

Finding Your Way

Medical Decisions When They Count Most



Finding Your Way was written by Sacramento Healthcare Decisions (SHD), a private nonprofit organization that gives the public a voice in improving healthcare policy and practice.

This information is based on SHD's 1997 Extreme Care, Humane Options (ECHO) Project. ECHO involved more than 2,000 community members and healthcare professionals in developing recommendations to improve medical care at the end of life.

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Americans are independent; they like to control their own lives. However, they rarely think about the final stage of life and, as a result, often are unprepared to face heart-wrenching decisions. Marilyn Webb suggests in her book *The Good Death: The New American Search to Reshape the End of Life* that while a good death was once a matter of sheer luck, now it “has more to do with the decisions we—and our healthcare providers—make about our medical treatment and terminal care . . .”

Finding Your Way prepares you for making these decisions. You will learn:

- **Why you should think about this issue now rather than later.**
- **How to address the complex issues that you or your family may face.**
- **What to expect from your doctor and other health professionals.**
- **How to advocate for compassionate care for yourself or a loved one.**

Research shows that people have strong feelings about care at the end of life. They worry about how their decisions will affect their families emotionally and financially. They want to work with their doctors to decide the right treatment. They fear their doctors will stop caring for them when the end is near. They want emotional and spiritual support, as well as good medical care. Most of all, they want to die as peacefully as possible, free from severe pain and suffering.

Most people first deal with end-of-life issues not with their own medical crisis but with the death of a relative or friend.

The Morrison Family

Tim and Nancy Morrison are in their 30s with two young children. Work and their children's activities fill their days. But a phone call from Tim's mother gives them pause. She tells them that after a two-year bout with cancer, Tim's boyhood friend Dave just died. Tim is shaken to learn that Dave stopped his cancer treatment several weeks ago.

Tim couldn't understand why Dave gave up the fight. He had never been a quitter before, and it was hard for Tim to accept that his friend had stopped the treatment.

Nancy, on the other hand, thought about how sick Dave had been with the cancer treatment. She could imagine that some people, like Dave, would finally decide that it was no longer worth it.

They talked about what each of them might have done in Dave's position. To their surprise, they discovered they actually had very different views about how they would make this kind of decision.

Nancy and Tim went to bed that night thinking of Dave and his family and wondering, "What if . . ."

Both Tim and Nancy had lost grandparents, but they had never thought about their own deaths until Dave died. His death prompted them to think about and discuss their views about dying. Realizing that one of them might have to be the decision-maker for the other, they talked over their own beliefs about what is important at the end of life.

Why, you might ask, should young, healthy people like Tim and Nancy bother with end-of-life planning when they have no need now?

There are several reasons. First, “advance care planning” allows you to think about important issues when you don’t need to make immediate decisions or aren’t under great emotional stress. It’s also good to know that your loved one understands your wishes should you unexpectedly become unable to speak for yourself. And if you become the decision-maker, you don’t have to guess what your loved one wants; you’re prepared to act based on what you know. Finally, if you and your family have different views, advance care planning can help avoid serious family conflict.



How to begin advance care planning

As it did for the Morrises, the subject often arises when a close friend or relative dies. News coverage of the death of a celebrity, magazine articles or community meetings on the subject may also bring it to your attention. You can begin by considering these questions:

- *What represents a good quality of life to you?*
- *What concerns you most about death or dying?*
- *How would you want to spend the last month of your life?*
- *Some people want everything possible done to delay death. Others don’t want dying to be prolonged. Where do YOU draw the line?*
- *Who should make these decisions for you if you can’t speak for yourself?*

Sharing your views with those important to you is a good way to explore this topic. This also can help you identify the person best able to speak for you if it becomes necessary.

Next steps

If you have a doctor, it is helpful to make sure he or she knows your specific views about end-of-life care. You may want to schedule an appointment to talk to your medical caregiver — such as your primary care doctor, nurse practitioner or specialist.

