May 21, 2020, DAS COVID-19 Webinar Series

Planning Ahead for the Care You May Need: Health Care Decisions in the Era of COVID-19



Rebecca Sudore, MD

Professor of Medicine, Division of Geriatrics, UCSF Director of the Innovation & Implementation Center in Aging and Palliative Care Research



Anne Kinderman, MD

Director, Supportive & Palliative Care Service, Zuckerberg San Francisco General Associate Clinical Professor, UCSF

Outline

- Advance Care Planning (ACP)
 - The goal of ACP
 - ACP & COVID-19 crisis
 - Tools to help people start ACP
- Palliative Care
 - Being in the hospital with COVID-19
 - Key things to consider
 - How Palliative Care can help

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."

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



San Francisco VA Medical Center Division of Geriatrics

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



San Francisco VA Medical Center Division of Geriatrics

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



Be Prepared: Take Control COVID-19 & YOU Have a hospital Share wishes + Choose a 'Go bag' medical encourage loved Advance Health decision ones to maker prepare 2

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://prepareforyourcare.org/covid-19

Making a Medical Plan During COVID-19

Plan for Medications

Make a list of your medications and keep it on hand

8

Advanta Nasi

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

Choose a medical decision maker
Share Your Wishes: This is MOST important
Consider an advance directive

Plan for Your Pets



Plan for Your Money and Bills



www.prepareforyourcare.org

Easy-to-Read **Advance Directive (AD)**

RCT:

- Doubled completion rates ۲
- Overwhelmingly preferred ۲ 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:



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.

Your Name

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



www.PrepareForYourCare.org Interactive, multi-media website



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.







5-Steps of PREPARE

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

Tell Others About Your Wishes

Ask Doctors the Right Questions

Your Action Plan

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 <u>model</u> ACP behavior



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

How to Ask a Decision Maker

How to Ask Someone to Be Your Decision Maker

PREPARE

You can watch this video with your friends and family.



How to Talk with Family & Friends



How To Tell Others About Your Wishes



How to Ask Clinicians Questions



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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Efficacy of the PREPARE Program



Sudore, et al. JAMA IM: 2 RCTs, 1400 English & Spanish speaking participants



Free PREPARE Easy-to-read Advance Directives and Other Tools Below. V



PREPARE Easy-to-Read Advance Directives:

Free to fill out and print for all states.

Get the PREPARE Advance Directive

Other PREPARE Tools for Providers and Organizations V

For Providers and Organizations:

- PREPARE Pamphlets
- · Tools for Group Movie Events
 - PREPARE Toolkit for Group Movie Events
 - PREPARE Movies
 - PREPARE Question Guide



Get Other PREPARE Tools

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



Part 2: Make your pers health care shokes

California Advanta Death Care Director

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, trianels, 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 is your life? Check as many as you want.

- Your family or triends Your peter Hobbies, such as pardening, 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 etse

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

Volar Name

Values & Space to write "Why" & **COVID** or other specific wishes

California Advances Health Care Disailles Part 2: Make your own health care sholoes

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 contlort 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 liness or with someone date to you who was very sick or dying?

- If you want, you can write down what want well or dat not go wall, and why-

If you were dying, where would you want to be?

Your Name

at home in the hospital nither Earn not sure

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

Part 2: Make your own health care choices What else should your medical providers and medical decision

maker know about you and your choices for medical care?

California Advance Health Care Direction

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 Narms

9

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)

PREP

Tailored answer automation

	Español Holp # Horne Si
Car	
If you	a were so sick that you may die soon, what would you prefer?
D	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.
8	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.
0	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.

choice? Or, why did you choose this option?

