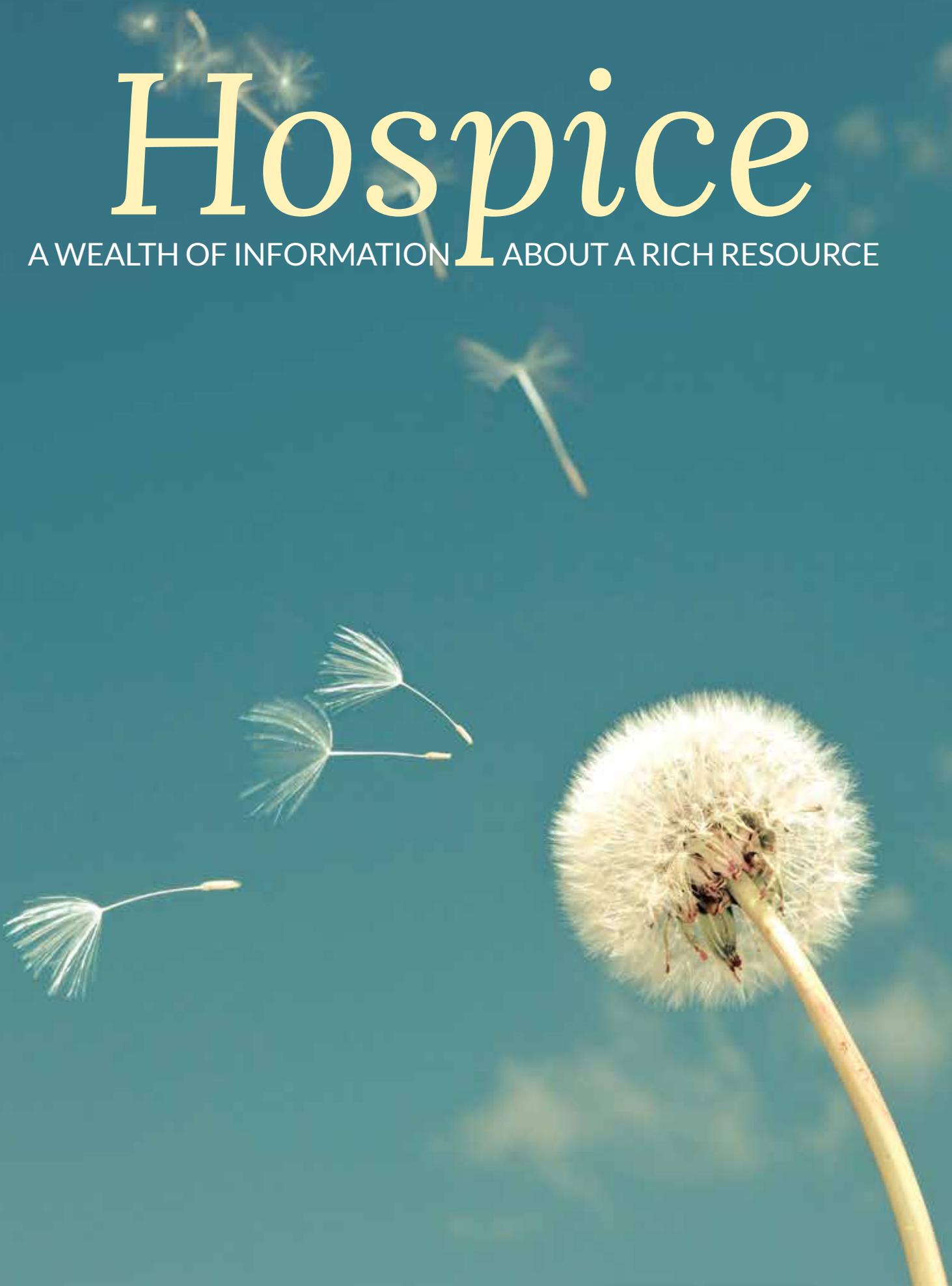


Hospice

A WEALTH OF INFORMATION ABOUT A RICH RESOURCE



HOSPICE is a PHILOSOPHY *of care*

One of the biggest misconceptions of “hospice” is it’s a place

“What is hospice?” That question is not asked often enough - or early enough. This publication’s goal is to remove the dark veil from hospice. Hospice is a philosophy of care for those nearing the end of life.

