

Your Values – Your Choice – End of Life Care Planning
 Sponsored by the End of Life Ministry at St. Aidan’s Episcopal Church, San Francisco
 30 April 2023 – in Person – following Church Service
 3 May 2023 – 7 pm – ZOOM – Evening Prayer Link
 Mileva Saulo Lewis, EdD, RN – Discussion Leader

NOTE: This information is intended to be a guide to facilitate decision making by providing you, your families, and designated decision makers with the appropriate questions to ask your health care provider/s when determining end-of-life care. It is not intended to be a substitute for conversations with your family, loved ones and health care provider and is not to be considered medical advice.

Legal Options - Dying In California – Focus for Today

- Advance Directive – your wishes, Appoint a designated decision maker – agent- surrogate – proxy – YOUR VOICE
- Physician Order for Life Sustaining Treatments (POLST)

Durable Power of Attorney for Health Care (DPAHC) - Advance Directive

- A gift you give your family, friends
- Legal and Ethical Foundation – Autonomy - Self Determination, Respect of person
- Legal document (does not require a lawyer)
- A surrogate or proxy or health care agent, Designated Decision Maker (DDM)
 - Makes health care decisions when you cannot speak for yourself
 - **Substituted Judgment - Carries out your wishes**
 - **No Advance Directive – Guessing - use best interest**

Role of a Surrogate, Proxy, Health Care Agent, Designated Decision Maker

- Your Voice when you cannot speak for yourself
- **Carries out your wishes - Substituted Judgment**
- **No Advance Directive – Guessing - Use best interest standard**
- **The Substitute/surrogate/proxy**
 - Enhances the good
 - Eliminates the bad features

Choosing a Surrogate

- Adult, Proximity, alternate
- How well do they know you and your choices?
- Do you trust that he/she/they can and will carry out your wishes?
- Are there potential family conflicts?

Qualities of a Surrogate

- Ability to make a reasoned judgment
- Adequate knowledge and information
- Emotional stability
- Partiality to the incompetent patient’s interests
- No conflict of interest, controlling influences

Health Care Decision Making - With Advance Directive

- Your Decision while you are Competent
- Your Advance Directive - Your Wishes - Clear and convincing evidence
- Not competent – The Substitute/Agent/Proxy/Surrogate

Health Care Decision Making – No Advance Directive

- All life support measures are used
- Disputes can be referred to a Health care ethics Committee or Mediation Service
- No longer a medical decision
- Next of Kin Laws – As of January, 2023
- In the absence of agreement- defer to “next of kin”

Physician Order for Life Sustaining Treatments - POLST -

- Calling 911 – Presumes you want ALL bells and whistles
- Doctor’s Order – your preferences
- POLST – honors your wishes away from Hospital
- Pink/Purple Paper
- VISIBLE - On your refrigerator or Entrance to your home
- Will be honored by Emergency Medical Services (EMS)

Technology - Life Sustaining Treatment or Prolonging Death Original Intent and Current Practice

- Cardio Pulmonary Resuscitation (CPR)
- Defibrillator
- Ventilator
- Artificial Hydration
- Artificial Nutrition

Life Sustaining Treatments – RIGHTS

- Autonomy - Right of Self-Determination
 - Right to accept
 - Right to refuse
- Obligation of others to accept – MD, Family, Friends
- Exceptions

Autonomy and Informed Consent

- Information – in language that is understood
- Understanding – Options & benefit and burden evaluation
- No coercion

Competence

- May vary over time
- Ability to perform a task
- Ability to decide – may vary with the task

Incompetence – An inability to:

- Express or communicate a preference or a choice
- Understand one’s situation and its consequences
- Understand relevant information; give a reason; rational reason

- Give risk/benefit reasons
- Reach a “reasonable” decision

Prudent Questions to Ask - Purpose – Goal – Desired Outcome – How will we know?

- Plan A – Hope for The Best
- Plan B – Plan for the worst
- Benefits of Doing, Not Doing
- Harms of Doing, Not Doing

Focus for Future Sessions

3 May 7 pm – ZOOM – Repeat of this Session

31 May – End of Life Care Planning, Part II - Health Related

- Voluntary Stop Eating and Drinking (VSED)
- Stop life-prolonging treatment (medications, mechanical interventions, etc.)
- Pain and terminal sedation to point of unconsciousness.
- Hospice, Palliative Care
- End-of-Life Option Act – Medical Aid in Dying

21 June - Options for the handling of the deceased’s body, and mortuary services

19 July - Planning your Memorial Service/Celebration of Life/Funeral

Session Evaluation

- What went well?
- What would you change for future sessions?

Organizations – Guides/Aides to Conversations about End of Life Care Planning

The Conversation Project is dedicated to helping people talk about their wishes for end-of-life care. No guide and no single conversation can cover all the decisions that you and your family may face. What a conversation can do is provide a shared understanding of what matters most to you and your loved ones. This can make it easier to make decisions when the time comes. The starter kit is free, available using the web site below. You can copy it and then complete it as it relates to you.

- <https://theconversationproject.org>
- <https://theconversationproject.org/wp-content/uploads/2020/12/ConversationStarterGuide.pdf>

The Conversation Project: Founder Ellen Goodman’s Ted-Talk

<https://theconversationproject.org/tcp-blog/ted-talk-featuring-ellen-goodman/>

Hospice Giving Foundation

<https://hospicegiving.org>

California POLST

<https://hospicegiving.org>

The Death with Dignity National Center:

<http://www.deathwithdignity.org/learn/healthcare-providers>

California Coalition for Compassion Care California:

- <http://coalitionccc.org>

HEALTH CARE SYSTEMS

KAISER PERMANENTE

Life Care Planning Document — These on-line resources are available to all – need not be a Kaiser plan member.

- What is Life Care Planning – Getting Started
 - <https://healthy.kaiserpermanente.org/health-wellness/life-care-plan>
- My Life – My Values – Consider your Values and Sentence Starters
 - <https://healthy.kaiserpermanente.org/health-wellness/life-care-plan/your-values>

SUTTER HEALTH

Hospice and Palliative Care – what is the difference?

<https://www.sutterhealth.org/health/caregiving-end-of-life/difference-between-palliative-care-and-hospice>

Advanced-Illness Management

<https://www.sutterhealth.org/services/palliative-advanced-illness-management>

Palliative Care:

<https://www.sutterhealth.org/services/palliative-advanced-illness-management/palliative>

DIGNITY HEALTH

End of Life Option Act Statement – Mercy Hospital

<https://www.dignityhealth.org/central-california/locations/mercymedical-merced/about-us/end-of-life-option-act>

Statement of Common Values:

<https://www.dignityhealth.org/central-california/-/media/Service%20Areas/central-california/Documents/statement-of-common-values.ashx?la=en&hash=3051D3CCBE2A9090533A3F0D97FDD84149C35172>

Advance Care Directives – Other Sources

California Medical Association – The document is not free

https://www.cmadoocs.org/store/info/productcd/AHCD_ENG/t/advance-health-care-directive-kit-english