

# heartnotes™

(A JOURNAL OF HOSPICE & PALLIATIVE CARE)

## Veterans, Hospice and Palliative Care



NEW PERSPECTIVES  
ON END-OF-LIFE  
SUPPORT FOR  
AMERICA'S VETERANS

**Make  
Holidays  
Happier**  
(See page 11)

**POLST: Make Your  
Wishes Known**

**New Research:  
Power of Palliative Care**

## editor's note

November is one of the most symbolic times for the end-of-life community. Not only is it National Hospice and Palliative Care Month, it marks National Family Caregivers Month, National Alzheimer's Disease Awareness Month and offers a time to honor our military men and women on Veterans Day. It's a perfect opportunity to reflect on the big picture of end-of-life care and come together around the needs of patients and families, their providers and caregivers.



This interdisciplinary approach and broad world view are foundational elements of hospice and palliative care. By respecting the spectrum of a patient's needs — medical, physical, emotional, spiritual and social — and understanding the challenges families face as they cope with an impending death, hospice programs are uniquely positioned to support the entire patient-family unit and provide comfort and support during one of the most complex phases of life.

Hospice is also a safe place to talk, to share and remember. Hospice professionals are tremendously skilled at creating a judgment-free environment where patients and families can speak honestly about their concerns, their hurts and their fears — and, find resolution, consolation and peace of mind. Preparing for death, and then mourning a loss, are incredibly personal experiences, and they are a direct reflection of your life, values and history. End-of-life care must mirror each patient's needs and honor their wishes and dignity.

This month, we're examining a wide range of patient and family needs. In this issue of *Heartnotes*, you'll learn how hospices are opening the dialogue with veterans and helping them process their military experience. You'll hear from a social worker who has excellent tools and tips for keeping connections strong when you have a loved one in a nursing home or assisted living facility. And, two family caregivers share the challenges they faced and how they got extra help.

Ultimately, it's all about communication: being willing to talk about tough topics, respect differences, understand each individual's needs, ask for help and receive support. I hope *Heartnotes* helps stimulate that conversation, and I invite you to send your thoughts, comments and questions to me at [jenn\\_gatti@uhc.com](mailto:jenn_gatti@uhc.com).

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<sup>™</sup> 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<sup>™</sup> Hospice and Palliative Care and the services we provide, please call 1-877-765-3917 or visit us online at [EvercareHospice.com](http://EvercareHospice.com).

Evercare<sup>™</sup> Hospice and Palliative Care is offered by Evercare Hospice, Inc. Evercare Hospice and Palliative Care is committed to the policy that all persons shall have equal access to its programs, facilities, and employment without regard to race, sex, religion, color, age, national origin, disability, sexual orientation or other protected factor.

# \* contents



4 {Caring for our Heroes}



8 {Making Connections}



12 {POLST}

4 Caring for our Heroes:  
Veterans and end-of-life care.

8 Making Connections:  
Visiting your loved one in a nursing home.

12 POLST:  
Making your wishes known.

14 In Their Own Words:  
Caregiver perspectives.

17 Advances in Care:  
Palliative care improves quality, extends life.

19 Resources:  
Websites and information for you.



# CARING FOR OUR HEROES:

## VETERANS AND END-OF-LIFE CARE

**T**HE GREATEST MILITARY LOSSES of life today are not taking place on the battlefield, but at the deathbeds of America's veterans. More than 50,000 veterans die each month, representing roughly 28 percent of all the deaths in the United States.

Veterans often take great pride in their service, seeing it as a period of time when they did something meaningful in the world. However, not all veterans see their service as positive or as having made any difference. This has resulting complications, especially for veterans in hospice. Understanding how veterans view their service, whether it is positive or negative, has implications for how they view their life and their death.

### WHAT'S DIFFERENT FOR DYING VETERANS?

Through her experience as clinical coordinator at the Bay Pines VA Medical Center in St. Petersburg, Fla., Deborah Grassman has closely observed some important differences and lessons for providing end-of-life care to veterans. "It's only in the past ten years that we have started to realize that many things can influence a veteran's death," she says. Factors influencing veterans' experiences at the end-of-life include age, whether enlisted or drafted, branch of service, rank and combat or POW experience.

### SUPPORT FOR VETERANS

Grassman presents a powerful and informative educational session on how health care professionals can attend to those differences. She has given the presentation to rapt professional audiences locally, nationally and in a recent VA educational teleconference.

