



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



PREPARE™ for your care

How to Use ▾ The PREPARE 5 Steps ▾ Summary of My Wishes Advance Directive Tools for Providers ▾

Español No Talking on This Page Sign In

PREPARE has 2 programs with video stories to help you:

1. Have a voice in **YOUR OWN** medical care
2. Help **OTHER PEOPLE** with their medical planning and decisions

PREPARE™ for YOUR care

Have a Voice in Your Medical Care

This step-by-step program makes it easy with video examples

Click here to do **YOUR OWN** medical planning

PREPARE™ for THEIR care

Help Other People

Click here to learn how to help **OTHER PEOPLE** with their medical planning and decisions

New!

PREPARE Tools for Providers & Organizations

Free PREPARE Easy-to-Read Advance Directives Below ▾

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 for: This person is: They are able:

Part 2 Make your

This form lets you: This will let you: You will: You will:

Part 3 Sign the form

The form must be:

You can fill out Part 1, Part 2, and Part 3. Fill out only the parts you use. 2 witnesses need to sign Part 3.

Paunang Direktiba na Pangkalusugan

Ang form na ito ay nagsasabing para sa inyo na naging

Instrucción anticipada de atención de salud de California

Este formulario le permite indicar cómo deseas ser tratado si no puedes hablar por ti mismo.

加州醫療照護事前指示書

这份表格让您指定如果自己无法表达意见时的治疗意愿。



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

Co-Developed with Patients, Caregivers, and Communities



Literacy, Language, Culture



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

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



 PREPARE™ ForYourCare.org

Ann Intern Med. 2010 Aug

PREPARE Fills a Missing Puzzle Piece

PREPAREs people with skills to:

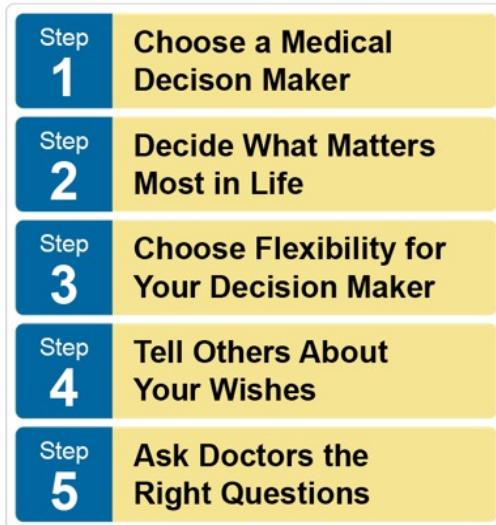
- Identify what is most important and how they want to live
- Talk with family, friends, medical providers
- Make informed decisions
- Get the care that is right for them



 PREPARE™ ForYourCare.org

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

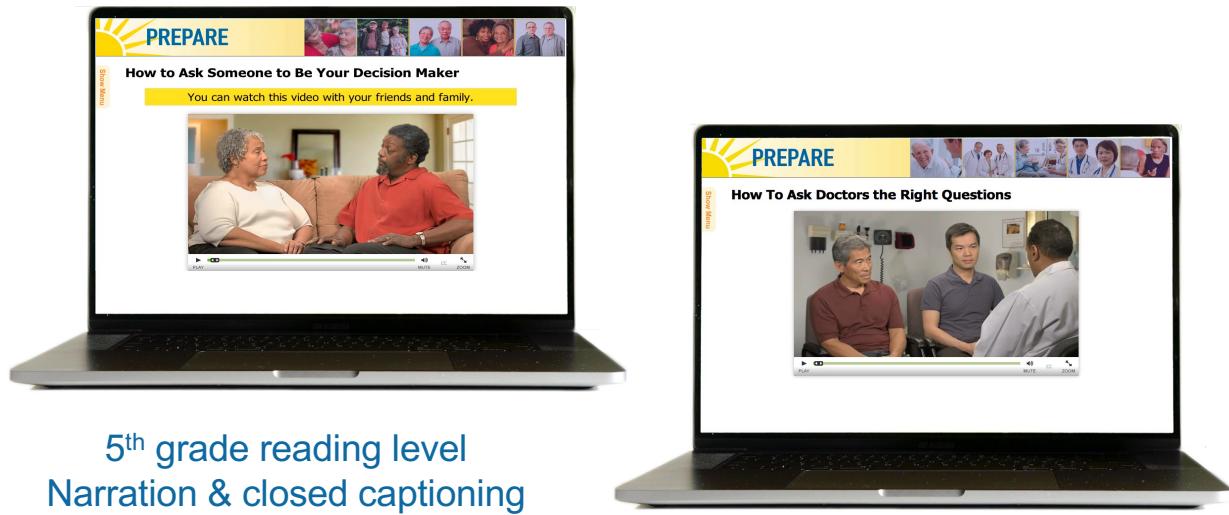
Walks People Through Step by Step



 **PREPARE**™ ForYourCare.org

PrepareForYourCare.org

Shows “How to” Videos



 **PREPARE**™ ForYourCare.org

Sudore, et al. JAGS 2021. <https://pubmed.ncbi.nlm.nih.gov/34081773/>

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 need. Always sign the form in Part 3. 2 witnesses need to sign on Page 14, or a notary on Page 15.

