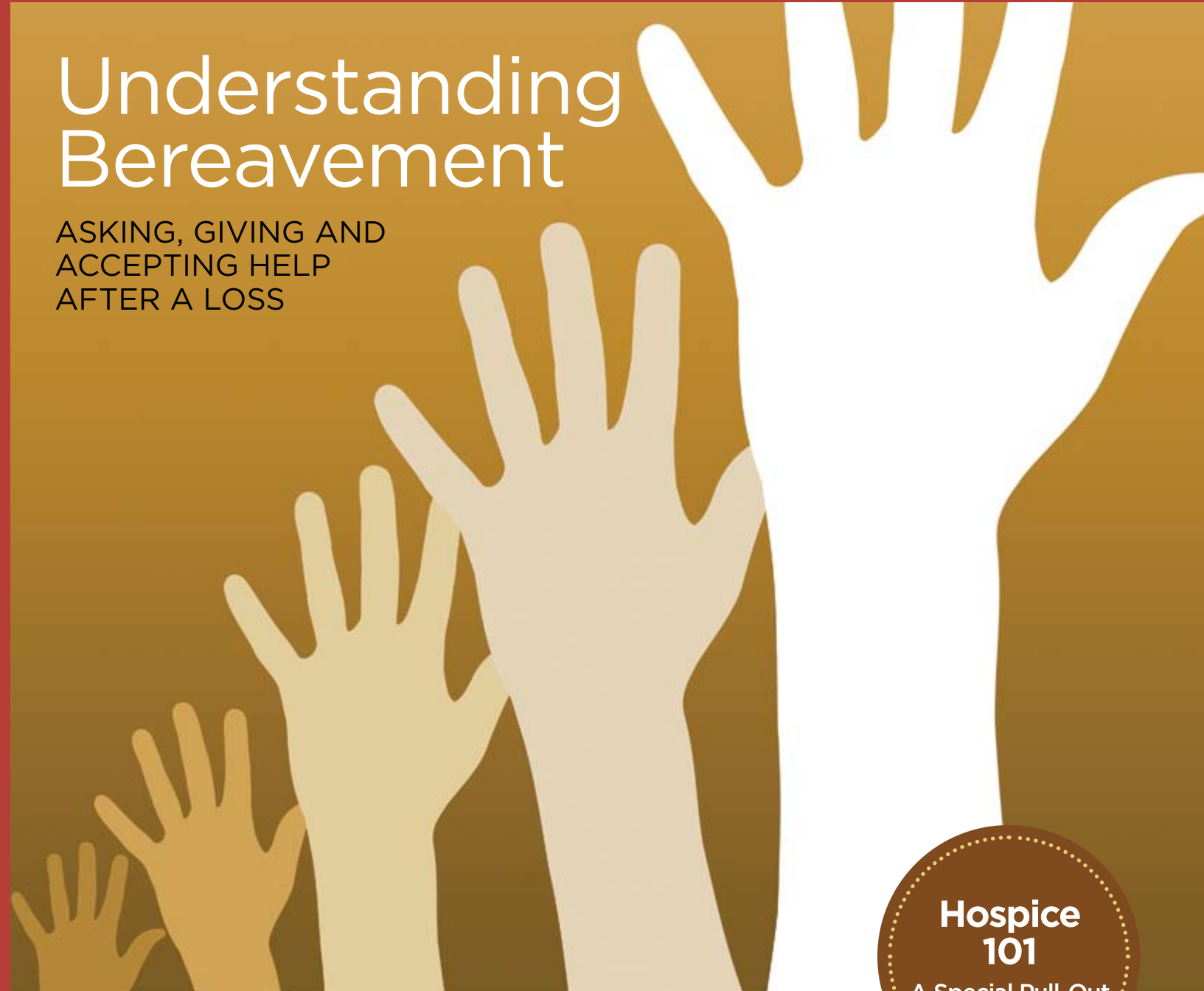
heartnotes™

(A JOURNAL OF HOSPICE & PALLIATIVE CARE)



Understanding Bereavement

ASKING, GIVING AND
ACCEPTING HELP
AFTER A LOSS



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Health Reform
Update

A Conversation
About Hospice

editor's note



This issue of *Heartnotes* marks the two year anniversary of our publication. It's been a complete honor to work with Evercare Hospice and with the many families, patients, clinicians, researchers, volunteers and community members who have given their expertise, experiences and time to this journal. It's through their voices, passion and commitment that we've been able to cast a bright light on the intrinsic value of hospice and palliative care.

