



How to Prepare for the Inevitable

A Discussion on End-of-Life Care and the Paperwork Involved

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Goals of this presentation

- Gain empowerment to start the conversation regarding End-of-Life care.
- Explore why you need to plan for End-of-Life using Advance Directives.
- Learn the difference between Advance Directive, Living Will, Medical Power of Attorney and MOLST (Medical Order of Life Sustaining Treatment) forms.
- Learn how to fill out these forms to reflect your wishes.
- Learn how to make changes in these documents if you change your mind about any of these decisions.
- Provide support and resources for how you can make your preferences known for life support nearing the end-of-life.
- Recognize that illness, suffering, disability, aging and dying are all natural and normal parts of life.



What is Advance Care Planning (ACP)?

Ongoing discussions between patients, family and healthcare providers aimed at:

- Learning about the different types of healthcare decisions that may need to be made as your health declines.
- Clarifying goals of care for your healthcare based on your needs, goals and values.
- It is an essential part of a life well lived.
- Like financial and estate planning, end-of-life planning begins long before someone is faced with a crisis or life-limiting illness.
- ACP is done by completing your Advanced Directives, Living Will and possibly a MOLST form.
- It is also done by having ongoing conversations with your family and healthcare providers to ensure understanding of your disease process.



Most important factors at End-of-Life

1. Making sure family is not burdened financially by my care
2. Being comfortable without pain
3. Making sure family is not burdened by tough decisions about my care and having loved ones around me
4. Being able to pay for the care I need

Source: Californian's Attitudes Toward End-of-Life Issues, Lake Research Partners, 2011. Statewide survey of 1,669 adult Californians, including 33 respondents who have lost a loved one in the past 12 month.



What are goals of care?

- What is most important to you as you near the end of your life?
- A conversation addressing “goals of care” helps patients and families with a serious illness clarify their values regarding end-of-life care.
- Your providers want to respect your values by caring for you in a way that reflects your hopes, expectations and values.



How do you explore goals of care with your provider

- **Gather information** from all providers/consultants; setup a meeting with patient, family and primary care or attending provider; invite your pastor or spiritual leader.
- **Gain an understanding** of current condition and disease process.
- **Ask your provider to explain** your medical information and known course of your disease process.
- **Make sure your provider confirms your understanding and provides further explanation.** Tell the provider in your own words your understanding of your health situation.
- **What are your priorities?** What are your hopes, worries and expectations? What is most important to you?
- **Review:** Are there any treatments you would not want?
- **Recommend:** What plan or treatments will help meet your goals?



How do you start
these conversations?

Consider...

Do you have one or more chronic and/or progressive diseases like:

- COPD Chronic Obstructive Pulmonary Disease
- CHF Congestive Heart Failure
- Diabetes
- Other Cardiovascular or Pulmonary Disease
- Chronic Kidney Disease
- Neurological disorder like Parkinson's or Dementia


What do you and your family understand about your current health situation?

What does the future look like in regard to your health?

Most of us make better decisions if we understand our disease progression and possible outcomes.

Continue the conversation

- Do you have worries, fears, concerns or mistrust about your disease progression and how you receive healthcare?
- When your health condition declines, when would it be ok to shift your focus from aggressive treatments to a focus on comfort and good quality of life?
- Do you value being independent, or would you be ok if you needed more care and had to live in a nursing home?
- Would you prefer to spend your last days and hours at home or in a hospital or other facility?
- Are there kinds of treatments you would want or not want in certain situations?
- Would you want to be kept alive on life support even if you may not be able to talk, eat or interact with your family?