Your Name _____

PREPARE California Advance Health Care Directive

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 Escoger una persona decidiante, página 3**
Una persona decidiante es una persona que puede tomar decisiones médicas por usted si usted no puede hacerlo por sí mismo.
- Parte 2 Tomar sus propias decisiones de atención de salud, página 7**
Este formulario le permite escoger el tipo de atención de salud que desea. De esta manera, las personas encargadas de su cuidado no tendrán que adivinar qué 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. Para leer la Parte 1, Parte 2, o ambas.

Llene solamente las partes que desea. Siempre firme el formulario en la Parte 3.

Es necesario que 2 testigos firmen en la página 14. (Un testigo es necesario en la página 15.)

Su Nombre _____

PREPARE Wisconsin Advance Health Care Directive

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顧。

指示書分為三部分：

- 第一部分 選擇一位醫療代理人，第3頁**
在選擇您的代理人之後，您的醫療代理人將幫您做決定。
- 第二部分 選擇您的醫療選擇，第7頁**
指示書將讓您選擇自己想要的醫療照顧，這樣，若您無法表達意見時，他人將能知道您的選擇。
- 第三部分 在指示書上簽名，第13頁**
請在簽名欄位簽名。請在第14頁簽名。

您可以填寫第一部分或第二部分，或兩部分都填寫。

請填寫您的姓名，並在第13頁簽名。

請填寫您的姓名，並在第14頁簽名。

兩位見證人必須在第14頁簽名。

PREPARE New York Advance Health Care Directive

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 _____

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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.

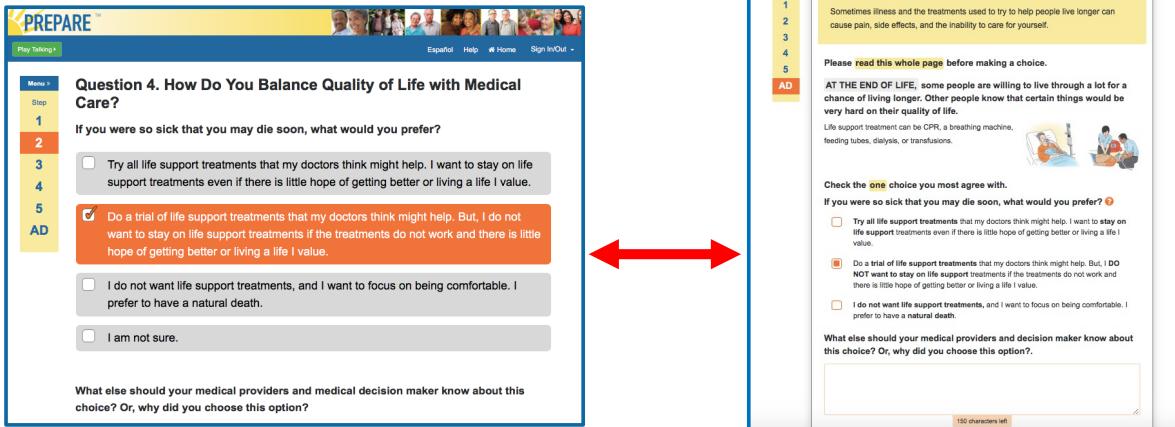
If you want, you can write why you feel this way.

*** 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?

PREPARE

No Talking on This Page California Advance Health Care Directive

Part 2: Make your own health care choices

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.

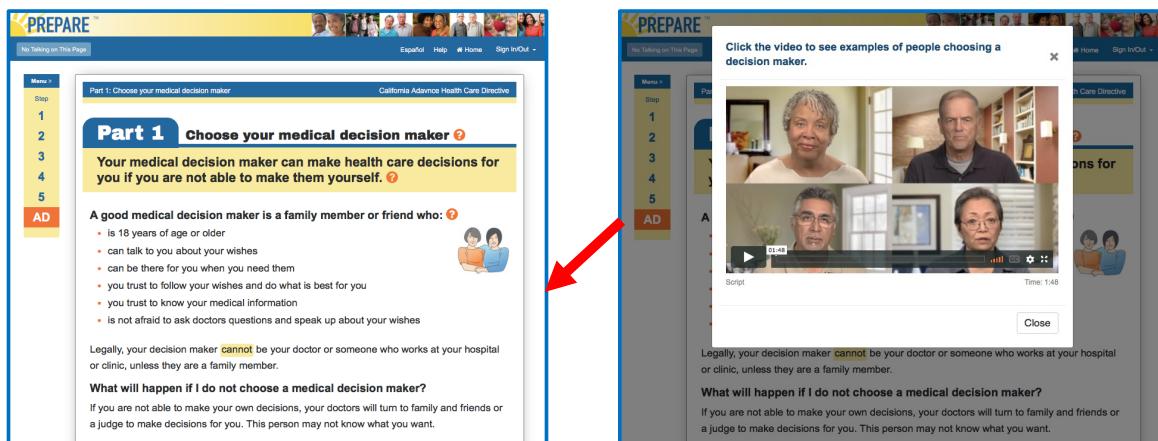
I do not want life support treatments, and I want to focus on being comfortable. I prefer to have a natural death.

