

Life can bring unexpected events. Having a plan in place in case you are unable to state your medical wishes can bring you and your loved ones comfort.

End of Life Statistics

- Three out of four people die in a hospital or assisted living facility
- Most healthcare costs come from our last few months of life

Importance of Having a Plan

- Provides peace of mind
- Ensures your family, or health care agent, understands your choices
- Reduces family distress
- Helps minimize healthcare costs

What are Your Wishes?

Consider the following:

1. Your comfort toward end of life
2. Quality of life
3. The environment where you want to spend your last days (home, hospital, care facility)
4. Cultural and religious beliefs
5. Support
6. Making peace with family members
7. Who will have access to your healthcare wishes
8. Funeral wishes

What is Advance Care Planning?

- Identifying choices
- Planning for care
- Choosing a person to speak for you
- Documenting your wishes
- Plan for how chronic illness may affect you in the future
- Informing others of your choices
- Ensures family members and friends respect your wishes, even if they don't agree

Understanding CPR

- CPR is a way to temporarily help the heart pump and gets oxygen into the lungs when the heart has stopped beating
- 15% of all adults who have CPR in the hospital survive
- For example, out of 20 people, 3 would leave the hospital and go home, 17 will go to a care facility or die

Why it is Important to Write Your Wishes

- You will receive the most aggressive care available that gives you the best chances of surviving
- Quality of life is not considered

Advance Directive vs POLST

What is the difference between an Advance Directive and POLST?

	Advance Directive	POLST
Population	<ul style="list-style-type: none">Everyone should have one	<ul style="list-style-type: none">Serious illness with limited life left
Outcomes	<ul style="list-style-type: none">Shared decision makingChoosing a health care agent and expressing wishes	<ul style="list-style-type: none">Medical orders for treatmentBased on shared decision making for end of life
Who is responsible for completing	<ul style="list-style-type: none">PatientMay be revised as needed	<ul style="list-style-type: none">Provider with patient or health care agentBecomes an order for the physician

When should I complete advance care plan documents?

It is recommended that every adult complete an Advance Directive. It is never too early. POLSTs are completed within the last few months of life, when a person is expected to have only a few months to live. Advance care planning can be part of your regular medical follow up visit. Insurance may bill for a visit specifically made for advance care planning but this topic can often be discussed during a regular follow-up visit that is covered. Check with your insurance or provider before making an appointment specifically for advance care planning.

Options to file Advance Directive in your medical record

- Upload to MyUCDavisHealth, referenced below under Resources and Websites
- Bring to a clinic
- Fax to Health Information Management at 916-734-2126
- E-mail to Health Information Management at hs-roi@ucdavis.edu
- Mail to UC Davis Health, Health Information Management, 2315 Stockton Blvd., Bldg. #12, Sacramento, CA 95817



Resources and Websites

- MyUCDavisHealth: <https://health.ucdavis.edu/login/>
Click on Menu, then choose End-of-Life Planning under My Record
- Overview of end of life planning: www.coalitionCCC.org
- POLST information: www.capolst.org

Advance Health Care Directive Fact Sheet for Consumers

What is an Advance Health Care Directive (AHCD)?

An AHCD is a way to make your health care wishes known if you are unable to speak for yourself or prefer someone else to speak for you. An AHCD can serve one or both of these functions:

- Power of Attorney for Health Care (to appoint an agent)
- Instructions for Health Care (to indicate your wishes).

Is the AHCD different from a Durable Power of Attorney for Health Care?

The AHCD was enacted by July 2000 legislation and replaced the DPAHC and the Natural Death Act Declaration. However, if you had already completed one of these forms that was valid before July 1, 2000, it is still valid now.

I've never completed an "advance health care directive" before. Why should I?

Persons of all ages may unexpectedly be in a position where they cannot speak for themselves, such as an accident or severe illness. In these situations, having an "advance health care directive" assures that your doctor knows your wishes about the kind of care you want and/or who the person is that you want to make decisions on your behalf.

Does this mean only *one* person can decide for me? What if I want others involved, too?

