FACTS ABOUT FRIENDS OF HOSPICE

PROBLEM

Most people find out about hospice too late to benefit fully from this important end-of-life program.

While hospice programs are plentiful, only about a third of those who could benefit from hospice care actually receive it. Often, those who do enroll benefit for only a few days; half of California’s hospice patients are in a program for 17 days or fewer according to median length-of-stay statistics. At just 18 days, local hospice programs serving Butte, Tehama and Glenn counties report similarly short median lengths of stay for 2005.

Communications programs have failed to achieve adequate awareness and understanding of hospice as an end-of-life option.

THE CAMPAIGN

The “Friends of Hospice” campaign intends to increase awareness of hospice, as well as to encourage people to talk to their families about their wishes should they be faced with a life-threatening illness.

The California Hospice Foundation (CHF), along with three area hospice programs and five community groups dedicated to the community’s health and well being, has created a pilot program to increase awareness of hospice, as well as encourage people to talk to their families about their wishes, should they be faced with a life-threatening illness. The “Friends of Hospice” coalition includes: Enloe Medical Center Hospice, Butte Home Health and Hospice, and Paradise Hospice, a department of Feather River Hospital, along with: Butte-Glenn Medical Society; the California State University, Chico, School of Nursing; the American Cancer Society; the Chico Area Interfaith Council and Passages Adult Resource Center.

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HOW IT WORKS

No communications program to date has attempted to mobilize a valuable potential resource—those who believe in the value of hospice because they have been touched by its special care. Volunteers, donors and those who have benefited from hospice will be invited to become “Friends of Hospice” and help spread the word to their networks of family and friends.

The heart of the campaign is a direct mail letter that invites these people who have been touched by hospice to send postcards or e-mails to their friends and families. In their messages, supporters will identify themselves as someone affected by hospice, and offer their willingness to talk about their experience. They also will encourage their contacts to begin discussions with family members about end-of-life wishes.

Anyone who feels they can help spread the word about hospice can get involved by sending an email or postcard to their network of friends and by becoming better informed. On May 22, resources for the program will be available through three mechanisms: new web pages and an order form added to the California Hospice Foundation website (www.hospicefoundation.info); a dedicated toll-free telephone number (1-877-248-1122); and postage-paid reply postcards that will be sent to selected households in Butte, Glenn and Tehama counties. Until May 22, questions can be directed to the California Hospice Foundation at (916) 925-3770 or by email to Margaret Clausen, President and CEO of the California Hospice Foundation: mclausen@calhospice.org.

WHEN

The pilot program is scheduled to begin prior to Memorial Day weekend and is expected to run for six to eight weeks.

EXPECTED OUTCOME

The campaign expects to increase awareness and understanding of hospice, as well to spur conversations about advance care planning. If successful, the pilot campaign will be expanded.

CHF

CHF is a 501(c)(3) charitable foundation. Its mission is to improve access to quality hospice and palliative care services through education and public awareness.

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BACKGROUND INFORMATION

The Problem with Hospice

No one wants to think about facing an illness for which there is no cure. Yet, when someone we love faces such a circumstance, we want them to be as comfortable as possible, in the setting where they feel supported and secure. According to the Robert Wood Johnson Foundation, 70 percent of Americans would prefer to die at home rather than in an institution, but only a quarter of the population does so.

While hospice programs are plentiful, only about a third of those who could benefit from hospice care actually receive it. Often, those who do enroll benefit for only a few days; half of California’s hospice patients are in a program for 17 days or less according to median length-of-stay statistics.

How Hospice Helps

Hospice is a form of health care that is provided to people who are confronting a fatal illness and for whom curing the disease is no longer a realistic goal. Hospice provides an all-inclusive set of services needed to manage all of a person’s symptoms and complications. It can be provided to people facing a variety of diseases such as cancer, end-stage heart disease, dementia, and lung disease, among others. By providing pain and symptom management, as well as emotional and spiritual support for the individual and family, hospice helps people to live as fully as possible, in comfort and with dignity. The exact services and resources that someone needs are tailored to the needs of the individual and family, based on an assessment of an interdisciplinary team that includes a -- more --
physician, nurses, and social workers. The same team – along with spiritual counselors, home health aides, therapists, and volunteers – ensures that services and resources are provided when needed, without the family having to locate and arrange for them.

**Why More People Don’t Receive Hospice Care**

If only a third of people of those eligible are receiving this type of care, what is getting in the way? Most of the barriers come down to lack of awareness and accurate understanding of the program, even though hospice has been around since the 1970s.