"If veterans have seen combat, they have seen horrific things," Grassman says. Some are able to integrate that experience into their lives and as a result may be better equipped psychologically to cope with their own deaths. "These veterans are role models for how to have a good death, and in a death-denying society, that's important," she says. Still others suffer from post-traumatic stress disorder (PTSD), with symptoms that can include social isolation, alcohol abuse, and anxieties.

For some veterans, the effect of combat experience may remain buried for years, emerging only when the veteran is very sick and dying. In these cases, veterans may experience anxiety, agitation and resurrected memories connected to war experiences, Grassman says. Their medical caregivers need to differentiate these symptoms and treat them appropriately.

Doug Weadick, chaplain for the hospice unit at the Orlando, Fla., VA Health Center, has made similar observations. He notes, "When you're dying, you look back on significant events. Combat is a form of intimacy—very

traumatic, life changing. It defined who they were and became. What I see is that they [veterans] want to process these events at the end of their lives."

Weadick says there is almost an audible sigh of relief for veterans who meet others like themselves on the hospice unit. "They're home—they're with people who have gone through the same things. They don't have to share their war stories. They just know the other person has gone down the same path."

Health professionals caring for veterans at the end-of-life should keep these factors in mind:

- » The veteran's experience with military culture and the camaraderie of other veterans.
- » A culture of stoicism that might prevent veterans from admitting to being in pain, or from asking for pain medication.
- » The causes of terminal agitation, which may be related to PTSD or to disease-related terminal restlessness.
- » The possibility of paradoxical reactions to medications.

"I've seen many variations on these themes," says Dr. James Hallenbeck of the VA Palo Alto hospice unit. "I try to teach doctors on our unit to establish a relationship that starts with respect for the veteran. They were part of an

experience that those who weren't there can't imagine. For a lot of our veterans, it's just polite to say, 'What branch of the service were you in?' If you acknowledge that aspect of their lives, you have a better chance of establishing respect and a connection," he says.

### THE PERSONAL TOUCH: CONNECTING WITH VETERANS

Many Evercare Hospice sites honor veterans and their families with special visits on important military occasions.

"Our program started on Memorial Day 2009," explains Atlanta Volunteer Coordinator Dee Zeitounian. "We visited several of our hospice patients in hospitals and nursing homes and presented them with a special plaque recognizing their contributions. It was a wonderful day, with all of the veterans being so proud and so grateful. They really appreciated being remembered and thanked for their service."

The visits were made even more memorable because of the hospice volunteers who attended. [Irene] is an U.S. Army Captain and Evercare Hospice volunteer, and she took part in all the patient visits. "The veterans were thrilled to have an active military person come in uniform and spend time with them," Dee says. "We're so lucky to have someone like Irene who not only volunteers, but who brings other active military men and women on these visits. It really means a lot to our patients, to be able to share memories with someone who is serving our country today." ❖

*There is a sigh of relief for veterans who meet others like themselves on the hospice unit.*

*Over 37 percent of the veteran population is 65 years old or older, compared with 13 percent of the general population.*

"Our program started on Memorial Day 2009," explains Atlanta Volunteer Coordinator Dee Zeitounian. "We visited several of our hospice patients in hospitals and nursing homes and presented them with a special plaque recognizing their contributions. It was a wonderful day, with all of the veterans being so proud and so grateful.



## \* Unique Health Risks and Implications for America's Veterans

Each group of veterans who have served in a war or conflict have experienced a unique set of health risks. These exposures and experiences can surface as veterans age and directly affect their end-of-life care needs. Below are common health risks and implications for veterans of five major military events:

### World War II

As "Atomic Vets," World War II veterans were the first to serve in the nuclear age. Exposure to radiation has been associated with a number of disorders including leukemia, various cancers and cataracts. Unique health risks for World War II veterans include:

- » Tuberculosis, rheumatic fever and hepatitis
- » Frostbite/cold injury
- » Mustard gas testing
- » Exposure to nuclear weapons and nuclear cleanup.