It's very appropriate that the fall issue of *Heartnotes* comes on the eve of National Hospice and Palliative Care Month, which is observed every November. National Hospice and Palliative Care Month is a time when end-of-life organizations come together to share information and education about the role that palliative care and hospice play within the medical community, and in support of the health care system as a whole. It's also a time when families and friends are encouraged to have the sometimes difficult conversations about end-of-life wishes. These talks are so important but too often neglected, because they force us to speak openly and acknowledge our private fears and anxieties about death.

This issue of *Heartnotes* is all about opening up and getting honest about what it means to have a loved one in the last stages of life. In our cover story about bereavement, we discuss the complex process of grief and how differently we each process those powerful feelings, as we strive to accept a loss. Our special pull-out section, Hospice 101, provides a primer on what hospice is, what to expect from hospice and gives you the tools to start the dialogue about choosing a hospice provider. And, in our focus on Evercare[™] Hospice and Palliative Care, family members and staff share what hospice has meant to them and why they believe in it.

Thank you very much for supporting *Heartnotes* through your readership, contributions and feedback. You are essential to this publication, and I'm so glad you've joined us on this journey. ::

Sincerely yours,

Jennifer Gatti

If you have questions or feedback about Heartnotes, please email Jennifer Gatti at jenn_gatti@uhc.com.

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

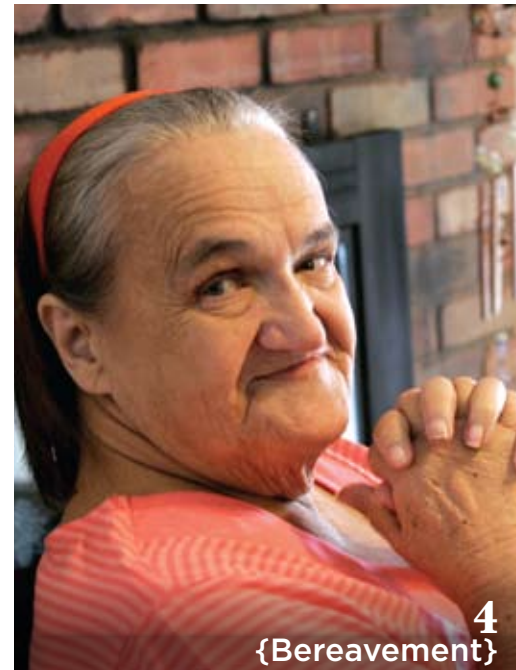
Palliative care is for those who have advanced illness but are continuing curative therapies. Care includes physician consultation and support services for the patient and family. This can be a time to learn about how an illness is likely to progress and plan for end-of-life care.

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.

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BEREAVEMENT:

MOVING THROUGH A LOSS, EMBRACING THE FUTURE

TO DIFFERENT DEGREES, PEOPLE often define themselves by their relationships. We are wife, husband, mother, father, sister, brother, son, daughter, partner, friend. When our loved one dies, we become widow, widower, grieving friend, bereaved sister and so on. A significant loss may change how we view the world around us, how we relate to other people and how we are viewed. While it is clear that life is and will be different without the presence of the person who died, many bereaved people find themselves struggling to redefine their place in the world.

Bereavement is the emotional and physical response to the death of a loved one. Within hospice, it refers to the grief process and related services that hospices provide to families and friends. The questions that arise during bereavement often raise questions about the beliefs, attitudes and norms that shaped our lives before the loss. It is not unusual to wonder when we will be “done” or to look for milestones in our journey as a measure of progress.

The death of someone close to you can be one of the most stressful events in a person’s life. Loss can affect everything about us, including our emotions, physical sensations, thought patterns, behavior, spirituality and social relationships. No two individuals react to loss in exactly the same way. There are

many reasons for these differences including personality, health, coping skills, culture, family background and other stressors and life experiences. The time spent grieving also depends on your relationship to the person who died and how prepared you were for the loss.

It is very common for grieving people to be surprised at the intensity of the feelings that emerge and re-emerge during bereavement. Surrendering to grief requires tremendous courage and it takes strength to admit that we are scared or angry or lonely. Regardless of how grief is expressed, there are a number of natural responses that most people can expect at some point in their journey.

