Multifaceted Approaches to Advance Care Planning

Rebecca Sudore, MD
& select PCQN Members
Agenda

- Define ACP & PCQN Data
- Clinician Training: Karen Knops, MD Overlake Hospital
- Health Systems: Chris Pietras, MD, UCLA
- Community Engagement: Sherry Michael, MSW, Collabria Care
- Patient Activation
- Questions & Action Planning
What is ACP?

“We are on the same page, yet we can’t seem to agree on anything.”
Standardizing ACP Definition

• No formal prior definition

• Most often → life sustaining treatments & advance directives

• 2014 IOM report: various descriptions
Delphi Panel ➔ Definition

• Delphi convened to rank ACP outcomes. Unable to agree on a definition ➔ halted

• **Who Cares?** ➔ A consensus definition needed to standardize research and guide policy and quality metrics.
10 Rounds of Delphi Panel

• Example Tension: Values vs. Treatments

“Documentation of treatment preferences for CPR is the most important.”

vs.

“DNR/DNI…may say less about a patient's overall values…and is less informative than documented discussions of values, preferences, and goals.”
<table>
<thead>
<tr>
<th>Population</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Populations to include? Adults, children, parents?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Scope</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Prescriptive or broad?</td>
</tr>
<tr>
<td>3. Focus on patient or clinician behaviors?</td>
</tr>
<tr>
<td>4. Include surrogates, family and friends?</td>
</tr>
<tr>
<td>5. Used for healthcare audiences and the public?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Purpose – What constitutes ACP?</th>
</tr>
</thead>
<tbody>
<tr>
<td>6. On a continuum or a one-time event (directive/order)?</td>
</tr>
<tr>
<td>7. Appropriate when healthy or only in serious illness/EOL?</td>
</tr>
<tr>
<td>8. Focus on preparing a surrogate or the individual?</td>
</tr>
<tr>
<td>9. Focus on discussions or documentation?</td>
</tr>
<tr>
<td>10. Address life goals/values or medical treatments?</td>
</tr>
<tr>
<td>11. Focus on future or current in-the-moment decisions?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>How to Conduct ACP</th>
</tr>
</thead>
<tbody>
<tr>
<td>12. Assess readiness to engage in ACP?</td>
</tr>
<tr>
<td>13. Include a discussion of prognosis?</td>
</tr>
</tbody>
</table>

| Semantics |
Consensus Definition of ACP

• **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 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.”
Consensus Definition of ACP

- **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 and 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.”
PCQN
Advance Care Planning

Spring Meeting
April 20-21, 2017
## Reason for Referral

<table>
<thead>
<tr>
<th>Reason</th>
<th>Inpatient</th>
<th>Community</th>
</tr>
</thead>
<tbody>
<tr>
<td>GOC/ACP</td>
<td>72%</td>
<td>38%</td>
</tr>
<tr>
<td>Pain</td>
<td>19%</td>
<td>74%</td>
</tr>
<tr>
<td>Symptom management</td>
<td>15%</td>
<td>51%</td>
</tr>
<tr>
<td>Hospice</td>
<td>18%</td>
<td>4%</td>
</tr>
<tr>
<td>Support pt/family</td>
<td>21%</td>
<td>33%</td>
</tr>
<tr>
<td>Support tx decision</td>
<td>-</td>
<td>25%</td>
</tr>
</tbody>
</table>
Full Code at Time of Consult

Code Status at Time of PC Request - Full
01/01/2013 - 04/19/2017

PCQN Percent: 51.6

Report Data Last Updated on Apr 19, 2017 at 23:05 Excludes patients with non-applicable status for chosen variable. Excludes members with N < 5
## Code status

<table>
<thead>
<tr>
<th></th>
<th>At initial evaluation</th>
<th>Post consult</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full</td>
<td>52%</td>
<td>29%</td>
</tr>
<tr>
<td>Partial</td>
<td>6%</td>
<td>5%</td>
</tr>
<tr>
<td>DNR/DNI</td>
<td>38%</td>
<td>65%</td>
</tr>
</tbody>
</table>
## Advance Directive and POLST

