



Online, Secure, Advance Care Planning
Program in English & Spanish



The PREPARE Team

- **UCSF:** Rebecca Sudore, MD, Jana Powell, Clarissa Ferguson, Brookelle Li
- **UC Law:** Sarah Hooper, JD, Denise Watt, JD
- **People Designs:** David Farrell, MPH
- **Community Advisory Board:** Patients, Caregivers and experts in aging, ethics, health literacy, communication, behavior change



Need for Advance Care Planning



- Populations are aging, the burden of chronic illness is increasing, people are not prepared for decision making
- **Advance care planning (ACP)** is an important quality metric
 - It prepares patients & surrogates for medical decision making
 - Improves satisfaction with communication and care
 - Decreases surrogate burden, PTSD, complicated grief



McMahan, Sudore et al. *J Am Geriatr Soc.* 2020

<https://www.cms.gov/outreach-and-education/medicare-learning-network-mln/mlnproducts/downloads/advancecareplanning.pdf>

Online, Secure ACP Program with Videos and Easy-to-Read Advance Directives




<https://www.ncoa.org/article/evidence-based-program-prepare-for-your-care>

Co-Developed with Patients, Caregivers, and Communities



Literacy, Language, Culture

Based on Decades of Research



ACADEMIA AND CLINIC

Annals of Internal Medicine

Redefining the “Planning” in Advance Care Planning: Preparing for End-of-Life Decision Making

Rebecca L. Sudore, MD, and Terri R. Fried, MD

Based on New and
Improved ACP Models

Life sustaining
treatments



NEW & IMPROVED




PREPARETM for your care

Preparation for communication
& medical decision making



PREPARETM ForYourCare.org

Ann Intern Med. 2010 Aug

PREPARE Fills a Missing Puzzle Piece

PREPAREs people with skills to:

- Identify what is most important and how they want to live
- Talk with family, friends, medical providers
- Make informed decisions
- Get the care that is right for them




PREPARETM ForYourCare.org

Sudore RL. & Fried TR. Ann Intern Med, 2010

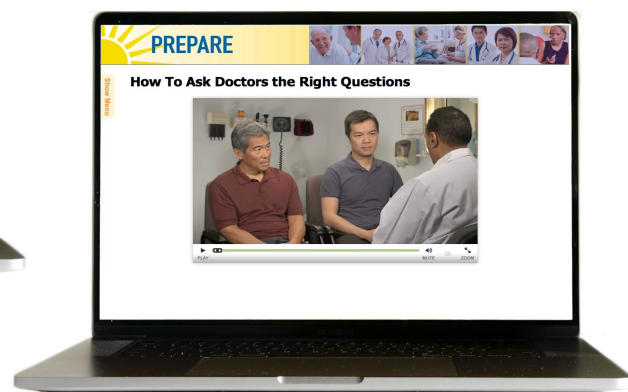
Walks People Through Step by Step

- | | |
|------------------|--|
| Step
1 | Choose a Medical Decision Maker |
| Step
2 | Decide What Matters Most in Life |
| Step
3 | Choose Flexibility for Your Decision Maker |
| Step
4 | Tell Others About Your Wishes |
| Step
5 | Ask Doctors the Right Questions |

Shows “How to” Videos



5th grade reading level
Narration & closed captioning



Integrates Easy-to-read Legal ADs for **all** US states in English & Spanish and 13+ in Chinese



California Advance Health Care Directive

This form lets you have a say about how you want to be cared for if you cannot speak for yourself.

This form has 3 parts:

Part 1 Choose a medical decision maker, Page 3
A medical decision maker is a person who can make health care decisions for you if you are not able to make them yourself. This person will be your advocate. They are also called a health care agent, proxy, or surrogate.

Part 2 Make your own health care choices, Page 7
This form lets you choose the kind of health care you want. This way, those who care for you will not have to guess what you want if you are not able to tell them yourself.

Part 3 Sign the form, Page 13
The form must be signed before it can be used.

You can fill out Part 1, Part 2, or both.
Fill out only the parts you want. Always sign the form in Part 3.
2 witnesses need to sign on Page 14, or a notary on Page 15.

PREPARE ForYourCare.org

Instrucción anticipada de atención de salud de Wisconsin

Este formulario le permite indicar cómo desea ser atendido si usted no puede hablar por sí mismo.