Emotional Reactions

You may experience a wide range of feelings and mood swings. Unexpected waves of sadness and tears are very common. Guilt, anger, regret, anxiety, relief, sorrow, gratitude, helplessness and loneliness may be present in varying degrees. Many people hold a secret wish that they would die in order to be with their loved one. It can be very hard to imagine a future without the person who died. While these are not unusual thoughts, if you find yourself making a plan to end your life, seek out a friend or a medical or bereavement professional immediately.

Physical Sensations

Physical complaints are not unusual. These may include hollowness in the stomach, tightness in the chest and throat, increased sensitivity to noise, decreased energy, dry mouth, trembling, nausea and trouble sleeping or eating.

Change in Thought Patterns

Grieving people often experience a sense of disbelief, confusion, inability to concentrate and difficulty remembering. Decision making abilities may be impaired and you may be preoccupied with thoughts of the person who died. Many people feel as though they are on “auto pilot.” While these changes can be frightening, they are typical and will subside as you move through your healing process.

Behavior

You may have unusual dreams, become irritable or restless, withdraw socially or lack the desire to participate in activities that had been enjoyable. Many people find themselves visiting places or carrying objects that remind them of the person who died. Others may avoid reminders of the loss by returning to normal routines as quickly as possible.

Spirituality

Grief often has a direct impact on our faith system. Some people find comfort with a deepening or rediscovering of faith. For others, the experience of loss may lead them to challenge basic beliefs about religion, death, afterlife and personal mortality. It is not uncommon to feel angry that our loved one was not saved. It may be helpful to seek support from members of your religious community.

Social Relationships

When we are grieving, we need times of solitude to be with our thoughts and to rest. It is not unusual for people coping with loss to want to withdraw from other people or the pressures and decisions of daily life. You may feel lonely, isolated, different and separated from everyone else. You may be convinced that no one understands. Many grieving people are amazed that the normal patterns of life continue while their lives have been turned upside down. It is important to remember, however, that we need people to help us — to listen, to hold us and to remember our loved one with us.

Coping with the Holidays

When someone close has died, holidays inevitably bring fresh memories and a re-experience of painful grief. You might feel numb much of this holiday season, but next year’s holidays may send a new wave of grief your way. For many, the anticipation of a holiday is worse than the actual day. Make a plan for the holiday that is approaching. If it is difficult to decide what you want to do, think about what you don’t want to do. Discuss your plan with your family.

There’s no ignoring the holiday in hopes it will go away. Everywhere you look, you will probably be reminded that this is a holiday season. Stores will be decorated and there will be holiday ads in the newspaper and on TV. People will greet you with a “happy” or a “merry” without realizing it may not be a happy or merry time for you.

Here are some tips for navigating the holiday season:

- » Allow some time to feel sad. Have a good cry if you need to.
- » Be careful with excessive use of alcohol or medications.
- » Try to keep on a routine. Eat as well as you can, get rest and keep up with regular exercise.
- » If you need some quiet time, take it.
- » Some people feel that a change of pace is more helpful than old familiar traditions. Do you want to do something entirely different, such as spend the holiday at the beach or in the mountains where you won’t be so acutely reminded of your loved one’s absence? You may find that sometimes new traditions may develop in the midst of your grief.
- » Set priorities! Grief is exhausting, and you may tire quickly. Save your energy for the most important things.
- » If you aren’t up for a large family affair, have a scaled-down event with the people who make you feel most comfortable and relaxed.
- » Be prepared to receive correspondence from friends who have not heard of the death and may inquire about your loved one’s health or activities.

The death of someone close to you can be one of the most stressful events in a person’s life.

It is very common for grieving people to be surprised at the intensity of the feelings that emerge and re-emerge during bereavement.

Most importantly, as the holidays approach, don't be surprised at the intensity of your grief. Feelings of anger, panic, depression, despair, guilt, regret, fearfulness and loneliness, as well as physical symptoms, feel stronger at this time. This is perfectly normal. It is not a setback; it is how grief works. Tell

important people in your life that this is a difficult season and let them know what they can do to help. Reach out for what you need, accept what others give, and give yourself permission to move through the holidays in your own way. ❖

* Signs of Healing

The progress through grief can be so slow that it is difficult to see signs of improvement. The following¹ are clues that will help you to see that you are beginning to work through your grief.

