Advance Care Planning During COVID-19

A Town Hall
April 16, 2020

National Center for Medical Legal Partnership
AT THE GEORGE WASHINGTON UNIVERSITY

In case of technical difficulties
– yours or ours – relax.

We are recording this town hall,
and will post it on our website.

National Center for Medical Legal Partnership
AT THE GEORGE WASHINGTON UNIVERSITY

8 THINGS EVERY MEDICAL-LEGAL PARTNERSHIP CAN DO RIGHT NOW TO RESPOND TO COVID-19

APRIL 2020

Challenges Facing Medical-Legal Partnerships During the Pandemic

On March 30, 2020, the National Center for Medical-Legal Partnership convened a COVID-19 Town Hall with 250 medical-legal partnership practitioners who identified several challenges they are facing in responding to the pandemic. Many of these challenges are operational in nature, including diminishing referrals due to providers' focus on immediate medical needs, uncertainty about what issues to prioritize, and concerns about how to stay connected now that legal team members can no longer work on site. The strategies in this tip sheet respond specifically to these operational challenges.

Participants also reported difficulties around working on cases remotely, particularly where patient-clients lack access to technology. We recommend that MLP attorneys check out the resources available from the Legal Services National Technology Assistance Project.

Additionally, participants expressed concerns around specific needs the pandemic has created for different populations, and challenges related to rapidly evolving local, state, and federal policies around evictions, public benefits, special education access, unemployment, and estate planning. We curated a digital digest of resources that can help MLPs respond to some of these issues. This list will be updated regularly throughout the crisis.

This tip sheet was compiled with information from our March 30th COVID-19 Town Hall, and includes insights from Emily Benfer (Columbia Law School), Mallory Curran (Mallory Curran Consulting), Donna Levin and Kerri McGowan Lowrey (Network for Public Health Law), Randye Retkin (LegalHealth, NYLAG), Keegan Warren-Clem (Texas Legal Services Center), and staff from the National Center for Medical-Legal Partnership.

01

Let health care providers drive your MLP's immediate response and service priorities.

How frequently legal teams hear from their health care partners right now will vary significantly based on the depth of the partnership when the crisis began. Regardless, as health care providers reach out to legal team members with concerns and questions about what they are seeing, MLPs should pivot consults and services to focus on answering their questions and providing support to address their concerns.

For example, the team at LegalHealth, a division of the New York Legal Assistance Group (NYLAG) in New York City, has heard from a lot of health care providers about individuals who are experiencing homelessness coming to the ER when they should be going to shelters. In response, LegalHealth has been doing advocacy with NYLAG's Shelter Advocacy Project to push for beds in shelters and in other isolation facilities where medically needed.

COVID-19 Resources for MLPs

- COVID-19 operational tip sheet for MLPs
- Recordings of previous town halls
- COVID-19 digest of resources re: telework and substantive legal issue areas

medical-legalpartnership.org/mlp-resources

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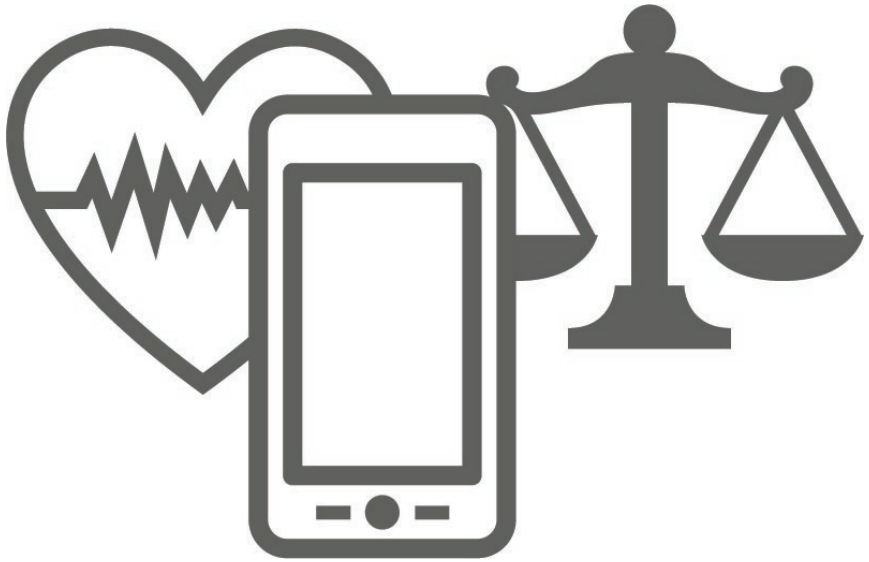


Delivering Telelegal Services During COVID-19

Perspectives from Rural & Urban MLPs

Thursday, April 30 at 1 p.m. Eastern

National Center for Medical Legal Partnership
AT THE GEORGE WASHINGTON UNIVERSITY

Today's Participants

Organizations	Number
Legal Services	44
Health Centers	23
Hospitals	5
Law Schools	9
Other	15

Biggest ACP Questions

- Challenges with electronic signatures, remote notarizations, reaching clients with limited access to tech
- Desire for templates that can be used
- Role of advocates vs. SWs vs. attorneys in ACP
- Population concerns (cultural sensitivity, legality of ACP for folks with dementia, outreach to folks unstably housed)
- ACP for HC staff
- Pursuing custody/guardianship cases when courts have limited services

Topics for Today's Advance Care Planning Town Hall

- Clinical Context for ACP Right Now: Why is it important, where should it occur and what are the goals? (Dr. Rebecca Sudore)
- Legal Barriers to Remote Execution & Potential Solutions: State laws, status of pandemic orders, principles of informed consent, and ethical issues for MLP attorneys. (Sarah Hooper)
- Q & A featuring ACP presenters and Randye Retkin, LegalHealth, NYC

Faculty

Sarah Hooper
Executive Director
UCSF/UC Hastings Consortium
of Law, Science & Health Policy

Ellen Lawton
Director
National Center for
Medical-Legal Partnership

Randye Retkin
Director
LegalHealth, NYLAG

Rebecca Sudore
Professor of Medicine
University of California,
San Francisco

Advance Care Planning and the COVID-19 Crisis

Sarah Hooper, JD

Executive Director of the UCSF/UC Hastings Consortium on Law, Science & Health Policy
Policy Director of the Medical-Legal Partnership for Seniors
Adjunct Professor of Law at UC Hastings College of Law

Rebecca Sudore, MD

Professor of Medicine, Division of Geriatrics, UCSF
Director of the Innovation and Implementation Center in Aging & Palliative Care
Direct of or the Vulnerable Populations Aging Research Core of the NIA-funded Pepper Center

Outline

- ACP: The Clinical Context
  - The goal of ACP
  - ACP during COVID-19 crisis
  - Tools to help clients/patients
- ACP: Legal Barriers & Strategies
  - Common barriers in state laws
  - Status of pandemic orders
  - Strategies to help clients/patients

What is Advance Care Planning?

- **Definition:** ACP is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding current or future medical care.

- **Goal:** The goal of ACP is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness."

Sudore et al., Delphi Panel Consensus Definition. JPSM 2017

Why is ACP Important?

- Improved patient satisfaction with care
- Improved quality of life
- Less unwanted medical care aligned with wishes
- Less stress for the surrogate decision maker

Advance Care Planning Realities

- Advance care planning ~ 33% for the past 10 years
- Lower among minority populations, ~ 15-20%
- ~ 10-20% discussed wishes with medical provider
- Among ICU decedents, ~ 20% no ACP before death

COVID-19 Clinical Realities

- Serious illness affecting both young and old (median 56 yrs)
- Clinical picture can worsen very quickly
- Families, surrogates not able to visit ER/hospital
- Older patients not bringing hearing aids, glasses, or cell phones or chargers
- Frontline providers are DESPERATE to know any information about the person and family contacts

Online Advance Care Planning Program in English & Spanish

www.prepareforyourcare.org

Health Literacy Considerations

- Average reading level in the US = 8th grade
  - Medicaid and elderly = 5th grade

- Most advance directive documents written beyond the 12th grade (post-graduate) level.