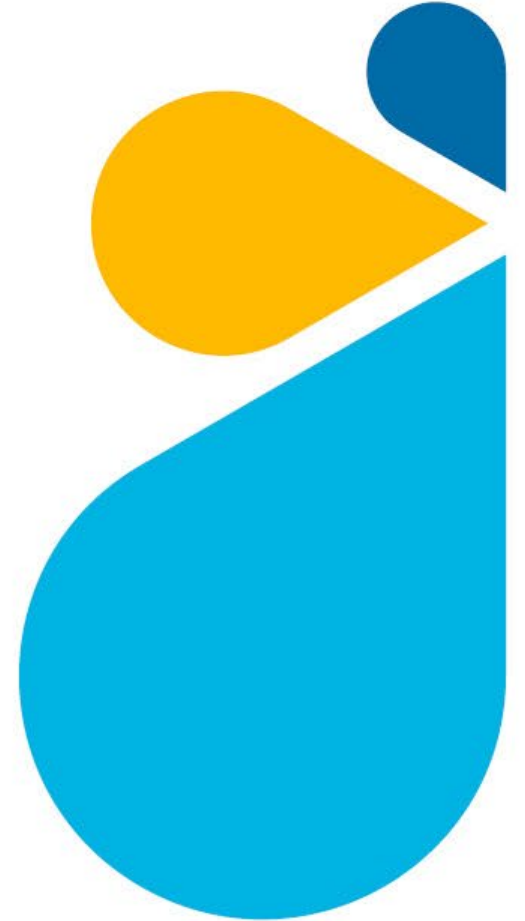
Everyone has their own ideas and values.
There are so many choices to consider.

Think about...

- What do you value or what really matters most to you?
- What are your experiences with losing a loved one?
- Who helps you with your major life decisions?

These questions bring about conversations on what is important to you nearing the end of life to help guide decision making.

It also helps your family and providers give you the care you would want, even if you cannot speak for yourself.



Benefits of Advance Care Planning

- Treatment consistent with patient wishes
- Improved quality of care and quality of life
- Improved patient and family satisfaction with care
- Improved end-of-life care
- Reduced physical and psychological distress in the last days of life among patients and families



Why do you need an Advance Directive?

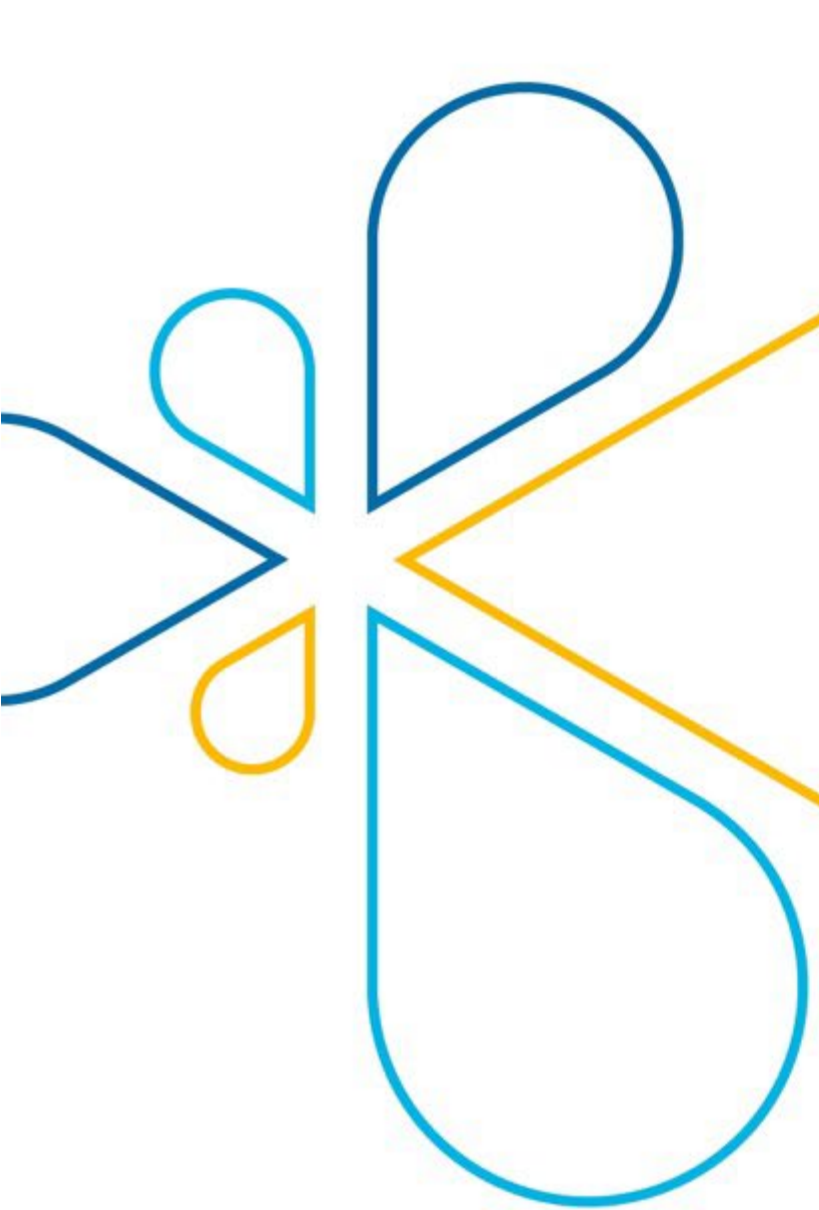
(also called a Living Will or Durable Power of Attorney)