### Korean War

Cold injuries, including frostbite and immersion (trench) foot, were a major medical problem for U.S. personnel. These cold-related problems may worsen as veterans grow older and develop complicating conditions such as diabetes and peripheral vascular disease, which place them at higher risk for late amputations. Unique health risks for Korean War veterans include:

- » Cold Injury
- » Exposure to nuclear weapons
- » Chemical warfare experiments

### Vietnam

Vietnam was the first war in which the U.S. failed to meet its objectives. This situation magnified the stress associated with Vietnam veterans' combat

experiences. Vietnam veterans are now 50 to 75 yrs old; by 2014, 60 percent of these veterans over age 65. Unique health risks for Vietnam veterans include:

- » Length and time of service
- » Mental health issues
- » Environmental hazards and exposure to Agent Orange
- » Infectious diseases, including Hepatitis C

### Gulf War

While there are not specific syndromes or illnesses associated with Gulf War veterans, they experience multi-symptom-based medical conditions more often, including ALS, fibromyalgia, chronic fatigue syndrome and multiple chemical sensitivity. Unique health risks for Gulf War veterans include:

- » Psychiatric illnesses, particularly post traumatic stress disorder (PTSD), anxiety, depression and substance abuse
- » Exposure to smoke
- » Contact with chemical or biological agents

### Operation Enduring Freedom/Iraqi Freedom

U.S. troops who have served in Afghanistan, Pakistan and neighboring countries of the former Soviet Union have greater exposures to environmental hazards, including raw sewage, contaminated water and food, air pollution and severe sand and dust storms. Other health risks for these veterans include:

- » Infectious disease
- » Cold injury
- » Combined penetrating, blunt trauma, and burn injuries (blast injuries)
- » High altitude illnesses

## \* National Survey Examines Caregiving and Veterans

In November, we acknowledge two very important groups who are true heroes and provide invaluable service to our society. November is National Family Caregivers Month, celebrating the more than 65 million family caregivers, and on November 11 we commemorate Veterans Day, honoring our nation's military veterans.

In a landmark research study to be announced in time for Veteran's Day, the UnitedHealth Foundation has provided a grant to the National Alliance for Caregiving to shine a spotlight on the family caregivers of America's military veterans. These caregivers represent approximately 18 percent of the total caregiver population. While there has been much media and other attention paid to the issues faced by returning veterans, this will be the first look at family caregivers of U.S. veterans that probe the family caregivers themselves on the issues they face and what services and programs may help them.

The research will take a look at the family caregivers of veterans across the lifespan: from World War II and Korea, to Vietnam and Desert Storm, to current returning veterans from Iraq and Afghanistan. The study will look at the various caregiving relationships of our veterans as well as the conditions which have called for caregiving support. These caregiving situations include adult children or older spouses supporting an older veteran from earlier wars who may have service-related disabilities

or chronic illness; a parent caring for a younger adult child veteran who may have post-traumatic stress syndrome, traumatic brain injury or physical disabilities; husbands caring for wives who are military veterans, and other family members and friends caring for a veteran.

The research will uncover the caregiver's own health and wellness issues, their mechanisms for coping with stressful caregiving situations, the changes to their family dynamic due to caregiving, the services and programs which have helped them and the gaps where more attention could be paid to support them.

While the focus is on the specific issues the family caregivers of veterans face, the responses and potential areas for ongoing research or support will apply to a broader spectrum of family caregivers who may be facing similar issues, especially in the less explored areas of caregiving research including physical disabilities and mental health issues.

Both the UnitedHealth Foundation and the National Alliance for Caregiving intend for this study to create broad-based awareness through media, policymakers and other thought leaders. In addition it will help to identify or shape programs and services to better support family caregivers of veterans and serve as a call to action for national and local community-based organizations to better serve these valuable members of our society.

### Sources:

Military History Toolkit: Service Related Diseases, Illnesses, and Conditions. Veterans Advisory Council, a Taskforce of the National Hospice and Palliative Care Organization.

Veterans Hospice Resources, National Hospice and Palliative Care Organization (nhpco.org).

VA Transforms End-of-Life Care for Veterans: a brochure from the Department of Veterans Affairs and NHPACO.

*These veterans are role models for how to have a good death.*



Melissa Plourde, LSW

# MAKE CONNECTIONS:

## VISITING YOUR LOVED ONE IN A NURSING HOME

**a** S A SOCIAL WORKER, FAMILY members often tell me that they struggle when visiting their loved one in a nursing home. They feel guilty because they are hesitant to go and don't know what to do or say once they get there.