Hospice is not a place, though many patients and their families assume it is a place. Hospice is an approach to care not tied to a specific place. There are hospice houses in Maine, Massachusetts, New Hampshire and Vermont; and hospitals that provide in-patient hospice care, but more than 90% of hospice services are administered in a patient’s home, the home of a family member/loved one, a community residence or a skilled nursing facility.



Clarifications on hospice

HOSPICE IS NOT MORBID

Hospice care professionals do not come into your home and hit you with a “death hammer.” It’s not gloom, doom and sad faces, with you bedridden in a dark room, slowly passing away – though many think of it that way.

Hospice caregivers make it possible for patients to live their lives with joy and activity. Sure, there are times when symptoms leave patients unable to do everything they want to do. Professional caregivers do their best to manage symptoms to help a patient enjoy their remaining time.

A primary goal of hospice caregivers is discovering what is most important to you and how to make that happen. It’s about:

- Spending more time with your children and grandchildren
- Getting in the car, going to the beach and having a chocolate ice cream cone
- Picking strawberries
- Going on one more great fishing trip
- Sewing a baby blanket
- And, too many things to list in one article

A patient’s final wishes are a huge part of hospice care. It’s more about what patients will receive than what gets taken away. You may no longer be able to drive, but if seeing a live musical is on your bucket list, caregivers will do their best to get you a seat – or bring a singer to you, if you’re not well enough to travel.

HOSPICE IS NOT ONLY FOR THE FINAL DAYS

There’s a built-in negative connotation to the word, “hospice.” Some people hear it and think, “That’s the end. Time to die.” That is not necessarily so. Entering into hospice care does mean a terminal illness is diagnosed and there is a short life expectancy. But, the focus for caregivers is not on how to help someone die, but how to help patients live their best life for their remaining days. Hospice professionals and volunteers make the best experiences possible with a patient’s remaining time. They help you:

- Come to closure
- Do the things you want to do and enjoy doing

- Ease your mind into a living mode as opposed to an “I’m dying” mode

Medicare outlines that two physicians can qualify a patient for hospice if the patient has a diagnosis of (about) six months or less to live. Often, patients in a hospice program are still doing some things to care for themselves, getting out of bed, getting dressed, taking care of personal hygiene, for example. They are mobile, alert and are living! By living, they still do the things that bring joy to their lives.

Once patients become part of a hospice program, many wish they had known about it sooner. (See the article about early education on Page 4.)



IT'S NOT JUST FOR PEOPLE WITH TERMINAL CANCER

Professional caregivers begin the hospice conversation with someone, and they say, “But, I don’t have cancer. I can’t go to hospice.” Hospice provides care and support for patients with any diagnosis with a life expectancy of (about) six months or less. Cancer is the principal diagnosis for hospice patients at 30.1% (according to a 2017 study from the National Hospice and Palliative Care Organization).

The other diagnoses for hospice patients include: circulatory/heart disease (17.6%), dementia (15.6%), other (13.9%), respiratory (11%), stroke (9.4%) and chronic kidney disease (2.3%). ■

Talking About Hospice **NOW**

Education is Key and the Earlier the Better

“I don’t want to talk about it,” is something we hear often when the topic is death. Many of us are “trained” at a young age to be terrified of death, making us averse to the subject. Therefore, as it’s not discussed, we generally don’t plan for it – despite its inevitability.

Unfortunately, that also means hospice care discussions and advance directive conversations often delay until a patient is at crisis level. Advance directives include legal documentation such as a living will, power of attorney and do not resuscitate (DNR) orders.

HAVE THE CONVERSATION BEFORE THE CRISIS

Death Cafés and The Conversation Project encourage people of all ages to talk about their end-of-life wishes. They’ve been effective in encouraging people to talk about what they would like to happen before they get to crisis mode.