Advance care planning is used to make your wishes known so your family and healthcare providers can make decisions about your treatments in case you are unable to make decisions or communicate your own preferences for medical care.

About 1/10 of us will have a diagnosis of dementia, further complicating advanced care planning.

When someone is deemed incompetent, they can no longer fill out Advance Directives. It is up to the next of kin to make these decisions. Sometimes families must make decisions without ever having these conversations. This can be burdensome for family members.





“While death is dreadful and a real ground
for fear there are worse things than death.”
— St. Francis of Assisi

Living Will – completed by a lawyer (as part of financial/ estate planning)

Living Will

To my family members, my physician(s) and hospital caretakers:

Should the time come when it is medically confirmed that there is no reasonable hope for my recovery, I direct that I be allowed to die naturally, receiving only the administration of comfort care. I do not wish to have my life prolonged by artificial means. Should I become unable to participate in decisions regarding my medical treatment, it is my intention that my wishes be honored by my family and my physician(s).

Explanation of the Maryland Advance Directive form

Steps of an Advance Directive

- Select your healthcare agent/medical power of attorney and possibly a backup agent. Your agent will make healthcare decisions for you in accordance with what your agent determines to be in your best interest. Your agent will consider your personal values and beliefs along with the help of healthcare professionals.
 - You decide what power or limitations you want for your agent and how your agent is to decide on specific issues or situations.
 - Optional — decide if there are other “people my agent should consult”
 - Effectiveness of agent’s authority — When does your agent’s power start?

This usually happens when you cannot speak for yourself.

- Make your treatment preferences known if you are in a:
 - Terminal Condition
 - Persistent Vegetative State
 - End Stage Condition
- Signature and Witnesses

Select a Medical Healthcare Agent (Medical Power of Attorney/ Healthcare Proxy)

- Name someone who you trust and who can abide by your wishes according to your goals, preferences, values and how you may have handled other major decisions in the past.
- Your agent will make decisions based on what is in your best interest; considering benefits, burdens and risks of the choices presented by providers.
- Having a conversation with your agent is just as important as filling out the legal documents.



What if your agent is unavailable?

- You may elect a back up agent
 - You may also name “people my agent should consult with” when major decisions need to be made
- What if I do not want to appoint a healthcare agent or medical power of attorney?
 - Your healthcare providers will abide by your Advance Directive and/or MOLST form preferences



My agent's power in in effect...

- Immediately after signing the document
 - You still have a say as long as you are able to speak for yourself and have competency
 - or
- When you have lost the ability to make decisions on your own



Choose whether your agent has flexibility in making decisions for you (Maryland Form)

- My stated preferences are meant to guide whoever is making decisions on my behalf and my healthcare providers; I authorize them to be flexible in applying these statements if they feel that doing so would be in my best interest.

or

- I want whoever is making decisions on my behalf and my healthcare providers to follow my stated preferences exactly as written, even if they think that some alternative is better.



What if?

What if I feel like my agent knows what is best for me and I feel confident they would know what to do in any situation?

- Part II of the Advance Directive (Living Will) can be left blank.
- You can give your agent full control over any decisions that need to be made for you if you cannot speak for yourself.