Language Considerations

- 61 million people in U.S. (~20%) speak language other than English at home
  - 40 million Spanish, 3.4 million Chinese
- Lack of linguistically-appropriate materials

2012, US Census Bureau; Pérez-Stable, EJ & Karliner, LS,. J Gen Intern Med 2012; Sudore, et al., Patient Educ Couns 2009 June; Schenker Y, et al., Ann Intern Med. 2008 Aug

Cultural Considerations

- Non-Western views on autonomy & decision making
  - ~20% do not want to make own medical decisions

- Mistrust and experiential racism
  - Minorities given less information by clinicians and less time for discussion → mistrust forms

Crawley L, et al.,. JAMA. 2000; Kwak J, et al., Gerontologist. 2005; Singh JA,et al.. Am J Manag Care. 2010; Smith AK, et al. JAMA. 2009 ; Gordon HS, et al. Cancer. 2006; Rhodes R, Teno JM. J Clin Oncol. 2009

Easy-to-Read Advance Directive (AD)

RCT:

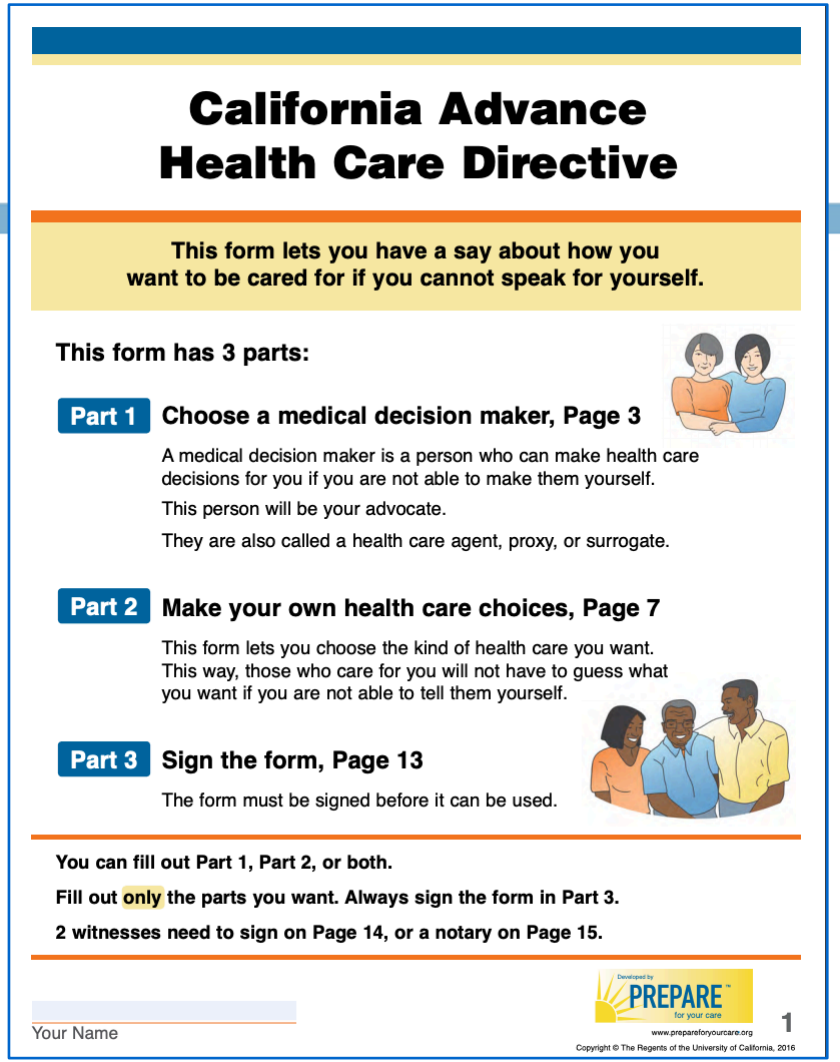
- Doubled completion rates
- Overwhelmingly preferred

regardless of literacy/ language

10 languages

www.PrepareForYourCare.org

Sudore RL et. al., Patient Educ Couns 2007



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.

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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.

Your Name

Developed by PREPARE for your care

www.prepareforyourcare.org

1

Missing Puzzle Piece

- **PREPARE** people with skills to:
  - identify what is most important and how they want to live
  - talk with family and friends
  - talk with medical providers
  - make informed decisions
  - get the care that is right for them

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

www.PrepareForYourCare.org
Interactive, multi-media website

- Welcome
- View the PREPARE Pamphlet
- 1 Choose a Medical Decision Maker
- 2 Decide What Matters Most In Life
- 3 Choose Flexibility for Your Decision Maker
- 4 Tell Others About Your Wishes
- 5 Ask Doctors the Right Questions
- Your Action Plan

Hide Menu

Welcome to PREPARE!

PREPARE is a program that can help you:

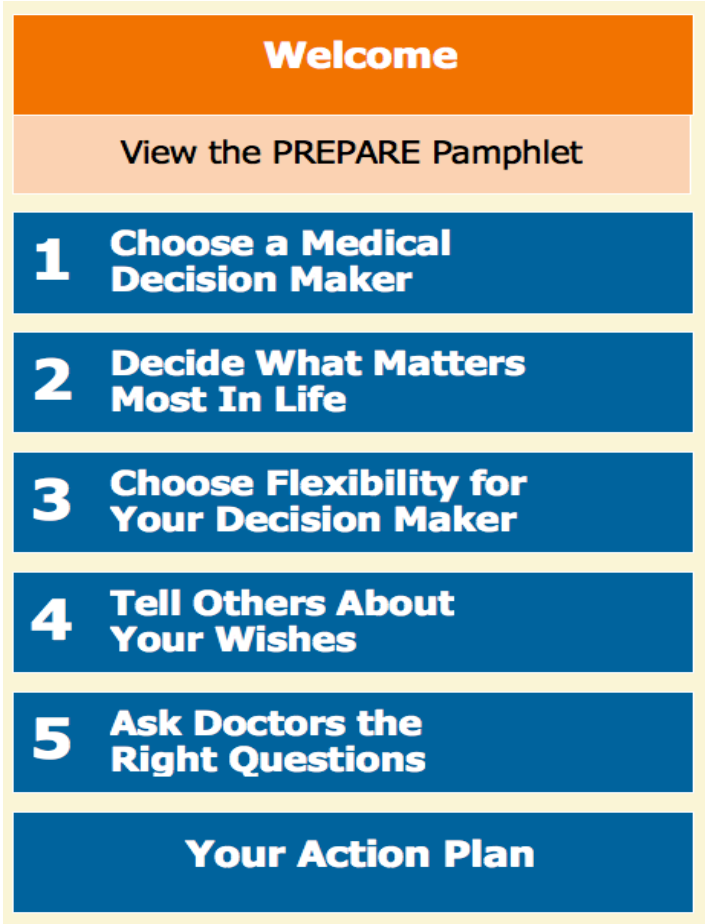
- make medical decisions for yourself and others
- talk with your doctors
- get the medical care that is right for you

You can view this website with your friends and family.

Click the NEXT button to move on.

NEXT

5-Steps of PREPARE



PrepareForYourCare.org

Creating PREPARE

- Co-created with diverse populations
- Easy to understand: 5th-grade reading level
  - Voice-overs & closed captioning (Eng/Span)
- Range of video stories:
  - Surrogate availability
  - Decision making preferences
- Videos that **model** ACP behavior

*** Sudore RL et. al.,** J Pain & Symptom Manage, 2012

How to Ask a Decision Maker

Show Menu

How to Ask Someone to Be Your Decision Maker

You can watch this video with your friends and family.