Also, you may want to complete a document called an *advance directive*, such as a Medical Power of Attorney. This allows you to state in writing who will speak for you if you can't communicate and to indicate your treatment preferences. Or you may complete a Living Will, which states your wishes about life-sustaining measures if you are terminally ill or permanently unconscious. All states have at least one type of advance directive as a legal document, and in California, both functions are combined in an Advance Health Care Directive.

Completing an advance directive may help if family members do not know what you want or may not agree on the type of care you should receive. While an advance directive is useful, talking with those closest to you is just as important.

Advance Care Planning Steps

- **Consider your personal values about quality of life. What makes living meaningful to you?**
- **Choose someone you trust to speak for you should you become unable to communicate.**
- **Talk with your decision-maker and other loved ones about your views.**
- **Talk with your doctor about your views on medical treatment near the end of life.**
- **Complete an advance directive (see page 12).**

When facing hard decisions

Advance care planning is a process rather than a single decision. Most likely you will face a series of choices as your health and personal goals gradually change over time. However, if faced with having to make decisions now—



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for yourself or a loved one—there are things you can do to make sure the last months, weeks or days of life reflect your or your loved one’s wishes about living and dying.

The Thompkins Family

Ada Thompkins is an 82-year-old retired teacher with three grown children and seven grandchildren. After losing her husband several years ago, Mrs. Thompkins’ physical and mental abilities gradually declined, leaving her in need of increasing help from her children. The Thompkins are a close-knit family with a long tradition of shared activities.

Three years ago, when Mrs. Thompkins suffered a severe stroke that left her unable to move her body or talk, she was placed in a nursing home, where her family visited every day. Hospitalized several times for pneumonia, she now has a permanent feeding tube, is very weak, and no longer recognizes her family.

Mrs. Thompkins has returned to the hospital, where she is receiving intensive treatment for her heart condition. When her oldest son Fred arrives, he worries, “I just don’t know if this is what Mom would have wanted.” For all their closeness, the family has never discussed their personal values about the last months of life. They have never talked about dying.

Situations like this are common. So are the questions they raise: If this were your mother, would you know how she wants to live her last days? If you were Mrs. Thompkins, what would you hope your children would do? Unlike the Morrises, who started talking about their views on dying as young adults, the Thompkins don’t know their mother’s wishes. Since she can no longer communicate, her family has to imagine what she might want.

When a family makes these kinds of decisions for a loved one, they need to consider several things:

1. *Medical condition and chances for improvement*

It is sometimes difficult for people to accept that a loved one is at the last stage of life, especially since doctors usually can't predict how long someone will live. The subject of dying is often avoided for fear that it means "giving up." Yet, when family members are helped to face what lies ahead, they are better able to seek the care best suited for their loved one. The first step is understanding the patient's medical condition now and what may come later.

If you are the decision-maker for a loved one like Mrs. Thompkins, you will want to ask the doctor:

- *Is it still possible to cure her disease or illness?*
- *If not, what are her chances of at least improving?*
- *Given her current condition, what do you expect in the next few weeks? In the next few months?*
- *Are other medical problems likely to arise?*

2. *Treatment options*

In general, there are three goals of treatment for someone in the last phase of life:

- **Restoring the person to a healthier state.**
- **Supporting the person to maintain his or her current level of health.**
- **Providing comfort without trying to prolong life.**

All of us hope that medical science will provide cures, and if not, at least help improve health. Yet with severe illness, terrible accident, or advanced age, it may no longer be possible to make a person well. At that point, continued treatment may support life and keep the person comfortable.

But for some patients the treatments or machines that support life also may cause or prolong suffering. When that happens, life-sustaining measures—such as breathing machines, CPR,

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feeding tubes, IV fluids and antibiotics—can be stopped or not used at all. *Comfort care* (sometimes called Palliative Care) then becomes the focus. It aims at controlling pain and other symptoms while preserving dignity and addressing the emotional and spiritual needs of the patient and family.