Friends, loved ones and caregivers are sometimes guilty of shutting down any talk of dying from an illness. We offer platitudes such as, “You’re going to get stronger.” Once we slam that door shut, your loved one may not open it again. Instead, if and when the subject of death and dying arises, take a pause and let your

loved one explore it – even if it’s uncomfortable to do so.

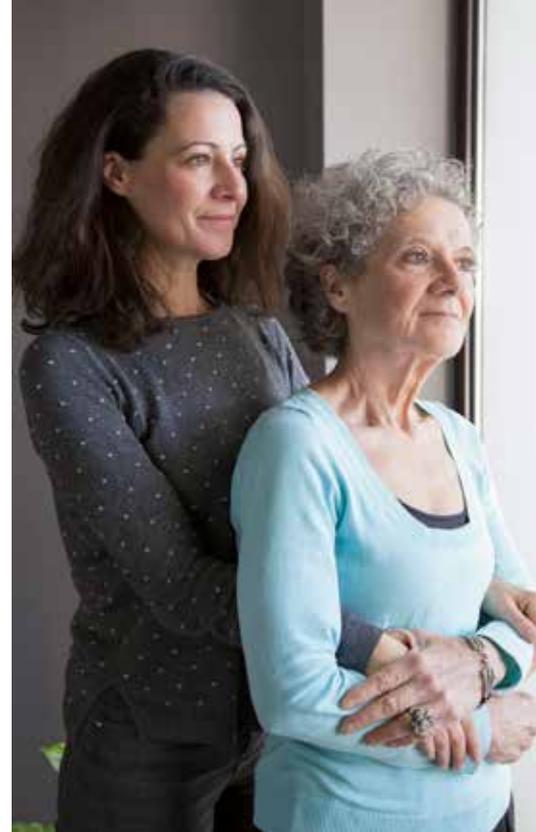
It’s fair to state that we are not – and our families are not – in the best mindset to make big decisions when a health crisis occurs.

Fortunately, that mindset is slowly changing with community education events. The death positive movement, which involves casual and convention-style events, is growing across the globe. Local health organizations host regular events, such as the Dying to Talk Café from the Concord Regional VNA.

If you have an aging parent or family member or know someone with a serious, potentially terminal diagnosis, ask yourself what would help open the door to a talk about hospice:

- A conversation with a primary care physician?
- A casual meeting with a hospice caregiver?
- A family meal?

Hospice professionals provide education around goals of care at events such as Death Cafés, getting people thinking about their end-of-life wishes. You have the opportunity to make some big decisions while you’re still well, and it is often easier on your family when these things are in place.



Hospice professionals also do a lot of hospice benefit outreach education with healthcare professionals. Patients may open up to their doctor before a family member, asking, “Do I want to continue this treatment? I’m not sure I want to keep going to the hospital all the time.” When a patient opens that door, it’s beneficial to know all options, including hospice care.

A growing percentage of physicians realize the importance of getting patients into hospice earlier in order to provide a better quality of life. Symptoms are managed allowing patients to do more things they want to do, as opposed to going back and forth for hospital stays. ■

Variety of Hospice Care Services

Hospice services vary for each patient. Benefits may include medical and social services, nursing aides, homemaker services, counseling, medications for pain and managing the disease, and therapies ranging from physical to speech.

Roles of the hospice team include, but are not limited to:

- Managing patient pain and other symptoms
- Providing medications and medical devices
- Instructing the family on caring for the patient
- Delivering services such as speech and physical therapy
- Providing inpatient care when pain or symptoms become too difficult to manage at home, or the caregiver needs respite time
- Assisting the patient and family members with the emotional, psychosocial and spiritual aspects of dying
- Providing grief support and counseling to the family

Hospice Volunteers are Priceless



The hospice care movement began with volunteers in church basements and volunteers remain a core element of hospice. While some volunteers have a professional healthcare background – such as retired nurses – professional caregiving experience is not a prerequisite. Some volunteers begin their service after having some experience with hospice care, such as a family member receiving care, and the volunteer wants to give back to the community.