Recently, I was in the lobby of a nursing facility, waiting to meet with the Social Worker. While I waited, a resident in a wheelchair was sitting with two family members who appeared to be her son and grandson. After 10 minutes of sitting in silence, the elder asked her visitors, "And why are you here today?" The son lovingly said, "Because we love you, Ma. We want to see how you are. That's why we come every week." With that said, they fell silent again and remained so until I left the area 10 minutes later.

I could tell by their tone and body language that they clearly loved their mother and grandmother. They genuinely wanted to be there and see her. They wanted her to know they loved her. But, they just didn't know what to do in their time with her, or how to communicate with her.

Here are a few activities you can try to make your time together more enjoyable. Based on their physical and/or mental capabilities, most elders enjoy keeping busy, with both their minds and their hands. Always stay aware of their physical ability and when they need to rest.

» Look at picture books or family photo albums together, reminisce about the memories they bring up.

- » Play simple games such as cards, board games, tic-tac-toe and puzzles.
- » Ask questions about their life, including their childhood, career, military service, marriage, etc. Tip - Then, record their life in print, scrapbook form, video or audio for family to treasure.
- » Share trivia and brain teasers.
- » Go for a walk, or if they can be taken out, go for a drive, day trips to the ocean, park or museum.
- » Bring your pet or a friend's (make sure to get facility approval first).
- » Watch musicals, comedies or TV shows from their era.
- » Do crafts (you can buy kits or ask the Activities Director for ideas or supplies).
- » Bring the holidays in with related songs, shows, crafts and decorations.
- » Read aloud poems, newspapers, books or magazines (and look at the pictures together).
- » Keep the hands busy - fold clothes together (even over and over again), toss a ball, make paper dolls.
- » Paint, draw and color pictures.

- » Make scrapbooks or collages about topics they enjoy by cutting out pictures from magazines.
- » Give a manicure and/or hand massage.
- » Talk about current events, your children/grandchildren and historical events.

### ART, MUSIC AND TOUCH

In his book *I'm Still Here*, Dr. John Zeisel's research speaks of the benefits of the arts in the elderly and those with dementia. It focuses on connecting with people with Alzheimer's through their abilities that don't diminish with time, such as understanding music, art, facial expressions and touch. Dr. Zeisel demonstrates that people with dementia are highly creative and emotionally intelligent. For example, he suggests taking your loved one to a museum. The different textures, colors and designs promote conversation, memories and emotions. If they can't be taken out, explore art books and magazines.

Try music! Play the music they grew up with and favorite music you know that they always loved. If you are not sure, try different types starting with big band, jazz, religious/gospel, show tunes, children's songs, classical and cultural music. Look for a positive response such as smiling, swaying and nodding. Even those with dementia can often recall the tune or lyrics of songs they knew earlier in

life. If they have some range of motion, try dance. (Always check with the nurses first to ensure this type of movement is appropriate). If your loved one is unable to get out of their wheelchair or bed, encourage simple movements like swaying arms.

Most people enjoy and benefit from touch. This is especially true for those at end-of-life. In my experience with hospice patients, giving a gentle massage, hugs, kisses and holding hands almost always brings comfort. (Just make sure there are no signs of discomfort or pain, like flinching, frowning and pulling away.) When you cannot think of what to do or say, simply reach out to your loved one and put your hand on theirs.

I'd also offer some tips and suggestions about what not to do:

- » Do not: Rush in or stand by the door the whole time, as if you're on the way out.
- » Do not: Stare out the window, keep checking your watch or look bored.
- » Do not: Go on and on about your problems or obstacles to visiting.
- » Do not: Change the subject if your loved one expresses negative or sad feelings.
- » Do not: Spend all your time with other residents and/or staff.

*Most elders enjoy keeping busy, with both their minds and their hands.*

*Be patient.  
Remember, you are  
there because you  
love this person.*



*Bottom line:  
Don't give up, and  
don't stop going.*

Take responsibility for making these visits worthwhile and something you both enjoy. If one idea doesn't succeed, try another. Remember, you are there because you love this person. Don't give up, and don't stop going. I always say, "I cannot change a terminal diagnosis, but I can change the way they live out their days." So can you.

