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Palliative Care

What Matters Most:
A Virtual Advance Care Planning Workshop

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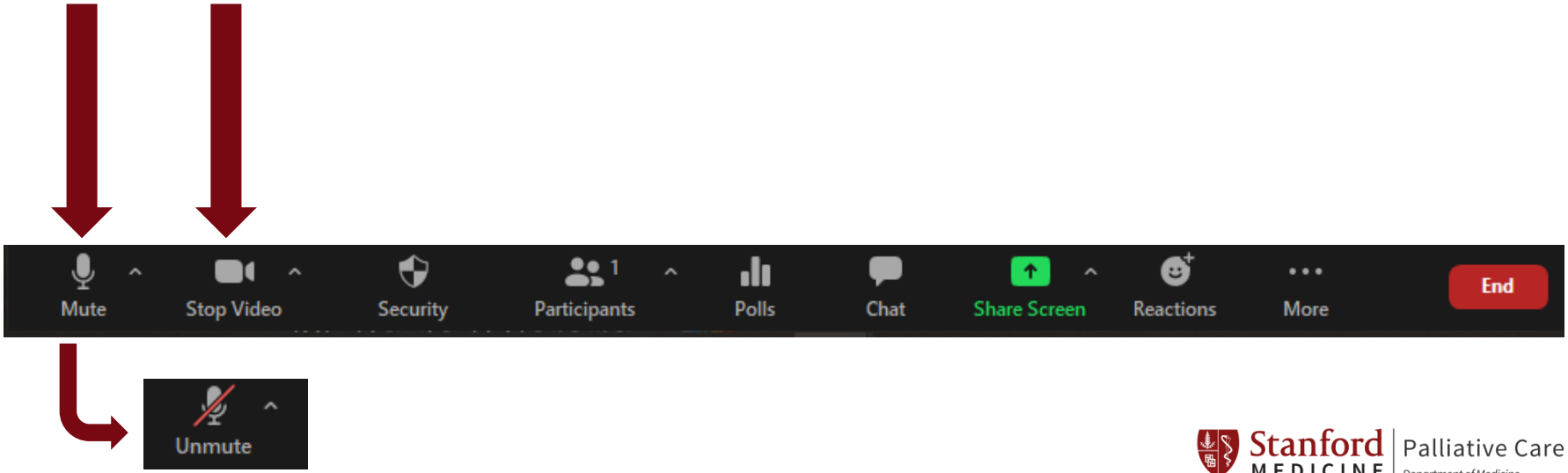
Quick Intro to a ZOOM Webinar

- Please feel free to share your video
  - No judgment if you are in your PJs!
- Please MUTE yourself if you are not talking



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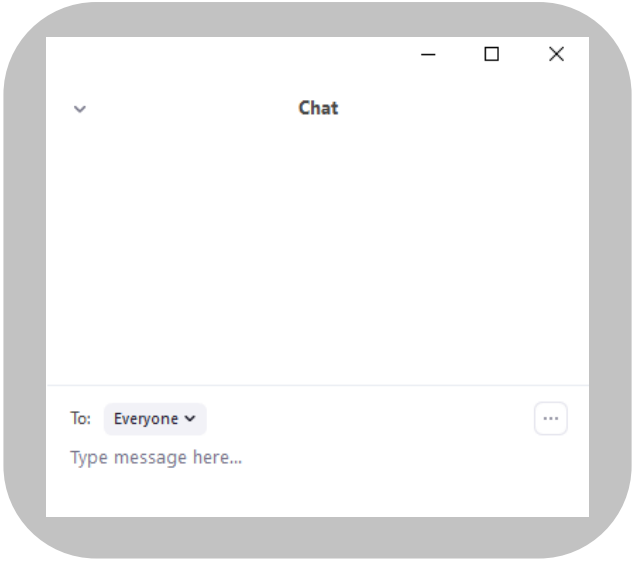
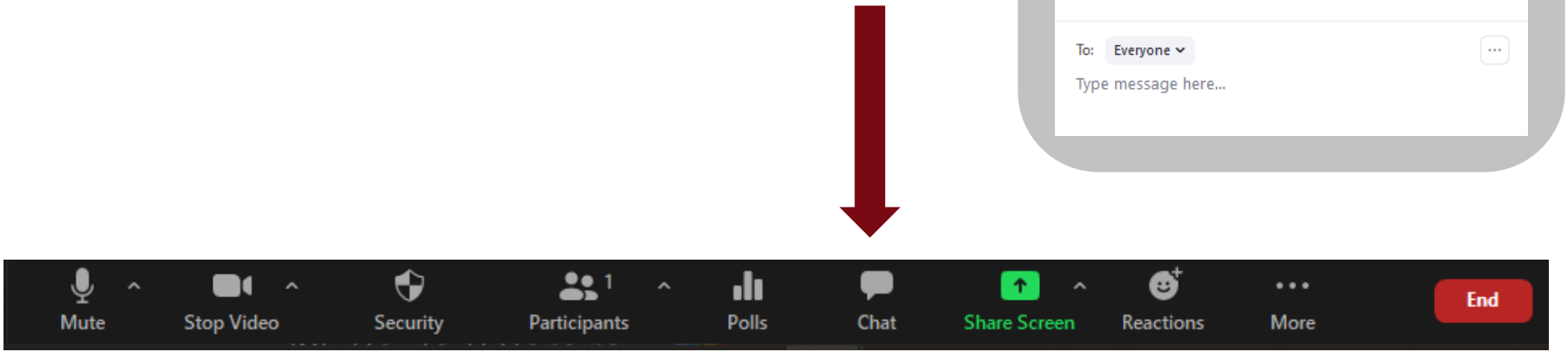
Quick Intro to a ZOOM Webinar