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

 PREPARE™ ForYourCare.org

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 follow your wishes and do what is best for you
- 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.

Script Time: 1:48

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.

 PREPARE™ ForYourCare.org

Makes ACP Easier on Patients & Clinicians

Proven Outcomes in Randomized Trials



 **PREPARE™** ForYourCare.org

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% 

 **PREPARE™** ForYourCare.org

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:

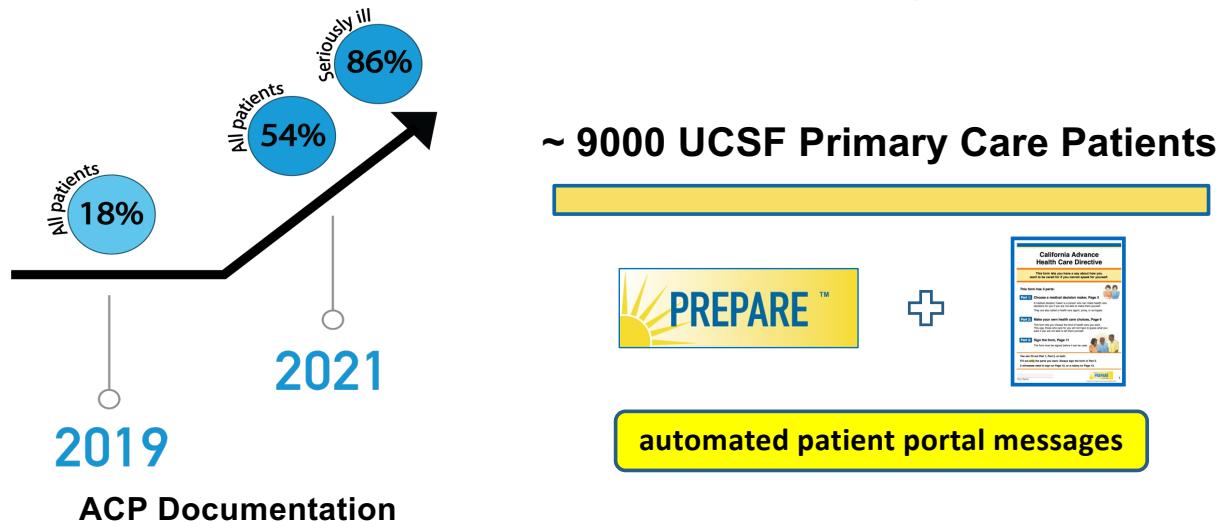
- Outdated models of ACP (i.e., check boxes)
- Limited health and digital literacy
- Cultural and language diversity
- Visual, hearing, cognitive impairment



