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Advance Healthcare Directives

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Advance Healthcare Directives

- In California, we call it an Advance Directive
- Other states call it a living will, durable power of attorney for healthcare, designation of agent, etc.
- What it includes:
 - **What** you want if your brain doesn't work
 - **Whom** you want to speak for you
- If you want your decision maker to be a good advocate for you, you need an Advance Directive
- You can change the form as your health changes or your personal preferences change

Where Can You Get the Form?

- Front desk of your hospital
- Some doctor's offices
- www.caringinfo.org
- www.AgingWithDignity.org
- If you are part of the VA, they have their own form
- If you are part of another health organization, they may also have their own form
- You can do it yourself for free
- You can but don't have to use a lawyer

When Does the Advance Directive Go Into Effect?

- 1. Does the patient realize there is a decision that needs to be made?
- 2. Can the patient understand what is being said about the disease and the treatment options?
- 3. Can the patient understand the consequences of each of the different options, including the option to do nothing?
- 4. Can the patient think about what he or she wants to do based on his or her own values/beliefs and how the choices would affect his or her life?
- 5. Can the patient communicate his or her decision to the doctor and explain why he or she has made this decision?

The Decision-Making Framework

Framework	Ranking	Definition
Autonomy	Best option	Autonomy means a person with decisional capacity is allowed to make decisions about what will happen to his or her own body.
Substituted Judgment	2 nd best option	Substituted Judgment is used when the person has lost decisional capacity. Someone else will make the decisions based on the <u>patient's values and wishes</u> .
Best Interest Standard	3 rd best option	A decision maker and/or the healthcare team, who may or may not know the patient, will make the decision without the benefit of knowing what the patient would want. What would a generic or reasonable person want in this situation?

Your Role as The Decision Maker - Substituted Judgment

- The decision maker is supposed to step into the patient's life and speak with the patient's voice—not his/her own voice
- *“What would the person be telling us if he or she were able to speak right now?”*
- Consider all that is known about the person
 - What she/he has said in the past?
 - What are her/his values, religion and culture?
 - What would be important to her/him?
- *“If my husband could speak right now, he would be telling you _____.”*

California Probate Code 4714

- The surrogate decision maker **MUST** make health care decisions according to the patient's instructions or wishes, if known, or in the patient's best interest as determined by the patient's personal values (NOT the surrogate's values) if the patient's wishes are not known.
- *If you can't do this, that's okay. Have someone else be the decision maker.*

Quick Tips – Whom should you pick?

- 1. Pick someone who will understand what the doctor is saying.
- 2. Pick someone who knows you well and has listened to what you want.
- 3. Pick someone who won't fall apart in a crisis.
- 4. Pick someone who will do what you have asked, even if it difficult to do.
- 5. Pick someone who is close by geographically.
- 6. Write down whom you don't want to be involved in the decision making.
- 7. You can pick two or three people to work together as your decision makers. You can also state who you don't want participating.
- 8. Your spouse, significant other or partner may not be your best choice, and you may want to choose someone else.
- 9. In the "Other" section of the form, state whom you do and don't want to be told your medical information.

Better Information = Better Decisions

- When asked what patients might want if they were in advanced dementia state in a skilled nursing facility:
 - 50% comfort care
 - 21% everything done
 - 18% some interventions
 - 11% unsure
- After being shown a 2-minute video of a patient with advanced dementia being cared for in a SNF:
 - 89% comfort care
 - 0% everything done
 - 11% some interventions or unsure
 - Differences regarding race, ethnicity and education level disappeared

Be Sure You Know What You are Choosing!

- 1. Patients don't understand what really happens during CPR
- 2. Patients think it works just like on television
- 3. Patients don't understand that they may come back to life in a worse condition than they were in before, both mentally and physically
- 4. Patients don't understand that the type of death they are choosing is probably not what they would want if they understood

Making the Decisions Meaningful

- **People have strong preferences about how they want to receive care.**
 - *“What makes your life worth living?”*
 - *“What would be a fate worse than death?”*
 - *“What would be an acceptable level of better?”*
- **End of life conversations are about respect**

“It is important that is to know how to treat you with respect if you can’t speak for yourself. In your culture/religion/family, are there certain things that must be done for someone when he/she is sick/dying/has died.”