- » You can review both pleasant and unpleasant memories. In early grief, memories are painful because they remind you of how much you have lost. Now it feels good to remember, and you look for people to share memories with.
- » You can enjoy time alone and feel comfortable. You no longer need to have someone with you all the time or look for activities to keep you distracted.
- » You look forward to holidays. Once dreaded occasions can now be anticipated with excitement, perhaps through returning to old traditions or creating new ones.
- » You can reach out to help someone else in a similar situation. It is healing to be able to use your experience to help others.
- » The music you shared with the one you lost is no longer painful to hear. Now, you may even find it comforting.
- » Some time passes in which you have not thought of your loved one. When this first happens, you may panic, thinking, "I am forgetting." This is not true. You will never forget. You are giving yourself permission to go on with your life and your loved one would want you to do this.
- » You can enjoy a good joke and have a good laugh without feeling guilty.
- » Your eating, sleeping, and exercise patterns return to what they were beforehand.
- » You no longer feel tired all the time.
- » You have developed a routine or a new schedule in your daily life that does not include your loved one.
- » You have patience with yourself through "grief attacks." You know they are becoming further apart and less frightening and painful.
- » The vacated roles that your loved one filled in your life are now being filled by yourself or others. When a loved one dies he or she leaves many "holes" in your life. Now those holes are being filled with other people and activities, although some will remain empty. You are more at ease with these changes.
- » You can take the energy and time spent thinking about your loss and put those energies elsewhere, perhaps by helping others in similar situations or making concrete plans with your own life.
- » You acknowledge your new life and even discover personal growth from experiencing grief.

¹You Know You Are Getting Better When... Helen Fitzgerald and the American Hospice Foundation, August 2002.

Coping With the Holidays Checklist

This checklist can help you plan for upcoming holidays. Use the checklist to help sort out your thoughts about how you want to spend your energy. Place a check mark by what you want to do this year. Share this with your family or have them do one of their own and compare notes.

HOLIDAY CARDS

- Mail as usual
- Shorten your list
- Include a "Holiday Letter"
- Elect to skip this year

DECORATIONS

- Decorate as usual
- Modify your decorations
- Ask for help
- Let others do it
- Make changes, such as an artificial tree instead of a real one
- Have a special decoration for your loved one
- Choose not to put up decorations

HOLIDAY MUSIC

- Enjoy as usual
- Avoid turning the radio on
- Shop early before stores play holiday music
- Listen to it, have a good cry, and allow yourself to feel sad

SHOPPING

- Shop as usual
- Give cash
- Shop through catalogs or the Internet
- Ask for help
- Shop early
- Make your gifts
- Give baked goods
- Shop with a friend
- Ask for help wrapping gifts
- Do not exchange gifts now, but later
- Make a list of gifts to buy before you go out

TRADITIONS

- Keep the old traditions
- Attend holiday parties
- Don't attend holiday parties
- Go to an entirely new place
- Bake the usual holiday foods
- Buy the usual holiday foods
- Bake, but modify what you usually do
- Attend a religious service
- Do not attend a religious service
- Attend a different place of worship
- Spend quiet time alone
- Visit the cemetery
- Open gifts on the usual day
- Open gifts at another time

HOLIDAY DINNER

- Prepare as usual
- Go out for dinner
- Invite friends over
- Eat alone
- Change time of dinner
- Change routine of dinner
- Change location of dinner
- Ask for help

POST-HOLIDAY & NEW YEAR'S DAY

- Spend as usual
- Go out of town
- Avoid New Year's parties
- Attend a New Year's party
- Hold a New Year's party
- Spend time with only a few friends
- Write your hopes for the new year in a journal
- Go to a movie
- Go to bed early

Adapted from materials created by the American Hospice Foundation, 2005.

VOLUNTEER PROFILE:

BARBARA M.

Barbara M. has been an active community volunteer for nearly two decades, primarily contributing her energy and compassion to at-risk children. "My focus had been programs that serve young families," she explains. "But, when I heard the need for hospice volunteers, I saw that this might be a place where I was well suited to a hard-to-fill role."

Barbara has a background in nursing and psychology, and she supported her mother through a two-year battle with cancer. "I knew what it was like personally to go through a loss; I understood the medical side of death and dying, and I felt comfortable supporting others through their grief," she says. "I see death as a very natural part of life. I don't fear it, and I thought that might be something that could be useful within hospice."