 PREPARE™ ForYourCare.org

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

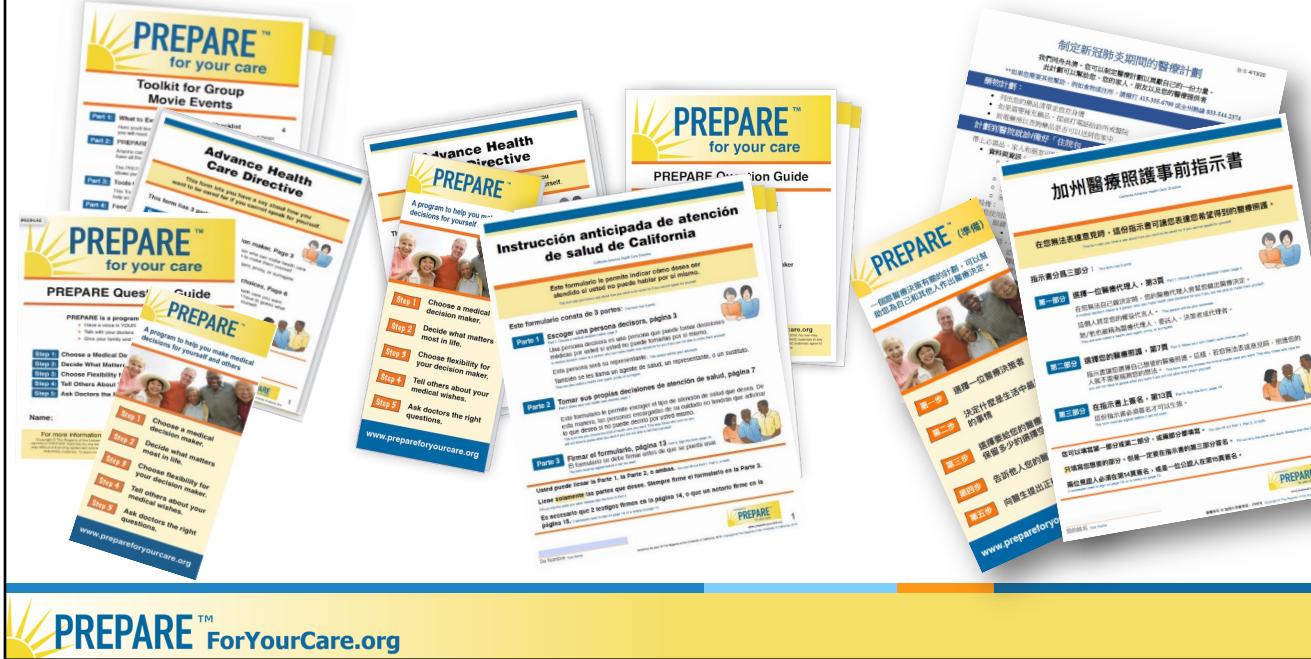
Proven Success in Health Systems



 PREPARE™ ForYourCare.org

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

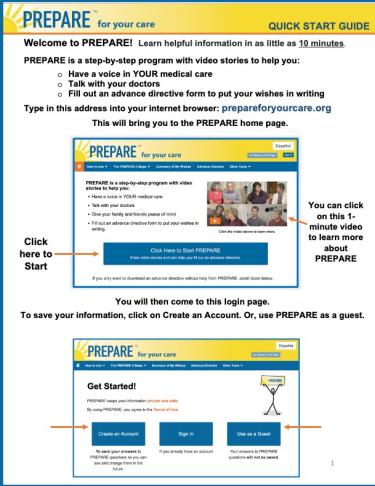
PREPARE Tools for Clinicians



PREPARE Primes Patients

PREPARE Primes Patients

Quick Start Guide for Patients



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

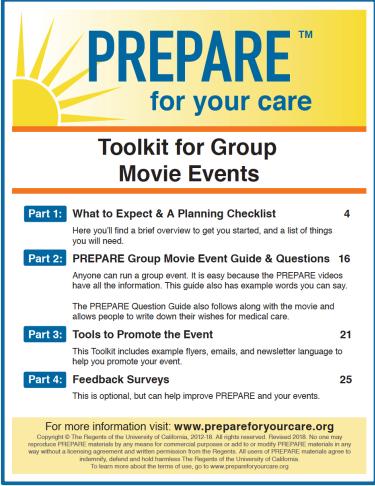
This will bring you to the PREPARE home page.

Click here to Start

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



Part 1: What to Expect & A Planning Checklist 4

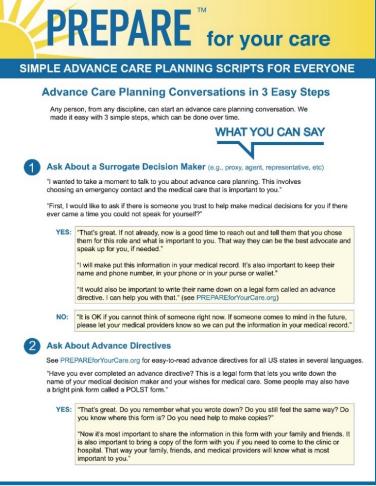
Part 2: PREPARE Group Movie Event Guide & Questions 16

Part 3: Tools to Promote the Event 21

Part 4: Feedback Surveys 25

For more information visit: www.prepareforyourcare.org

Simple Scripts



WHAT YOU CAN SAY

1 Ask About a Surrogate Decision Maker

2 Ask About Advance Directives

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

[PREPARE ForYourCare.org](http://www.prepareforyourcare.org)
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

[Click Here To Get the Program Guide](#)

[PREPARE for THEIR care](http://www.preparefortheircare.org)

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



 **PREPARE™** ForYourCare.org

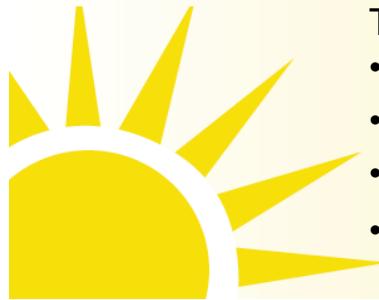
Summary of the PREPARE Innovation

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



 **PREPARE™** ForYourCare.org

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**