*Melissa Plourde, LSW is part of the Evercare Hospice Community Outreach team in Central Massachusetts. To learn about Evercare Hospice's interdisciplinary approach to end-of-life care, visit [EvercareHospice.com](http://EvercareHospice.com). ❄️*



**Sources:**

[http://www.alz.org/living\\_with\\_alzheimers\\_101\\_activities.asp](http://www.alz.org/living_with_alzheimers_101_activities.asp); seniors-site.com

Ziesel, J. 2009. I'm Still Here: A Breakthrough Approach to Understanding Someone Living With Alzheimer's. Avery Press.



**Gale Sheehy**

*Photo: Georgia O'Keefe Museum*

## \* New Book, Play Share Stories of Caregiving

Noted author and journalist, Gail Sheehy's book, *Passages in Caregiving*, was released in May to much fanfare. The book includes information about Evercare's Solutions for Caregivers program for employers and individuals and highlights an Evercare member and her care manager, Kathy Hawk. In the January issue of *Heartnotes* we'll have more about a new play based on Gail's personal caregiving journey with her husband. To learn more about Solutions for Caregivers, call 1-866-463-5337 or visit [EvercareHealthPlans.com/Caregiver](http://EvercareHealthPlans.com/Caregiver).

## \* Good Gifts for Nursing Home and Assisted Living Residents

*SNAPforSeniors®*, a comprehensive senior housing resource in the nation, offers this advice on welcome gifts during the holidays for nursing home and assisted living residents.

When space is an issue, what's the best holiday gift for a loved one in a nursing home? Below are some suggestions that are easy to find, take nominal space and help residents stay engaged and active.

**Holiday decorations.** It's not uncommon to see wrapped gifts under a tree and beautiful plants in the entry way of most senior housing settings. Most residents still want to adorn their private space with their own holiday symbols and decorations. A seasonal gift might be a few small poinsettia plants to liven up their apartment, a small menorah, a decorated wreath or ornaments to hang by the window.

**Food items.** Most families have traditional foods specific to the holidays. Consider items that are not difficult to chew and have a relatively long shelf life. An example could be cookies, fruitcake or an assortment of holiday candies to have on hand when friends visit. A festive holiday basket filled with jams, jellies, crackers and cheese could be a gift shared with fellow residents.

**DVDs of Classic Movies and TV shows.** Re-experiencing the old days is a favorite pastime for seniors. Whether it's the "Best of Lawrence Welk," western movies, or Hollywood classics with the Rat Pack, DVDs can bring smiles and stimulate conversations about younger days.

**CDs of their favorite music.** Music from the senior's years of youth, such as big band, jazz or classical tunes, could bring many hours of pleasure and be a gift that keeps rekindling old memories.

**Digital Photos.** Having an assortment of older and more recent photos of family and friends available would delight their living space while they muse at the latest technology. A digital photo frame is far more likely to be viewed than the traditional photo album which tends to gather dust.

**Magazine subscriptions.** There is a magazine for practically every hobby and interest. Purchasing a one or two year annual subscription can be a personalized gift that can bring ongoing pleasure to the individual, knowing that you cared enough to remember their particular area of interest. In addition, it stimulates their mind to read and stay current on hot trends related to their favorite subject matter.

**Books on tape.** For many seniors with compromised eyesight, listening to interesting new novels can bring hours of entertainment. It can also give the senior a reason to engage in conversation about the latest written works with extended family and friends, making them feel able to contribute in contemporary works of art.

**Calendar with family photos.** Select 12 of your special photos and make a calendar on your own home computer, or have it done at a photo or print shop. On the calendar, note the birthdays of all close family members as a reminder throughout the year. You can also buy a box of birthday cards for your resident to send to family members throughout the year.

**Blankets.** Room temperatures tend to vary from room to room in senior housing, so having your own personal blanket or cover-up from head to toe can be ideal. Consider machine washable fabric, which is easy to clean.

**Medic Alert Membership.** The non-profit organization, online at [www.medicalert.org](http://www.medicalert.org), offers a bracelet or necklace with a toll free number inscribed along with the senior resident's name and other essential information (e.g. allergies, medical conditions such as diabetes) on the back to a 24-hour emergency response service. The family member who takes out the annual subscription can access and update the personal health information for the senior resident any time. The service includes family notification, medical profiles with medication dosages and medical device information. If you are a caregiver living near or far, you can have peace of mind knowing that this service will provide access to current information to help the senior during a medical emergency or natural disaster.