<table>
<thead>
<tr>
<th>Advance Directive</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pending</td>
<td>2,516</td>
<td>3.0%</td>
</tr>
<tr>
<td>Unknown</td>
<td>307</td>
<td>0.4%</td>
</tr>
<tr>
<td>Not on chart at PC request</td>
<td>61,822</td>
<td>74.0%</td>
</tr>
<tr>
<td>On chart at PC request</td>
<td>18,851</td>
<td>22.6%</td>
</tr>
<tr>
<td>Completed at d/c (not on initial chart)</td>
<td>1,965</td>
<td>3.2%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>POLST</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pending</td>
<td>4,649</td>
<td>5.6%</td>
</tr>
<tr>
<td>Unknown</td>
<td>397</td>
<td>0.5%</td>
</tr>
<tr>
<td>Not on chart at PC request</td>
<td>69,310</td>
<td>83.0%</td>
</tr>
<tr>
<td>On chart at PC request</td>
<td>9,140</td>
<td>10.9%</td>
</tr>
</tbody>
</table>
## POLST completion by Disposition

### UCSF

<table>
<thead>
<tr>
<th>Discharge Location</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home</td>
<td>All Locations Not Selected</td>
</tr>
<tr>
<td>N</td>
<td>%</td>
</tr>
<tr>
<td>------</td>
<td>------</td>
</tr>
<tr>
<td>Polst Complete at live d/c (not full code)</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>177</td>
</tr>
<tr>
<td>No</td>
<td>105</td>
</tr>
<tr>
<td>Total</td>
<td>282</td>
</tr>
</tbody>
</table>

\[ x^2 = 1.1 \quad \text{p-value} = 0.4787 \]

### PCQN

<table>
<thead>
<tr>
<th>Discharge Location</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home</td>
<td>All Locations Not Selected</td>
</tr>
<tr>
<td>N</td>
<td>%</td>
</tr>
<tr>
<td>------</td>
<td>------</td>
</tr>
<tr>
<td>Polst Complete at live d/c (not full code)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>4,127</td>
</tr>
<tr>
<td>Yes</td>
<td>2,809</td>
</tr>
<tr>
<td>Total</td>
<td>6,936</td>
</tr>
</tbody>
</table>

\[ x^2 = 92.4 \quad \text{p-value} = 0.0000 \]
## POLST by Diagnosis

### Primary Diagnosis Leading to PC Consult

<table>
<thead>
<tr>
<th></th>
<th>All Dx Not Selected</th>
<th>Cancer</th>
<th>Cardiovascular</th>
<th>Pulmonary</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
<td>N</td>
<td>%</td>
<td>N</td>
</tr>
<tr>
<td>Polst Complete at live d/c (not full code)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>3,989</td>
<td>60.4%</td>
<td>3,209</td>
<td>60.2%</td>
<td>1,214</td>
</tr>
<tr>
<td></td>
<td>9,462</td>
<td>60.4%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>2,611</td>
<td>39.6%</td>
<td>2,119</td>
<td>39.8%</td>
<td>777</td>
</tr>
<tr>
<td></td>
<td>6,210</td>
<td>39.6%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>6,600</td>
<td>100.0%</td>
<td>5,328</td>
<td>100.0%</td>
<td>1,991</td>
</tr>
</tbody>
</table>

\[ \chi^2 = 0.0 \quad p\text{-value} = 0.9133 \]
Agenda

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Advance Care Planning: Clinician Training

OVERLAKE MEDICAL CENTER
SPRING 2017
PCQN
Where we’ve been, who we are

• In 1952, Seattle Eastside residents of Bellevue formed the nonprofit Overlake Memorial Hospital Association, and opened a 56-bed hospital in 1960.

• 2014 marked the opening of the Heart & Vascular Center and the Neuroscience Institute in 2015.