How to Talk with Family & Friends

PREPARE

Show Menu

How To Tell Others About Your Wishes

How to Ask Clinicians Questions

Show Menu

How To Ask Doctors the Right Questions

Name: Rebecca S

Summary of My Wishes

Step 1: Choose a Medical Decision Maker

- You have chosen and asked John Doe (your spouse/partner) to be your decision maker
- You want John Doe to make medical decisions for you only if you cannot make your own decisions

Step 2: Decide What Matters Most in Life

- What is most important to you are: family and friends, religion, living on your own and caring for yourself, not being a burden on your family
- You feel that there may be some health situations that would make your life not worth living, such as never being able to wake up from a coma
- You want to try treatments for a period of time, but stop if you are suffering

Step 3: Choose Flexibility for Your Decision Maker

- You chose TOTAL flexibility in medical decision making for your decision maker

Step 4: Tell Others About Your Wishes

- You told your decision maker about your wishes. But you have not yet told your doctor and family and friends

Step 5: Ask Doctors the Right Questions

- When making decisions with your doctor, you want to share decision making with your doctor
- You **WOULD** want your doctor to tell you how sick you are or how long you have to live

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Your Name

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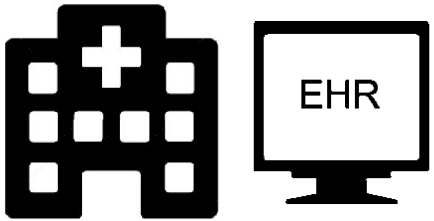
JAMA Internal Medicine

EVIDENCE:
2 RCTs : 1400 Eng & Span patients

ACP

Clinician or Facilitator

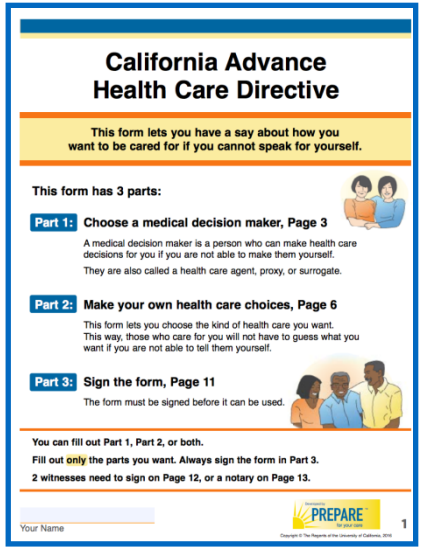


Healthcare System

The Focus

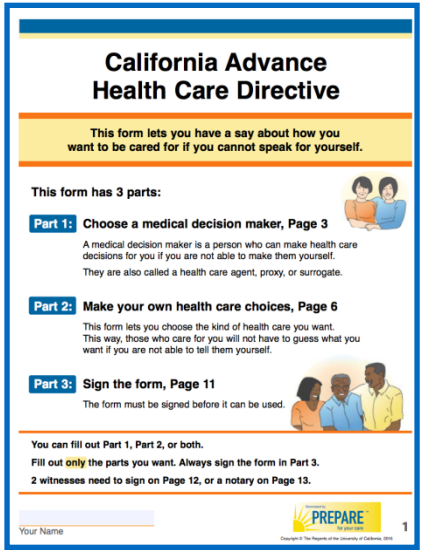
Patients

Intervention: Patient-facing ONLY



vs.

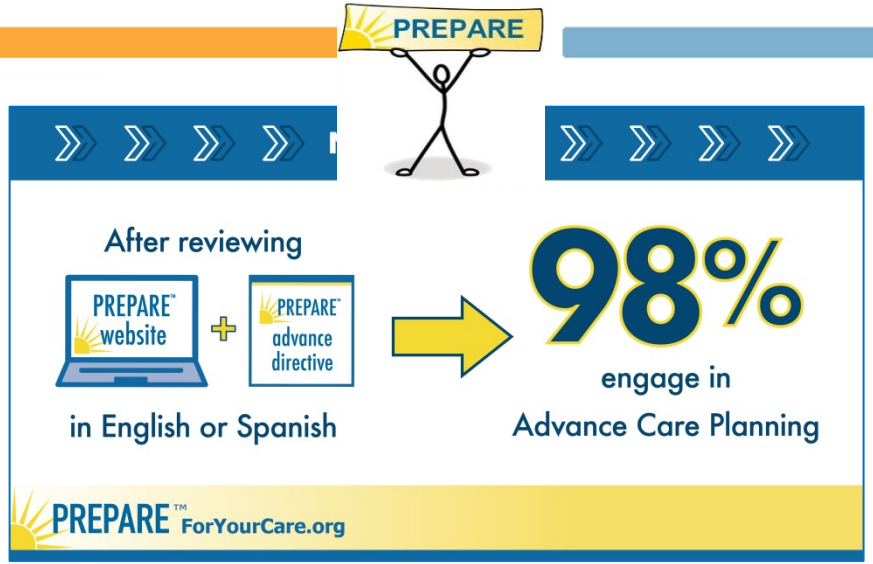
+

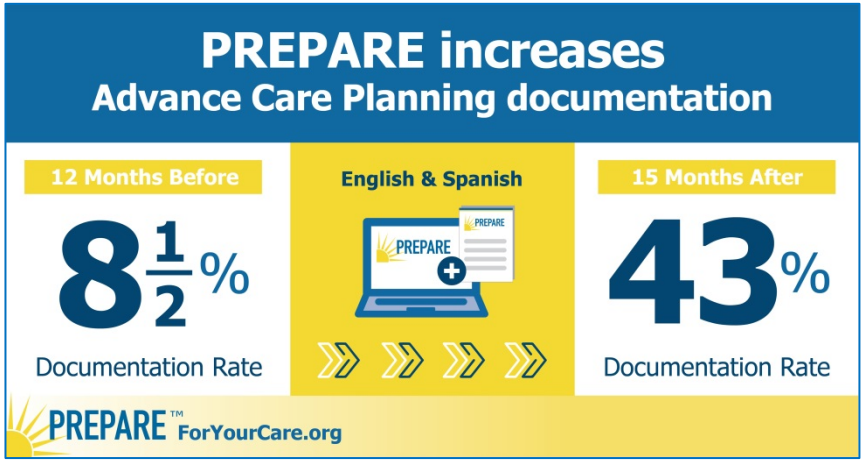


www.PrepareForYourCare.org

*There were no clinician- or system-level interventions or education. Only patient education was provided.
H_o – Patients would be empowered to complete the forms and talk about their wishes with clinicians.

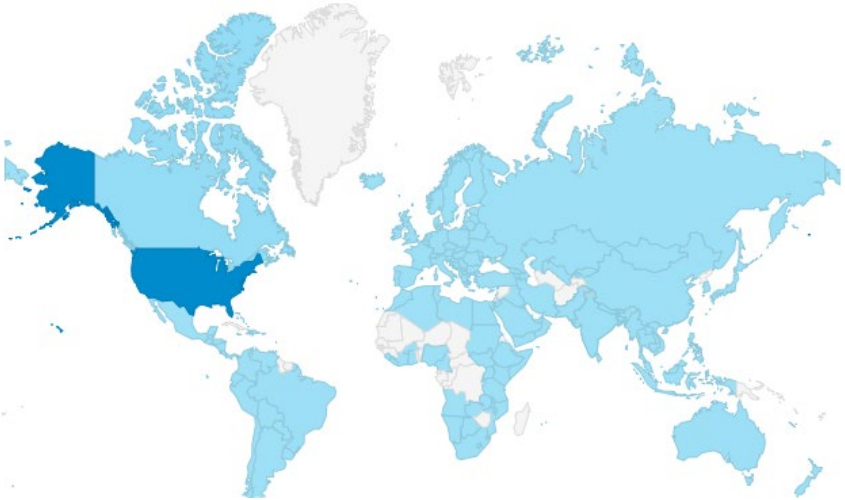
Efficacy of the PREPARE Program





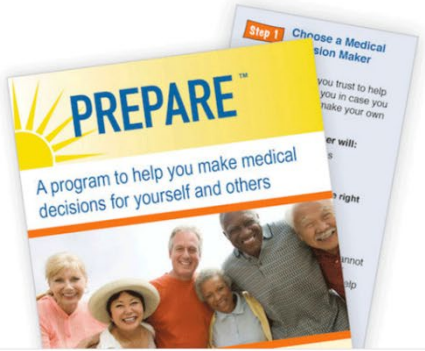
The Reach of PREPARE

- Over 200,000 unique users, over 115 countries
- 5x increase use during COVID-19 crisis

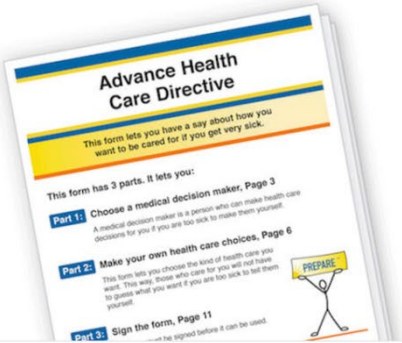


PREPARE Tools

Get the PREPARE Pamphlet



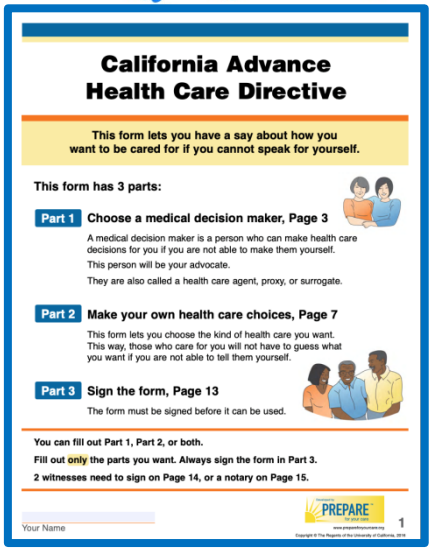
Get the PREPARE Easy-to-Read Advance Directive



PREPARE™ for your care

PREPARE Question Guide

Easy-to-read ADs for all US States in English & Spanish



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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.

