# Voice Your Choice

### Share What Matters to You

This booklet offers simple explanations and additional resources to help you think about, talk about, and complete an advance directive. If you have additional questions or need more information about Advance Health Care Directives, please call Enloe Medical Center's Case Management department at (530) 332-7502.





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# MAKING YOUR WISHES KNOWN IS IMPORTANT

Most of us know we should make our end-of-life and medical treatment wishes known. However, thinking and talking about this can be tough and many of us put it off.

Yet having this conversation and specifying your wishes in an advance directive can bring a sense of relief to you and your loved ones, and ensure you receive the treatment you would want if the unexpected happens.

Not sure where to start? We'll walk you through it.

### An advance directive: your essential tool

The best way to state your wishes is to complete an advance directive. This is a legal document that tells your health care providers the kind of medical care you do—and don't—want in the event you are unable to speak for yourself or if you prefer someone else to speak for you. (Please note that there are several types of advance directives, which we explain later in this booklet.)

Advance directives also tell your care team who you would like to speak for you. In California, this person is called your "agent."

Completing an advance directive not only helps your care team, it can also spare your loved ones the pain of uncertainty and possible conflict.



### BY THE NUMBERS

**60%** of people say making sure their family is not burdened by tough decisions is extremely important to them.

**56%** have not communicated their end-of-life wishes.

**82%** of people say it's important to put their wishes in writing.

**23%** have actually done it.

Source: Health Affairs (2017)

### **ADVANCE DIRECTIVE FAQS**

Here are some of the questions people often have about advance directives, specifying an agent and related items.

### Why should I complete an advance directive?

Because anyone, at any age, can suffer an accident or illness unexpectedly and become unable to speak for him or herself. In these situations, having an advance directive ensures your care team

and loved ones know your wishes, the kind of care you want, and/or who you want to make decisions on your behalf. For these reasons, anyone over the age of 18 is encouraged to complete an advance directive.

# I thought doctors made all the life-and-death decisions?

Actually, health care providers tell you about your medical condition, your treatment options and what may happen with each option. However, the decision to have, refuse or stop a treatment is yours.

# What if something happens to me and I haven't completed an advance directive?

If you're unable to speak for yourself, your care team will turn to one or more of your family members or friends regarding your treatment. The most appropriate decision-maker will be someone with a close relationship to you, who is aware of your values and beliefs, and is willing and able to make decisions. However, to ensure you receive the care you would want, it's best to complete an advance directive and share your wishes with your loved ones.

"A few years ago I got a call from the hospital asking me to come in and make decisions for a friend who had listed me as their agent. I had no idea! When you list someone as your agent, be sure to talk to them about it, and give them a copy of your Advance Health Care Directive."

—The friend of a former Enloe patient

### Where can I get an advance directive form?

California Advance Health Care Directive forms are available at www.enloe.org/directive, at most Enloe reception areas and from Enloe social workers. Many websites also offer these forms along with guides and other tools to help you complete them. (Refer to the "Resources" section of this booklet.)

# When I complete an advance directive, can only one person make decisions on my behalf? What if I want others involved, too?

It's best to name just one person as your agent. Often, several family members are involved in decision-making. While most of the time this works well, occasionally people disagree about the best course of action. Because of this, it's best to name just one person. However, you can specify a backup agent as well. You can also indicate if there is someone you do not want making decisions on your behalf.

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

Your agent will make all decisions for you, just like you would do for yourself if you could. Your agent will be able to:

- Choose your health care provider
- Decide where you'll receive care
- Speak with your care team
- Review your medical record and authorize its release
- Accept or refuse all medical treatments
- Make arrangements if you die

Be sure to instruct your agent on these matters so he or she knows how to decide for you. The more you tell your agent, the better he or she will be able to make decisions on your behalf.