Many people don’t realize that hospice is fully covered under Medicare, Medicaid and most private insurers. Another barrier comes from rigid criteria associated with Medicare, the largest payer for hospice services. When Medicare decided to cover hospice in the early 1980s, it wanted to avoid duplication with the chronic and long-term care system. It therefore requires physicians to certify that a patient is expected to live for six months or less. Many physicians are reluctant to sign certifications out of concern that they might somehow be held liable for their prognosis, especially since they know there is no scientific basis on which they can accurately predict the duration of many life-threatening illnesses. By deciding that hospice would be only for incurable illnesses, Medicare also forced an awkward choice: patients had to agree to give up curative care if they wanted to receive hospice care. Having enrolled in a hospice program, many people do not know they can re-enter the mainstream health care system to seek curative care again if a new treatment becomes available or if they change their minds.

Breakdowns in communication and the stigma of dying in American culture also play a role in inhibiting access to hospice. Families may feel that turning to hospice is giving up. Physicians may see turning to hospice as an admission of medical failure, or as withdrawing hope, making them reluctant to bring up the possibility of hospice.

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What Hospice Beneficiaries Say about Hospice

Once people are enrolled, hospice evokes strong, positive feelings from many. According to a recent study published in the Journal of the American Medical Association, nearly three-quarters of family members receiving hospice services rated care as “excellent” compared to less than 50 percent of those who received care in an institutional setting or just home health services. Study authors evaluated such aspects of care as physical comfort and emotional support, shared decision-making, respect, and coordinated care – all of which are goals of hospice.

Friends of Hospice: A New Approach to Increase Understanding

The California Hospice Foundation (CHF), along with three area hospice programs and five community groups dedicated to the community’s health and well being, has created a pilot program to increase awareness of hospice, as well as encourage people to talk to their families about their wishes, should they be faced with a life-threatening illness. The Friends of Hospice coalition includes: Enloe Medical Center Hospice, Butte Home Health and Hospice, and Paradise Hospice, a department of Feather River Hospital, along with: Butte-Glenn Medical Society; the California State University, Chico, School of Nursing; the American Cancer Society; the Chico Area Interfaith Council; and Passages Adult Resource Center.

CHF believes this may be the first communications effort that has attempted to mobilize an untapped resource – people whose lives have been touched by hospice. The Friends of Hospice campaign will invite hospice families, volunteers and donors to spread the word about hospice by sending their network of contacts an email or postcard. These messages will offer support and information should their contacts ever need to know about hospice, and encourage them to talk to their families about end-of-life -- more --
To support the program, the Friends of Hospice coalition will host informational meetings, and provide printed and downloadable information about hospice and advance directives, including a guide to help people broach the subject of end-of-life wishes.

The campaign is expected to kick off just before Memorial Day and run for six weeks. If successful, the program will be implemented in other California communities.

### About Advance Health Care Directives

In addition to increasing awareness and understanding of hospice, the Friends of Hospice campaign hopes to encourage families to have conversations about end-of-life wishes – known as an advance health care directive. Only one in every five adults in the United States has completed such a directive. Studies show that family members are poor at predicting what someone would want if facing a serious illness. The Friends of Hospice campaign recommends that individuals document their wishes, and encourage other loved ones to do the same thing. The advance health care directive is a written expression of what a person does and doesn’t want, to be used if he or she becomes ill and can’t communicate or make decisions. California was the first state in the nation to legally recognize advance directives in 1976. By 1992, all 50 states, as well as the District of Columbia, had passed legislation to legalize some type of directive. Before completing such a document, people should make sure that it is accepted in California and that it reflects their individual wishes and choices.

### Support for the Friends of Hospice Campaign

The Friends of Hospice campaign is an experimental communications approach developed by the California Hospice Foundation, a 501(c)(3) charitable foundation. The greater Chico area was chosen as the site for the pilot because of its collaborative hospice

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organizations and strong history of community involvement. Governed by a volunteer board of trustees (composed of hospice professionals and community members across the state), CHF advocates hospice awareness through outreach and education. The foundation’s main goal is to enhance the quality of life for people by improving end-of-life care and expanding access to hospice and palliative care. The Friends of Hospice campaign is made possible by charitable donations and generous pro bono support from nearly a dozen marketing and public relations professionals.