- To ask a question:
  - Click on the “Chat” box
  - Type your question and press “Enter” or “Return to post your question or comment





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Roadmap

- Getting to know each other
- What is Advance Care Planning?
- Why think about this now?
- Where do I start?

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Getting to Know Each Other: Ground Rules

- This can be difficult. This is personal.
- Be kind to yourself. Be kind to others.
- Only share what you feel comfortable sharing with everyone in the meeting.

Getting to Know Each Other

- Why am I here?

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Defining Palliative Care

- **Definition:**
  - Palliative care is specialized health care for **people living with a serious illness**.
  - This type of care is focused on **providing relief from the symptoms and stress of the illness.**
  - The goal is to **improve quality of life** for both the **patient and the family.**

Center to Advance Palliative Care (CAPC), 2019

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Defining Palliative Care

- Provided by a specially-trained **team**, palliative care specialists work together with a patient's other doctors to **provide an extra layer of support**.

- Palliative care is based on the needs of the patient, not on the prognosis. It is appropriate **at any age and at any point in a serious illness** and **can be delivered with curative treatment.**

Center to Advance Palliative Care (CAPC), 2019

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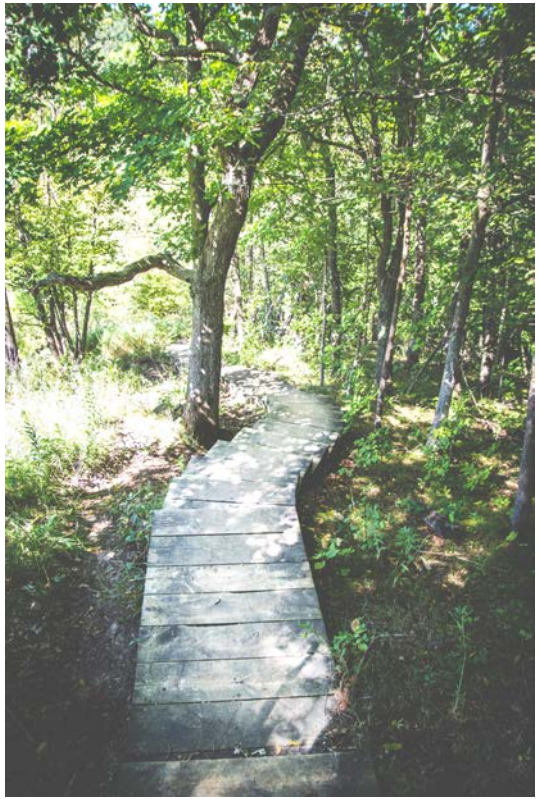
Palliative Care

Hospice

Getting to Know Each Other



- What brought you here?

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Roadmap

- Getting to know each other
- **What is Advance Care Planning?**
- Why think about this now?
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What is Advance Care Planning?

- Advance care planning is **making decisions** about the health care you would want to receive **if you become unable to speak for yourself**.
- These are **your decisions to make**, regardless of what you choose for your care.
- The decisions are **based on your personal values**, preferences, and discussions with your loved ones.

National Hospice and Palliative Care Organization, 2019

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What Type of Decisions Should We Think About?

- Who would you want to make decisions for you if you were unable to communicate?
- What makes life worth living given your current health status?
- What would be important to you if you were seriously ill or even at the end of your life?

What Type of Decisions Should We Think About?