Often many family members *are* involved in decision-making. And most of the time, that works well. But occasionally, people will disagree about the best course of action, so it is usually best to name just one person as the agent (with a back up, if you want). And you can also indicate if there is someone who you do NOT want to make your decisions for you.

But I thought the doctors make all those life-and-death decisions anyway?

Actually, doctors tell you about your medical condition, the different treatment options that are available to you and what may happen with each type of treatment. Though doctors provide guidance, the decision to have a treatment, refuse a treatment or stop a treatment is yours.

What if something happens to me and no form has been completed?

If you are not able to speak for yourself, the doctor and health care team will turn to one or more family members or friends. The most appropriate decision-maker is the one with a close, caring relationship with you, is aware of your values and beliefs and is willing and able to make the needed decisions.

My "values and beliefs?" But I haven't talked with anyone about these!

That's why it is a good idea to talk with family or close friends about the things that are important to you regarding quality of life and how you would want to spend your last days and weeks. Knowing the things that are most important to you will help your loved ones make the best decisions possible on your behalf. If your agent doesn't know your wishes, then he or she will decide based on what is in your best interest.

What if I don't want to appoint an agent? Or don't have one to appoint?

You do not have to appoint an agent. You can still complete the Instructions for Health Care and this will provide your doctors with information to guide your care.

What kinds of things can I write in my Instructions for Health Care?

You can, if you wish, write your preferences about accepting or refusing life-sustaining treatment (like CPR, feeding tubes, breathing machines), receiving pain medication, making organ donations, indicating your main doctor for providing your care, or other things that express your wishes and values. If you have a chronic or serious illness, you also may want to talk with your doctor about specific treatments that you could face and ask him/her to help you document your decisions on a POLST form.

A POLST form – I've never heard of that!

POLST stands for Physician Orders for Life-Sustaining Treatment and was adopted in California in 2009. This is a voluntary form, which must be signed by you (or your agent) and your physician, and indicates the types of life-sustaining treatment you do or do not want if you become seriously ill. POLST asks for information about your preferences for CPR, use of antibiotics, feeding tubes, etc. POLST doesn't replace your AHCD, but helps translate it into medical orders that must be followed in all healthcare settings (home, nursing home, hospital).

If I appoint an agent, what can that person do?

Your agent will make all decisions for you, just like you would if you could. Your agent can choose your doctor and where you will receive your care, speak with your health care team, review your medical record and authorize its release, accept or refuse all medical treatments and make arrangements for you when you die. You should instruct your agent on these matters so he/she knows how to decide for you. The more you tell them the better they will be able to make those decisions on your behalf.

When does my agent make decisions for me?

Usually the agent makes decisions only if you are unable to make them yourself – such as, if you've lost the ability to understand things or communicate clearly. However, if you want, your agent can speak on your behalf at any time, even when you are still capable of making your own decisions. You can also appoint a "temporary" agent – for example, if you suddenly become ill, you can tell your doctor if there is someone else you want to make decisions for you. This oral instruction is just as legal as a written one!

Are there other oral instructions that don't involve a written form?

Yes. You can make an individual health care instruction orally to any person at any time and it is considered valid. All health care providers must document your wishes in your medical record. But it is often easier to follow your instructions if they are written down.

Can I make up my own form or use one from another state?

Yes. That's why this law is so flexible. Any type of form is legal as long as it has at least 3 things: 1) your signature and date, 2) the signature of two qualified witnesses, and 3) if you reside in a skilled nursing facility, the signature of the patient advocate or ombudsman. These signatures, however, must include special wording.

Sounds difficult. Do I need an attorney to help with this?

No. Completing an advance health care directive isn't difficult and an attorney is not necessary. But actually the most important part of this is talking to your loved ones. Without that conversation, the best form in the world may not be helpful!

OK, I'll talk to them! But what should I do with the form after I complete it?

Make copies for all those who are close to you. Take one to your doctor to discuss and ask that it be included in your medical record. Photocopied forms are just as valid as the original. And be sure to keep a copy for yourself in a visible, easy-to-find location – not locked up in a drawer.

What if I change my mind?