Este formulario consta de 3 partes:

Parte 1 Elegir una persona decisora, página 3
Una persona decisora es una persona que puede tomar decisiones médicas por usted si usted no puede tomarlas por sí mismo. Esta persona será su representante. También se les llama un agente de salud, un representante, o un sustituto.

Parte 2 Tomar sus propias decisiones de atención de salud, página 7
Este formulario le permite elegir el tipo de atención de salud que desea. De esta manera, las personas encargadas de su cuidado no tendrán que adivinar lo que desea si no puede decirlo por usted mismo.

Parte 3 Firmar el formulario, página 13
El formulario se debe firmar antes de que se pueda usar.

Usted puede llenar la Parte 1, la Parte 2, o ambas.
Llene solamente las partes que desee. Siempre firme el formulario en la Parte 3.
Es necesario que 2 testigos firmen en la página 14, o un notario en la página 15.

PREPARE ForYourCare.org

紐約州醫療照護事前指示書

在您無法表達意見時，這份指示書可讓您表達您希望得到的醫療照護。

指示書分為三部分：

第一部分 選擇一位醫療代理人，第3頁
在無法自我決定時，您的醫療代理人應幫助您做出醫療決定。這個人將是您醫療代理人。他們也稱為健康代理人、委託人、決策權代理人。

第二部分 選擇您的醫療照護，第7頁
指示書讓您選擇自己想要的醫療照護。這樣，當您無法表達意見時，照顧您的人就不需要推測您的想法。

第三部分 在指示書上簽名，第13頁
這份指示書必須簽名才可以生效。

您也可以填寫指示書的一部分或全部。
只填寫您想要的部分，但一定要在指示書的第三部分簽名。
兩位見證人必須在指示書第14頁簽名。

PREPARE ForYourCare.org



Part 2: Make your own health care choices California Advance Health Care Directive

Part 2 Make your own health care choices
Fill out only the questions you want.

How do you prefer to make medical decisions?

Some people prefer to make their own medical decisions. Some people prefer input from others (family, friends, and medical providers) before they make a decision. And, some people prefer other people make decisions for them.

Please note: Medical providers cannot make decisions for you. They can only give information to help with decision making.

How do you prefer to make medical decisions?

☐ I prefer to make medical decisions on my own without input from others.
☐ I prefer to make medical decisions only after input from others.
☐ I prefer to have other people make medical decisions for me.

If you want, you can write why you feel this way, and who you want input from.

What matters most in life? Quality of life differs for each person.

What is most important in your life? Check as many as you want.

☐ Your family or friends
☐ Your pets
☐ Hobbies, such as gardening, hiking, and cooking
☐ Your hobbies
☐ Working or volunteering
☐ Caring for yourself and being independent
☐ Not being a burden on your family
☐ Religion or spirituality: Your religion
☐ Something else

What brings your life joy? What are you most looking forward to in life?

Your Name

Values & Space to write “Why” & other wishes

Part 2: Make your own health care choices California Advance Health Care Directive

Quality of life differs for each person at the end of life.
What would be most important to you?

AT THE END OF LIFE
Some people are willing to live through a lot for a chance of living longer. Other people know that certain things would be very hard on their quality of life.

• Those things may make them want to focus on comfort rather than trying to live as long as possible.

At the end of life, which of these things would be very hard on your quality of life?
Check as many as you want.

☐ Being in a coma and not able to wake up or talk to my family and friends
☐ Not being able to live without being hooked up to machines
☐ Not being able to think for myself, such as severe dementia
☐ Not being able to feed, bathe, or take care of myself
☐ Not being able to live on my own, such as in a nursing home
☐ Having constant, severe pain or discomfort
☐ Something else

☐ OR, I am willing to live through all of these things for a chance of living longer.

If you want, you can write why you feel this way.

What experiences have you had with serious illness or with someone close to you who was very sick or dying?
• If you want, you can write down what went well or did not go well, and why.

If you were dying, where would you want to be?
☐ at home ☐ in the hospital ☐ either ☐ I am not sure

What else would be important, such as food, music, pets, or people you want around you?

Your Name

Part 2: Make your own health care choices California Advance Health Care Directive

What else should your medical providers and medical decision maker know about you and your choices for medical care?