- Are there limitations you would put on life-prolonging treatment?
- Would you want to receive cardiopulmonary resuscitation or be placed on a breathing machine?

“The Tree of Life”

Health Care Decisions

What Makes Life Worth Living

Health Status

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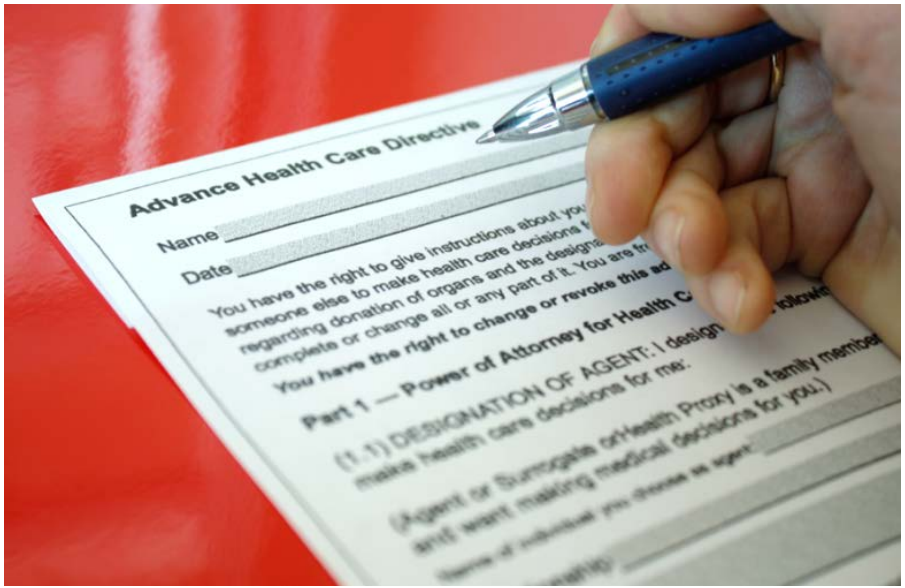
Definitions



- **Advance Directive (AD)/Living Will:**
  - A written document that helps you tell doctors (and your loved ones) how you want to be treated if you cannot speak for yourself.
  - Consider what treatments you would (or would not) want.

Definitions

- **Durable Power of Attorney for Health Care (DPOA)/Health Care Proxy (HCP)/Surrogate Decision Maker**:
  - Names someone to make medical decisions for you at a time when you are unable to do so.
  - This person should be familiar with your values and wishes.

National Institute on Aging, 2019

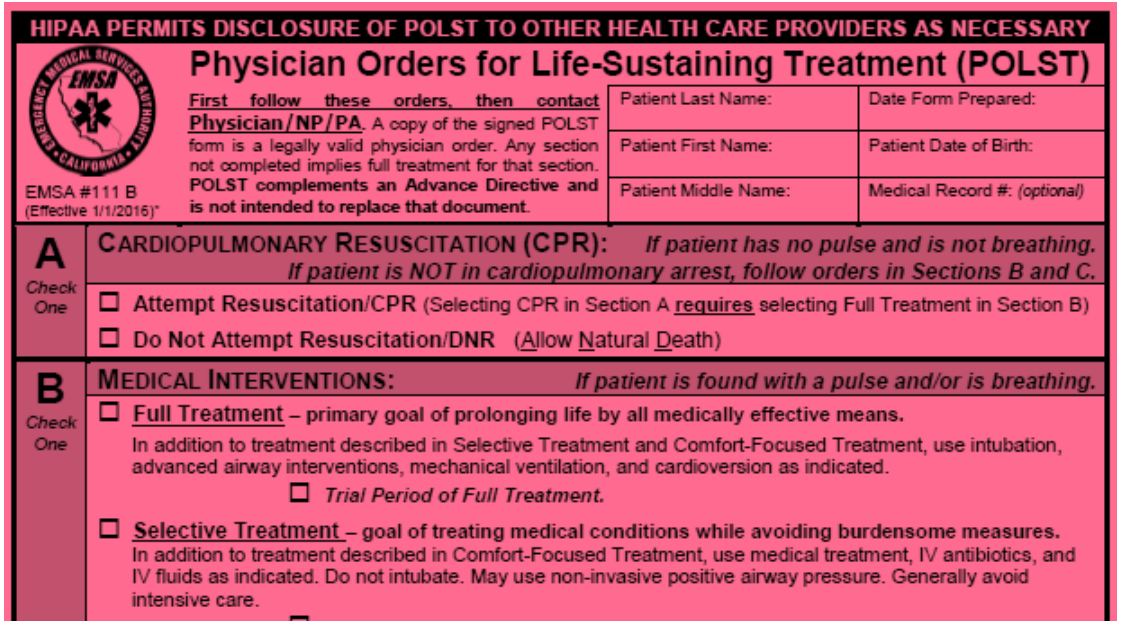
Definitions

- **Do not resuscitate/Do not intubate (DNR/DNI):**
  - A physician order placed in the hospital
  - Would not want CPR (cardiopulmonary resuscitation) or other life-support measures (such as a breathing machine).