## POLST: MAKING YOUR WISHES KNOWN

**M**AKING SURE YOUR LOVED ones and doctors know what kinds of medical treatment you want toward the end of your life is very important for your well being and peace of mind. That's where POLST comes in.

POLST (Physician Orders for Life-Sustaining Treatment) is a form that clearly says what kinds of medical treatment patients want toward the end of their lives. Printed on bright pink paper and signed by both a doctor and patient, POLST helps give seriously ill patients more control over their treatment. The form works even if the patient later loses the ability to say what he or she wants.

The form also helps you talk with your health care team and your loved ones about your choices. Too often, patients near the end of their lives may get treatment they do not want. These treatments may not help them live longer or better. In this way, POLST can help reduce patient and family suffering, and make sure that your wishes are known and honored. POLST makes sure your family members and caregivers know exactly what treatments you do and do not want. No one has to guess or argue.

POLST is currently in use or under development in over 30 states. Your doctor, nurse, social worker, or chaplain can help fill out the POLST form. Make sure you talk with your doctor about the treatments you want or don't want. The form must be signed by your doctor, and you or the person you pick to make decisions for you. Once signed, the POLST form will become part of your medical record. The form stays with you all the time.

POLST allows you to choose the person you want to speak for you and provides a general guide to what you want. It is a signed medical order that your health care team can act upon and tells your exact wishes about certain medical treatments. POLST goes where you go, whether to your home, your hospital, or your long-term care facility.

### WHAT THE TREATMENT OPTIONS MEAN

The POLST form lists some of the common medical treatments you can choose to have or not have. Your doctor can help you decide which treatment options will best help you reach the goals you have for your care. Treatment options include:

» **Resuscitation.** Cardiopulmonary resuscitation can benefit healthy people, but it is not usually helpful for people who are seriously ill. It can cause broken ribs or punctured lungs. Even if the heart is started again, the brain can be damaged by lack of air. Older patients and those with serious illness often lose physical and mental ability even if the heart is started again.

» **DNR:** Do Not Resuscitate (or DNR) is a medical order not to try resuscitation because the patient does not want it or because it won't help. DNR is also called Allow Natural Death.

» **Comfort Measures:** These medical treatments are always provided. They are meant to make you feel comfortable and

reduce your pain. They are not meant to make you live longer.

» **Antibiotics:** Antibiotics fight infections like pneumonia and reduce the symptoms and pain caused by those infections. They do not relieve the suffering that is caused by other health conditions.

» **Intravenous (IV) Fluids:** These are fluids that are put into your body through a tube placed in a vein. Usually, IV fluids are given for a short time to help you get through a specific illness.

» **Artificial Nutrition/Tube Feeding:** Tube feeding can help people who cannot swallow now but are expected to get better. However, people near the end of life may feel more comfortable without a feeding tube and want to eat what they can by mouth. Tube feeding can cause pneumonia and may result in swelling and infection. As a person nears the end of life, their need for food and fluids will lessen. During this time, their bodies are not able to use food and fluids like a healthy person. Near the end of life, tube feeding can actually cause increased bloating and discomfort.

It's important for you to understand what each of these options mean, so make sure you talk to your doctor before you make any decisions. You can then choose what treatment options you want and don't want.

### RESEARCH SHOWS POLST IMPACT

A recent study published in the Journal of the American Geriatrics Society showed that the use of POLST helps patients avoid unwanted interventions and better ensures that their wishes are respected. The study was supported by the National Institute of Nursing Research (NINR), part of the National Institutes of Health, and used 60-day chart data from more than 1,700 living and deceased long-stay nursing facility residents in Oregon, Wisconsin and West Virginia.

The study analyzed the levels of treatment received by residents with or without POLST

forms or traditional medical orders (such as a DNR order). The study found that residents who used a POLST form to indicate their preference for just comfort care were 59 percent less likely to receive life-sustaining medical interventions. Similarly, residents with POLST orders for just comfort care were 67 percent less likely to receive life-sustaining treatments than those with POLST orders for full treatment.

"It is fairly common for nursing facility residents to have orders about CPR in their medical charts. However, CPR orders alone are not very helpful in telling the health care provider about the person's interest in receiving other treatments," says lead author Susan Hickman, Ph.D., associate professor in the schools of nursing at Indiana University and Oregon Health & Science University. "In our study, 98 percent of residents with POLST forms had orders about medical interventions beyond resuscitation, in comparison to just 16 percent without POLST forms. This means they had orders about their preferences for treatments such as hospitalization, antibiotics, and feeding tube use. POLST tends to provide much more specificity for care providers."