You can revoke your form (or your oral instructions) at any time. Also, it's a good idea to try and retrieve old forms and replace them with new ones.

Do doctors or hospitals require a patient to have an Advance Health Care Directive form?

No, they cannot require you to complete one. But doctors and hospitals should have information available to you and your family about the form and your right to make healthcare decisions.

Resources

Check the *Coalition for Compassionate Care of California* website at www.coalitionccc.org for updates on advance health care directive materials and community education programs.

Advance Health Care Directive Forms:

- Download forms in English, Spanish and Chinese from the Coalition website at www.coalitionccc.org.
- Forms are often available at no charge from your local hospital – call the Social Services or Patient Education department. Or ask your doctor.
- The California Medical Association has an *Advance Health Care Directive Kit* available in English or Spanish for \$5 that includes a form, wallet card and answers to commonly asked questions about advance directives. To order single copies, call 1-800-882-1262 or visit www.cmanet.org.
- *Five Wishes* is a user-friendly advance directive that addresses the medical, personal, emotional and spiritual wishes of seriously ill persons. To order single copies in English or Spanish at \$5 each, send a check or money order to Aging With Dignity, PO Box 1661, Tallahassee, FL 32302-1661. A companion 30-minute video is available for \$19.95. For more information call 1-888-5-WISHES.
- Caring Connections has state-specific forms that can be downloaded from its website at www.caringinfo.org.

Fact Sheets in Other Languages:

- Additional fact sheets in multiple languages are available on the Coalition website at <http://www.coalitionccc.org/advance-health-planning.php>.

Booklets for Consumers:

- *Finding Your Way: A Guide for End-of-Life Medical Decisions*. This 13-page, easy-to-read booklet helps those who are starting the advance care planning process or considering whether to initiate or withdraw life-sustaining treatment when the end of life is near. Also available in Spanish.
- *Mrs. Lee's Story: Medical Decisions Near the End of Life*. This 16-page booklet written in Chinese and English relates the story of 91-year old Mrs. Ming Lee to introduce health issues that concern Chinese elders and their families. It includes basic information on advance care planning and advance directives, pain management and hospice care.

These booklets are available to view online, or purchase through CCCC's online store at www.coalitionccc.org.

Advance Care Planning – Conversation Guide

We'd like to think our loved ones will always be healthy, independent and able to make decisions for themselves, but things can change suddenly. They might have an accident or a serious illness and no longer be able to speak for themselves. When that happens, doctors often turn to their loved ones to speak for them. If that happens, will you know what care they would want?

Talking with loved ones now and helping them plan for future medical needs is the best way to make sure that their wishes will be respected. But, talking about this is not always easy.

The Coalition for Compassionate Care of California has developed this guide to help you start the conversation.

In it you will find:

- Suggestions on how to raise the issue
- Responses to concerns they might express
- Questions you might want to ask

As your loved one reflects on and expresses her/his wishes, we recommend you encourage her/him to:

- Write her/his wishes down in an Advance Directive document. An Advance Directive is a statement, shared with both family and the doctor, about how she/he wants to be treated if she/he becomes seriously ill and cannot speak for herself/himself.
- Appoint a spokesperson – a Healthcare Power of Attorney – you or someone else who understands her/his wishes and will be able to speak for her/him if she/he is unable to do so.

Once you start talking, don't feel that you need to get everything done at once. Rather, view it as a process. Even after your loved one has made her/his wishes known, these wishes may change over time. Once you've started, however, it will be easier to talk about changes or related issues in the future.

Keep in mind that other family members and loved ones also need to understand your loved one's wishes. Depending on how close they may be, geographically or emotionally, this can be challenging. Encourage your loved one to talk to family members – one at a time or at a family gathering. Offer to support her/him as she/he reaches out to any who may be resistant. The more those close to your loved one are aware of her/his wishes, the more likely those wishes will be carried out.

Ways to raise the issue

Talk about the recent illness or death of a relative or someone you know, or someone in the news, like a celebrity. What did you think about what happened with so-and-so? Is that the kind of care you would have wanted? Why or why not?

