If you had to make tough decisions for yourself or others…

What would you hope for?

• That clinicians have time and training to
• communicate clearly and compassionately

• That you have a framework for how to:
  – Identify what is most important to you
  – To be able to communicate with others
  – And to make informed medical decisions
Major Communication Deficits

- Patients are not empowered
- Surrogates are not empowered

Advance Directives & Health Literacy
CAHCD

• SFGH Ethics

• > 15% ICU pts unrepresented

• Low ACP rates

White DB, Crit Care Med. 2006

Advance Care Planning (ACP) Process

• Clinician initiates conversation or gives materials

• Patient asks questions

• Patient identifies wishes

• Patient discusses wishes with surrogate

• Patient discusses wishes with doctor

• Patient full understanding & documents

• Clinician places in medical record
Advance Care Planning (ACP) Process

- Clinician initiates conversation or gives materials
- Patient asks questions
- Patient identifies wishes
- Patient discusses wishes with surrogate
- Patient discusses wishes with doctor
- Patient full understanding & documents
- Clinician places in medical record

Patient tasks affected by:
- literacy
- language
- culture

Health Literacy

- “The degree to which individuals have the capability to obtain, process, and understand basic health information and services needed to make appropriate health decisions.”
- Average reading level = 8th grade
- Medicaid and the elderly = 5th grade

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


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

Advance Directives = High Stakes

- Checkbox responses can have life & death consequences


Your agent will have the right to:

(e) Make anatomical gifts, authorize an autopsy, and direct the disposition of your remains.
POLST Understanding

- **What does this mean?**
  “I only want to be on machines for a few days. My family knows this.”

- 50% understood section, ~ 30% discordant w/ goals

Hickman, SE et al. *J Palliat Med.*, 2017

Advance Directive Confusion

- “My mom passed away….and she had signed the paper in the hospital, but it was totally wrong, because she didn't really understand it. We had another one filled out, and that one said, ‘Do you want to be resuscitated? Do you want to be on a machine or not?’ And she said ‘no.’ And then the questions were in conflict. One said yes; one said no….That really confused us. She got really frustrated. She didn’t want to talk about it anymore.”

Sudore RL et al., JPSM, 2012
Prior RCT:
- Doubled completion rates
- Overwhelmingly preferred

10 languages

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Are ADs Enough?

“We got the DNR in writing. But in making the decisions, which there were many, that was just one. Because the first decision was to put him in a nursing home. We were married 30 years and I could no longer take care of him (tearful). Then the second decision was whether to put him on a feeding tube because he had stopped eating and I wasn’t ready to let him go.”

Sudore RL et al., J Pain and Symptom Management, 2013
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
PREPARE es un programa paso a paso con historias en video para ayudarle a:
- Ser participante en SU cuidado médico
- Hablar con sus doctores
- Darle tranquilidad a su familia y amigos

Los videos de PREPARE le ayudan a responder preguntas sobre sus deseos médicos.
- Usted puede imprimir un resumen de sus deseos
- Usted también puede llenar un formulario de instrucciones anticipadas de atención de salud de fácil lectura

Haga clic en el video para aprender más.

Comience a usar 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

• Easy to understand: 5th-grade reading level
  – Voice-overs & closed captioning

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

• Videos that **model** ACP behavior

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

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**How to Ask a Decision Maker**

*PREPARE*

**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

How To Tell Others About Your Wishes

How to Ask Clinicians Questions

How To Ask Doctors the Right 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

Stages of Person-Centered Decision Making

First Steps® ACP
Target Population:
- Adults who have not started or engaged in a planning process

Next Steps™ ACP
Target Population:
- Individuals engaged in active disease management experiencing complications

Advanced Steps ACP
Target Population:
- Individuals in their last few years of life

Shared Decision Making in Serious Illness™
Target Population:
- Individuals with serious illness making a current healthcare decision
ACP is a Process

Readiness to Engage

First Steps ➔ Next Steps ➔ Advanced Steps

Life Course

Respecting Choices®
Person-Centered Care

Improving Advance Care Planning (ACP): The VA PREPARE Trial

www.PrepareForYourCare.org

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JAMA Intern Med, May 2017

University of California, San Francisco
Division of Geriatrics
Background

ACP

Clinician or Facilitator

Patient

Healthcare System

Intervention: Patient-facing ONLY

www.PrepareForYourCare.org
PREPARE & Easy-to-Read AD Increased ACP Documentation in the Medical Record

6 months before baseline | Easy-to-Read AD | AD + PREPARE

- < 1%
- 25%
- 35%

*p = 0.04

PREPARE + AD Increased Behavior Change > AD Alone

- Self-efficacy
- Readiness

Mean ACP Engagement Process Scores

- PREPARE+AD
- AD-only

Overall p < 0.001
Trial County Hospital

- Trial 986 English & Spanish-speaking older adults
- San Francisco General, 4 primary care clinics
- 12 month follow up, 86% retention
- 45% Spanish, 80% non-white, 40% limited literacy
- Baseline ACP: 11% English speakers, 7% Spanish

PREPARE & Easy-to-Read AD Increased ACP Documentation in the Medical Record
**Conclusion**

- Easy-to-use, patient-facing PREPARE tools, with minimal clinician/system-level input, can increase ACP documentation 35-43%.

- Combining PREPARE plus an easy-to-read AD resulted in higher ACP documentation and engagement than the AD alone.
Implications: Patient-facing ONLY

- PREPARE and the easy-to-read AD may be useful ACP interventions on a population level, especially in resource-poor health systems.

- Likely to be synergistic with other clinician/system interventions, more research is needed.

Updates & Dissemination
Updated Intro Videos

Click the video above to learn more.

FREE PREPARE Tools

Get the PREPARE Pamphlet

Get the PREPARE Easy-to-Read Advance Directive

PREPARE QUESTIONS

A guide to help people and their loved ones prepare for medical decision making.
New Easy-to-read ADs for all US States in English & Spanish

California Advance Health Care Directive

[Image of a map of the United States with a highlighted area showing California]

PREPARE Pamphlet

Trifold English, Spanish, Chinese
PREPARE Questions

Step 1: Choose a Medical Decision Maker

Can you think of a friend or family member who will be able to make medical decisions for you if you become too sick to make your own decisions?
- [ ] Yes
- [ ] No.

When do you want someone to make medical decisions for you?
- [ ] Only when you lose the ability to make your own decisions.
- [ ] Someone will make medical decisions for me if I become too sick to make my own decisions.
- [ ] Someone will help me make medical decisions for my life, even when I can make my own decisions.

Step 2: Decide What Matters Most in Life

Here’s a chance to think about what matters most in your life and for your medical care.

Question 1: What is most important to you?

[ ] Family or friends
[ ] Work
[ ] Hobbies
[ ] Personal appearances
[ ] Being in control
[ ] Not being a burden on my family
[ ] Something else:

In writing what is most important, who can help you decide on the medical care that is right for you.

Journal of Palliative Medicine, 2018
PREPARE & RC Collaboration

ACP

Clinician or Facilitator

Healthcare System

Patient

First Steps  Next Steps  Advanced Steps
PREPARE & RC Collaboration Ideas

- What do you see as synergistic between PREPARE and RC?
- What concerns you when thinking about using both?
- Ideas or strategies to effectively use both?
- Ideas for clinical or research design resulting in a synergistic program?

Thank You!

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