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

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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.”

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
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 @convoprocess
Pack a Hospital 'Go bag' today!

https://prepareforyourcare.org/covid-19

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**Making a Medical Plan During COVID-19**

<table>
<thead>
<tr>
<th>Plan for Medications</th>
</tr>
</thead>
<tbody>
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<td>Make a list of your medications and keep it on hand</td>
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</tbody>
</table>

**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**
PREPARE

Online Advance Care Planning Program in English & Spanish

www.prepareforyourcare.org
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
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 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.
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
4. Tell Others About Your Wishes
5. Ask Doctors the Right Questions

Your Action Plan

PrepareForYourCare.org
Creating PREPARE

• Co-created with diverse populations

• Easy to understand: 5\textsuperscript{th}-grade reading level
  – Voice-overs & closed captioning (Eng/Span)

• Range of video stories:
  – Surrogate availability
  – Decision making preferences

• Videos that \textbf{model} ACP behavior

* Sudore RL et. al., J Pain & Symptom Manage, 2012
How to Ask Someone to Be Your Decision Maker

You can watch this video with your friends and family.
How to Ask Clinicians Questions
**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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**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.

Your Name

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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.

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

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
Values & Space to write “Why” & COVID or other specific wishes
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
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Get Other PREPARE Tools
PREPARE Pamphlet

Trifold
English, Spanish, Chinese
Group Movie Events

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

Welcome
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
Your Next Steps
Watch the full movie

For group movie events, please see our Toolkit.

Get the PREPARE Toolkit

Toolkit for Group Movie Events

Part 1: What to Expect & A Planning Checklist
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
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
This toolkit includes example flyers, emails, and newsletter language to help you promote your event.

Part 4: Feedback Surveys
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
Group visits through Video
Pack a Hospital 'Go bag' today!
https://www.youtube.com/watch?v=x1rZdXoB_t8

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### Making a Medical Plan During COVID-19

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  - 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
All Hands on Deck: Simple Scripts

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

https://prepareforyourcare.org/covid-19
Scripts

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

1. Where can people start?

2. How do you recommend organizations use PREPARE tools?
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If I need to go to the hospital, what can I expect?
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

- 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)

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 it helps keep you alive
- Life Support for a trial period
- Non-invasive treatments only
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!
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?

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