OPTIONAL: How do you prefer to get medical information?
Some people may want to know all of their medical information. Other people may not. If you had a serious illness, would you want your doctors and medical providers to tell you how sick you are or how long you may have to live?

☐ Yes, I would want to know this information.
☐ No, I would not want to know. Please talk with my decision maker instead.

If you want, you can write why you feel this way.

* Talk to your medical providers so they know how you want to get information.

Your Name

Pre-populates Answers to Legal AD forms

- Tailored answer automation

Question 4. How Do You Balance Quality of Life with Medical Care?

If you were so sick that you may die soon, what would you prefer?

☐ Try all life support treatments that my doctors think might help. I want to stay on life support treatments even if there is little hope of getting better or living a life I value.

☒ Do a trial of life support treatments that my doctors think might help. But, I do not want to stay on life support treatments if the treatments do not work and there is little hope of getting better or living a life I value.

☐ I do not want life support treatments, and I want to focus on being comfortable. I prefer to have a natural death.

☐ I am not sure.

What else should your medical providers and medical decision maker know about this choice? Or, why did you choose this option?



How Do You Balance Quality of Life with Medical Care?

Sometimes illness and the treatments used to try to help people live longer can cause pain, side effects, and the inability to care for yourself.

Please read this whole page before making a choice.

AT THE END OF LIFE, some people are willing to live through a lot for a chance of living longer. Other people know that certain things would be very hard on their quality of life.

Life support treatment can be CPR, a breathing machine, feeding tubes, dialysis, or transfusions.

Check the **one** choice you most agree with.

If you were so sick that you may die soon, what would you prefer?

☐ Try all life support treatments that my doctors think might help. I want to stay on life support treatments even if there is little hope of getting better or living a life I value.

☒ Do a trial of life support treatments that my doctors think might help. But, I DO NOT want to stay on life support treatments if the treatments do not work and there is little hope of getting better or living a life I value.

☐ I do not want life support treatments, and I want to focus on being comfortable. I prefer to have a natural death.

What else should your medical providers and decision maker know about this choice? Or, why did you choose this option?

Guides People in AD Completion

- Additional information and videos available if needed

Part 1 Choose your medical decision maker

Your medical decision maker can make health care decisions for you if you are not able to make them yourself.

A good medical decision maker is a family member or friend who:

- is 18 years of age or older
- can talk to you about your wishes
- can be there for you when you need them
- you trust to know your medical information
- is not afraid to ask doctors questions and speak up about your wishes

Legally, your decision maker **cannot** be your doctor or someone who works at your hospital or clinic, unless they are a family member.

What will happen if I do not choose a medical decision maker?

If you are not able to make your own decisions, your doctors will turn to family and friends or a judge to make decisions for you. This person may not know what you want.



Click the video to see examples of people choosing a decision maker.

Time: 1:48

Close

Legally, your decision maker **cannot** be your doctor or someone who works at your hospital or clinic, unless they are a family member.

What will happen if I do not choose a medical decision maker?

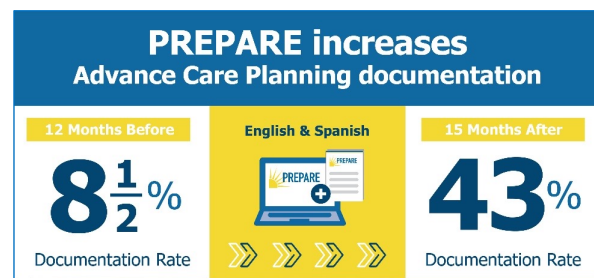
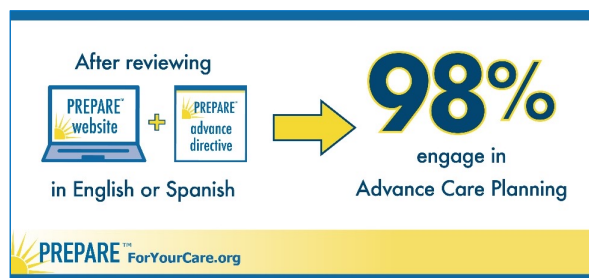
If you are not able to make your own decisions, your doctors will turn to family and friends or a judge to make decisions for you. This person may not know what you want.