Maryland Part II: Living Will

Delaware has “Other Medical Instructions”

There is a space for optional goals and values statements

- “I do not want to suffer, if there is no hope for meaningful recovery, let me die naturally.”
- “I do not want to be dependent on others to care for me, I value my independence.”
- “I prefer to die at home with family close by.”
- “I value length of life over quality of life, I want to be kept alive on life support.”



Living will — making End-of-Life decisions in certain conditions

You make your preferences known when your attending doctor and a Board-Certified Neurologist or Neurosurgeon certify that you are in one of these conditions:

- **Terminal condition** — death is imminent, even if life sustaining procedures are used; discontinuance of medical treatment implemented for the purpose of sustaining life or the life process.
- **Persistent vegetative state (permanently unconscious/irreversible coma)** — you are not conscious and are not aware of your surroundings, and there is no reasonable expectation that you will ever regain consciousness.
- **End-stage condition (serious illness or frailty)** — your incurable condition will continue its course until death and has already resulted in loss of capacity and physical dependency. A condition based on the fact that your providers would not be surprised if you die within the year.



Advance Directive form — Five Wishes website

Here is the kind of medical treatment that I want or don't want in the four situations listed below. I want my Health Care Agent, my family, my doctors and other health care providers, my friends and all others to know these directions.

Close to death:

If my doctor and another health care professional both decide that I am likely to die within a short period of time, and life-support treatment would only delay the moment of my death (Choose *one* of the following):

- I want to have life-support treatment.
- I do not want life-support treatment. If it has been started, I want it stopped.
- I want to have life-support treatment if my doctor believes it could help. But I want my doctor to stop giving me life-support treatment if it is not helping my health condition or symptoms.

In A Coma And Not Expected To Wake Up Or Recover:

If my doctor and another health care professional both decide that I am in a coma from which I am not expected to wake up or recover, and I have brain damage, and life-support treatment would only delay the moment of my death (Choose *one* of the following):

- I want to have life-support treatment.
- I do not want life-support treatment. If it has been started, I want it stopped.
- I want to have life-support treatment if my doctor believes it could help. But I want my doctor to stop giving me life-support treatment if it is not helping my health condition or symptoms.

Permanent And Severe Brain Damage And Not Expected To Recover:

If my doctor and another health care professional both decide that I have permanent and severe brain damage, (for example, I can open my eyes, but I can not speak or understand) and I am not expected to get better, and life-support treatment would only delay the moment of my death (Choose *one* of the following):

- I want to have life-support treatment.
- I do not want life-support treatment. If it has been started, I want it stopped.
- I want to have life-support treatment if my doctor believes it could help. But I want my doctor to stop giving me life-support treatment if it is not helping my health condition or symptoms.

In Another Condition Under Which I Do Not Wish To Be Kept Alive:

If there is another condition under which I do not wish to have life-support treatment, I describe it below. In this condition, I believe that the costs and burdens of life-support treatment are too much and not worth the benefits to me. Therefore, in this condition, I do not want life-support treatment. (For example, you may write "end-stage condition." That means that your health has gotten worse. You are not able to take care of yourself in any way, mentally or physically. Life-support treatment will not help you recover. Please leave the space blank if you have no other condition to describe.)

Delaware Advance Directive Form (sample)

About your options: It is important to read each option fully before **choosing**. Please note that you may to choose only one option under each qualifying condition but you may choose a different option under a different qualifying condition. You will also have the opportunity to write-in any other medical instructions.

Qualifying Condition: Terminally Ill.

After you have read all options, write your initials on the line next to the option you have selected that represents your choice for treatment instructions. You may only select one option.

_____ **Option 1: My Agent will make decisions on my behalf:** In the event I become terminally ill and I am unable to understand, make or communicate my wishes, I direct that my Agent make all medical decisions on my behalf.