Training for hospice care volunteers includes:

- Introduction to Hospice and Palliative Care
- Concepts of Death, Dying, and Grief
- Communication Skills
- Psychosocial and Spiritual Dynamics of Death and Dying
- Understanding Families and Family Dynamics
- Self-Care and Managing Personal Stress

Continued on page 6

Hospice Volunteers are Priceless

Continued from page 5

A myriad of volunteer opportunities exist. The mindset is, if someone wants to volunteer, a coordinator finds a fit rather than saying, “No thank you.”

The main functions of volunteers are friendly visits, performing some tasks that are important to the patient or family and providing some relief for the primary caregiver. Volunteers sit with a patient who cannot be alone while caregivers run errands or take a nap.

Ask a hospice organization about the specific services volunteers perform. Here is a list of services mentioned by hospice organizations interviewed for this guide, but they do not apply to all organizations:

- Transportation to appointments
- Preparing meals for delivery
- In-office clerical support
- Delivering flowers to patients
- Household tasks such as laundry or cleaning for patients or family members
- Watering plants or gardening
- Utilizing their skills, such as performing massage on patients
- Singing, playing an instrument
- Simply being there for comfort and companionship

Hospice administrators work closely with their organization’s volunteer coordinators on special requests or ideas. Part of hospice is allowing patients to live their fullest life.

VNA of Manchester and Southern NH has a team of sewing volunteers constructing items such as clothing protectors (two-sided, Velcro and lots of fun patterns!), walker bags for carrying items such as magazines and tissues and activity pillows for dementia and Alzheimer’s disease patients. Those feature buttons, snaps, zippers, bows and more to ease and calm patients.

Here’s a great example from Concord Regional Visiting Nurse Association of how a volunteer used an existing skill to bring joy to a patient:

“This patient had gorgeous rose gardens. One of her great sadness’ was she could no longer tend her roses. I called our volunteer coordinator, and she found someone to go to this woman’s home. When I visited, I could hear them in the garden, laughing. She was in her wheelchair and she directed the volunteer where to prune. They had a beautiful relationship.” ■





Pediatric Hospice

Children and infants who enter into pediatric hospice care make up a very small percentage of hospice patients. In fact, everyone aged 65 and younger account for only 5.1% of hospice patients, according to statistics from the National Hospice and Palliative Care Organization (revised in July 2019).

The youngest hospice patients are babies in utero who have short life expectancy due to serious defects diagnosed before birth. Children with an ongoing illness that becomes terminal likely have a pediatric team already in place that the family trusts. Hospice professionals often add onto the pediatric team in place, either in the home or hospital. For example, a hospice nurse aligns with a

pediatric nurse in order to have a specialist with age-appropriate care assisting with symptom management.

The hospice team can assist the family's journey from the hope for a cure to the reality of the situation with a terminally-ill child. Disagreements create more tension for families, but hospice staff help bridge these differences of opinions and restore unity, which is essential to the family's emotional survival. Hospice professionals are specially trained to help in any way possible to ease the burden on the family.

Hospice staff can assist with medications, help with bathing and other chores while the family focuses on their child - laughing, crying, having a pizza party,

watching favorite movies, or reading together. When the time comes, a hospice team assists with end-of-life planning, too.

Some parents may be reluctant to talk about death with their child, but children often understand more than we think, and they welcome the opportunity to talk about what is happening. Some children appreciate the opportunity to say goodbye to friends and family. One hospice professional noted that a family did not want their 11-year-old son to be told he was dying, but when the hospice worker went to meet him, he said he had looked up hospice online and knew what it was all about. He was grateful for the opportunity to clear the air. ■



The Rise of Palliative Care

Here are the Differences Between Hospice Care and Palliative Care

Confusion exists between palliative care and hospice care; they are not the same thing. Think of them like this: All hospice care is also palliative care, but not all palliative care is hospice care. Palliative care often begins as early as the time of diagnosis, and occurs at the same time as treatment. Hospice care begins when treatment is no longer focused on a cure. Hospice care is focused on comfort as the disease progresses.

Both palliative care and hospice care ease physical symptoms, but hospice is for the weeks and months at the end of life. The function of palliative care is providing pain and stress relief to patients with a serious health problem. The goal of both hospice care and palliative care is to help improve a patient's quality of life.