Although this comfort care approach should always be offered to those near the end of life, patients and families often don't know about it. Hospice programs specialize in comfort care, but other healthcare teams may provide it in hospitals, nursing homes or at home. If your doctor doesn't discuss comfort care, be sure to ask about these services.

Questions to ask about your loved one's treatment options:

- *Is there any treatment that will help regain her health? Are there side effects?*
- *Is there treatment to prolong her life? What kind of life will she have?*
- *What will be provided if we decide to focus on comfort only?*
- *Is hospice available? What services will it provide?*
- *What other help is available for the family at this time?*

3. Quality of life

The person's quality of life is usually the most important thing to consider when thinking about comfort care. While the patient is the best one to decide his/her own quality of life, sometimes families need to do this for their loved one, as in the case of Mrs. Thompkins. Although the Thompkins don't know their mother's views or wishes, they can begin by thinking about how she might feel about her quality of life now.

Questions to consider:

- *Is she able to enjoy the things that bring her pleasure?*
- *How much discomfort is she now experiencing?*
- *Is she able to talk or respond to others, especially family members?*
- *Does her medical treatment fit with her cultural values and religious beliefs?*
- *If she could talk to you about her care, what would she say?*

When the time comes, judging a loved one's quality of life can be difficult. Even if you believe your loved one would not want to continue having life-sustaining measures, it can be hard to let go. You may feel guilty that you have not done everything you could. You may worry about money problems or unsettled family issues. Talking with a spiritual leader or a counselor can help you with these concerns.

Involving others in the process

You and your family do not have to face these choices alone. Your doctor can give you medical information and advice. Nurses, social workers, chaplains, support groups and your faith community also can help with emotional support or the day-to-day problems of caring for someone who is dying— whether in a hospital, nursing facility or at home. Talking to these caregivers as early as possible can help you when making difficult decisions.

Sometimes, you may not agree with the doctor about the best course of action. If this occurs, speak openly about your concerns. If you are still unsure, you may want to seek another doctor's opinion, ask for a care team meeting, or speak with a patient assistance employee from your hospital or health plan. In some cases, hospital ethics committees—with doctors, nurses, chaplains, community members and others—can help you and your family with these concerns and help solve conflicts.



If your loved one is very ill, many doctors may be involved. This can make it hard to stay well informed and talk clearly with all of them. If this happens, you need to be forthright—set up meetings with the doctors, write down your questions in advance, keep notes, and be available when changes occur. Nurses can play an important role in helping you. If there are many family members, you might also consider naming one as the main contact person to talk with doctors.

All those involved in caring for a person who is dying—family members, doctors, nurses, social workers, clergy and other support staff—have a role in making sure that end-of-life care is compassionate.

The checklists on the following pages tell you what you should expect from your doctor, as well as those actions you should take yourself.

Whether you are in the early stages of planning like the Morrisons, faced with decisions for a family member like the Thompkins, or somewhere in between, you can help to shape the last stage of life. Advance care planning, good communication, and shared decision-making are important ways to obtain end-of-life care that will bring peace of mind to you and your family.

“Modern medicine may have made dying harder, but it has also given us the gift of time—the time to prepare, the time to heal family wounds, the time to bring psychological and spiritual closure. If we can take advantage of it, it has given us something unique in history: the time to tie up loose ends and orchestrate a death that is good.”

Marilyn Webb
The Good Death

Checklist

How Your Doctor Should Work With You

Your doctor should:

Discuss advance care planning.

- ✓ Give you time to talk about your concerns.
- ✓ Ask about and respect your values and decisions.

Provide clear and complete information.

- ✓ Make sure that you understand important information.
- ✓ Discuss future decisions, giving you time to consider and plan.
- ✓ Discuss treatment options and goals, including comfort care.

Encourage decisions that all can accept.

- ✓ Provide time for you to consider different treatments.
- ✓ Involve you and your family in developing the plan of care.
- ✓ Encourage discussion with others if there is disagreement.