_____ **Option 2: Prolong Life:** In the event I become terminally ill and I am unable to understand, make or communicate my wishes, I direct that my life be prolonged as long as possible using all possible treatments within the limits of generally accepted health-care standards, with the following exceptions (initial those treatments – if any – you do not want, even if they could prolong your life):

I DO NOT WANT the treatments initialed below:

- _____ heart-lung resuscitation (CPR)
- _____ ventilator (breathing machine)
- _____ dialysis (kidney machine)
- _____ surgery
- _____ blood transfusions
- _____ chemotherapy or radiation treatment
- _____ artificial nutrition or hydration through a conduit (tube feeding)
- _____ antibiotics

_____ **Option 3: Do not Prolong Life:** In the event I become terminally ill and am unable to understand, make or communicate my wishes, I direct that no life sustaining measures be taken, with the following exceptions (initial those treatments – if any – you do want, even if they could sustain your life):

I DO WANT the treatments initialed below:

- _____ heart-lung resuscitation (CPR)
- _____ ventilator (breathing machine)
- _____ dialysis (kidney machine)
- _____ surgery
- _____ blood transfusions
- _____ chemotherapy or radiation treatment
- _____ artificial nutrition or hydration through a conduit (tube feeding)
- _____ antibiotics

COMFORT CARE

Regardless of the option I chose above regarding end of life decisions. (Initial ONE choice below)

_____ I wish to be treated to relieve pain or provide comfort, and I understand that such treatment might shorten my life or suppress my appetite or breathing.

_____ I do not wish to be treated to relieve pain or provide comfort.

Maryland Advance Directive Part II

Choose full life support to keep me alive or allow natural death with or without artificial nutrition in terminal, vegetative or end stage condition

- Keep me comfortable and allow natural death to occur. I do not want any medical interventions used to try to extend my life. I do not want to receive nutrition and fluids by tube or other medical means.
 - This is the best choice if you prefer to die at home.
- Keep me comfortable and allow natural death to occur. I do not want any medical interventions used to try to extend my life.
 - But, if I am unable to take nourishment by mouth however, I want to receive nutrition and fluids by tube or other medical means. You will may need to be in a facility who can provide nutrition.
- Try to extend my life for as long as possible, using all available interventions that in reasonable medical judgement would prevent or delay my death.

Signature and witnesses

- Only the person filling out the Advance Directive can sign or change it.
- Your Health Care Agent cannot be a witness.
- Anyone who knowingly gains financially from your death cannot witness these documents.
- Some states do require notary — Maryland and Delaware do not.



What is the difference between a MOLST (Medical Order for Life Sustaining Treatments) and Advance Directive forms?

Advance Directive

The Advance Directive form is a legal document and can only be changed by you. The Delaware form addresses most treatments on the MOLST form.

It is used when you can not speak for yourself

MOLST

A MOLST addresses your code status and can be changed based on your “goals of care.”

- Hopes
- Quality of life
- Expectations
- Outside influence

What is Code Status?

A doctor must write an order based on your wishes for life support Full Code or DNR (Do Not Resuscitate) Order.

You can choose full code status — CPR (if your heart stops), ventilator, tube feedings, dialysis, antibiotics

You can choose or limit any of these treatments.

You can change this order anytime.

What is a MOLST form?

It is a medical order for life sustaining treatment — options of care that range from full code (CPR) and life support to Do Not Resuscitate order or “Allow Natural Death”.

It is a doctor’s order and can be changed with each admission.