Palliative Care Reduces Unwanted Hospitalization

Multiple studies show palliative care lowers the need for hospitalizations, including readmissions, and those who do require hospitalization have shorter stays when palliative care is part of healthcare.

Heart disease, cancer and diabetes cause the majority of deaths and disability in the United States, and lead the \$3.3 trillion annually spent on healthcare in this country, according to U.S. Centers for Disease Control and Prevention.

A study by Florida TaxWatch claims palliative care could reduce societal healthcare costs by \$103 billion over the next 20 years. Additionally, the study says palliative care reduces hospital costs with fewer 9-11 calls, emergency department visits and urgent hospitalizations.

A Crucial Element of Healthcare

Palliative care teams provide a crucial element to the healthcare system. Since 2000, hospitals with palliative care programs more than tripled, according to the Center to Advance Palliative Care.

Palliative care often combines specialty doctors, nurses and other medical providers with a patient's regular doctors. They team to provide the best possible treatment and care for the patient. Palliative care happens at any age and during any stage of a serious illness.

Education about hospice care and palliative care options should happen before you or someone in your family is facing a medical crisis, said multiple New Hampshire healthcare professionals interviewed for this guide. ■

Hospice Care: Dementia and Alzheimer's Disease

Patients in hospice with Alzheimer's disease or dementia have additional, escalating care needs. In the later stages of dementia, patients perceive the world primarily through the senses. Touch, sight, taste, sound and smell become the avenues to reach them.

Hospice teams provide care for late- or end-stage dementia patients in nursing home settings or sometimes still in the family home. Comfort care is a big part of the therapy, as these patients typically have increased anxiety, confusion and challenges communicating.

Tools for comfort allow family members or caregivers to take a brief respite. Lap blankets and weighted blankets are a great tool, as they are interesting to feel and hold and the weight can relieve anxiety. Think of it like a child's "blankie."

Home Health & Hospice Care in Merrimack, NH offers a program for late-stage dementia patients and their families called the Seasons Program. Some

dementia patients are non-verbal, so the activities center on sensory therapies like music, live and recorded.

Stimulating the senses via aromatherapy, music therapy, pet therapy or massage can bring relief and a sense of calm. Other calming options hospice caregivers employ, include:

- Looking at photos together of a patient's favorite things, such as gardening
- Reading books or poems out loud to a patient
- Stimulating their hands with aprons with ties or buckles
- Rubbing lotion with a favorite scent onto the patient's skin
- Brushing or combing a patient's hair
- Getting some fresh air outside together on a pleasant day ■

Medicare and Hospice

The Medicare Hospice Benefit currently covers hospice costs for the majority of hospice patients in the United States. Through the benefit, hospice patients receive medical care, pain management, emotional support and spiritual support (the latter two for both the patient and their family members).

Medicare also covers healthcare costs not related to the terminal illness, though patients are responsible for deductible and co-insurance fees. Patients also pay ongoing Medicare premiums to receive services. Call 1-800-MEDICARE or visit medicare.gov for more information on applying for Medicare coverage.

The National Hospice and Palliative Care Organization (NHPCO) completed its most-recent study on Medicare and hospice in 2017. In 2017, 1.49 million patients on Medicare received hospice benefits, a rise of 4.5% from 2016.

The average length of service for Medicare patients enrolled in hospice in 2017 was 76.1 days. The average spend per Medicare hospice patient in 2017 was \$12,722. Medicare paid U.S. hospice providers \$18.99 billion dollars for 2017 care, up 6.3% from 2016.

Medicare-certified hospice organizations grew 9.6% over 2014-2017, and now there are more than 4,500 organizations nationwide.

Also, your chosen hospice care agency assists in determining whether your personal insurance covers the benefit and other options that are available if hospice care is not a covered service. ■

↑ 4.5%

More patients on Medicare received hospice benefits

↑ 6.3%

Amount Medicare paid U.S. hospice providers

↑ 9.6%

Number of Medicare-certified hospice organizations



Entryway to Community Hospice House, Merrimack, NH



The Future of Hospice?