• Overlake now totals 349 licensed beds and directly employs over 120 providers through its affiliate, Overlake Medical Clinics. 1 million East side residents

Palliative care inpatient consult service established 2010
Inpatient → clinics TBD
Summary – Past Overlake Efforts

- No formal staff training to date
- Palliative care social worker → Palliative Care team → Hospital care teams
- WA State POLST, end-of-life laws, SDM tool certification program
- “Honoring Choices”
  - Trained facilitator (MSW)
  - Outpatient – DPOA for healthy individuals
Summary – Training experiences elsewhere

Observations of what works for ACP clinician training

- Effort employs all aspects of the organization (including marketing)
- Roles are clear
- Right tools, not just a mandate
- Coupled with other pillars and initiatives*
- Effort is sustained

Atlantic Health, Meridian, Hackensack University Healthcare System, Wellspan, Reading Health System, Lehigh Valley Health Network
Concerns

- **Plans or Planning?**
  - Conversations that produce no document can still help
  - Poor conversations = Poor documents
  - Good documents can be usurped by poor communication later
  - Unintended consequences of early ACP – People who *pursued* ACP are health literate, carefully choose proxy, tend to limit intervention

- **EHR - got documentation?**
  - Upgrade pending
  - Linking notes
Concerns – Limits of qualitative data

“Plans are useless, but planning is everything”
Dwight Eisenhower

“Everybody has a plan - until they get punched in the face”
Mike Tyson
ACP training: 30 years and counting
Exploring narrative co-creation

- Anticipate <
- Summarize the context <
- Concern yourself - beyond the physical ^
- Explore/Explain in context of goals and challenges ^
- Next steps may be a document, may be “home work” or follow up conversation >
- Document! >

- Alternative to “SHARE” – matches other training, can be a part of the experience
Exploring training: Narratives

**Anticipation**

- Right tool for the job (POLST, AD, language, adolescent version, etc)
- Right participants (capacitated patient, likely surrogates, trusted healthcare professional)
- Right mindset for patient and provider
  - “Talk about talking about it”
  - Coaching model
  - Kenosis
- Patient anticipation – email/poster
Exploring narrative co-creation

Documentation

- Obtaining existing documents before visits, “pre-planning” documents
- Written literature, BC/WC, recording
- Systems: EMR, interprovider communication
Next Steps

- Workshop using 2 clinical scenarios
  - BBNfoundation.org – trained actors with videotaping

- Coordinate with existing efforts, key stakeholders
  - Patient/physician satisfaction
Tools that compel

- Not “one more thing”
- We have an obligation to delight
- Reminders – EMR, environmental cues
- It is easier to implement for ACP if the steps are second nature
- Manage downside risks of ACP while promoting increased use of ACP
- Promote ACP as a process, from “Planning to Plan” to POLST completion or request for PAS
“Nobody Wants to Read Your Sh*t”

by Steven Pressfield

What’s the answer?
1) Streamline your message. Focus it and pare it down to its simplest, clearest, easiest-to-understand form.
2) Make its expression fun. Or sexy or interesting or scary or informative. Make it so compelling that a person would have to be crazy NOT to read it.
3) Apply that to all forms of writing or art or commerce.

*this talk was created with the ASCEND process
Advance Care Planning and the Electronic Health Record

Chris Pietras MD
Palliative Care Program Director
Hospice and Palliative Medicine Fellowship Program Director
UCLA Department of Medicine
We’re trying to make the electronic health record work for us!

- Remind us to engage in advance care planning
- Streamline documentation of advance care planning
- Make it easy to find and review any previous documentation
**GOALS OF CARE & ADVANCE CARE PLANNING**

**DATE OF SERVICE:** 4/18/2017

**PRIOR DIRECTIVES:**
- I reviewed the patient's medical record which contains [ ] has a POLST or advance directive, [ ] POLST, [ ] advance directive.

**MEETING PARTICIPANTS:**
- A discussion was held with the patient and his/her surrogate decision maker regarding advance care planning and goals of care. Participants included: [ ] and [ ], Christopher J. Patras, MD.

**SURROGATE DECISION MAKER CONTACT INFORMATION:**
- [Blank single 1/1977]: [patient and his/her medical decision makers]: [patient's medical decision maker(s)]: [patient] at the time of our conversation, the patient [Blank single 1/1977]: does not have medical decision making capacity for the topics discussed.

**TOPICS OF CONVERSATION:**
- We discussed the following: [Blank single 1/1977]: [patient's medical decision maker(s)]: [patient]. At the time of our conversation, the patient [Blank single 1/1977]: does not have medical decision making capacity for the topics discussed.