Adapted from National Institute on Aging, 2019

Definitions

- **Physician Orders for Life-Sustaining Treatment (POLST):**
  - A physician order outside of the hospital.
  - Types of interventions healthcare professionals would take outside of the hospital.



HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTH CARE PROVIDERS AS NECESSARY

Physician Orders for Life-Sustaining Treatment (POLST)

EMSA #111 B
(Effective 1/1/2016)"

First follow these orders, then contact Physician/NP/PA. A copy of the signed POLST form is a legally valid physician order. Any section not completed implies full treatment for that section. **POLST complements an Advance Directive and is not intended to replace that document.**

Patient Last Name:	Date Form Prepared:
Patient First Name:	Patient Date of Birth:
Patient Middle Name:	Medical Record #: *(optional)*

A Check One — CARDIOPULMONARY RESUSCITATION (CPR): *If patient has no pulse and is not breathing. If patient is NOT in cardiopulmonary arrest, follow orders in Sections B and C.*

☐ Attempt Resuscitation/CPR (Selecting CPR in Section A requires selecting Full Treatment in Section B)

☐ Do Not Attempt Resuscitation/DNR (Allow Natural Death)

B Check One — MEDICAL INTERVENTIONS: *If patient is found with a pulse and/or is breathing.*

☐ Full Treatment – primary goal of prolonging life by all medically effective means.
In addition to treatment described in Selective Treatment and Comfort-Focused Treatment, use intubation, advanced airway interventions, mechanical ventilation, and cardioversion as indicated.

☐ *Trial Period of Full Treatment.*

☐ Selective Treatment – goal of treating medical conditions while avoiding burdensome measures.
In addition to treatment described in Comfort-Focused Treatment, use medical treatment, IV antibiotics, and IV fluids as indicated. Do not intubate. May use non-invasive positive airway pressure. Generally avoid intensive care.

Adapted from National Institute on Aging, 2019

Roadmap

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- **Why think about this now?**
- Where do I start?

Its always too early, until its too late”

-The Conversation Project, 2013

Most people agree that this is important

- **90%** say **talking to your loved ones about end of life** care is important
  - Only **27%** have actually done so
- **60%** say that making sure their **family is not burdened by tough decisions** is “extremely important”
  - But **56% have not communicated** their end of life wishes
- **82%** say it’s important to put their **wishes in writing**
  - Only **23%** have actually done it

Sources: CDC, Conversation Project National Survey (2013), Survey by the California Healthcare Foundation (2012)

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Most people need help with decision-making

- **40% of all hospitalized patients** are **incapable of making their own treatment decisions**
- **70% of decedents** age 60 and older at death **faced treatment decisions in the final days of life and were incapable of participating** in these decisions.

Raymont (2004) Lancet
Silveira (2010) NEJM

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0.9% SODIUM CHLORIDE
INJECTION, USP

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Even for people who are healthy

Does any of this make a difference?

- If patients had advance care planning conversations:
  - More likely to have their **wishes known and followed** (Detering et al. 2010; Houbin 2014)
  - **Family members** are **more** likely to be **satisfied** with the quality of death (Detering et al. 2010)
  - **Less likely to receive intense interventions** (mechanical ventilation, CPR, die in ICU, use feeding tube) (Zhang et al. 2009, Teno et al 2008, Wright et al. 2008, Brinkman-Stoppelenberg 2014)
  - **More likely** to receive outpatient **hospice** and be referred to **hospice earlier** (Zhang et al. 2009, Wright et al. 2008)