Telehealth and telemedicine, delivery of healthcare services virtually or via a telecommunications device, grows annually in the United States, as healthcare organizations use technology to consult with patients and help them save money on office visits. Telehealth uses services such as video, email, smart phones and wireless tools for healthcare provider-to-patient communication.

Hospice organizations and patients may soon use these options to communicate securely via text about symptoms. Currently, many hospice organizations utilize a calling/answering service where patients and caregivers can reach out 24 hours a day.

At 3 a.m., alone in the dark with someone you care about is often the scariest, loneliest time there is – and minutes feel like hours waiting for a call back from an on-call hospice worker. To have advice just a text message away provides relief to caregivers and patients. Telehealth's real-time connection offers near-immediate benefits such as improved, timelier access to professional care. It can also cut down on travel time for office visits.

Once in place, telehealth services can augment what hospice already does. Technology does not replace care; it enhances it. That said, telehealth in hospice care is in its infancy, as it takes a lot of work and training to implement such a big, new part of an existing program. The National Hospice and Palliative Care Organization offers a detailed source for best practices in implementing a telehealth program, which can be found on their website, nhpco.org. ■





Special Services for Veterans

When volunteer coordinators connect patients with volunteers, it's helpful to know when a volunteer has been part of the armed services. There is an existing camaraderie in the relationship between an armed services veteran volunteer and a veteran patient, and it can be mentally beneficial for hospice patients to share stories with a confidant.

Hospice social workers can help patients arrange for a military funeral service and burial, or can assist the family if the patient does not have the time or capacity to make the arrangements.

The National Hospice and Palliative Care Organization and Department of Veterans Affairs program, We Honor Veterans, trains armed services veterans to assist with veterans who are hospice patients. The shared experience and vernacular often builds trust and powerful relationships between the veterans. Volunteers are a comforting companion to hospice patients, and the volunteers also offer support to family members of the hospice patient.

The We Honor Veterans program better prepares hospices to:

- Build professional and organizational capacity to provide quality care for Veterans
- Develop and/or strengthen partnerships with the VA and other Veteran organizations
- Increase access to hospice and palliative care for Veterans in their community
- Network with other hospices across the country to learn about best practice models

Training for veteran volunteers includes:

- Introduction to Hospice and Palliative Care
- Concepts of Death, Dying, and Grief
- Communication Skills
- Psychosocial and Spiritual Dynamics of Death and Dying
- Post-Traumatic Stress Disorder (PTSD)
- Understanding Families and Family Dynamics
- Self-Care and Managing Personal Stress

Concord Regional VNA partners with local skilled nursing facilities to offer recognition events for veterans called “pinning ceremonies,” in which the veteran is given a pin and a certificate based on the branch of military service in which the veteran served. Volunteers looking to take part in the Concord program may call (603) 224-4093 ext. 2826.

Home Health & Hospice Care in Merrimack, NH, has a pool of veteran volunteers that are on call for any day of the week to provide a pinning ceremony or simply to provide some one-on-one time with a fellow veteran. These veterans visiting veterans go to individual homes, Community Hospice House in Merrimack or a skilled nursing facility.

VNA of Manchester and Southern NH honors veterans with a ceremony at a variety of nursing/patient care facilities each year. The Hearts and Harmonies singers perform songs associated with each branch of the military and other patriot songs. Boy Scouts also perform a flag folding ceremony.

On Veterans Day each year, employees with Bayada Hospice in Concord, NH, who are former armed service members, come to work in uniform to visit veteran patients. ■



When to begin the hospice conversation: **Now**

One reason people put off talking about hospice is they're trying to protect the feelings of the people they love. If you were to ask your spouse, "What do you think about hospice care?", they may reply, "I don't know. Am I going to die soon?"

Hospice caregivers find that even the word hospice brings thoughts of "the end" to some people. That's why it's important to educate those we care about on what hospice is really about – living as fully as possible with symptoms managed.

It's a much easier conversation to have when someone is not already in crisis mode.