### When does my agent make decisions for me?

Usually when you're unable to make them yourself, for instance, if you lose the ability to understand or communicate clearly. However, if you wish, 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 health care provider if you would prefer a temporary agent to make decisions for you. Oral instructions are just as legal as written ones.

### Can I give other oral instructions?

Yes. You can give individual health care instructions orally to any person, at any time, and they're considered valid. All health care providers must document your wishes in your medical record. However, it's easier to follow instructions if they are written down.

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

That's fine. You can still complete the "Instructions for Health Care" portion of your advance directive to guide your care team without specifying an agent.

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

You can write if you would like—or would not like—life-sustaining treatment (such as CPR, feeding tubes or breathing machines) and pain medication. You can also specify if you do or don't want to donate your organs. You can name your main health care provider, too, and jot down other notes that express your wishes and values.

### How does my AHCD or POLST get into my medical record?

You must properly distribute your advance directive forms for them to work! Check that medical records at your primary care office and local hospitals (or skilled nursing facility, if applicable) have your most recent forms on file. For more information about distributing your forms, go to page 7.

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

Yes. In California, the law regarding advance directives is very flexible. Any type of form is legal as long as it includes your signature and date, the signature of two qualified witnesses, and (if you reside in a skilled-nursing facility) the signature of the patient advocate or ombudsman.



### I filled out an Advance Health Care Directive. Will it work in another state?

Most states accept Advance Health Care Directives from other states. However, if you regularly spend time in another state, speak to a patient representative at a hospital in that state to see what he or she recommends.

### Will my advance directive affect who is in charge of my estate?

No. The California Advance Health Care Directive and other advance directive forms only deal with your health care wishes. No one will be able to control your money or property based on your advance directive.

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

No. Completing an advance directive isn't difficult, and an attorney is not necessary. Actually, the most important part of an advance directive is talking to your loved ones about your wishes. Without that conversation, the best form in the world may not help.

### What if I change my mind?

You can revoke your advance directive (or your oral instructions) at any time. However, if you do this, be sure to retrieve old forms anywhere you have given them out and replace them with the most up-to-date version.

### Do doctors or hospitals require a patient to have an advance directive form?

No. They cannot require this. However, health care providers and hospitals should have information available to you and your family about the form and your right to make health care decisions.

# Is the Advance Health Care Directive different from a Durable Power of Attorney for Health Care?

Yes. The Advance Health Care Directive (AHCD) was enacted by legislation in July 2000 and replaced the Durable Power of Attorney for Health Care (DPAHC) and the Natural Death Act Declaration. However, if you completed one of those forms and it was valid before July 1, 2000, it's still valid now.

### How is an Advance Health Care Directive (AHCD) different from a POLST or DNR?

These forms work together. An AHCD is something that you complete. It names the person you want to make decisions for you if you cannot speak for yourself – also known as your agent. It also provides general wishes about treatment options and after death care. Any competent adult should complete one so health care providers and family can use it as a guide. A POLST or DNR, meanwhile, is completed by your health care provider and gives specific medical orders regarding your wishes. A DNR tells emergency personal and healthcare providers not to attempt CPR. A POLST includes your wishes regarding several additional life-sustaining treatments. If you feel strongly that you do not want CPR, artificial ventilation, or a feeding tube, you should have a POLST. It protects your wishes in an emergent situation where you cannot speak for yourself. The DNR and POLST are meant for anyone who is frail due to advanced age or serious illness. For more information, visit www.polst.org.

### How can I make my wishes known to emergency personnel?

The Vial of Life Program offers a window decal and other materials that direct Butte County emergency personnel to medical information stored in a baggie in your refrigerator. Learn more about Vial of Life at <a href="https://www.buttecountyems.org/vial.html">www.buttecountyems.org/vial.html</a> or by calling (530) 332-6741.

### **ADVANCE DIRECTIVE OPTIONS**

When it comes to advance directives, you have several types to choose from. Learn about them below to see which one is right for you.