	Expand two withow 5
Pert 2. Make your own health care choices	Calibria Adamos Health Care Directive
How Do You Balance Quality of I	Life with Medical Care?
Sometimes liness and the treatments us cause pain, side effects, and the inability	
Please read this whole page before	making a choice.
A REAL PROPERTY AND A REAL	are willing to live through a lot for a a know that certain things would be
Life support treatment can be CPR, a breathin leading tubes, dialysis, or transfusions.	anadra. 👔 🎎
Check the one choice you most agn	ee with.
If you were so sick that you may die	soon, what would you prefer? 🥹
tear is a second s	ny doctors think might help. I want to stay on is little hope of goting better or living a life I
	that my doctors think might help. But, I DO satments if the treatments do not work and living a life I value.
i do not want life support treatmen prefer to have a natural death.	ts, and I want to focus on being comfortable, I
What else should your medical prov	iders and decision maker know about
this choice? Or, why did you choose	this option?.



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 - PREPARE Question Guide

Get Other PREPARE Tools







A program to help you make medical



nedical wishes.

questions.

www.prepareforyourcare.org

Ask doctors the right

Choose a Medical Ship! **Decision Maker**

Choose someone you trust to help make decisions for you in case you become too sick to make your own decisions.

A good decision maker will:

 ask doctors guestions respect your wishes

> If there is no one to choose right now, do Steps 2, 4, and 5.

How to say it:

"If I get sidk in the future and cannot make my own decisions, would you work with my doctors and help make medical decision for me?" OB

"I do not want to make my own medical decisions. Would you talk to the doctors and help make medical TREPARE decisions for me now and in the future?"



Trifold English, Spanish, Chinese

Decide What Matters Most in Life

This can help you decide on medical care that is right for you.

Five questions can help you choids what matters for your medical care.

- 1. What is most important in life? Friends? Family? Religion?
- 2. What experiences have you had with serious liness or death?
- What brings you quality of We? Quality of the is different for each person. Some people are willing to live through a lot for a chance of living longer. Others know certain things which he had no their works of the

4. H yo **Choose Flexibility** Dep 18 for Your Decision - 75 Maker 1

Flexibility gives your decision * Or maker leeway to work with your 10 doctors and possibly change your prior medical decisions 7 something - Or - 66 else is belter for you at that time.

How to say it:

5. Have

what

Errie

Total Flexibility:

"I trust you to work with my doctors. It is OK if you have to charge my prior decisions if something is better for me at that time."

Some Flexibility:

"It is OK if you have to change my prior decisions But. there are some decisions that it

never want you to change. These decisions are ...*

No Flexibility:

"Follow my wishes exactly, no matter what."



PREPARE Pamphlet



Your Medical Wahes This will help you get the medical care you want.

Tell Others About

How to say It:

To your decision maker and doctors:

"This is what is most important in my life and for my medical care...*

To your doctor and family and trianda:

"I chose this person to be my decision maker and I want to give them (TOTAL, SOME, or NO) flexibility to make decisions for me."

Your doctors can help you put your medical wishes on an advance directive form.



Ask Doctors the **Right Questions**

Eurelions ahead of time.

with you.

. Tail doctors at the start of the visit if you have questions.

How to say it:

If your doctor recommends something, ask about the:

- Benefits the good things that. could happen
- Risks the bad things that could hippen
- Options for different kinds of treatment
- What your life will be like after line advector of

Make sure you understand:







The PREPARE Movie

You can watch one part of the PREPARE Movie or the full movie by clicking a button below.

Group Movie Events







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



Group visits through Video







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

Choose a medical decision maker
Share Your Wishes: This is MOST important
Consider an advance directive

Plan for Your Pets



Advanta Nasi

Plan for Your Money and Bills

All Hands on Deck: Simple Scripts

COVID-19 Resources For Providers and Organizations



Simple Advance Care Planning Scripts for All Outpatient Health Professionals (Free)

At this unprecedented time in our history, advance care planning has to be ALL OF OUR JOBS. We have put together simple, easy-to-follow scripts that allow anyone as well as any medical provider from any specialty to begin the conversation and to help people begin to prepare before a medical crisis.

(Click here for a Spanish version.)

