

End of Life Care Planning

State of California Department of Justice



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We plan for the best life possible. Yet, all too often in this planning, we put off thinking out our final chapter for living well with peace of mind and without crisis.

Consider this: Research shows that 70 percent of Americans would prefer to be at home with loved ones in their final days, yet only about 25 percent die at home.

And, the most requested advice from legal aid is how to deal with end-of-life issues - amidst a family crisis.



If we can break this taboo, many people will be able to avoid dying alone, in pain and in unfamiliar institutional settings. Many families can avoid regrets, unresolved issues and being impoverished by end of life care.

To help you tackle this important planning for the best possible life, we offer a checklist and resource guide. This material is informational only and not intended as legal advice. If you have questions, please consult with your physician, lawyer or other appropriate person.

End-of-Life Care Checklist

- **Gathering Information for Decision-Making.** Talk with your doctor, family, close friends and other trustworthy advisors about your health care wishes, questions and concerns.

- **Prepare Your Advance Health Care Directive.** After learning your options and discussing your wishes, prepare an [Advance Care Directive](#). Keep a personal copy in a safe and accessible place, while letting key people know of your intentions. Consider addressing [Palliative Care/Pain Management](#) and [Hospice Care](#) in your advance health care plan.
- **Prepare An Estate/Financial Plan.** By developing an [Estate/Financial Plan](#), you can avoid surprises and help protect the long-term health of your assets. While difficult to predict future needs, it would be useful to learn what kind of financial assistance you may be able to receive under your health insurance plan, disability insurance plan and [Medicare](#). Address in advance your wishes for the often-taboo subject of funeral arrangements. Information is available from the California Department of Consumer Affairs.
- **Keep Information Safe And Accessible.** Your best plans will not be any good unless you and others can refer to them.

Hospice Care



Hospice care is designed to comfort and support patients and their families when the patient can no longer benefit from cure-oriented medical treatment. The typical hospice patient has a life expectancy of six months or less. While hospice often is understood to be a "place to go when you are dying," it more typically allows a dying patient to receive care at home surrounded by family and friends.

Hospice services are provided by a team of trained professionals - physicians, nurses, counselors, therapists, social workers, aides and volunteers -- who provide medical care and support services not only to the patient, but to the patient's family and loved ones. The care addresses the emotional, social and spiritual impact of the disease on the patient and the patient's family.

Note that hospice physicians are not a substitute for your own personal physician. Hospice physicians primarily prescribe medication for pain management and may have little expertise in other chronic health conditions you may have. Another way to put it is they focus on symptoms rather than causes, managing pain after it occurs rather than preventive medicine. Other medical conditions should continue to be treated by your primary care physician or relevant specialist to maximize your comfort and quality of remaining life (e.g. heart conditions, thyroid conditions, memory issues, diabetes, and even cancer if not related to the hospice diagnosis).

Hospice programs are proliferating in quantity and vary in quality. You should ask a knowledgeable person you trust such as your personal physician for recommendations, and then evaluate several before selecting one.

You should carefully review any hospice plan of care before signing it. There are a wide variety of services that are available, including physical therapy, but may not be provided if they are not listed in the plan of care. You should ask for a complete list of available services, and request that all those that you and your personal physician feel will be beneficial for you be included in your plan of care. Hospice receives per diem compensation, and therefore has a financial incentive to limit services to those specifically negotiated for in the plan of care.

As the primary health insurer for people age 65 and older, the Medicare program in the Social Security Administration offers certain hospice benefits for end-of-life care. Check with the federal Social Security Administration and your health insurance plan.

Resources

Note: This listing is intended as a starting point and provided for informational purposes only. There are many other resources available that you may wish to research. Listing here is not an endorsement of the

organization or its web page content. If you have questions, please consult with your physician, lawyer, accountant or other appropriate person.

- [California Hospice & Palliative Care Association](#)
- [Hospice Foundation of America](#)
- [Medicare - Social Security Administration](#)
- [Medicare Hospice Benefits Publication, pdf](#)
- [Medicare Coverage of Skilled Nursing Facility Care Booklet, pdf](#)
- [National Hospice and Palliative Care Organization](#)

Palliative Care/Pain Management

Being in pain at the end of life can be more terrifying than death itself. Modern health care focuses attention on this concern through pain management and palliative care.