**GOALS:**
- The patient's most important goals are: [Blank single 1/1977]: [patient and his/her medical decision makers]: [patient's medical decision maker(s)]: [patient].
- The patient's minimal acceptable outcome for [Blank single 1/1977]: [was not discussed].

**TREATMENT PREFERENCES:**
- Code status and intensity of care:
  - [Blank single 1/1977]: was not discussed today: [patient and his/her medical decision makers]: [patient's medical decision maker(s)]: [patient].
  - The patient's preference [Blank single 1/1977]: was not discussed today: [patient and his/her medical decision makers]: [patient's medical decision maker(s)]: [patient].

**OUTCOME AND PLAN:**
- The plans resulting from the meeting includes:
  - [Blank single 1/1977]: [was not discussed].
  - [Blank single 1/1977]: [was not discussed].

New Note by PIETRAS, CHRISTOPHER J.
Alternate Goals of Care Note Template

- Suggestions as to important aspects of the conversation

- Most people free type without a template
Tabs: Goals of Care
Inpatient POLST Reminders: At Admission and Discharge

- A text prompt (i.e., a line of text within the order set is added when the provider is completing the order set -- not a pop-up or best practice advisory/ BPA), appears only:
  - At admission: POLST is present: “POLST form is present and should be reviewed”
  - At discharge: No POLST, and code status is MODIFIED or DNR: “Recommended to complete a POLST form.”
Outpatient ACP Reminders: Health Care Maintenance

- Decision not to include yet
  - Until sufficient resources in place
  - Until training done or available
Planned Clinician Performance Feedback

- In collaboration with leadership reinforcement of the importance of ACP
- Monthly reports of both institutional and individual metrics
- E.g., Advance directives, POLST, GOC notes
Summing it up: using the EHR to promote ACP

- Remind us to engage in advance care planning
- Streamline documentation of advance care planning
  - The conversation: GOC notes
  - Advance Directives and POLST forms
- Make it easy to find and review any previous documentation
  - And alert us to any inconsistencies in the current plan
- Promote performance improvement and self-evaluation
History

- 1979: Hospice of Napa Valley opens at St. Helena Hospital
- 1988: Medicare Benefit Offered
- 1995: Hospice moves to Napa
- 1997: Becomes 501C(3) Nonprofit
- 1998: Adult Day Health Services Opens
- 1999: Adds Alzheimer’s Day Care Resource Center
- 2005: Moves to new building
- 2011: Launched Transitions Palliative Care program
- 2012: Opened La Boheme
- 2015: Launched Partners in Palliative Care Pilot
- 2016: Rebrand: Collabria Care
Partners in Palliative Care (PIPC) pilot

THE PIPC PILOT

Resolution Care
Interim Healthcare
Yolo Care
Collabria Care

4 Sites - 89 Patients

DIAGNOSES

48% Cancer
17% Cirrhosis
8% COPD
8% CHF
19% Other

PATIENT COMMENTS

“We feel blessed to have this team working with us”
“They genuinely care for us and we for them”
“There is no other service like this”
“Outstanding individuals”

Collabria Care

LOWEST: hospital/ED visits
HIGHEST: POLST completion
Partners in Palliative Care (PIPC) pilot

HOW PIPC CAN HELP YOU IMPROVE CARE FOR YOUR PATIENTS

1) Pain and symptom management – home visits and weekly phone check-ins help improve patient experience and reduce ED visits and hospital stays

2) POLST conversations are a priority! But they can take a lot of time - often 2-3 visits. PIPC staff will work with providers on POLST and Advanced Care Planning process

3) Social services and caregiver support helps improve outcomes

*If your patient is appropriate for palliative care but is not eligible for PIPC they will be offered Transitions*

HOW TO REFER A PATIENT TO PIPC OR TRANSITIONS PALLIATIVE CARE

TEL: 707.254.4161  
FAX: 707.258.9088

Collabria Care
Community Engagement

Professional and community outreach

Latino Outreach
  Latino Outreach Liaison
  Community organizations, health fairs, educational presentations