**Get Involved**

Anyone who feels they can help spread the word about hospice can get involved by sending an email or postcard to their network of friends, and by becoming better informed. Just before Memorial Day, resources for the program will be available through three mechanisms: new web pages and an order form added to the California Hospice Foundation website (www.hospicefoundation.info); a dedicated toll-free telephone number (1-877-248-1122), and postage-paid reply postcards that will be sent to selected households in Butte, Glenn and Tehama counties. Until May 22, calls can be directed to the California Hospice Foundation at (916) 925-3770 or by email to Margaret Clausen, President and CEO of the California Hospice Foundation: mclausen@calhospice.org.

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Hospice Backgrounder – 6

Selected References


# # #
Advance Directives - Getting Started

Considering what’s important at the end of life and taking steps to communicate and document those wishes...

- Provides direction, clarity, and purpose for family and caregivers,
- Allows family and caregivers to offer support with greater peace of mind and a clearer sense of purpose because they understand better what is desired by an individual, and
- Reduces one’s own fear by creating confidence that care will be tailored to one’s preferences
Why advance health care directives mean so much

If you’re like most people, you probably haven’t wanted to even think about the possibility of a life-threatening illness, much less taken steps to develop a plan or find out what family members want. You might feel sad just to imagine such a crisis. Further, the prospect of talking about end-of-life wishes – whether your wishes or those of someone you care about -- makes most of us a little anxious.

By considering the ideas in this discussion guide, you will either be able to clarify what you want so that your family doesn’t have to wonder, or help someone else to express what they might want.

**Taking steps to communicate and document those wishes...**

- Provides direction, clarity, and purpose for family and caregivers,
- Allows family and caregivers to offer support with greater peace of mind and a clearer sense of purpose because they understand better what is desired by an individual, and
- Reduces one’s own fear by creating confidence that care will be tailored to one’s preferences

This guide offers a range of ideas and suggestions to help begin discussions with those closest to you, and to gather important information. It doesn’t matter how you arrive at your understanding of your own wishes and those of your family members. What matters is that you took the first steps, and then continued until the plan could be communicated to others – both verbally and in the form of a written advance health care directive.
In thinking and talking about end-of-life care, the main goals of discussion are to:

- Discover values, preferences, and needs that will allow family, caregivers, and medical staff to provide care that reflects one’s wishes and desires.

- Identify an individual who will act and speak on one’s behalf and prepare others to act clearly, confidently, and compassionately to support them.

- Provide direction for specific end-of-life care decisions in an advance health care directive. An advance directive is a legally-recognized written document that conveys what a person does and doesn’t want, to be used if he or she becomes ill and can’t communicate or make decisions.

Documenting advance health care directives

The value of your discussions is best protected when recorded in legal documents. An advance health care directive is a written expression of what a person does and doesn’t want, to be used if he or she becomes seriously ill and can’t communicate or make decisions. Forms are readily available at no cost from physicians, hospitals, health plans, and the Internet. The California Hospice Foundation is also a good source. You don’t need an attorney or notary public to complete them. If you live in an institutional setting like a skilled nursing facility, you should be aware of special witnessing requirements.

- The Power of Attorney for Health Care designates the person (referred to as your “agent” or “proxy”) who can make medical decisions for you and access medical records if you are unable to do so yourself.

- Advance Health Care Directive forms include very specific preferences and wishes that provide a written record for your agent, family, and medical staff. California forms also allow you to name a health care agent.

Once forms have been completed and they are signed and witnessed, make at least four copies, keeping the original and one copy. Copies of your advance directives should be given to your personal physician, designated agent, and hospital or skilled nursing facility. Review your advance directives annually or whenever there is a change in your circumstances such as moving to a new area, changing doctors, or experiencing a change in health status.
Consider these four main topics in preparing end-of-life directives

1. **Comfort and personal treatment**

   To some, “death with dignity” may mean no resuscitation following a heart attack, while to others it may mean being in a familiar environment with loved ones present. Music, personal grooming, and care for pets or belongings are among many personal preferences that can be expressed. Some people want to be held, prayed for, talked to, or touched. Others don’t want to be seen by others when they are uncomfortable.

2. **Medical treatment**

   Most people have an opinion about being “kept alive on machines” at the end of life. These machines can include those that breathe for someone (ventilators), provide nutrition (feeding tubes), and deliver medication and fluids (IV’s). Medical treatment that extends life can also be as simple as antibiotics to treat pneumonia for a patient in a permanent coma.

   Most people fear pain and want to be comfortable. While it is generally assumed that medical care will include treatment of pain, it is important for someone to be clear about their desire for comfort and pain control. Sometimes pain control dims consciousness and limits communication. If one wants to remain conscious for as long as possible and is willing to experience some discomfort, it’s important to say so.