CPR Status: What should be done to try to prevent or manage an actual or impending cardiopulmonary arrest?
<input type="checkbox"/> Attempt CPR, Comprehensive Cardiopulmonary Resuscitation Efforts <ul style="list-style-type: none">• If cardiac and/or pulmonary arrest occurs, initiate cardiopulmonary resuscitation (CPR).• CPR should include comprehensive medical efforts to try to restore and/or stabilize heart and lung function and prevent arrest, including any form of artificial ventilation.
<input type="checkbox"/> No CPR, Option A-1, Intubate, Comprehensive Efforts to Prevent Arrest, Including Intubation <ul style="list-style-type: none">• If cardiac and/or pulmonary arrest occurs, resuscitation should not be attempted (No CPR). Allow death to occur naturally.• In order to try to prevent cardiopulmonary arrest, use comprehensive efforts to try to stabilize and/or restore heart and lung function, including intubation where indicated.
<input type="checkbox"/> No CPR, Option A-2, Do Not Intubate, Comprehensive Efforts to Prevent Arrest, No Intubation <ul style="list-style-type: none">• In order to try to prevent cardiopulmonary arrest, make a comprehensive effort to try to stabilize and/or restore heart and lung function, except for intubation. It is acceptable to use CPAP or BiPAP to try to prevent respiratory failure.• If cardiac and/or pulmonary arrest occurs, do not attempt resuscitation (No CPR). Allow death to occur naturally.
<input type="checkbox"/> No CPR, Option B, Palliative and Supportive Care, Palliative and Supportive Care Before and After Cardiopulmonary Arrest <ul style="list-style-type: none">• Do not initiate cardiopulmonary resuscitation (No CPR). Allow death to occur naturally.• Give supportive measures only, including 1) passive oxygen for comfort, 2) efforts to control any external bleeding (i.e., bleeding that is visible to an observer), 3) only medications indicated for symptom relief (e.g., pain management).• Do not attempt to prevent cardiopulmonary arrest. Do not intubate or use CPAP or BiPAP.

Artificial Ventilation: What should be done for respiratory failure where cardiopulmonary arrest is not involved?

_____ In case of respiratory failure (the individual cannot breathe adequately unaided), intubation and artificial ventilation may be initiated and continued for as long as breathing needs mechanical assistance, even indefinitely.

_____ In case of respiratory failure, intubation and artificial ventilation may be initiated and continued for a limited time (time limit up to _____ days) to see if artificial ventilation is effective in light of a patient's overall condition and underlying causes of respiratory failure. During that trial period, reassess the situation to determine if continued use of artificial ventilation is warranted or if it should be discontinued.

_____ In case of respiratory failure, only CPAP or BiPAP may be used for artificial ventilation, as indicated, and continued for a limited time (time limit up to _____ days), to see if any of these interventions are effective and their continued use is pertinent in light of the patient's overall condition and underlying causes of respiratory failure. However, do not intubate or place on a ventilator.

_____ Do not use artificial ventilation (i.e., no intubation, CPAP or BiPAP) under any circumstances.

Blood Transfusion: Should blood transfusions or infusion of blood products be given in case of bleeding?

_____ Blood and blood products (plasma, whole blood, and platelets) may be administered if indicated to replace or try to stop blood loss or to treat life-threatening anemia. This does not mandate transfusion for anemia or acute blood loss, regardless of medical indication, but authorizes it if it is medically indicated.

_____ Do not give any blood transfusions or blood products.

Code Blue

In the hospital, when your heart stops and you elect to be a “Full Code”, we call a “Code Blue”.

This is an emergency treatment using a team of doctors, nurses, pharmacists, technicians, a hospital supervisor and a chaplain to do many things at one time to try to get your heart to start again.

Treatments include CPR (chest compressions), assistance with breathing, IV medications and electric shocks.



If my heart stops, and I require CPR, what are my chances of a full recovery?

CPR

CPR was designed to resuscitate patients who had a sudden cardiac arrest BUT are otherwise in good health.

