



California Hospice Foundation



# CHOICES

*Empowering People*

Fall 2011

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## Hospices and Patients Share Stories Through Social Media

Social media has changed the way people and organizations communicate, connect and collaborate with others. It's called 'social' media because the platforms are interactive and conversational, and help individuals and organizations build relationships and community.

Hospice patients use blogs and Facebook pages to stay in touch with friends and family. Teri Collet, Director of Social Services at Community Hospice in Modesto, has seen social media facilitate emotional support for patients and caregivers. "Social media allows patients to communicate with others when they have the energy, or when they feel alone at three in the morning and can't pick up the phone." The same tools also help reduce caregivers' feelings of isolation.

### Sharing the End-of-Life Journey

Hospice Journey, a free personal (and private) website for patients and their families, is another tool many hospice social workers and volunteers have introduced to their patients. Vanessa Callison-Burch, one of the founders of Hospice Journey, says 400 families have created Hospice Journey websites. "We took the best parts of online collaboration and social media for Hospice Journey, but designed it for a specific purpose: to help families share updates, coordinate care and reflect on what matters as they are living with dying."

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*If you or anyone you know has a need for Hospice Information and Referral services please call the California Hospice Foundation's toll free number: 888-252-1010*

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## Hospices and Patients Share Stories continued from cover page

Hospice Journey was designed to be easy to use. “When families get started,” says Vanessa, “they really get into it. Patients and families are benefiting in all the ways we had hoped.” Instead of fielding dozens of individual emails and phone calls, patients and caregivers post updates for invited family and friends. The Lend a Hand section makes it easy for caregivers to ask for help. A guestbook provides a place for them to share their love, support, stories, memories and photos.

Chelsea Mathis, Marketing and Outreach Coordinator at Hospice of the Valley in San Jose, saw a patient “use Hospice Journey to describe in detail the hospice experience for her followers and help them accept and even appreciate her dying process. One of the greatest benefits of Hospice Journey for her was the outpouring of messages of support and love from her followers. She said it was like being sainted.”

The Reflections section with its questions to spark contemplation and discussion “gives patients the opportunity for life review -- to say the things that are so valuable to say and come to a peaceful place before they die,” says Vanessa. Teri says, “One of the tragedies of sudden death are the things left unsaid which make grief worse. Hospice Journey facilitates sharing and creates closure for the patient and family members.”

The Resources section provides information about hospice care, allowing friends and family to become more knowledgeable and comfortable with the patient’s situation. Vanessa says, “The main focus of Hospice Journey is to support patients and families, but we also want to educate the friends and families about hospice care and provide a way for them to support the hospice through donations.”

To learn more about Hospice Journey, please visit their website at <http://www.hospicejourney.org/>.

*Author Deirdre Reid is a writer and blogger at Reid All About It in North Carolina.*

### MORE SOCIAL MEDIA

**Find us on Facebook!** CHF’s Facebook page provides links to advice, news and inspirational stories. To find us, search for “California Hospice Foundation” and click “like” to receive our postings. (If you need help setting up a Facebook account, visit <http://tinyurl.com/join-fb-help>.)

**We Honor Vets**, a program dedicated to helping hospices serve the special needs of veterans, has both a Facebook page and a Twitter account. Visit their website at <http://wehonorveterans.org/> for direct links.

## Ten Things You May Not Know About Hospice

Most Americans have heard about hospice care. They know that hospices care for people at the end of life. Most people know a family or friend who was helped by hospice when faced with the serious illness and death of a loved one. But there’s so much more to know.

For example, did you know that hospice provides what the majority of Americans say they want at the end of life? Excellent pain management, comfort, and support for the patient and family caregivers.

### Ten more things you should know about hospice:

1. Hospice is not a place but a special kind of care.
2. A hospice care team is made up of doctors, nurses, social workers, counselors, spiritual care providers, trained volunteers and other skilled professionals who provide high-quality, compassionate care.
3. Hospice care is available to people of all ages with any kind of life-limiting illness, including cancer, advanced Alzheimer’s disease, heart disease, lung disease, kidney disease, HIV/AIDS and other life-limiting illnesses.
4. Hospice care is fully covered by Medicare, Medicaid, and most private insurance plans and HMOs.
5. Hospice provides all medications and medical equipment needed to keep a person safe and comfortable.
6. There’s no limit to the amount of hospice care a person can receive; it’s available as long as a doctor believes a patient is eligible.
7. Most care is provided at home but hospice is also available in nursing homes, assisted living and long term care facilities and hospice inpatient units.
8. Hospice care can include complementary therapies, such as music and art, to bring additional comfort to patients and families.
9. Hospice programs offer grief support to the families they care for as well as to others in the community who are grieving.
10. More than 1.5 million people receive hospice care every year in the United States.