Makes ACP Easier on Patients & Clinicians

Proven Outcomes in Randomized Trials



RCTs: 1400 English/Spanish-speaking Older Adults: Patient-facing → **Primes Patients, Decreases Disparities**



Directly observed visits:

- ~50% greater patient empowerment, clinician responsiveness
- ~50% increased real-time goal concordant care: 33% → 59% 🏆

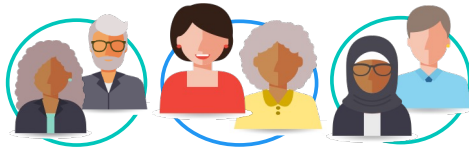


Sudore et al. JAMA IM 2017; Sudore et al. JAMA IM 2018; Freytag et al. JAGS 2020; Nouri et al. JAGS 2021; Rennels et al. JAGS 2023

Decreases Health Disparities

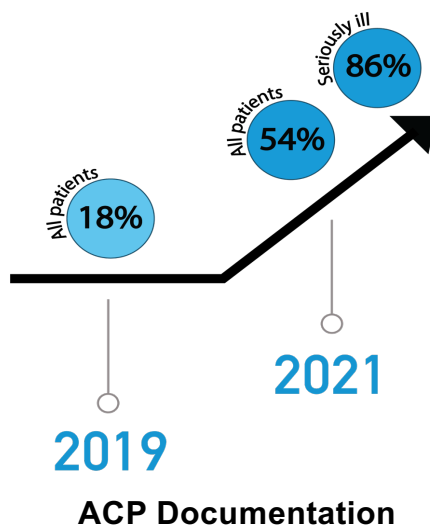
PREPARE, co-created with communities to address:

- Outdated models of ACP (i.e., check boxes)
- Limited health and digital literacy
- Cultural and language diversity
- Visual, hearing, cognitive impairment



Sudore et al. *JAMA Intern Med.* 2018; Scheerens, Sudore et al. *J Am Geriatr Soc.* 2021

Proven Success in Health Systems



~ 9000 UCSF Primary Care Patients



automated patient portal messages



Walling, Sudore, et al. *J Palliat Med.* 2019. Preliminary, blinded trial findings

PREPARE Tools for Clinicians



PREPARE Primes Patients

PREPARE™

A program to help you make medical decisions for yourself and others

- Step 1** Choose a medical decision maker.
- Step 2** Decide what matters most in life.
- Step 3** Choose flexibility for your decision maker.
- Step 4** Tell others about your medical wishes.
- Step 5** Ask doctors the right questions.

www.prepareforyourcare.org



California Advance Health Care Directive

This form lets you have a say about how you want to be cared for if you cannot speak for yourself.

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Part 1: Choose a medical decision maker, Page 3

A medical decision maker is a person who can make health care decisions for you if you are not able to make them yourself. They are also called a health care agent, proxy, or surrogate.

Part 2: Make your own health care choices, Page 6

This form lets you choose the kind of health care you want. This way, those who care for you will not have to guess what you want if you are not able to tell them yourself.

Part 3: Sign the form, Page 11

The form must be signed before it can be used.

You can fill out Part 1, Part 2, or both. Fill out **only** the parts you want. Always sign the form in Part 3. 2 witnesses need to sign on Page 12, or a notary on Page 13.

Your Name _____

PREPARE™

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1

Quick Start Guide for Patients

PREPARE™ for your care QUICK START GUIDE


Welcome to PREPARE! Learn helpful information in as little as 10 minutes.

PREPARE is a step-by-step program with video stories to help you:

- Have a voice in YOUR medical care
- Talk with your doctors
- Fill out an advance directive form to put your wishes in writing

Type in this address into your internet browser: prepareforyourcare.org

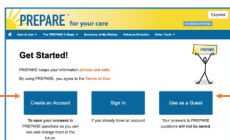
This will bring you to the PREPARE home page.



You can click on this 1-minute video to learn more about PREPARE.

You will then come to this login page.

To save your information, click on Create an Account. Or, use PREPARE as a guest.