Barbara quickly found herself drawn to clinical services, volunteering one-on-one with patients and then with families during their bereavement process. "As a culture, we can be so harsh and unforgiving when it comes to death," she says. "We are quick to write off people at the end-of-life, as though they don't have value. People want interaction and companionship throughout their lives, even in the final phases. No one wants to be alone, or die alone."

That same need to be respected as an individual flows into Barbara's bereavement volunteering. "There is no 'right' way or single way to grieve," she says. "People get told that they shouldn't be grieving after 6 months or a year, when

in fact it can be a long and unpredictable process. People need safe spaces to feel what they feel, when they're feeling it, and hospice creates that safe haven for them."

Serving as a bereavement and a patient volunteer might seem intimidating, but Barbara emphasizes that it's really about finding and bringing comfort. "Much of what I do is very simple, the everyday actions of sitting with someone, talking about their life and experiences, holding a hand. It's just the action of being present, of acknowledging each person's humanity through the end. It's so important, and something I'm really honored I've been able to do." ❖❖

Barbara M.



"People need safe spaces to feel what they feel, when they're feeling it, and hospice creates that safe haven for them." – Barbara M.



HOSPICE 101:

UNDERSTANDING END-OF-LIFE CARE

HOSPICE 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 special pull-out 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. ❖

* 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: _____

* 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 2007¹ 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.

¹Comparing 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.



Lora C.

VOICES OF CARE: HELP BEHIND THE SCENES

VOLUNTEERS ARE FUNDAMENTAL to the hospice concept and are a vital part of the hospice team, serving as an inspiration to patients, families and staff. Read on to learn how this volunteer is serving patients and families from the front lines and behind the scenes.

LORA C.

When thinking about the role of a hospice volunteer, you might first picture someone who sits at a patient's side. In fact, there are many people who contribute their time and expertise behind the scenes, supporting the administrative aspects of running a hospice program.

Lora C. has been an office volunteer at Evercare Hospice in Macon, Georgia since March 2009. "I love coming into that office, and I love knowing that my work helps everyone else serve people in need," she says. "It's easily the most rewarding thing I've ever done."

Lora works side-by-side with Evercare Hospice staff for as much as 4 hours a day, two to three days a week. "I'm a Realtor, so my schedule is flexible," she explains. "Also, with being in real estate for so many years, I know all about forms, filing and managing paperwork. It's a great feeling to be able to

do the administrative tasks that need to get done and help lift the burden off patients and families."

Even though Lora gives her time within the hospice program office, her efforts are felt every day by families and loved ones. She supports families after a loss by sending out condolence cards, helping to plan memorial services and by scheduling bereavement appointments.

Lora says that she also gets inspired by just being in a hospice environment. "Never in my life have I met so many positive, interesting and energetic people," says Lora. "They make you feel good about being there, and I know they really appreciate everything that volunteers do."

While hospice volunteering has been a fulfilling experience for Lora, it wasn't something she planned to do. "A good friend of mine works at Evercare Hospice, and she encouraged me to give it a try. What I found is that, if you allow yourself to have an open mind about hospice, your heart will follow. I opened my mind, and my heart fell right in."

Lora's personal commitment to hospice is clear and compelling. "I can't see myself not being a volunteer — it's a part of me now," she says. "If there's a way to give, or a need to fulfill, I want to do everything I can to help." ❖

*"If you allow yourself to have an open mind about hospice, your heart will follow. I opened my mind, and my heart fell right in."
— Lora C.*

i To learn more about Evercare Hospice and Palliative Care's trained volunteer program, or to apply to become a hospice volunteer, please visit www.EvercareHospice.com or call any of the program offices listed on page 17.

EVERCARE HOSPICE SECTION:

IN THEIR OWN WORDS:
A CONVERSATION ABOUT HOSPICE

RECENTLY, EVERCARE™ HOSPICE & Palliative Care sat down with family members, friends and hospice staff to discuss their experiences and learn what makes Evercare Hospice and Palliative Care different from other providers. In their own words, we're honored to share these perspectives on how hospice can enhance care, empower patients and families and improve quality, even as a patient approaches the last phases of life.

WHAT BROUGHT YOU TO HOSPICE?