**California Advance Health Care Directive:** This is a standard advance directive that allows you to name an agent to make decisions on your behalf and lets your health care provider know the care you do and don't want. (This form is included in the back pocket of this booklet.)

**Five Wishes:** This advance directive includes the same information as the California Advance Health Care Directive and lets you specify how you would like to be cared for and remembered. (Learn more at www.agingwithdignity.org.)

**Living Will:** This document states the medical treatment you do or don't want to sustain your life in certain situations. In California, your living will and medical power of attorney are combined into a single form called an Advance Health Care Directive.

Physician Orders for Life-Sustaining Treatment (POLST): This form must be signed by you (or your agent) and your health care provider. It indicates the types of life-sustaining treatment (CPR, antibiotics, feeding tubes, etc.) you do (or don't) want if you are seriously ill. This form does not replace your Advance Health Care Directive. Rather, it translates your wishes into medical orders that must be followed when you cannot speak for yourself and there is not enough time to reach your decision maker. When completed, you provide a copy of your POLST to your local hospital. It should also be with you if you are admitted to a skilled nursing facility, and it should be available for emergency personnel if you are at home. As with any advance directive, you can change it whenever you want. If you can communicate, your verbal requests will be honored. Learn more at www.polst.org or ask your health care provider.

**Thinking Ahead:** This easy-to-use workbook and companion videos help people with cognitive challenges—or those who like to keep things simple—complete an advance directive. This workbook is available in English, Spanish and Chinese at <a href="www.dds.ca.gov/ConsumerCorner/ThinkingAhead.cfm">www.dds.ca.gov/ConsumerCorner/ThinkingAhead.cfm</a>.

**Do Not Resuscitate (DNR):** This is a form that you (or your agent) and your health care provider sign if you do not want to receive CPR and advanced life support, including advanced airway support and mechanical ventilation, if your heart stops and you stop breathing. California Emergency Medical Services also offers a Prehospital DNR that can limit the scope of emergency care you receive outside the hospital.

**Prehospital DNR form:** This California state form allows you to indicate that you don't want CPR started if something happens to you outside a hospital. Normally, emergency medical personnel are required to start CPR when someone needs it. This form must be signed in advance by your health care provider. It works like a POLST, but is limited to CPR. For more information about the Prehospital DNR form, go to <a href="https://emsa.ca.gov/dnr\_and\_polst\_forms/">https://emsa.ca.gov/dnr\_and\_polst\_forms/</a>.

**Dementia Provision:** This is language that can be added to any advance directive or living will to advise health care providers and family members of your wishes if you have Alzheimer's disease or another form of dementia. (Learn more **www.compassionandchoices.org**.)

### **COMPLETING AN ADVANCE DIRECTIVE**

Now that you know more about advance directives and the different options you have to make your wishes known, how can you go about completing a form? Follow these steps.

- STEP 1 Think about what "quality of life" means to you. Then ask yourself what medical care you would and wouldn't want if you were seriously ill or injured and unable to speak for yourself. Learn about the benefits and burdens of specific medical treatments, such as CPR, ventilation, hydration and feeding tubes, at the end of life. Research options on trustworthy websites and discuss questions with your health care providers. If you're a person of faith, explore what religious beliefs might affect your choices. (Refer to the "Resources" section of this booklet.)
- STEP 2 Talk about your wishes with your agent and your family. This is one of the most important conversations you can have. If this is difficult, tools like Go Wish can make it easier. (Refer to the "Resources" section of this booklet.)