Increased Latino outreach efforts due to pilot
Partners in Palliative Care

Two primary goals of PIPC were:
- Reduce ER / Hospitalizations
- Facilitate Advance Care Planning

Developed a team: PNN, MSW, CHW
- Team intake approach
- Consent form – ACP participation
- CHW – Interpretation / cultural awareness
Advance Care Planning in the Home

Not in crisis mode

• Time for clarification of goals of care
  – Opportunity for family/friend involvement
  – Spiritual and cultural issues

• Multiple interdisciplinary team visits
  – Allow additional time for interpretation

• Facilitate conversations with physicians
Latino Community - CHW

45% of PIPC patients were monolingual

Complex medical - psycho/social issues

Average age 58

- CHW provided interpretation, cultural awareness
- CHW role enhanced trust/relationship building
  - Available for physician visits with PNN
  - Knowledge of community resources
  - Present for ACP conversations
  - ACP conversations average 2-3 visits
Advance Care Planning: Making it Easier & Getting it to our Communities

Rebecca Sudore, MD, Professor of Medicine
Advance Directives

YOU DON'T CALL THIS A LEGAL DOCUMENT DO YOU?

I CAN UNDERSTAND EVERY WORD OF IT!!
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.”

Sudore RL et. al., J Pain and Symptom Management, 2012
CALIFORNIA
ADVANCE HEALTH CARE DIRECTIVE

Explanation
You have the right to give instructions about your own health care. You also have the right to name
someone else to make health care decisions for you. This form lets you do either or both of these
things. It also lets you express your wishes regarding donation of organs and the designation of your
primary physician. If you use this form, you may complete or modify all or any part of it. You are free
to use a different form.

Part 1 of this form is a power of attorney for health care. Part 1 lets you name another individual as
agent to make health care decisions for you if you become incapable of making your own decisions or if
you want someone else to make those decisions for you now even though you are still capable. You may
name an alternate agent to act for you if your first choice is not willing, able, or reasonably available to
make decisions for you. (Your agent may not be an operator or employee of a community care facility or
a residential care facility where you are receiving care, or an employee of the health care institution
where you are receiving care, unless your agent is related to you, is your registered domestic partner, or
is a co-worker. Your supervising health care provider can never act as your agent.)

Unless the form you sign limits the authority of your agent, your agent may make all health care
decisions for you. This form has a place for you to limit the authority of your agent. You need not limit
the authority of your agent if you wish to rely on your agent for all health care decisions that may have
to be made. If you choose not to limit the authority of your agent, your agent will have the right to:

(a) Consent or refuse consent to any care, treatment, service, or procedure to maintain, diagnose, or
otherwise affect a physical or mental condition;
(b) Select or discharge health care providers and institutions;
(c) Approve or disapprove diagnostic tests, surgical procedures and programs of medication; and
(d) Direct the provision, withholding, or withdrawal of artificial nutrition and hydration and all other
forms of health care, including cardiopulmonary resuscitation;
(e) Make anatomical gifts, authorize an autopsy, and direct the disposition of your remains.

Part 2 of this form lets you give specific instructions about any aspect of your health care, whether or
not you appoint an agent. Choices are provided for you to express your wishes regarding the provision,
withholding, or withdrawal of treatment to keep you alive, as well as the provision of pain relief. Space
is provided for you to add to the choices you have made or for you to write out any additional wishes. If
you are satisfied to allow your agent to determine what is best for you in making end-of-life decisions,
you need not fill out part 2 of this form.

Part 3 of this form lets you express an intention to donate your bodily organs and tissues following your
death.

Part 4 of this form lets you designate a physician to have primary responsibility for your health care.

After completing this form, sign and date the form at the end. The form must be signed by two qualified
witnesses or acknowledged before a notary public. Give a copy of the signed and completed form to
your physician, to any other health care providers you may have, to any health care institution at which
you are receiving care, and to any health-care agents you have named. You should talk to the person
you have named as agent to make sure that he or she understands your wishes and is willing to take
the responsibility.