The study also found no significant difference in reported symptom frequency or in the level of symptom management provided to residents who were POLST users compared to non-POLST users. This finding indicates that the presence of a POLST order did not impact the degree of comfort care received by the residents.

"Many individuals and their families still struggle with a lack of continuity of care and poor communication with health care practitioners about their treatment wishes," noted NINR Director Patricia A. Grady, Ph.D., RN. "This study underscores the importance of identifying effective ways to make sure that the type of end-of-life health care requested by the individual is in fact provided. Health care professionals can use this information to help individuals make better informed choices about the type and level of care they wish to receive." ❖

<sup>1</sup>Hickman SE, Nelson CA, Perrin NA, Moss AH, Hammes BJ, Tolle SW. The Journal of the American Geriatrics Society. 2010; 58:1241-1248.

*"Because my mom made her own decisions by filling out a POLST form, I didn't have to guess about what she wanted. This was comforting for both her and our family."*

— Paul Waterstraat

*"When patients have a POLST form, we know exactly what treatments they want and don't want. It clears up any confusion, and gives patients peace of mind."*  
— Steve Lai, MD

## caring for caregivers



# IN THEIR OWN WORDS: FAMILY CAREGIVERS

**IF YOU'VE TAKEN PERSONAL** responsibility for the long-term care of a loved one, you are a caregiver. It can be a challenging and stressful role. Balancing both the care of the loved one with your own personal responsibilities, especially if you are working full-time and have children of your own.

Evercare understands that caregivers need care too. That's why we created Solutions for Caregivers. We provide the support caregivers and their loved ones need. We may then also coordinate local resources to make sure your loved one is getting all the care they need and you can finally breathe a much needed sigh of relief.

Our experienced care managers will visit your loved one whether they live in your home, in town or across the country. They provide an objective assessment of your loved one's situation, develop a care plan and discuss recommendations with everyone involved: the care recipient, the family members, doctors and other care providers.

We offer services to support you and your family including an in home assessment by a registered nurse, a personalized care plan, unlimited access to our care resource center for referrals to local resources, caregiver coaching services and care coordination

services. We can provide support for caregivers facing many issues including long distance caregiving, elder care issues, caring for someone with a serious illness, post hospitalization care and convalescent from an injury or surgery. You, your children, other family or friends may request this service on your behalf.

In their own words, two caregivers share their perspectives on balancing their family's needs and the support they've received from Evercare.

**Thelma Duggin.** My mother lives in Alabama and I'm 1,100 miles away. This last couple years, she started having problems with arthritis slowing her down.

**Carolyn Magill.** My uncle has non-Hodgkin's lymphoma, which he's been suffering from for about five years. I live in Minnesota now and he's in Massachusetts, so I perhaps noticed it more than my family members even because each time I would go home I could see a remarkable difference than the previous time that I visited.

**Thelma:** I'm up here; it doesn't make sense for me to move back there. But it's very difficult when you're me cause you just don't know

what's happening and I know my mother. My mother will not tell you if she has a problem, if she's not feeling well today.

**Carolyn:** Being far away is heartbreaking and it makes you feel like you need to be home every weekend, but it's not feasible. So a program like a Solutions for Caregivers enables you to have a local presence and let them know that you care and that you're involved.

**Thelma:** When I talked to Evercare and I said "One of the first things I need is someone who can at least take her places that she needs to go and just check in on her." And they told me the program, they said, "Well we'll send somebody first and do a whole evaluation."

**Carolyn:** So I made a call, and Solutions for Caregivers had someone go out to the house within a week.

**Thelma:** The evaluation of her gave an idea of where your starting point was, and what the



issues were and what you really needed to do. So they put together a whole care plan.

**Carolyn:** I think it was the first time that my cousins heard my uncle talk about the pain that he was in, the emotional difficulty that he was having asking for help, admitting when he was having trouble with various aspects of daily living.

**Thelma:** It has made so much difference to know someone else is interested and is involved.

**Carolyn:** Once Evercare had recommendations about who we could bring to the home, they went one extra step and identified who those resources were and actually even helped to coordinate.