Share an article or story about the topic. Maybe there was a movie, a segment on the evening news, or a TV show that got you thinking.

Use the opportunity of a medical appointment or build on a financial planning session to discuss her/his wishes.

Responding to concerns

“I am feeling fine, so we don’t need to talk about this now. We can wait and handle things as they come up.”

We’d both like to think that you will always be healthy and able to make decisions for yourself. But things can happen suddenly. Things can change. You might have an accident or develop a serious condition and not be able to speak for yourself. So, making your wishes known now will help everyone, including the doctors, be able to care for you the way you want.

Or...

You make decisions every day about your life and your healthcare. I’ve seen how independent you’ve always been, how you have operated on your own for so long. That’s why I want to understand your wishes to make sure that you maintain your independence as long as possible. Why leave really important decisions to chance?

There is no need to talk about this because “The doctor will make the decisions anyway,” or “I trust you (your father, your brother) to know what to do,” or “It’s all in God’s hands anyway...”

Though your doctor will help, she or he will still turn to us (your family) to make the choices for you. It will be very difficult for us to know what to do if you haven’t talked about your wishes. And, it puts a real burden on all of us to have to make decisions on your behalf when we aren’t sure what you would want.

“My attorney has taken care of it all,” or “I’ve already filled out the form.”

It’s great that you have already started the planning process. If the time comes that you can’t make decisions for yourself, it would help me and others who love you if we could understand what care you would want. Perhaps we could start by sitting down together and reviewing your form.

“This is too hard (or morbid or depressing) to talk about.”

While it can be hard to talk about, it’s very important for our family. If we have to guess what you would like, we will feel anxious about making the right decision. And, we may disagree and not know what to do. Talking about this now will be a wonderful gift you can give to me and all of us who love you. Let’s see how it goes.

Questions you might ask

- If you could plan it today, what would the last day or week of your life look like?
- Who would be there?
- Where would you like to be?
- What are your ideas and hopes about the end of your life?
- What are your fears or concerns about the process of dying?
- Have you thought about what kinds of care you might want during a severe illness or when you are dying?
- Where would you prefer to spend your last days if you are ill? At home, with one of us, in a nursing home, or in the hospital?
- Who do you want to make medical decisions for you if you are unable to speak for yourself?
- Do you believe that life should always be preserved as long as possible? If not, what kinds of mental or physical conditions would make you think that life-prolonging treatment should no longer be used? For example, if you were:
 - Unaware of your surroundings
 - Unable to appreciate or continue important relationships
 - Unable to think well enough to make everyday decisions
 - In severe pain or discomfort
- Is there any particular music, flowers, photographs or art you would like to have around you near the end of life?
- What are your wishes regarding a funeral? Burial vs. cremation?



Understanding California's End of Life Option Act

What is the End of Life Option Act?

This is a new California law that will allow a terminally ill patient to request a drug from his or her physician that will end the patient's life. Patients who choose to end their lives this way, and who carefully follow the steps in the law, will not be considered to have committed suicide. Physicians who help their patients with this process, and who carefully follow the steps in the law, will be providing a new, legal form of end of life care and will not be subject to legal liability or professional sanction for doing so.

This end of life option is voluntary for both patients and their physicians.

Who can use this option?

To receive the aid-in-dying drug, a patient must be 18 or older and a resident of California. The patient must also:

- Have a terminal disease. A physician must determine that the disease cannot be cured or reversed and is expected to result in death within 6 months.
- Have the capacity to make medical decisions.
- Not have impaired judgment due to a mental disorder. (Not all people with mental disorders have impaired judgment.)
- Have the ability, physically and mentally, to take the drug at the time they want to take it.

Patients cannot request aid-in-dying in advance directives or other documents. Healthcare agents, surrogates, and conservators cannot request aid in dying for a patient, even if they know that is what the patient would have wanted.

How does a patient obtain aid-in-dying?