You have the right to revoke this advance health care directive or replace this form at any time.
Advance Directives are Important

RCT:
- Double completion rates
- Overwhelmingly preferred

FREE
10 languages

http://www.iha4health.org/our-services/advance-directive/

Sudore RL et. al., Patient Educ Coun, 2007
“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, 2012
Forms and checkboxes

• No form or checkbox will ever eliminate the uncertainty and the complexity of the human condition.
Paradigm Shift

“I’m afraid you’ve had a paradigm shift.”
Redefining the “Planning” in Advance Care Planning: Preparing for End-of-Life Decision Making

Rebecca L. Sudore, MD, and Terri R. Fried, MD

Life sustaining treatments

Preparation for communication & decision making
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
Online Advance Care Planning Tool in English & Spanish

www.prepareforyourcare.org
“No, what I said was we need more stakeholders.”
Creating PREPARE

- Expert panel
  - Health Literacy
  - Geriatrics & Palliative Care
  - Behavior change
- 13 focus groups*
  - Patients, surrogates
- Cognitive interviews
- Videos that model behavior: *HOW

* Sudore RL et. al., J Pain and Symptom Management, 2012
Creating PREPARE

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

• Balanced content of videos:
  – Race/ethnicity, gender
  – Aggressive vs. comfort care
  – Surrogate availability, ~ 15% socially isolated
  – Decision making preferences, ~ 20% no decisions

* Sudore RL et. al., J Pain and Symptom Management, 2012
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

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
How to Ask Someone to Be Your Decision Maker

You can watch this video with your friends and family.
How to Ask Someone to be Your Decision Maker

How to say it:

"My doctor thinks it is important to choose someone to help make medical decisions for me in case I get sick in the future and cannot make my own decisions. If this happens, would you be willing to work with my doctors to help make medical decisions for me?"

This is one example. Your situation may be different.
Choosing a decision maker can be hard.

Here are some examples of how other people made it easier. Click the pictures to see their stories.

For Jorge, thinking about it was scary

Helen would rather leave her health to prayer

Click the NEXT button to move on.
How to Tell Others About Your Wishes
How to Ask Questions

How To Ask Doctors the Right Questions
Summary of My Wishes

Talk to your doctor about your medical wishes.
You will do this by July 30.

Summary of All Steps

**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 have close family and friends who may have strong opinions about your medical care.
- 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.
- When making decisions with your family and friends, you want your family and friends to make all medical decisions for you.
- You WOULD want your doctor to tell you how sick you are or how long you have to live.
For Your Medical Provider

**Goals of Care Information:** This document reflects preferences your patient chose on the advance care planning website called PREPARE (www.prepareforyourcare.org). This is not a legal document.

**SURROGATE DECISION MAKER**

Who is the surrogate:

John Doe (your spouse/partner)

**When surrogate is to make decisions:**

When do you want someone (the surrogate) to make medical decisions for you?

- [x] I ONLY want someone to make medical decisions for me if I become too sick to make my own decisions.
- [ ] I want someone else to make medical decisions for me now, EVEN when I can make my own decisions.
- [ ] I am not sure.

**Flexibility or leeway for the surrogate:** Meaning permission to change prior medical decisions.

How much flexibility do you want to give your medical decision maker (surrogate)?

- [x] TOTAL FLEXIBILITY: It is OK for your decision maker to change any of your prior medical decisions if the doctors think it is best for you at that time.
- [ ] SOME FLEXIBILITY: It is OK for your decision maker to change some of your medical decisions. But, some decisions you NEVER want changed, even if the doctors recommend it.
- [ ] NO FLEXIBILITY: Your decision maker must follow all of your medical wishes exactly, no matter what. It is NOT OK to change your decisions, even if the doctors recommend it.
- [ ] I am not sure
To help you fill out advance directive forms

Your Name: __________________________

Medical Decision Maker

Some forms call a medical decision maker by different names:

- a health care proxy
- or, a durable power of attorney for health care
- or, a surrogate decision maker

You chose John Doe to be your decision maker.
You would write his or her name on that part of the form.

Some forms ask about when you want your decision maker to make decisions for you.

You chose that you want your decision maker to make medical decisions for you ONLY if you cannot make your own decisions.

Some forms ask about flexibility for your decision maker. On some forms, flexibility is called leeway.