In California, all hospitals and nursing homes are required to assess a patient's pain condition as a fifth vital sign - along with the patient's pulse, temperature, respiration and blood pressure. California also is taking a leading role by requiring all medical schools in the state to train physicians on pain management and end-of-life care.

Palliative care is given to patients who face serious illness for which there is not a cure. Often called "hospice-type care," palliative care seeks to make the patient's life as comfortable as possible by controlling pain and symptoms, by easing the patient's concerns over daily living needs, and by helping the patient and family address psychological and spiritual needs. Respect for the patient's culture, beliefs and values are essential components of palliative care.

Ensuring Good Pain Management

- Since different types of illnesses will require different approaches, ask your doctor how he/she will manage pain that can result from your

illness. Your doctor should see that you have access to appropriate pain specialists.

- Consider how much pain you may be able to endure in exchange for other quality-of-life factors such as alertness and physical ability.
- Easing your pain is a priority so let your caregivers know when you are experiencing pain.
- Be as specific and thorough as possible in describing your pain. Alert your doctor when you are unable to do specific things and when the pain is better or worse. Consider indicating your pain using a scale of 1 to 10.
- Once you create a personal pain management plan, be sure to use it to avoid physical discomfort.

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- [Cancer Care, Inc.](#)
- [Genetic Alliance](#)

Advance Health Care Directive: What's Important To You

An "advance health care directive" lets your physician, family and friends know your health care preferences, including the types of special treatment you want or don't want at the end of life, your desire for diagnostic testing, surgical procedures, cardiopulmonary resuscitation and organ donation.

By considering your options early, you can ensure the quality of life that is important to you and avoid having



your family "guess" your wishes or having to make critical medical care decisions for you under stress or in emotional turmoil.

Advance Health Care Directive Checklist

The material prepared for this checklist is intended as informational only and not as legal advice. "If you are unsure of your options or have questions, we suggest that you talk with your physician, your lawyer and other trusted advisors."

- **Gather Information For Decision Making.** Your physician is a good place to start for understanding your options on health care treatment at the end of life. In addition, many organizations have information that may be useful.
- **Discuss Your End-of-Life Decisions With Key People.** Talk about your decisions with your family, physician and others who are close to you. Some questions to consider for discussion:
 - What is important to you when you are dying?
 - Are there specific medical treatments you especially want or do not want?
 - When you are dying, do you want to be in a nursing home, hospital or at home?
 - What are the options in [Palliative Care/Pain Management](#) and [Hospice Care](#)?
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- **Prepare Your Advance Care Directive Form.** Under state law, you have a legal right to express your health care wishes and to have them considered in situations when you are unable to make these decisions yourself. California consolidated various earlier forms used to indicate health care preferences into one Advance Care Directive. All valid health care directives executed before July 1, 2000 can remain in effect under California Probate Code section 4701. Earlier forms included

Natural Death Act Declaration, Directive to Physicians and Durable Power of Attorney for Health Care.

While state law requires certain provisions to appear in your health care directive, there is no single form in use to document your wishes. View [California Probate Code Sample Form, pdf](#).

A wide array of resources are available on advance health care directives, including FAQs provided by health and hospice care providers such as the [California Medical Association](#).

- **Designate Person To Carry out Wishes.** Select who should handle your health care choices and discuss the matter with them. You could name a spouse, relative or other agent.
- **Inform Key People Of Your Preferences.** Notify your doctor, family and close friends about your end-of-life preferences. Keep a copy of your signed and completed advance health care directive safe and accessible. This will help ensure that your wishes will be known at the critical time and carried out. Give a copy of your form to:
 - The person you appoint as your agent and any alternate designated agents
 - Your physician
 - Your health care providers
 - The health care institution that is providing your care
 - Family members
 - Other responsible person who is likely to be called if there is a medical emergency

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- **Advance Health Care Planning - National Hospice and Palliative Care Organization**
- **The Agent's Role In End-of-Life Care - Robert Wood Johnson Report, pdf**
- **American Association of Retired Persons (AARP)** is a membership organization addressing health care, consumer protection and other issues for older Americans.
- **California Coalition for Compassionate Care** is a statewide collaborative of more than 50 organizations representing healthcare providers, consumers and state agencies committed to improving end-of-life care for Californians.
- **Communicating Your End-of-Life Wishes, pdf**