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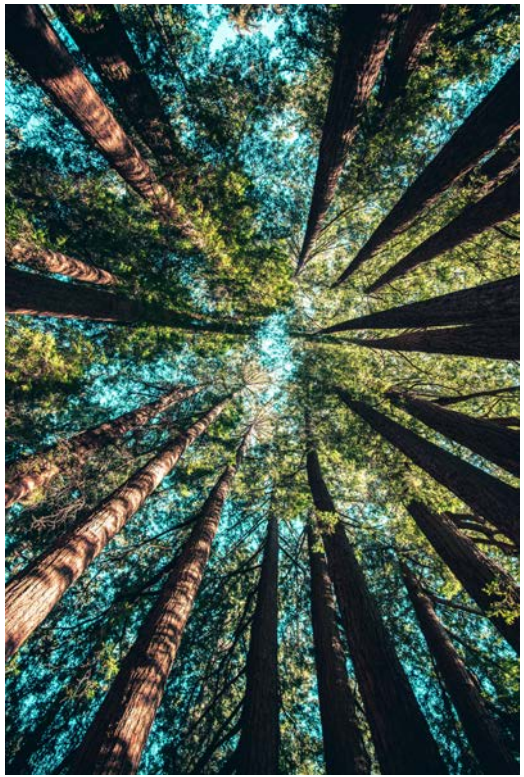
1. Talk with your doctor

- People make different decisions depending on their health status
- Don’t be afraid to ask your doctor(s)

2. Think about what matters most



- Consider hopes, goals, priorities, values
- Consider worries, fears
- Consider tradeoffs
  - What can you not live without?
- Uncertainty is OK

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Photo by Casey Horner on Unsplash

3. Choose a DPOA/Health Care Proxy

- It's impossible to think through every scenario

- What makes a good surrogate decision maker
  - Knows your values
  - Able to bring your voice
  - Available

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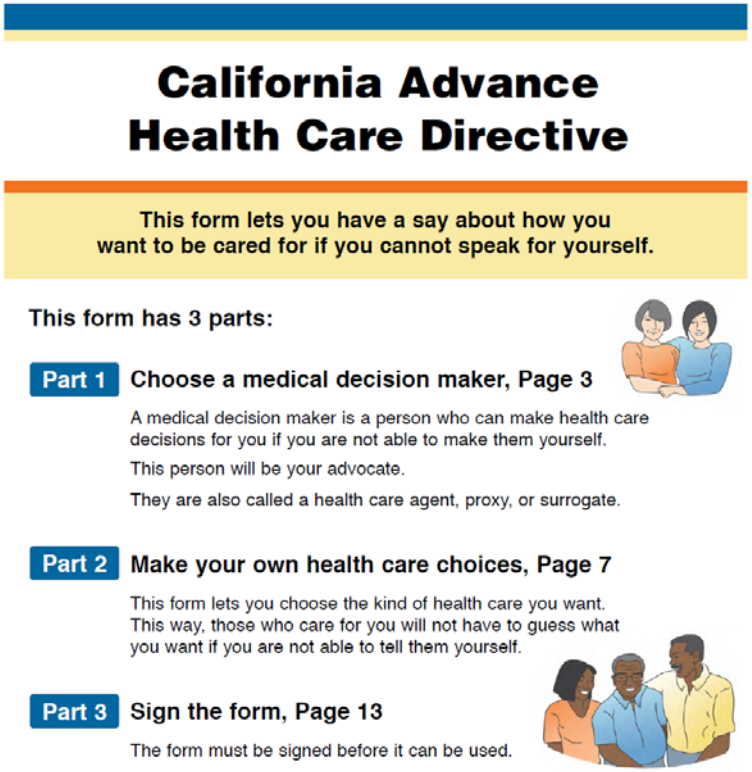
4. Complete an Advance Directive



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.

- Putting some thoughts in writing can be helpful

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Additional Resources

- The Conversation Project
  - https://theconversationproject.org
- PREPARE For Your Care
  - https://prepareforyourcare.org
- Stanford Palliative Care Advance Care Planning Website
  - www.med.stanford.edu/palliative-care

How Do I Get Palliative Care at Stanford?

- You can refer yourself
  - Call our clinic at (650) 724-0385
  - Website: http://med.stanford.edu/palliative-care.html
- You can ask your doctor to place a referral
- Locations in Palo Alto, South Bay, and Emeryville
  - TeleHealth also available!

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Thank You!

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Other Options in Serious Illness

- No matter what, we are here to support you and your family
- If at any point, you choose not to pursue life-prolonging therapy or treatment, there are still ways to care for you and ease suffering from illness

Practical Advice for Preparing for Serious Illness

- Set up a Video Chat app with your loved ones (Skype, FaceTime, Zoom, Google Duo, WhatsApp)
- Plan for Medications – keep a list, keep a supply, call clinic early if need refills
- Plan for Pets – who could care for them if needed
- Plan for Money/Bills – who could help manage money if needed
- Plan for a Hospital Visit – Bring any advance directives, phone numbers for emergency contacts; bring glasses/hearing aids/dentures/mobility devices

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