Your Name

PREPARE

1

Instrucción anticipada de atención de salud de California

California Advance Health Care Directive

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

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

Este formulario consta de 3 partes: This form has 3 parts:

Parte 1 **Escoger una persona decisora, Página 3**

Part 1: Choose a medical decision maker, Page 3

Una persona decisora es una persona que puede tomar decisiones médicas por usted si usted no puede tomarlas por sí mismo.

A medical decision maker is a person who can make health care decisions for you if you are not able to make them yourself.

Esta persona será su representante. This person will be your advocate.

También se les llama un agente de salud, un representante, o un sustituto.

They are also called a health care agent, proxy, or surrogate.

Parte 2 **Tomar sus propias decisiones de atención de salud, Página 7**

Part 2: Make your own health care choices, Page 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 lo que desea si no puede decirlo por usted mismo.

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.

Parte 3 **Firmar el formulario, Página 13** Part 3: Sign the form, Page 13

El formulario se debe firmar antes de que se pueda usar.

The form must be signed before it can be used.

Usted puede llenar la Parte 1, la Parte 2, o ambas. You can fill out Part 1, Part 2, or both.

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

Fill out only the parts you want. Always sign the form in Part 3.

Es necesario que 2 testigos firmen en la página 14, o que un notario firme en la página 15. 2 witnesses need to sign on page 14, or a notary on page 15.

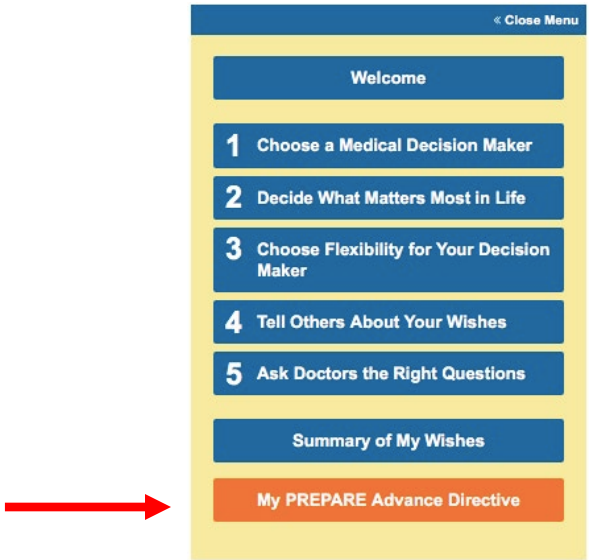
Su Nombre Your Name

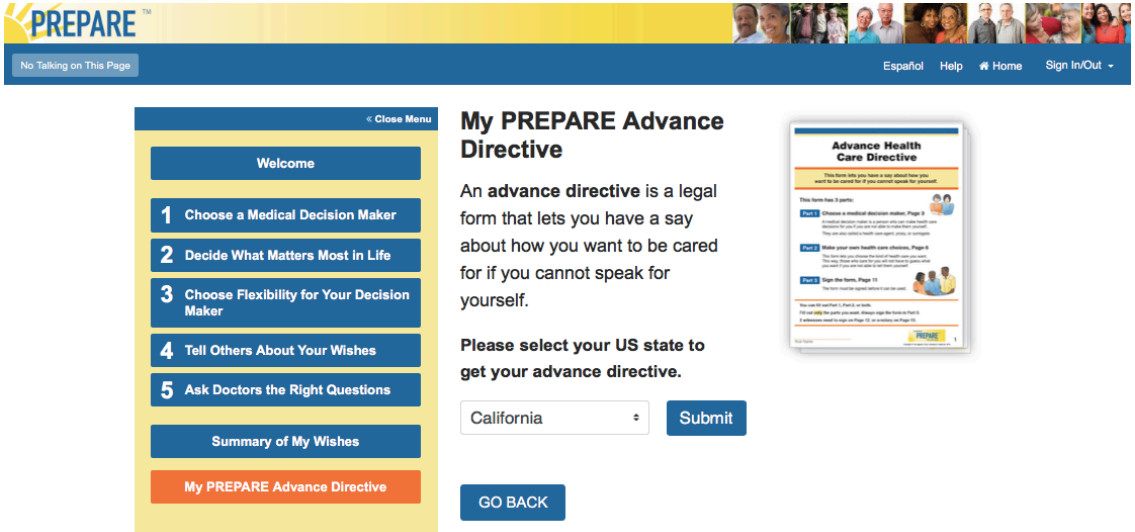
PREPARE

1

Guided AD Step for CA (other states coming)

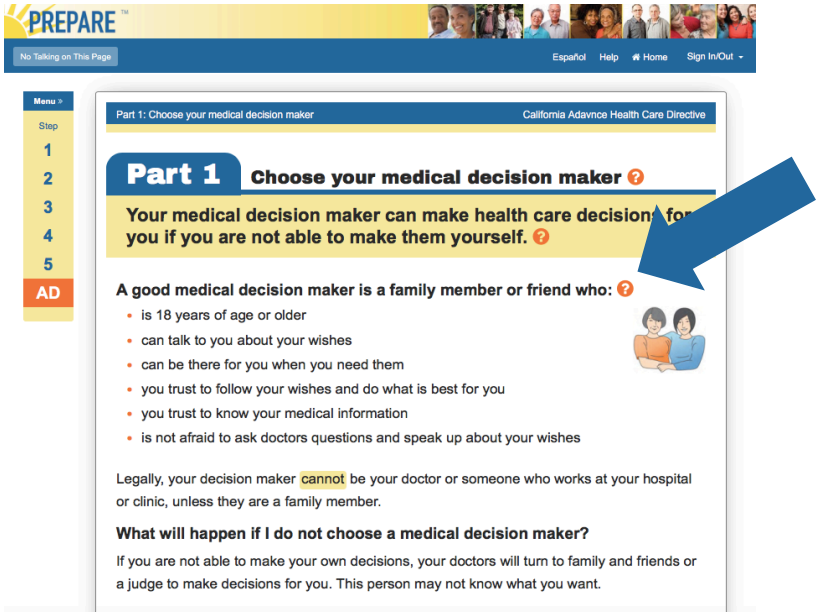
- Integrates and guides users to complete the AD

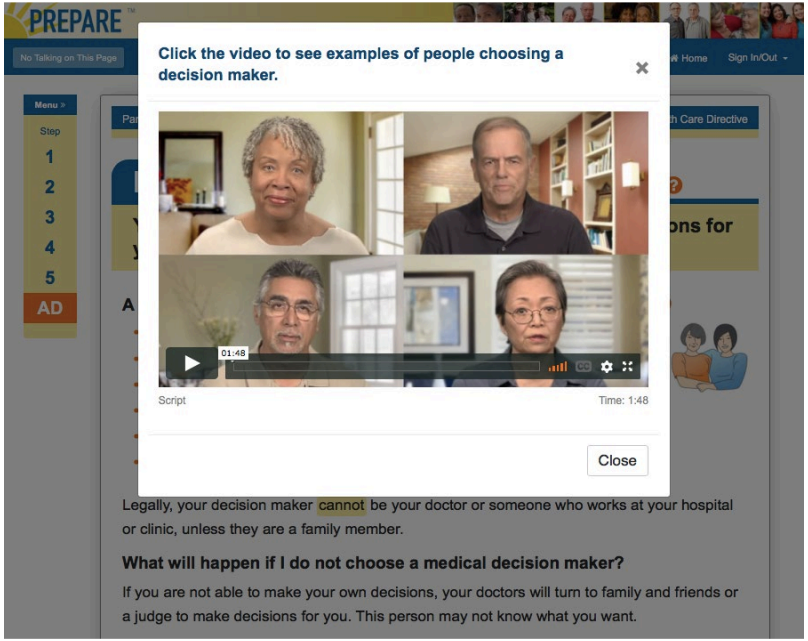




Guided AD Step for CA (Info & videos)