# Talking About Hospice

When faced with a life-limiting illness, you or your loved ones may be thinking about hospice care but may find it hard to bring the topic up with each other or with doctors. Here are some approaches that can be helpful when talking with loved ones.

## Choose the Right Time and Place

Plan for the conversation. Find a time that is free of interruptions. Let the conversation unfold naturally. Maybe you will bring the topic up initially and revisit it again later.

## Be Sensitive

People cope with end-of-life issues in many ways. People who are seriously ill need to feel they have choices. As you mention hospice as an option, remember to let your loved one know that they can change their mind at any time. Starting with hospice is not a commitment, but a way to get more support and have new choices.

## Be a Good Listener

Be willing to listen with an open mind and heart. Listen for the wants and needs your loved one expresses. These moments, although sometimes difficult, are important to both of you.

## Situations Other Families Have Faced

***“Mom doesn’t want to talk about hospice, but the rest of us need help. What can we do?”***

Most patients don’t want their loved ones to be burdened by their illness. Help your loved one understand that the greatest gift they can give their family is the ability to spend quality time with each other. Hospice supports the entire family so everyone can be physically and emotionally able to focus on what matters most to them at this very important time.

***“I don’t want my husband to feel that I’m giving up on him. Won’t talking about hospice give that impression?”***

This is a common concern. It’s important to remember that when patients choose hospice care, they’re not giving up – they’re gaining support and choices. We can meet with your loved one in person to talk about their health needs, learn their personal feelings and desires, and introduce the concept of hospice care. These conversations usually go more smoothly than families imagined possible and are often welcomed by the patient.

***“The doctor hasn’t said anything to us about hospice care. Should we bring it up?”***

Yes. Many doctors do not bring up hospice care because they don’t want to discourage a patient’s hope. They may actually be relieved if you bring up the topic. If you feel hospice may be a good option – now or in the future – let the doctor know your thoughts. If you are hesitant to talk to the doctor directly, a hospice can help with that communication.

***“My grandmother is in the hospital and we’re wondering if hospice could help. How do we find out more?”***

Hospital social workers and discharge planners should be knowledgeable about the many services provided by hospice. They can help with a referral to a hospice program. If you haven’t already had direct contact with a social worker, ask your doctor, a nurse or chaplain to put you in touch with one.

*These guidelines are provided by the Hospice of Santa Cruz. Please visit their website at <http://hospicesantacruz.org/> for more information.*

## NATIONAL HOSPICE AND PALLIATIVE CARE MONTH

November is **National Hospice and Palliative Care Month**, a time to draw attention and raise awareness of this special kind of care.

### What is Hospice Care?

Hospice care provides pain management, symptom control, psychosocial support, and spiritual care to patients and their families when a cure is not possible. California and Nevada hospices serve more than 100,000 people every year – and their family caregivers, too.

Many people only consider hospice care in the final days of life but hospice is ideally suited to care for patients and family caregivers for the final months of life.

### What is Palliative Care?

Palliative care brings the same interdisciplinary team care as hospice to people earlier in the course of a serious illness and can be provided along with other treatments they may still be receiving from their doctor.

Hospices are the largest providers of palliative care services and can help answer questions about what might be most appropriate for a person. Many hospitals also have palliative care teams available to provide services.

Hospice and palliative care services are available to people of all ages with any serious or life-limiting illness.

Hospice and palliative care combine the highest level of quality medical care with the emotional and spiritual support for patients and family caregivers. Hospice and palliative care can make a profound difference and help maximize the quality of life for all those they care for.

California Hospice Foundation



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## Help Us Celebrate!

Do you belong to a club, church or group? If so, you can help us celebrate **National Hospice and Palliative Care Month!**

If you have an upcoming meeting or if your organization has a library or location for materials, CHF can provide extra copies of this newsletter, *CHOICES*, FAQ sheets regarding hospice and palliative care, Medicare information and much more.

Much of this information can be downloaded from our website at <http://cahospicefoundation.com>. Or you may call us at 888-252-1010 and we would be happy to mail materials to you.

One of the most common sentiments shared by families who have been helped by hospice care is, "We wish we had known about hospice sooner." With your help, more will! ♻️