Group Medical Visit Toolkit

PREPARE™ for your care

Toolkit for Group Movie Events

Part 1: What to Expect & A Planning Checklist	4
Here you'll find a brief overview to get you started, and a list of things you will need.	
Part 2: PREPARE Group Movie Event Guide & Questions	16
Anyone can run a group event. It is easy because the PREPARE videos have all the information. This guide also has example words you can say.	
The PREPARE Question Guide also follows along with the movie and allows people to write down their wishes for medical care.	
Part 3: Tools to Promote the Event	21
This Toolkit includes example flyers, emails, and newsletter language to help you promote your event.	
Part 4: Feedback Surveys	25
This is optional, but can help improve PREPARE and your events.	

For more information visit: www.prepareforyourcare.org

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Simple Scripts

PREPARE™ for your care

SIMPLE ADVANCE CARE PLANNING SCRIPTS FOR EVERYONE

Advance Care Planning Conversations in 3 Easy Steps

Any person, from any discipline, can start an advance care planning conversation. We made it easy with 3 simple steps, which can be done over time.

WHAT YOU CAN SAY

1 Ask About a Surrogate Decision Maker (e.g., proxy, agent, representative, etc.)

"I wanted to take a moment to talk to you about advance care planning. This involves choosing an emergency contact and the medical care that is important to you."

"First, I would like to ask if there is someone you trust to help make medical decisions for you if there ever came a time you could not speak for yourself?"

YES: "That's great. If not already, now is a good time to reach out and tell them that you chose them for this role and what is important to you. That way they can be the best advocate and speak up for you, if needed."

"I will make put this information in your medical record. It's also important to keep their name and phone number in your phone or in your purse or wallet."

"It would also be important to write their name down on a legal form called an advance directive. I can help you with that." (see PREPAREforYourCare.org)

NO: "It is OK if you cannot think of someone right now. If someone comes to mind in the future, please let your medical providers know so we can put the information in your medical record."

2 Ask About Advance Directives

See PREPAREforYourCare.org for easy-to-read advance directives for all US states in several languages.

"Have you ever completed an advance directive? This is a legal form that lets you write down the name of your medical decision maker and your wishes for medical care. Some people may also have a bright pink form called a POLST form."

YES: "That's great. Do you remember what you wrote down? Do you still feel the same way? Do you know where this form is? Do you need help to make copies?"

"Now it's most important to share the information in this form with your family and friends. It is also important to bring a copy of the form with you if you need to come to the clinic or hospital. That way your family, friends, and medical providers will know what is most important to you."

Increased ACP documentation 44% to 71%
Increased surrogate designation 75% to 93%



Lum, Sudore J Am Geriatr Soc. 2020; Block, Sudore, et. al. J Am Geriatr Soc. May, 2020.

NEW Caregiver Program

PREPARE™ for THEIR care

PREPARE for **THEIR** Care will support you as you help other people with their medical planning and medical decisions.

Click on the topic that would be most helpful for you.



How To Use This Program and About Medical Planning



How To Help Other People With Their Medical Planning

When people can still speak for themselves



How To Make Medical Decisions for Other People

When people cannot, or do not want to, speak for themselves

PREPARE™ for THEIR care Click Here To Get the Program Guide



What Our Partners Are Saying

"PREPARE is the gold stand of ACP."

~ Healthcare Leader



"It breaks it down into doable actions, instead of walking into a fog of what ACP is all about"

~ Patient



"Patients come to their visits prepared, making ACP easier and more efficient."

~ Clinician

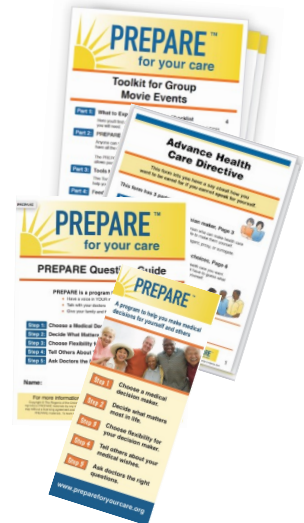
"After seeing examples on the website, deciding on my own wishes is a lot easier for me now."

~ Patient



Summary of the PREPARE Innovation

- ✓ Evidence-based, NCOA endorsed
- ✓ Proven outcomes in health systems
- ✓ Primes patients → easier for clinicians
- ✓ Accessible & decreases disparities
- ✓ Customizable
- ✓ Ongoing legal & content updates



Licensing Opportunities



The UC Regents offers several [licensing opportunities](#):

- Branding of materials and custom landing pages
- Data reporting
- Research
- Third party integration → **Powered by PREPARE**