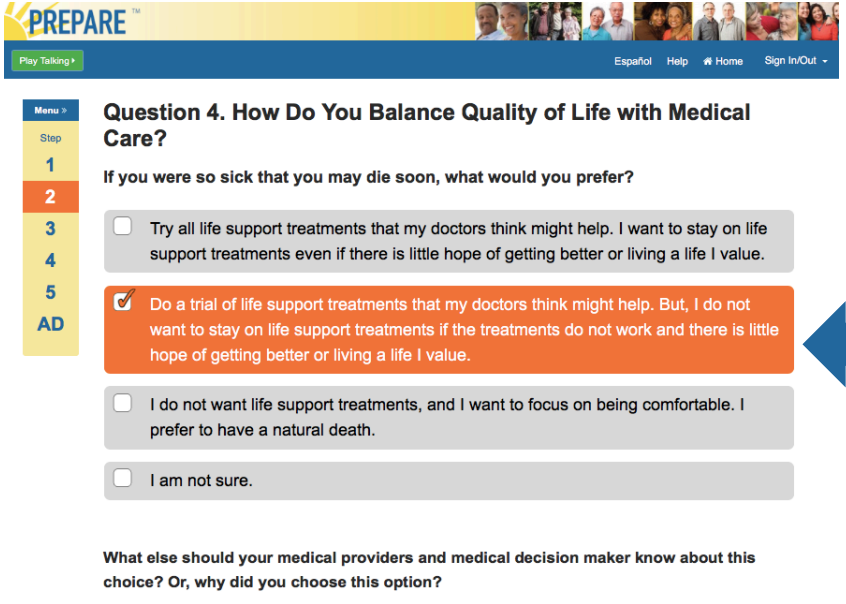
- Additional information and videos available if needed

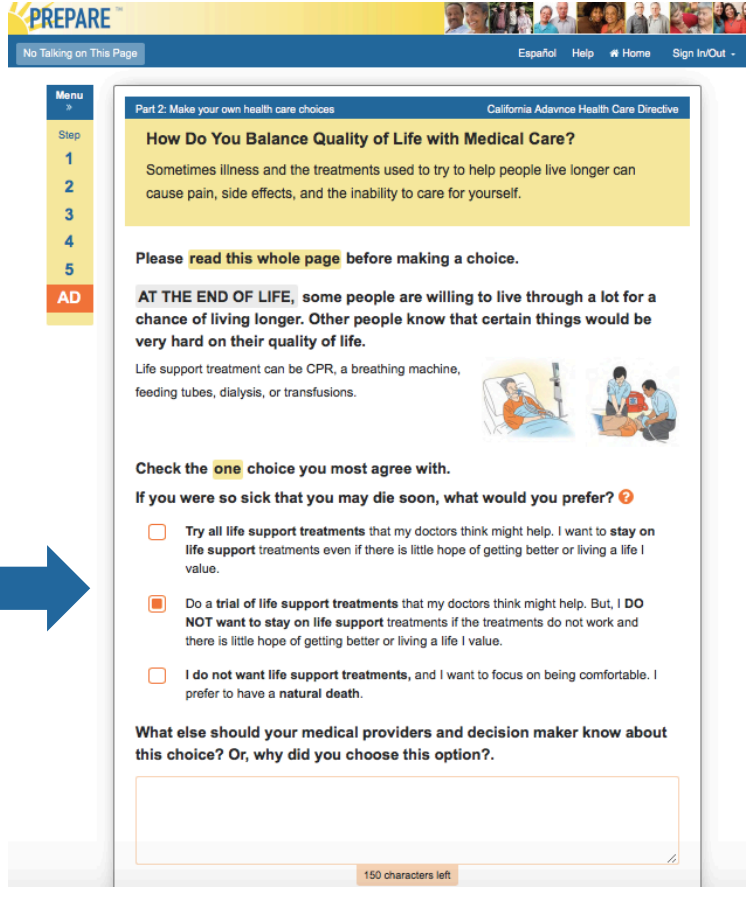




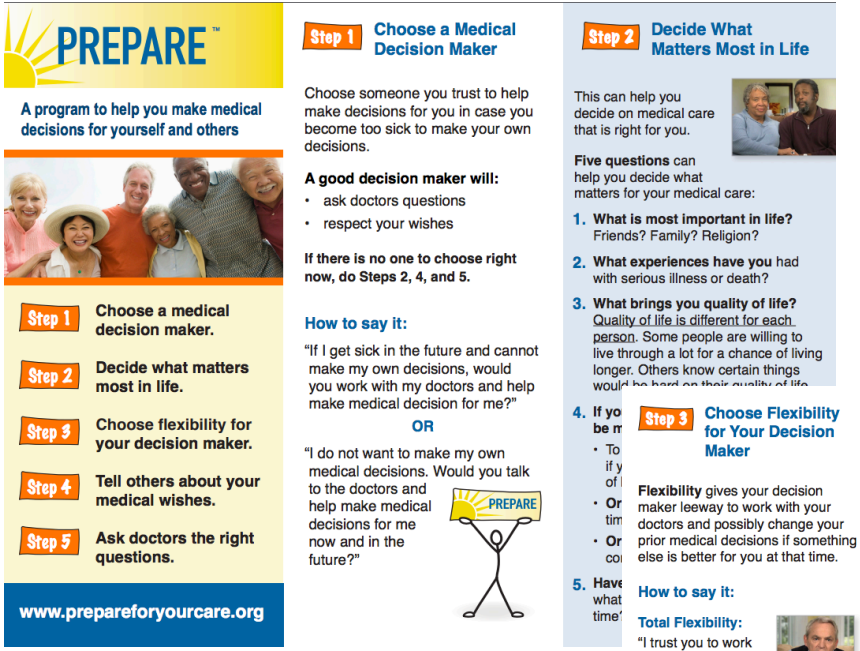
Guided AD Step for CA (pre-populates AD)

- Tailored answer automation



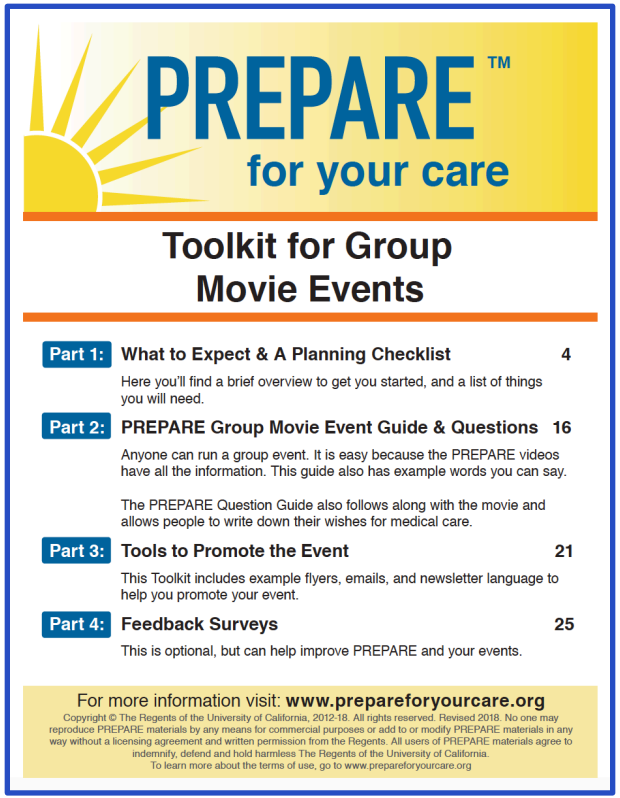


PREPARE Pamphlet



Trifold
English, Spanish,
Chinese

PREPARE Group Movie Events



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**

Zapata, Wistar, Lum, Horton, Sudore, Journal of Palliative Medicine, 2018

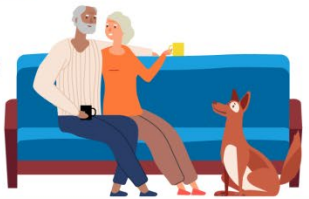
COVID-19 & YOU

Be Prepared: Take Control

1 Have a hospital 'Go bag'

2 Choose a medical decision maker

3 Share wishes + encourage loved ones to prepare



To learn more and get tools that can help go to: **PREPAREforYourCare.org** and **theconversationproject.org/covid19**