3. **Remembrance**

   The ways of recognizing someone after they have died range from joyous to somber, religious to secular, and private to public. One’s wishes can include preferences for religious services, memorials, and considerations for the handling of the body following death. The desire to donate organs and/or tissues and feelings about autopsy may be expressed. Preparation for remembrance can also include messages of love, forgiveness, and appreciation.

4. **Who will serve as health care agent**

   It’s not always the person who is closest who understands what someone would want at the end of life. Consider the person best able to carry out one’s wishes in an emotional situation and who will be able to deal with the health care system. Usually it is a good idea to identify someone who can speak on one’s behalf and an alternate.
Planning for end-of-life care is best done well before the plan is needed. Here are some general things you can do to set the stage:

**Identify why it is important to you to have this conversation**
- “I’m afraid that if you got really sick, I wouldn’t know what kind of care you would want.”
- “If I get very sick, I don’t want you to feel extra worry because you don’t know what I would want.”

**Ask permission to talk about end-of-life care**
- “Would you be willing to talk with me about how you would want to be cared for if you could no longer speak for yourself?”
- “Will you talk to me about what I would want if I were very sick?”

**Acknowledge feelings that come with just starting this conversation**
- “I understand that it’s hard to even think about this.”

**Prepare to listen and understand**
- “I want to know what’s important to you.”
- “I want you to know what’s important to me.”

**When it’s not an emergency**

The best reason for beginning the discussion about end-of-life wishes is this -- if we wait until we need to discuss it, it’s that much harder because of the pressure of the situation. So, it can be very helpful to link advance health care directives to wills, financial plans, and life insurance. For example, the occasion of a financial plan meeting might lead to a comment like this: “I met with our lawyer last week to be sure that my will is up-to-date. The lawyer reminded me that there will be medical decisions to make when I die, and he asked me if I had given my doctor any instructions. Can we talk about this?”

**Initiating conversations about your own advance directives**

Those who love you do not want to imagine a time when you are not healthy and present in their lives. Just acknowledging this lets your family know that their reluctance to talk about end-of-life wishes is understood. Let family members know that this planning is important to you and that their participation is an act of love. You can also tell them that you don’t want them to be burdened by uncertainty or disagreement when such directives might be needed. If you start by completing your own advance directives, it speaks to the importance you put on communicating your wishes.

**Initiating conversations about a family member’s advance directives**

You may worry that you are seen as morbid or intrusive if you raise end-of-life wishes to others. You can tell them you want to make sure they get what they want at a critical time, and to avoid misunderstanding within the family. Telling someone why it is meaningful to you allows the family member to approach the topic from a perspective that may be more comfortable.
Remember that advance care planning is an act of tremendous love. Your loved one may have avoided the subject to prevent upsetting you.

### Initiating conversations about your own advance directives

Start with those with whom you feel safest. Initially, it may be a doctor, pastor or attorney who can help you speak more openly about the issues that could arise. Once you have a sense of clarity about your wishes and preferences, approach those family members who will be involved in your care.

- “I realize you may be afraid to ask about what I want in case things don’t go well but I’d really like to talk with you about it.”
- “Your support at this time means so much to me. I need to talk about my care before I get sicker so I’ll know you understand what I want.”

### Initiating conversations about a family member’s advance directives

Remember that advance care planning is an act of tremendous love. Your loved one may have avoided the subject to prevent upsetting you.

- “I hope you know that I want to be able to help you in any way I can. If I understand the way you want to be cared for, I’ll be able to do a better job.”
- “I was telling a friend of mine about you and she asked me if you have an advance directive... She said it’s really important and we should talk about it if you can.”
Preferences about comfort and personal treatment

- Where someone is cared for
- Presence of others: any limits?
- Personal grooming
- Communication: talking, speaking as though someone is conscious
- Physical contact: touching, hugging
- Being told bad news
- Environment: music, art, flowers, etc.
- Care of belongings
- Care of pets

Medical treatment

- Pain management
- Breathing tubes/ ventilators
- CPR
- Dialysis
- Blood transfusion
- Feeding tube
- IV hydration
- Medications other than those for comfort

Remembering

- Preferences for services/ memorials
- Messages to be conveyed after death: appreciation, forgiveness, love
- Handling after death: burial, cremation
- Autopsy
- Donation of organs and tissues

Who will speak

- Qualifications that are important
- Agent
- First and second alternates
- Identify anyone to be excluded from decisions

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