Assist you in handling non-medical concerns.

- ✓ Involve social services for emotional and practical support, including financial concerns.
- ✓ Enlist help of chaplain or other resources to offer spiritual support.

Provide comfort care to you and your family.

- ✓ Make sure you and your family know what to expect during the dying process.
- ✓ Consider both your own and your family's needs as part of comfort care.
- ✓ Ensure pain relief and symptom control.
- ✓ Discuss hospice services.

Checklist

Steps for *Finding Your Way*

When doing advance care planning, you should:

- ✓ Consider your own views about the last stage of life.
- ✓ Discuss these views with your family or close friends.
- ✓ Pick a substitute decision-maker who knows you well and is able and willing to speak for you if you can't communicate. If you have no decision-maker, write down your wishes for care in an advance directive.
- ✓ Discuss your views with your doctors.
- ✓ Complete an advance directive form and give copies to your decision-maker and doctor.
- ✓ From time to time talk about this with family or friends, since personal views may change.

When facing difficult decisions, you should:

- ✓ Recognize that the dying process is complex. Unexpected medical, emotional, spiritual and practical issues may arise.
- ✓ If there is an advance directive, make sure it is in the medical record.
- ✓ Ask your doctor to discuss treatment options and goals for this stage of life.
- ✓ If the doctor's views don't agree with yours, talk to the doctor and try to work out differences.
- ✓ Realize that treatments and goals may change as the illness progresses and you may stop treatments if they no longer meet your goals.
- ✓ Be aware that intense feelings and family problems can make it hard to talk about these issues.
- ✓ If you are a spokesperson, make decisions based on your loved one's views, whether you fully agree or not.
- ✓ Make use of resources such as hospital chaplains, social workers and ethics committees.

Resources



Advance Directives

All states recognize at least one type of advance directive. While the laws of each state may vary on wording and restrictions, there are two main types of directives.

- *Medical Power of Attorney—Also known as a Power of Attorney for Health Care (or Health Care Proxy), this lets you choose someone to make your healthcare decisions if you cannot.*
- *Living Will—This document tells your doctors how you want to be treated if you become permanently unconscious or suffer from a terminal illness.*

In California, both types are combined in an Advance Health Care Directive.

For more information or to obtain an advance directive form:

- *Call your hospital's social services, patient education, admissions or chaplaincy department.*
- *Call the National Hospice and Palliative Care Organization Helpline at 1-800-658-8898.*
- *Download a legal form for any state from www.caringinfo.org.*

Hospice Programs

Most communities have hospice programs that provide medical, psychosocial, emotional and spiritual support for dying persons and their families, and support for grieving family members. Medicare and many health plans pay for hospice services. To learn more, ask your doctor or hospital for the name of a local hospice. Or contact the National Hospice and Palliative Care Organization Helpline (1-800-658-8898) or website (www.nhpco.org) for location of hospices near you.

Faith Communities

Communities of faith offer support to dying persons and their families through health ministry programs, faith community nurses, and clergy trained in pastoral care. Many religious communities also study end-of-life issues, addressing decisions such as stopping medical treatment or using feeding tubes. Ask your faith leader for more information.

Health Plans

If you belong to a health plan, contact its health education department for classes or materials, including printed information and videos on topics such as decision-making and advance directive forms.

Helpful Materials

Hard Choices for Loving People (by Chaplain Hank Dunn). This 80-page booklet provides detailed information about life-sustaining methods, as well as the emotional and spiritual aspects of end-of-life decisions. Also available in Spanish. To order, visit www.hardchoices.com or call (703) 707-0169.

Handbook for Mortals: Guidance for People Facing Serious Illness (by Drs. Joanne Lynn and Joan Harrold). This book provides counsel and practical information on where to look for help, what to expect with specific diseases, and how the experience affects dying persons and their loved ones. Published by Oxford University Press.



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