PREPARE™ For Your Care.org | the conversation project

#PrepareforCare #AdvanceCarePlanning
@prepareforcare @convoproject

Pack a Hospital 'Go bag' today!

https://www.youtube.com/watch?v=x1rZdXoB_t8

Making a Medical Plan During COVID-19

Plan for Medications

Make a list of your medications and keep it on hand

Plan for a Hospital 'Go Bag'

Bring what you may need from home

- Phone numbers
- List of medications
- Hearing aids, glasses, dentures
- Phone and chargers
- Advance directives

Plan for Your Medical Wishes

1. **Choose a medical decision maker**
2. **Share Your Wishes:** **This is MOST important**
3. **Consider an advance directive**

Plan for Your Pets

Plan for Your Money and Bills

Outline

- ACP: The Clinical Context
  - The goal of ACP
  - ACP during COVID-19 crisis
  - Tools to help clients/patients
- **ACP: Legal Barriers & Strategies**
  - Common barriers in state laws
  - Status of pandemic orders
  - Strategies to help clients/patients

Common Barriers in State Laws

Barrier	States
Requires Live Witnessing	AL, AK, AZ, CO, CT, DC, DE, FL, IL*, IA, IN, KS, KY, MA, MI, MN, MO*, MT, NE*, NV, NH, NJ, NY, NC, OH, RI*, SC*, TX, VT, VA, WA*, WV, WI*
Requires Notarization	CO, IN*, MO, NC
Add'l Reqs (SNFs, DPOAs)	CA, CT, DE, MI, ND, SC, TX, VT
No Digital Signature Legislation	All but CA, IL, MD, TX ID and ME affirmatively bar digital signatures on ADs
	* = req'd just for living will or DPOA portion

Pandemic Orders

- Executive authority to waive or modify regulations & guidance while emergency orders in effect (scope varies, unclear)

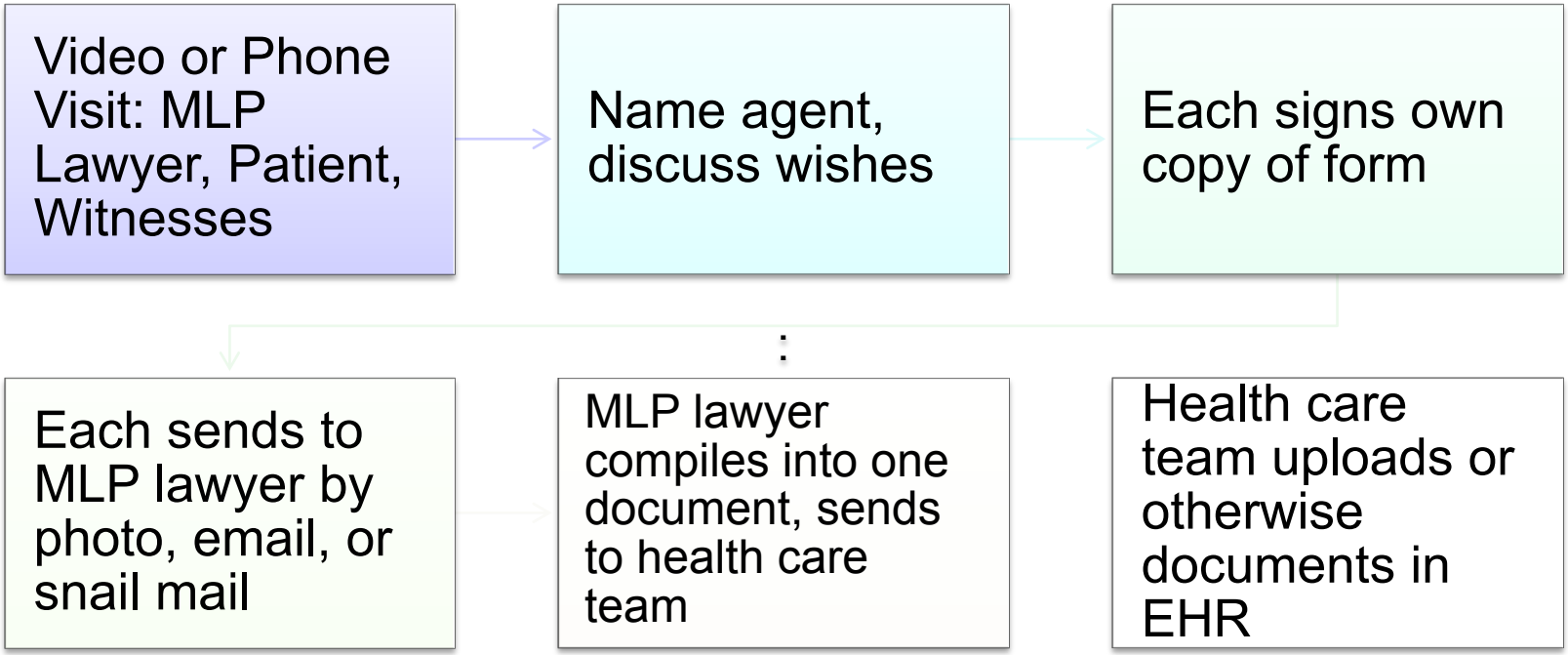
- E-notarization on wills/trusts: AL, AK, AZ, AR, CA, CO, CE, GA, HI, ID, IL, IN, IA, KS, KY, ME, MD, MI, MS, MD, NE, NH, NM, NY, RI, TN, VT, TX, WI, WY (as of 4/15/20, source: ACTEC.org)

- Cautions:
  - Limitations, exclusions!
  - Applicability to ADs unclear
  - Cost/technology still an issue for some MLP patient/clients

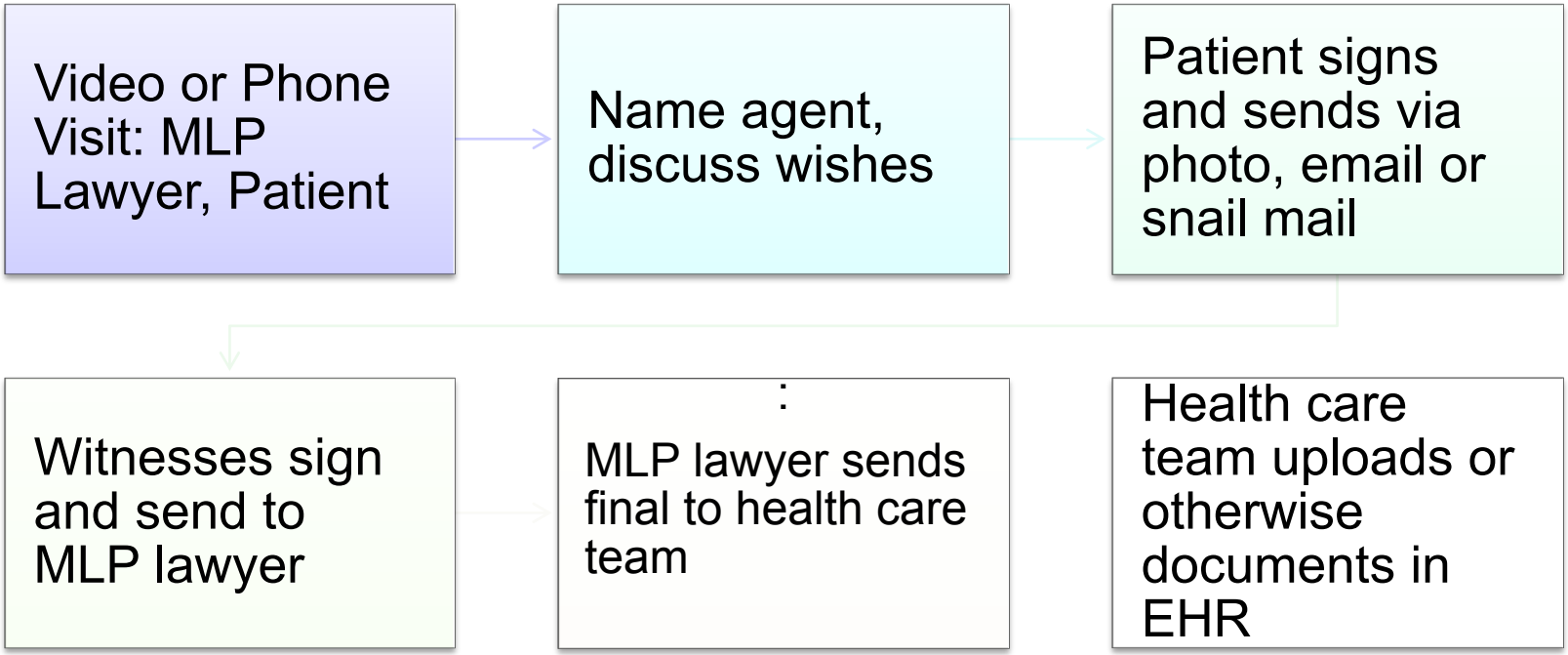
State Policy Ideas (CA example)