  If you need extra support, ask a social worker or a spiritual leader, like a pastor, priest, or rabbi, for assistance. Be steadfast—this often takes more than one conversation. If you're navigating serious illness or injury, this may become an ongoing conversation that gets easier with practice.
- STEP 3 Document your plan in an advance directive. Name the person who will be your medical decision-maker or agent. Then ensure that person is comfortable voicing your wishes and capable of advocating for you in a medical setting.
  Be sure to complete the sections of the form indicating your instructions for health care and other wishes, including the Dementia Provision, if applicable. It is okay to leave parts blank if you don't know what you want.
  Then ask two qualified witnesses to sign and date your advance directive, or have the form notarized.
- STEP 4 Distribute copies of your advance directive to your agent, loved ones, health care provider and to the medical center to be scanned into your medical record.

  Some people also carry a copy of their advance directive in their car and with other important documents when they travel. If you go into a skilled nursing facility, they should not fill out a new POLST if you already have one completed—unless you wish to update your wishes.

# STEP 5 - Update your health care wishes and redistribute your forms whenever any of the five D's occur:

- Decade-When you start each new decade of your life
- Death-When you experience the death of a loved one
- Divorce-When you go through a divorce or another major family change
- Diagnosis-When you are diagnosed with a serious health condition
- Decline–When you experience a significant decline in health, especially when it diminishes your ability to live independently

# Not sure how to start talking about your wishes? Try these icebreakers:

"I need your help with something..."

"I was thinking about what happened to \_\_\_\_\_\_, and it made me realize..."

"Even though I'm OK right now, I'm worried that \_\_\_\_\_\_, and I want to be prepared."

"I need to think about the future. Will you help me?"

"I just answered some questions about how I want the end of my life to be. I want you to see my answers. And I'm wondering what your answers would be."

Source: The Conversation Project



### AN ADVANCE DIRECTIVE IS A GIFT

Knowing you have thought about your options and talked things out with the people you love will give you and your loved ones peace of mind. It can also help your family, friends and health care providers pursue the treatment you want. Most people get a sense of relief when they take the time to voice their choice.



### **RESOURCES**

### **Enloe Cancer Center Library**

The Enloe Cancer Center Library offers a number of materials related to caregiving, a loved one's final days, grieving and explaining death to children, including these:

- "Being Mortal: Medicine and What Matters in the End" by Atul Gawande
- "Hard Choices for Loving People: CPR, Artificial Feeding, Comfort Care, and the Patient with a Life-Threatening Illness" by Hank Dunn
- "A Better Way of Dying: How to Make the Best Choices at the End of Life" by Jeanne Fitzpatrick and Eileen M. Fitzpatrick
- Go Wish: An easy way to talk about what is most important to you | Also available at www.gowish.org
- My Gift of Grace: A game that helps families talk about the end of life | Also available at www.mygiftofgrace.com
- Five Wishes DVD by Aging with Dignity, Inc. | Also available at www.agingwithdignity.org

The library is free and open to the public. For library hours or to make special arrangements to check out materials, please call (530) 332-3856 or go to www.enloe.org/library, where you can also view our online catalog.

### **Websites**

Enloe Medical Center—Advance Health Care Directive | www.enloe.org/directive Contains Advance Health Care Directive forms you can download and print in English and Spanish.

### Coalition for Compassionate Care of California | www.coalitionccc.org

Contains information specific to California, organized according to FAQs. You can also download advance directive forms, including an easy-to-read version and versions in multiple languages. The site also has a video for people with developmental disabilities and simple guides explaining the benefits and burdens of life support treatments.

### Compassion & Choices | www.compassionandchoices.org

This active nonprofit organization is committed to improving care and expanding choice at the end of life and offers lots of great information.

### The Conversation Project | https://theconversationproject.org/

Provides an easy-to-read "What Matters to Me" workbook in English and Spanish, a guide to choosing your agent, and a guide for talking with a health care team about your wishes.

Religious Groups' Views on End-of-Life Issues | www.pewforum.org/2013/11/21/religious-groups-views-on-end-of-life-issues

Offers summaries of how 16 religious groups address different end-of-life questions.

# Have additional questions or need someone to help you complete an advance directive?

Call Enloe's Case Management department at (530) 332-7502.

# **NOTES**

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