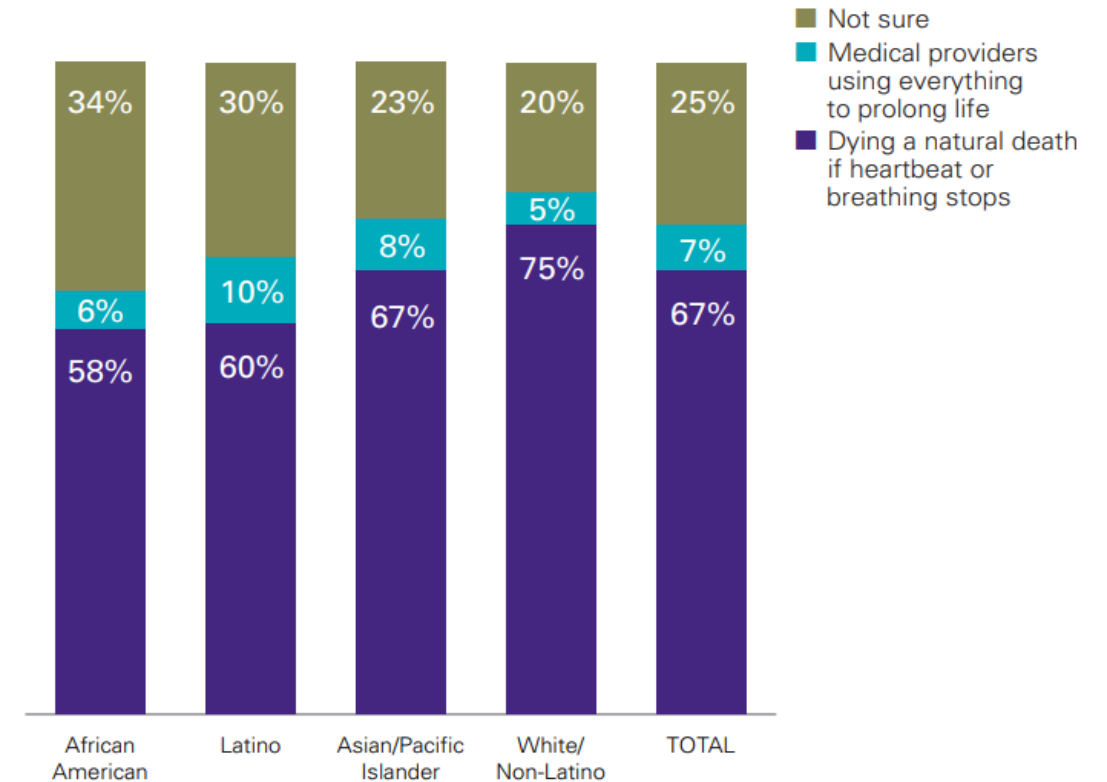
- The more health problems a patient has, the less likely he/she will recover if his/her heart should stop beating.
- In frail and/or elderly, CPR can be unhelpful or even harmful.
 - In patients who are older with chronic illness, the chance of surviving and going back to your current condition is less than 5%.
 - In older patients with Alzheimer's or Parkinson's disease, advanced cancer, end-stage heart, kidney or lung disease, survival rates fall to as low as 1%.
- If you survive the resuscitation, it is likely you will need to spend your remaining days in a nursing facility.



Prolonging life

- 58-75% polled prefer a natural death if heartbeat or breathing stops.
- 5-10% of people would want to be placed on life support. Almost 1/3 are unsure.
- By default, they will get the “Full Code” treatment unless their wishes are made known.


Preferences Around Prolonging Life, by Race/Ethnicity, California, 2011



Note: Segments may not add to 100% due to rounding.

Source: Californians' Attitudes Toward End-of-Life Issues, Lake Research Partners, 2011. Statewide survey of 1,669 adult Californians, including 393 respondents who have lost a loved one in the past 12 months.

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There is a tipping point when continued aggressive therapy can impose more suffering than the disease, causing more harm than good.

Choosing to not prolong life

- More than 80% of healthcare providers would choose DNR for themselves and their loved ones if they had a terminal diagnosis.
- More than 80% of Americans say they would not want intensive treatments or even hospitalizations at the end of life... but they do not clearly communicate these desires.

<https://med.stanford.edu/profiles/Periyakoil>



What happens if I do not make my wishes known or plan ahead?

By default, everyone gets the same treatment of Full Code Status and all available aggressive therapies which may include:

- Cardiopulmonary Resuscitation (CPR or chest compressions) IF your heart stops
- IV medications that may require you to be in an Intensive Care Unit
- Ventilator or respirator IF you can not breathe on your own
- Dialysis IF your kidneys fail
- Feeding tubes in your nose or abdomen IF you can not eat on your own
- IV fluids IF you can not drink

These are available options to all patients who need aggressive care to get better.

If you are in the end stage of a disease or advanced age, these treatments may cause more harm than good. These treatments may cause suffering and prolong the dying process.

So...what are my options?