- **Obtaining patient signature:** Clarify that California Probate Code §4673(a)(2) permits healthcare providers or witnesses to sign advance directives "at the direction of" the patient via a telehealth or phone visit and that such visit satisfies the "in presence of" requirement.
- **E-notarization:** Clarify that California Civil Code §1189(b) permits e-notarization for advance directives in California where the e-notary is otherwise duly licensed and authorized by another state.
- **Digital signatures:** Waive digital signature authentication requirements at California Probate Code §4673 (b)(1-7).
- **SNF residents:** Clarify that, for residents of skilled nursing facilities, the patient advocate or ombudsman may conduct witnessing under California Probate Code §4675 via telephone or web-based visits with the resident.
- **Patient signature on POLST:** Clarify that a patient or legally authorized representative's signature on a POLST may be obtained by a treating physician in the same manner as an advance directive as above.

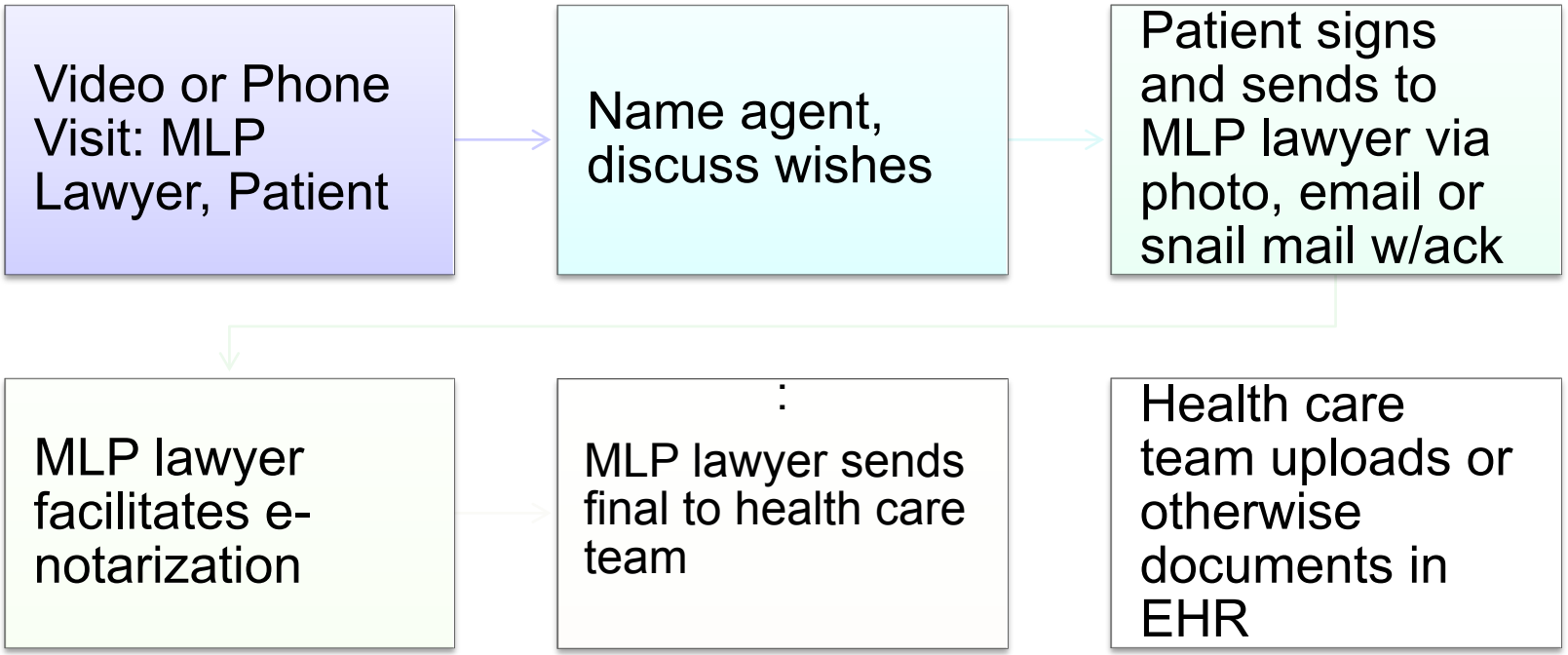
On-Ground Strategies: Synchronous Signing



On-Ground Strategies: Asynchronous Signing



On-Ground Strategies: Asynchronous Signing



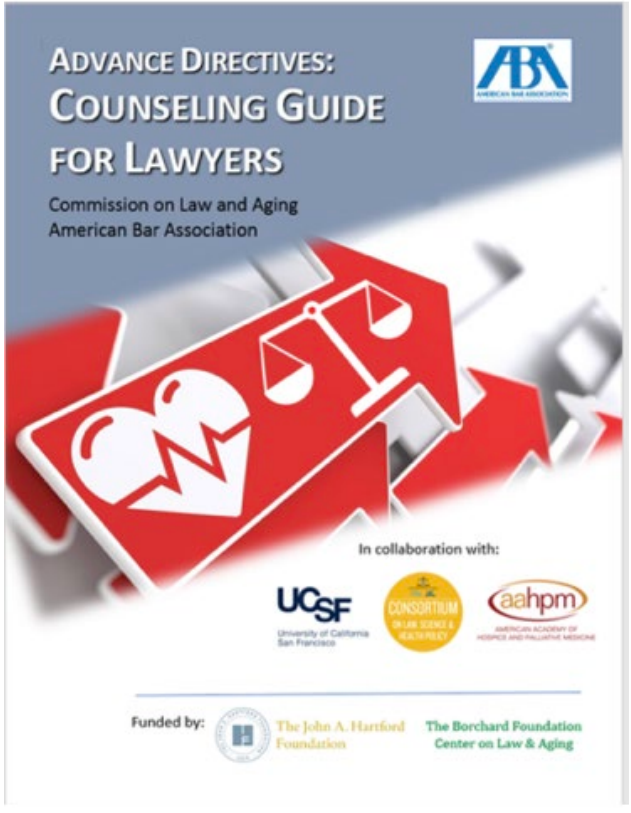
Creativity, Risk & Ethics

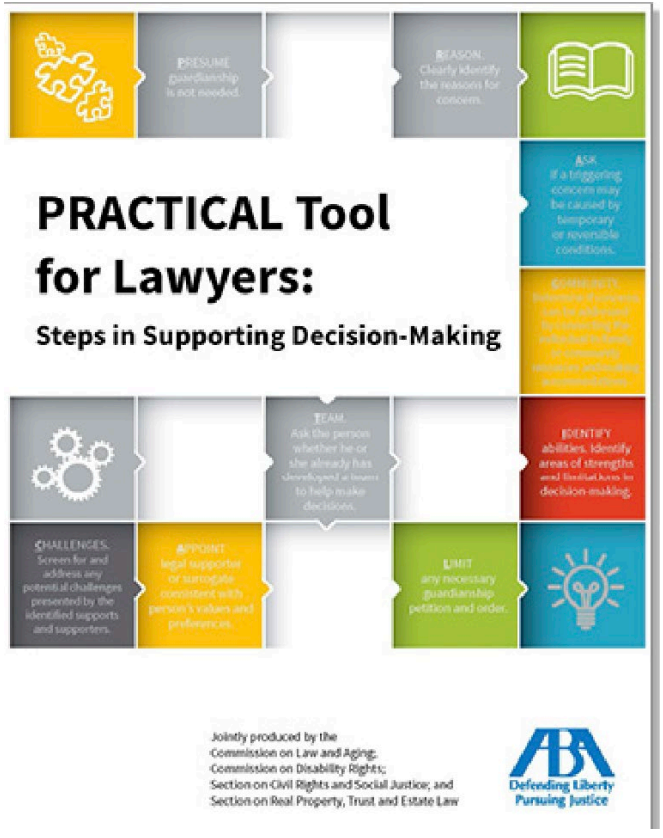
- Back to basics:
  - Read your statute thoroughly- don't rely on statutory forms as law
  - Specific instructions (living wills) diff than DPOAH
  - Remember basic principles:
    - Known wishes of patient always entitled to respect
    - ADs are just *evidence* of conversations/wishes
    - What other evidence/documentation can you help construct?