- Step 1: Ask about a surrogate
- Step 2: Ask about prior ADs
- Step 3: Give basic ACP information



Scripts

 Nurses, physicians, social workers, physical therapists, assistants, students...anyone

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

1. Where can people start?

2. How do you recommend organizations use PREPARE tools?

Outline

- Advance Care Planning (ACP)
 - The goal of ACP
 - ACP & COVID-19 crisis
 - Tools to help people start ACP
- Palliative Care
 - Being in the hospital with COVID-19
 - Key things to consider
 - How Palliative Care can help

If I need to go to the hospital, what can I expect?



Zuckerberg San Francisco General

Being in the Hospital Now: What is it Like?

New things

- Fewer people, less noise
- Visiting is very limited in most hospitals
- Staff will wear masks, sometimes face shields, even if you don't have COVID
- Some providers/staff may only meet with you by phone or video

Usual things

- Staff will wake you up to ask you questions, draw blood, examine you, etc.
- You will be seen by a doctor or advance practice provider (Nurse Practitioner or Physician Assistant) daily – usually just once a day
- Results can take time to come back

Being in the hospital with COVID



This Photo by Unknown Author is licensed under CC BY-SA

- Most people don't need invasive treatments
 - Special isolation unit of hospital
 - Staff wear more protective gear (gowns, masks, face shields, caps)
 - Most/all of your in-person visits will be from 1 doctor/1 nurse; other visits by phone/video
 - Most patients need oxygen by a small tube in the nose (canula)
 - Close monitoring of your vital signs, blood tests
 - No visitors connect by phone/video
 - Once you're out of the high-risk period, you go home to finish out quarantine (or to special isolation accommodations)

Being in the hospital with COVID

- 3 in 100 people in the US with COVID need intensive care
 - Most need mechanical ventilation
 - Many need to be sedated to get enough oxygen in, tolerate ventilator
 - Doctors communicate with your designated decision maker
 - Some people get better, but it takes a long time; some people die (chances increase with age)



This Photo by Unknown Author is licensed under CC BY-SA

CDC, MMWR March 27, 2020 / 69(12);343-346

Key things to think about before the hospital

- Who would you want to make decisions for you?
- If you get sicker very quickly, which of these best suits you?

Life Support for as long as	Life Support for a trial period	Non-invasive treatments only
it helps keep you alive		,

Key things to think about, in general

- What would be most important for your healthcare providers or loved ones to know if you became very sick and couldn't speak for yourself?
- What abilities are so important to you that you can't imagine living without them?
- If you became very sick with COVID, how much are you willing to go through for the possibility of having more time?
- Who in your life have you talked with about your priorities and your wishes? How much do they know?
- What gives you strength in hard times?

Palliative Care Can Help!



Zuckerberg San Francisco General Hospital and Trauma Center

Palliative Care Can Help!

- Things palliative care teams help with:
 - Identifying what's most important to you in life, as a guide for medical care
 - Providing clear information on what's going on
 - Gathering important people to talk about your condition
 - Helping relieve physical, emotional symptoms
 - Addressing spiritual needs, big questions of life
 - Getting you connected to resources you need
 - Coordinating care across different teams, settings
 - Supporting caregivers, loved ones

How do I get palliative care?

- Ask your doctor (hospital, primary care)
- Ask your insurance company
- getpalliativecare.org
- Palliative care is available in ALL hospitals in San Francisco
- Palliative care is increasingly available in clinics and homes
- Palliative care is sometimes available in nursing homes

Things to Remember

- These are uncertain and scary times, but there are things you can do to prepare yourself and your loved ones
 - Identify a decision-maker and have a conversation
 - Think about what would be most important to you if you got very sick
 - If you are worried about your risk of getting very sick with COVID, talk to your primary care provider
- Palliative care can help you and your loved ones, if you are dealing with serious illness (COVID or other illnesses)

Questions?



anne.kinderman@ucsf.edu rebecca.sudore@ucsf.edu



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