Quick Tips – What would you want?

- 1. This form goes into effect when your brain isn't working anymore, not just when you are dying.
- **2. Don't be too specific about the particular treatments you want or don't want, because you don't know what the medical situation will be when you need this form.**
- 3. Write out a meaningful recovery statement describing what kind of life you would want if you were disabled and couldn't think anymore.
- **4. Tell the doctors what they should do if you were going to live in a terrible condition, as well as what you would want if you were dying.**
- 5. Write down anything else you want your doctors and loved ones to know about where or how you want to die, organ donation preferences or autopsy instructions.
- Make sure that your decision makers, your doctors and the hospital get copies of your form and that you talk about it with those who will be involved in your care.

“A Meaningful Recovery”

“I value a full life more than a long life. If I have lost the ability to interact in a meaningful way with those that matter to me and have no reasonable chance of regaining this ability; or if my suffering is intense and irreversible, even though I have no terminal illness, I do not want to have my life prolonged. I would not then ask to be subjected to surgery or to resuscitation procedures, to intensive care services, or to other life-prolonging measures, including the administration of antibiotics, blood products or artificial nutrition and hydration. I also believe that the financial and emotional burden on my family should be considered in making these types of decisions.”

Making Your Form Personal

- *Where would you want to die?*
- *Whom do you want with you while you are dying?*
- *How do you want to live while dying?*
- *Is there value in “fighting” your illness? Even if you feel worse during your last days/weeks/months?*
- *Would you rather spend your time living your life without the side effects of treatments, even if it will be shorter because you are not receiving the treatment?*
- *What is important for you to do before you die?*
- *What if you aren't dying but in a terrible condition?⁴*

Talk to Your Doctor Before You Sign Your Form

- Before you meet with your doctor, go through the document at home and:
 - Write down what would be meaningful to you
 - Write down your questions about the treatment options
- **Before you sign your advance directive, ask the doctor:**
 - 1. Does what I have written down make sense to you? Have the doctor explain it in his/her own words.
 - 2. Will you be willing to honor my wishes? You want a doctor who will respect your choices.
 - 3. Is there anything else that I should consider including based on my illness/injury that I haven't thought about?

It Won't Work If Nobody Knows Where It Is or What You Meant!

- Who should you tell about it? Everyone. Make sure you have these important conversations with your doctors, your decision maker and your alternates
- Who should you give it to? Give copies to your decision maker, your alternates, your doctors, and the hospital in your neighborhood
- Where should you keep it? In your medicine cabinet, on your refrigerator, at your bedside, in your car, in your purse or anywhere else that might make it easy for someone to find it in an emergency

Decision Making Tools

- **Questions to Ask When Making Medical Decisions**
www.TheCaregiversPath.com on resource page
- **Go Wish Cards** www.gowish.org (English and Spanish)
- **Insider's Guide to Filling Out Your Advance Directive**
www.TheCaregiversPath.com on resource page
- **Thinking Ahead Project** <http://www.coalitionccc.org>
(English, Spanish, Korean, Chinese)
- **Consider the Conversation** – documentary about making the decisions meaningful
www.considertheconversation.org
- **The Caregiver's Path to Compassionate Decision Making: Making Choices for Those Who Can't** by Viki Kind
- **Pre-hospital DNR = "POLST"** www.CAPOLST.org and www.POLST.org (multiple languages including Braille)

POLST – Physician Orders for Life-Sustaining Treatment

- **Intended for the frail and elderly, those who have a compromised medical condition, a prognosis of one year of life or a terminal illness**
- **If you are healthy, you don't need this yet**
- POLST documents physician orders after discussion with the patient or decision maker regarding:
 - Patient's preferences regarding CPR
 - The amount of medical interventions, and
 - Artificially administered nutrition
 - Patient may use POLST to request or refuse interventions
- It is portable from one care setting to another – including in the home and in an ambulance