- Risk tolerance up to professional judgment, local law and environment

- MLP legal teams should be clear about ethical role here (not risk managers)

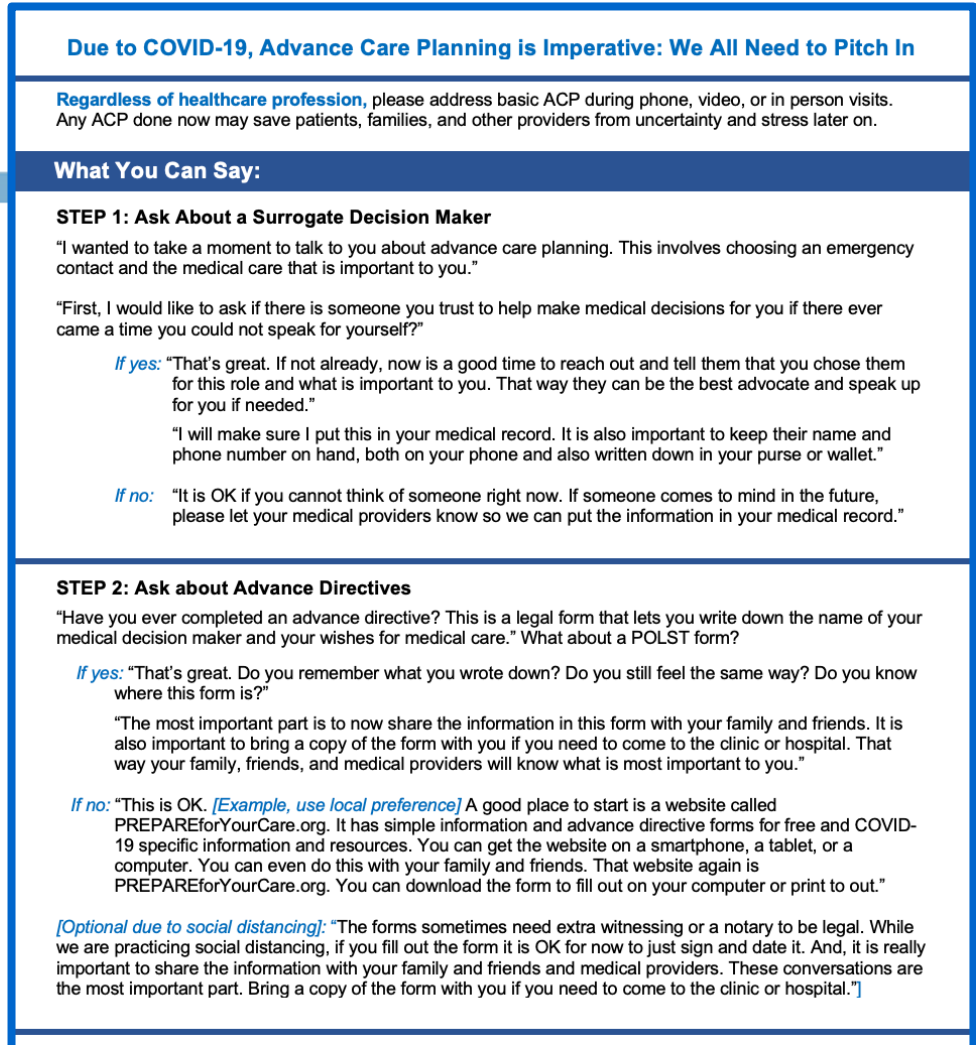
Best Practices Resources





Questions

- Can social workers, assistants, students do ACP?



Due to COVID-19, Advance Care Planning is Imperative: We All Need to Pitch In

Regardless of healthcare profession, please address basic ACP during phone, video, or in person visits. Any ACP done now may save patients, families, and other providers from uncertainty and stress later on.

What You Can Say:

STEP 1: Ask About a Surrogate Decision Maker

"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?"

If 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 sure I put this in your medical record. It is also important to keep their name and phone number on hand, both on your phone and also written down in your purse or wallet."

If 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."

STEP 2: Ask about Advance Directives

"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." What about a POLST form?

If 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?"

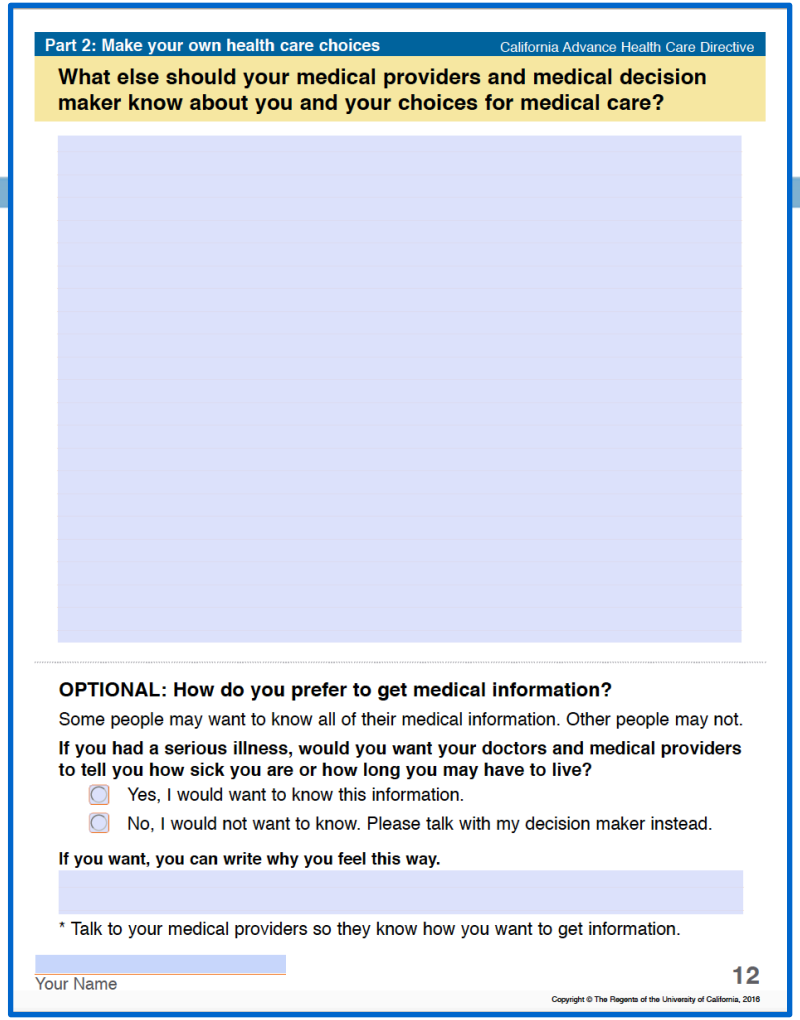
"The most important part is to now share the information in this form with your family and friends. It is also important to bring a copy of the form with you if you need to come to the clinic or hospital. That way your family, friends, and medical providers will know what is most important to you."

If no: "This is OK. *[Example, use local preference]* A good place to start is a website called PREPAREforYourCare.org. It has simple information and advance directive forms for free and COVID-19 specific information and resources. You can get the website on a smartphone, a tablet, or a computer. You can even do this with your family and friends. That website again is PREPAREforYourCare.org. You can download the form to fill out on your computer or print to out."

[Optional due to social distancing]: "The forms sometimes need extra witnessing or a notary to be legal. While we are practicing social distancing, if you fill out the form it is OK for now to just sign and date it. And, it is really important to share the information with your family and friends and medical providers. These conversations are the most important part. Bring a copy of the form with you if you need to come to the clinic or hospital."]

Questions

- What if people have dementia or COVID-specific wishes or wishes not on the directive?



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

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Thank You and More Questions

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