**Thelma:** I don't know how I could have done it.

**Carolyn:** One important aspect of the service is how much of my guilt and anxiety it helped to alleviate. I live thousands of miles away from home, so I could recognize the deterioration in his physical state but felt perilous to do anything about it, and what Solutions for Caregivers enabled me to do was to participate from afar.

**Thelma:** Evercare was fabulous. They found all the support we needed. 🌟

**i** To learn more, visit [EvercareHealthPlans.com/Caregiver](http://EvercareHealthPlans.com/Caregiver) or call 1-866-463-5337.



study period, with 77 assigned to the palliative care group and 74 to standard care.

Responses to the quality-of-life questionnaire showed significant improvement from enrollment to 12-week assessment in the palliative care group but worsening quality of life in the standard care group. Depression symptoms in the palliative care group were about half those reported in the standard care group at 12 weeks, although the rates of new antidepressant prescriptions among both groups was similar. While more than half the palliative care participants had documented resuscitation preferences, essential to ensuring that patients' goals and end-of-life wishes are respected, fewer than 30 percent of standard care participants had documented preferences.

More than half the standard care participants received what the study protocol defined as aggressive end-of-life care — chemotherapy within 14 days of death, a time when it is usually considered futile, and either no or late referral to hospice care — compared with only a third of the palliative care group. Despite the lack of such aggressive end-of-life care, patients in the palliative care group lived an average of 11.6 months, while survival for standard care patients was less than 9 months.

Temel says, "Traditionally, cancer care has focused on treating the disease itself, but now we realize we must also focus on managing patient's symptoms and distress related to their diagnosis. We hypothesize that the increased survival was due to improved mood and quality of life, to early and more comprehensive management of symptoms and complications, and possibly to more appropriate end-of-life care. Similar studies in patients with other types of cancers and in other care settings will help us better understand the impact palliative care can have on the well-being and health of all patients with cancer." Temel is an assistant professor of Medicine, and Jackson an instructor in Medicine at Harvard Medical School.

#### A BODY OF EVIDENCE FOR PALLIATIVE CARE

This new study adds to the body of evidence showing that many patients live longer with hospice and palliative care. A 2007 study that looked at Medicare beneficiaries with some of the most common diagnoses leading to death, found that patients who received hospice services lived on average, 29 days longer than those who did not receive hospice care. This study, published in the *Journal of Pain and Symptom Management* looked at 4,493 terminally ill patients with either congestive heart failure or cancer of the breast, colon, lung, pancreas, or prostate.

In an earlier *Journal of Pain and Symptom Management* study looking at patients with 16 of the most common terminal diagnoses, researchers found that hospice patients lived longer. On average, this ranged from 20 days for those with a diagnosis of gallbladder cancer to 69 days for the cohort of breast cancer patients.

"There's an inaccurate perception among the American public that hospice means you've given up," said J. Donald Schumacher, president and CEO of the National Hospice and Palliative Care Organization. "Those of us who have worked in the field have seen firsthand how hospice and palliative care can improve the quality of and indeed prolong the lives of people receiving care."

NHPCO encourages all families who are diagnosed with a serious illness to ask their healthcare providers about hospice and palliative care services. "The time to learn about these services is before a person is in a medical crisis. Patients and families must learn about these options of care as soon as possible," Schumacher added. ❖

## RESOURCES

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

» **EVERCARE™ HOSPICE & PALLIATIVE CARE** ([EvercareHospice.com](http://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.

» **STATE-SPECIFIC ADVANCE DIRECTIVES** are available for free download at [caringinfo.org/stateadownload](http://caringinfo.org/stateadownload).

» 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>.

» **WE HONOR VETERANS** ([WeHonorVeterans.org](http://WeHonorVeterans.org)), a program of NHPCO and the Department of Veterans Affairs, is designed to empower hospice professionals to meet the unique needs of dying veterans and their loved ones. Online resources help providers guide America's veterans and their families through their life stories toward a more peaceful ending.

» The **PHYSICIAN ORDERS FOR LIFE-SUSTAINING TREATMENT (POLST)** program is designed to improve the quality of care people receive at the end of life. It is based on effective communication of patient wishes and a promise by health care professionals to honor these wishes. Patient and family resources are available online at [ohsu.edu/polst](http://ohsu.edu/polst).

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

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

EVERCARE  
PO Box 5057  
Hopkins, MN 55343



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