You chose that your decision maker can have flexibility when making medical decisions for you.

Health Care Wishes

Some forms ask about treatments that are used to try to keep people alive, such as CPR or a breathing machine.

You chose wanting to try treatments for a period of time, but stop if you are suffering.

People who agree with this often mark down that they would be willing to try CPR and/or a breathing machine, but only for a little while.

Talk to your doctor about the options that may be right for you.
PREPARE Improves Patient Engagement in ACP

- Senior centers, 70 years, 92% never used a computer

Randomized Trial: Patient-facing ONLY

VS.

Results Coming Soon!!!
ACP Out to the Community
PREPARE as a Movie

Toolkits for creating movie events for libraries, churches, senior centers, group medical visits
Toolkit Testing

• Senior Centers

• Group Medical Visits
Senior Centers: The Videos were Easy to Understand

N=75

- 47% Strongly Agree
- 53% Agree
- I have no opinion
- Disagree
- Strongly Disagree
Ready to answer questions about preferences for medical care

N=75

- Strongly Agree: 38%
- Agree: 55%
- I have no opinion: 6%
- Disagree: 2%
- Strongly Disagree: 1%

San Francisco VA Medical Center
Division of Geriatrics
Recommend session to friend or family

N=75

- Strongly Agree: 68%
- Agree: 29%
- I have no opinion
- Disagree
- Strongly Disagree

Sample size: 75
Senior Center Feedback

• “I talked to my doctor about this last year, but this program helped me understand so much better. I will be talking to him and changing my plan.”

• “I was "wishy-washy" about my decisions and discussing them with family but this gives me a framework to work with.”
Group Medical Visits SFGH, n = 22

- Pre-to-post: 1 week
  - Surrogate designation 48% to 85%, $p = 0.01$
  - AD form completion 9% to 24%, $p = 0.21$
Vulnerable Populations
Cool New Stuff

PREPARE for Your Care helps you:
- Have a voice in YOUR medical care
- Talk to your doctors about your wishes
- Give your family and friends peace of mind

Start Using PREPARE

Comience a usar PREPARE

Learn more about PREPARE »
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 Advance Directives

California Advance Health Care Directive

This form lets you have a say about how you want to be treated if you get very sick.

This form has 3 parts. It lets you:

**Part 1:** Choose a medical decision maker.
A medical decision maker is a person who can make health care decisions for you if you are too sick to make them yourself.

**Part 2:** Make your own health care choices.
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 too sick to tell them yourself.

**Part 3:** Sign the form.
It 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 11 or a notary public on page 12.

Your Name: __________________________

California Advance Health Care Directive

This form lets you have a say about how you want to be cared for if you get very sick.

This form has 3 parts. It lets you:

**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 too sick to make them yourself.

**Part 2:** Make your own health care choices, Page 6
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 too sick to tell them yourself.

**Part 3:** Sign the form, Page 11
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 12, or a notary on Page 13.

Your Name: __________________________
Gordon & Betty Moore Funding

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Your Name
The Next Frontier

• Developing Chinese PREPARE 準備
  – Translation complete → videos

• Telehealth
Measuring ACP

• Redefine from advance directives → process of many behaviors over time

• ACP Engagement Survey
  – 4-item survey in English & Spanish
    • Screening & targeting

Sudore RL et. al., J Pain and Symptom Management, 2017
Thank You!

www.PrepareForYourCare.org

✉️ : rebecca.sudore@ucsf.edu

🐦 : @prepareforcare
4-Item: How ready are you to (5pt Likert):

1. Sign official papers naming a person or group of people to make medical decisions for you?

2. Talk to your decision maker about the kind of medical care you would want if you were very sick or near the end of life?

3. Talk to your doctor about the kind of medical care you would want if you were very sick…?

4. Sign official papers putting your wishes in writing?
Measures Readiness → Stage of Change

- Never thought @ it/not ready = Pre-contemplation
- Thinking @ doing it in next 6 mo = Contemplation
- Planning to do it in next 30 days = Preparation
- Already did it w/in 6 months = Action
- Did it > 6 months ago = Maintenance

Sudore RL et. al., J Pain and Symptom Management, 2017