Penny W., family member of an Evercare Hospice patient: She was able to walk again but there was a noticeable decline, and she was aware of it. She said, "I really would like to remain in my home." It was a godsend because she was able to stay in her house because of her affiliation with Evercare Hospice. We couldn't have done it without their support.

Jim C., family member of an Evercare Hospice patient: The hospital said, "We're done. We don't know what else to do." Sometimes you feel like you're by yourself. Evercare Hospice comes in and says, "We'll make your mom's health situation the best as possible, make her comfortable."



Jim C.

Sally B., family member of an Evercare Hospice patient: After her last fall, she said, "You know, I don't think I'm going to be the same as I was." And I think she decided, "If I couldn't be a contributing person around here anymore, or take care of myself and get myself out of bed, I think it's time to go meet my husband." And as soon as she made that decision, I involved Evercare Hospice in her care because I wanted to make sure her last days, or weeks or months really focused on her comfort.

Carolyn M., family member of an Evercare Hospice patient: My uncle has non-Hodgkin's lymphoma and he went in hospice in early May. He was undergoing chemotherapy treatment. It didn't improve things and really made him feel miserable. His quality of life mattered more than the longevity.

HOW DOES HOSPICE HELP?

Mark Leenay, Evercare Chief Medical Officer: Hospice care is a philosophy of care around providing services to maximize the comfort and function of an individual and their family. When you have a team caring for you, that doesn't just mean you've got three or four different types of people in your house – that means you've got a team that sits down together on a regular basis. In fact, it's mandated that they meet at least every other week and talk about you and your care plan, and whether or not you're having your needs met and how the family is dealing with this, and what else do we need to provide.

Tricia Ford, Evercare Hospice and Palliative Care Vice President of Operations: Hospice is about supplementing the health system for individuals facing end-of-life. There are more challenges at that time. Hospice is covered 100 percent by Medicare, Medicaid and most private insurance.

Sally B.: You actually get more care. More hands on care, more services. The aggressive services and technology that may not add any value to life really take the second seat. After a patient passes away or a loved one passes away, hospice will continue to work with the family and provide support. Because there is a period of time where you question, "Did I make the right decision? Did I do everything that I could do?" And so I think that's a very important role that hospice brings.



Ed Tropp

Ed Tropp, Evercare Hospice Chaplain: I think the most important thing that hospice does for an individual patient and their family is the fact that we give them dignity of life. We give them the best quality of life they have left, not necessarily the quantity of life, but the best quality of life that they have left.

Tricia Ford: Many people think that it's a place to go. Really, it's a service that comes to where the patient lives. Hospice provides nursing support, psychosocial support with social workers, spiritual care with chaplains. We have certified nurse aides who provide personal care, and volunteers. A big part of our team is our physician involvement, and all of these people work together.

Shelly S., loved one of an Evercare Hospice Patient: They don't only take care of the patient, they take care of the loved ones that are so close that forget to eat or forget to drink themselves, because they're wrapped up with their loved one.

Ed Tropp: A hospice team is there to support them and their family, to come along side that medical support they already have. So that we can work with them and work with their primary physician. It's additional support for them and their family, and I stress the family because the family is supported even up to the passing of a loved one for up to 13 months.

WHEN IS HOSPICE CARE APPROPRIATE?

Mark Leenay: The short answer is, if you're thinking about hospice you ought to talk to your doctor about it or talk to a hospice program and see if it might apply to you or not. You should never be afraid to bring the issue up. You should talk about hospice way upstream with your physician and tell them, "Let me know if and when we get to that point in time."



Shelly S.

Evercare Hospice comes in and says, "We'll make your mom's health situation the best as possible, make her comfortable."

- Jim C.

about evercare hospice

Shelly S.: If somebody mentions that maybe you should think about hospice, don't ever think about it as the end. Think of it, of it, as the beginning for this ill person.

Carolyn M.: I think that my family's ability to transition my uncle to hospice was directly related to the conversation that we had with our nurse at the Care Conference a few months earlier. She presented options not only for immediate action, but also for education about what might happen or what might be possible should his condition decline.

IS HOSPICE ABOUT GIVING UP?

Mark Leenay: Hospice, unfortunately, is a loaded word in this country. People sometimes believe it's about giving up, when in fact we all know it's really about providing different resources and better resources and more appropriate resources for what's happening.

Shelly S.: A lot of people don't want to call hospice. They're worried that, if I call hospice, it's like I'm admitting I'm going to lose my loved one.