Here are some questions or conversation starters you can use to begin the talk about hospice:

- "What thoughts wake you in the middle of the night?"
- "Hopefully, you won't need this any time soon, but let's chat about hospice care options."
- "Did you know most hospice patients receive care for about three months?"
- "Let's talk about it so neither you or I have to lie awake thinking about it." ■

Directives and Medical Intervention

End-of-life directives allow terminally-ill patients to express their wishes regarding care in their final days. Completing forms for directives is an important step, as they not only specify what medical treatments a patient wants to have but also which ones they do not want to have.



The directive documents identify who will make decisions if the patient is not able to and who will be involved in their final care. Directives can also be used to clarify wishes for funerals, memorial services or what will happen with the patient's remains after death.

Hospice caregivers assist with directives. Trained staff guides patients through the legal forms, helps with decision-making and generally reassures patients and their families about expectations in the final days and hours.

There are several different end-of-life directives that terminally-ill patients and their families might encounter, and all forms can be found by visiting healthynh.com. These are forms completed by adults over the age of 18 when they are capable of preparing them, but they only come into play when the patient has lost their ability to make medical decisions on their own.

Directive and medical intervention forms include:

- **A living will:** This document delineates the limits of medical intervention the patient would accept for prolonging life
- **Durable Power Of Attorney:** This document allows the patient to designate who will make healthcare decisions if/when the patient becomes unable to make them
- **Portable Do Not Resuscitate:** When you are outside of a healthcare facility, this document tells healthcare providers not to try to restart your breathing or heartbeat in the event that your heart stops beating or you stop breathing

The Five Wishes document specifies medical and legal directives and also includes pain management, family reconciliation, comfort issues and spiritual needs. It can be used as a guide and workbook, but it is not considered a legal document in New Hampshire. ■



What is POLST?

Provider Orders for Life Sustaining Treatment (POLST) clarifies which treatments may be used during a patient's final illness. POLST complements the traditional advance directives to ease the communication of medical orders that impact the end-of-life care choices.

POLST applies as soon as the patient consents to the orders in it and their physician signs it. It does not rely on a physician's determination that the patient has lost mental capacity to make decisions. POLST is enacted whether the patient is at home, in the hospital or elsewhere.

POLST implementation efforts in New Hampshire are guided by the NH Healthcare Decisions Coalition, a multi-disciplinary statewide group that continuously seeks to improve health decision making processes. ■

For additional information, visit healthynh.com.

Hospice Bereavement Services

Hospice carries families through difficult days as they return to living in a changed world after a loved one passes. Grief support for a patient's family members is a key part of hospice care.

Some family members are surprised to discover that bereavement services are available generally for 13 months after a patient has died. The services allow time for grieving through milestones such as holidays, birthdays, anniversaries and religious celebrations.

Bereavement services take a variety of forms, including calls, visits, written materials about grieving and support groups. Hospice bereavement services often include:

- Education to the community about normal grieving
- Ongoing contact with a hospice caregiver for support and education
- Support groups
- Holiday grief workshops
- Regularly scheduled memorial services and holiday remembrance programs
- Referrals to other resources in the community as needed
- Programs or camps for bereaved children

Services are also available to families who did not have a loved one in hospice care, such as those who lose someone in an automobile accident, a heart attack or other sudden death. ■

Hospice guide sources:



BAYADA Hospice

194 Pleasant St., Suite 9, Concord, NH
(603) 724-6689, bayada.com/hospice/services.asp



Concord Regional Visiting Nurse Association

The Slusser Center, 30 Pillsbury St., Concord, NH 03301
(603) 224-4093 or (800) 924-8620, crvna.org



Home Health and Hospice Care

7 Executive Park Drive, Merrimack, NH 03054
(603) 882-2941 or (800) 887-5973, hhhc.org



Home Care, Hospice & Palliative Care Alliance of New Hampshire

8 Green St., Suite 2, Concord, NH 03301
(603) 225-5597, homecarenh.org



Visiting Nurse Association of Manchester & Southern New Hampshire

1070 Holt Ave., Suite 1400, Manchester, NH 03109
(603) 622-3781 or (800) 624-6084, manchestervna.org

As of this guide's publishing, there are 32 hospice organizations in Maine, 96 in Massachusetts, 25 in New Hampshire and 15 in Vermont, according to National Hospice Locator. Visit nationalhospicelocator.com to find a hospice organization near you.

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