If a patient wishes to receive the aid-in-dying drug, the patient and his or her physician must follow the steps in the law carefully. Below is a summary of key steps but not a comprehensive list:

- The patient's attending physician (the physician primarily responsible for their illness) must decide that the patient's illness is terminal, meaning it cannot be cured or reversed and the patient will likely die in six months or less. The physician must also determine that the patient has capacity to make medical decisions.
- The patient must make two verbal requests, at least 15 days apart, directly to his or her physician (the attending physician) as well as one request in writing. The written request must be on a special form that is witnessed and signed by the patient. The patient must discuss this decision with his or her physician without anyone else present (except an interpreter, if needed), to make sure the decision is voluntary.
- The patient must then see a second physician (a consulting physician) who can confirm the patient's diagnosis, prognosis, and ability to make medical decisions. If either physician thinks the patient might have a mental disorder, the patient must also see a mental health specialist to make sure his or her judgment is not impaired.
- The patient and physician must discuss all of the following:
 - How the aid-in-dying drug will affect the patient, and the fact that death might not come immediately.
 - Realistic alternatives to taking the drug, including comfort care, hospice care, palliative care, and pain control.
 - Whether the patient wants to withdraw the request.
 - Whether the patient will notify next of kin, have someone else present when taking the drug, or participate in a hospice program. The patient is not required to do any of these things.
 - Ensure the patient knows they do not have to take the drug, even once they have filled the prescription.
- If the patient still wishes, the physician will write a prescription for the drug. Before taking the drug, the patient must sign a form that says they took the drug voluntarily.

Do patients have to take the drug they requested?

No. If the patient has received the drug, they can take it whenever they want, or not take it at all. Taking the drug is the patient's choice alone. The patient must take the drug himself or herself. Others can help prepare the drug and sit with the patient, but the patient must be the one to physically take it.

Do doctors have to give patients aid-in-dying if they ask for it?

No. A physician's participation is voluntary. In addition, entire facilities (such as hospitals or nursing homes) can decide not to participate in aid-in-dying and can prohibit employees and contractors from doing so as well. However, physicians or facilities who do not participate in aid-in-dying must have a written policy that is given to patients, and can't prevent someone from referring patients to a physician who does participate. Since the law requires the patient's "attending physician" to be the person that helps him or her with aid-in-dying, patients should learn about physician or facility policies when choosing who provides their care, if this is important to them.

How does the law protect patients from being pressured to end their lives?

The Act contains a number of protections for patients:

- Two witnesses must be present when the patient signs the written request form. The witnesses sign the request form if they agree that the patient has the mental ability to make decisions and is voluntarily asking for aid-in-dying.
- At least one of the witnesses must be unrelated to the patient or not entitled to inherit part of the patient's estate. At least one of the witnesses must be someone who does not work for the facility where the patient is receiving care. A physician who is treating or diagnosing the patient cannot be a witness.
- The physician who provides in aid-in-dying to a patient cannot be related to that patient or eligible to inherit from that patient.
- It is a serious crime for anyone to try to force a patient to request or take aid-in-dying drugs.
- Patients can change their minds and take back their request for the drug at any time, regardless of their mental state.
- An interpreter who helps the patient get aid-in-dying cannot be related to the patient or be eligible to inherit from that patient.
- The law does not allow someone to end a patient's life by lethal injection, mercy killing, or active euthanasia. Those actions are still illegal in California.

How does the Act affect a patient's insurance, wills or other contracts?

The Act protects patients from feeling financial or other pressure to end their lives by placing restrictions on what insurance companies and others can do. Patients can never be denied life or health insurance or annuities based on requesting or taking an aid-in-dying drug. A health insurer cannot tell a patient that aid in dying is covered unless the patient asks. A health insurer also cannot refuse treatment for the illness at the same time it offers coverage for aid-in-dying. Finally, a will, contract, or other agreement cannot require a patient to receive aid-in-dying or prevent them from doing so. Patients cannot request aid-in-dying in an advance directive, POLST, living will, or other form.

This document provides only information about the law and does not constitute legal advice. We recommend that you seek the advice of a lawyer for specific questions about your situation.

Prepared by:

UCSF/UC HASTINGS CONSORTIUM
ON LAW, SCIENCE, & HEALTH POLICY



UC HASTINGS
COLLEGE OF THE LAW