Maria Slotten, Hospice Bereavement Coordinator: Hospice does not mean giving up. Hospice does not mean throwing in the towel. Hospice really can just provide that extra layer of support.

Carolyn M.: You're still being seen, you're still receiving medication, there are still people who are helping you improve the quality of your life. It's not an admission that your life is over.



Lynette Reiling

WHY CHOOSE EVERCARE HOSPICE AND PALLIATIVE CARE?

Tricia Ford: What makes Evercare Hospice different is the expertise of the staff. Our medical directors make patient visits in their home or wherever they reside.

Lynette Reiling, Hospice Volunteer Coordinator: One of the places where we really shine is once we get a contact, we're on it. Even if it's coming in at 3 o'clock on Friday afternoon, or we get a call on a weekend or we get a call over the holiday. It's not, "Well, we'll put it on hold until everybody is back in the office." We have people that will go out and work with the family and admit the patient.

Ed Tropp: Evercare Hospice has a very loving, caring, comforting team aspect. And the team that gets involved with the patient is very concerned, not only for the patient, but for their welfare. And for the family.

Tricia Ford: This world, this life we are in is about the people that we touch and the relationships we're in. So it's all about giving. It's about trying to meet the patient and family where they're at in their stage of illness. We're a resource along the way on their journey. ☘

CONTACT US

TO LEARN MORE ABOUT EVERCARE™ HOSPICE AND PALLIATIVE CARE, PLEASE VISIT US ONLINE AT WWW.EVERCAREHOSPICE.COM, CALL 1-877-765-3917 24 HOURS A DAY OR CONTACT ANY OF OUR PROGRAM OFFICES.

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Maria Slotten



J. Donald Schumacher

ADVANCES IN CARE: HEALTH CARE REFORM AND ADVANCE CARE PLANNING

AS U.S. HEALTH CARE REFORM legislation is introduced, examined and debated, the hospice and palliative care community is playing an important role in clarifying a proposed Medicare enhancement from the U.S. House of Representatives: coverage for advance care planning.

Advance care planning is an opportunity for patients to talk with health care professionals about their personal health care choices and is based on each patient's individual values. It empowers patients to make their own, informed decisions and provides a forum to document a patient's plans, so that those wishes and preferences will be known and ready if needed.

"The importance of patient wishes has always been integral to the hospice philosophy of care, and we understand why the provision in the House bill would only serve to benefit Americans," explains J. Donald Schumacher, president and CEO of the National Hospice and Palliative Care Organization. "Discussing advance care planning before a Medicare beneficiary finds him or herself in a medical

crisis will help ensure the patient gets the care that he or she wants."

Under this provision, a patient's advance care consultation would be with a physician, physician assistant or nurse practitioner — in many cases, the same health care professional that a patient has been seeing for years. The consultation would be voluntary and, just like other Medicare consultations, would be reimbursable. Beneficiaries could elect to have the consultation once every five years or when they face an important health situation.

The provision has bi-partisan support in Congress and reinforces the principles of the 1991 Patient Self-determination Act, which already allows for advance care planning and stresses the importance of a patient's wishes.

"This provision exists to ensure Americans have the tools to make their wishes known and to assist health care providers in honoring these wishes," says Schumacher. "It is not about limiting care, or about having choices made for the patient, or about saving money. Planning ahead for your health care — now, while you are able to — is a gift you can give to yourself and to those you love." ❖❖

Advance care planning empowers patients to make their own, informed decisions.



For more information about advance care planning, visit www.caringinfo.org/planningahead or "Are You Traveling Without a Map? A Layperson's Guide to Advance Care Planning" at www.nhpco.org.

RESOURCES

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

» **EVERCARE HOSPICE & PALLIATIVE CARE** (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 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) 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 <http://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://evercarehospice.com/pdf/MedicareHospice02154.pdf>.

» The U.S. Department of Health and Human Services **OFFICE ON HEALTH CARE REFORM** (www.healthreform.gov) includes news, research, resources and online discussion forums.

» **AGING WITH DIGNITY** (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).

» The **AMERICAN HOSPICE FOUNDATION** (www.americanhospice.org) supports programs that serve the needs of terminally ill and grieving people of all ages.

» **AARP** (www.aarp.org) offers resources, tools and advice about advance directives and on life after a loss at the "Family" section of their website.