Options

- Early in your disease process, you can choose aggressive therapy, even if it is causing pain and reducing your quality of life; the benefits outweigh the burdens.
- As you age or have a disease progress to end stage, your focus and goals of care may change.
- You can continue aggressive therapy with the goals of reducing pain and having good quality of life.
- You can choose some therapies (that are less painful/aggressive) while focusing on comfort and good quality of life.
- You can stop all therapies that you feel are burdensome and focus on quality of life and comfort.
- You can change or shift back and forth from any of these options based on how you feel.



Palliative care as an option

- Providing palliative care means patient and family centered care that optimizes quality of life by anticipating, preventing, and treating suffering (defined by CMS).
- Using palliative care throughout the continuum of an illness helps to address physical, intellectual, emotional, social and spiritual needs, to facilitate patient autonomy, access to information and choices.
- Palliative care aims to improve the quality of life for both patients and their families. **This form of care is offered alongside curative or aggressive treatments or therapies.**
- A palliative care team helps patients and families establish goals of care and helps discern when to change the focus from curative to comfort.



What is comfort care?

- Comfort care is defined as a patient care plan that is focused on symptom control, pain relief, and quality of life.
- It is typically administered to patients who have already been hospitalized several times, with further medical treatment unlikely to change the outcome.
- Home Hospice care should be considered at this time.



Home hospice care

When goals of care are quality of life and comfort and you have made a decision to not continue aggressive treatments or readmission to the hospital...consider home hospice care.

- This does not mean you are giving up hope or that death is imminent — some patients live more than six months with hospice care.
- You are entitled to elect your Hospice Medicare Benefits if you meet requirements.
- This consists of a team (provider, nurse, chaplain, social worker and healthcare aid) who cares for you and supports your family in your home. Their goal is to help you increase quality of life and reduce pain and suffering.



What is important when you get closer to the end of your life?

- Physical comfort — pain, shortness of breath, skin irritations, digestive problems, temperature sensitivity, fatigue
- Mental and emotional needs — anxiety, depression, worry, fear
- Spiritual needs — finding meaning in one's life and ending disagreements, healing relationships

Your hospice team has special training to help guide you and address these needs.

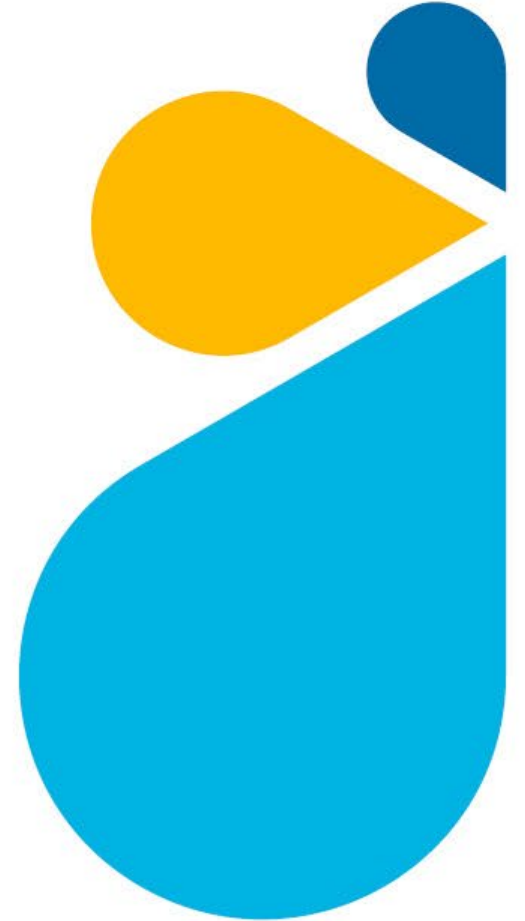
- Four Things That Matter Most: A Book About Living by Ira Bock
 - "Please forgive me", "I forgive you", "Thank you", and "I love you" — carry enormous power.
 - In many ways, they contain the most powerful words in our language.



Stages of grief

- Denial
- Anger
- Bargaining
- Acceptance


Your hospice team can help you and your loved ones address stages of grief.



Advanced Care Planning helps your healthcare team provide individualized care

- Your providers want what is best for you in your unique situation!
- They can provide the best treatment for you when they know what is most important to you.
- You have choices as to how aggressive you would like your treatment to be.
- Your goals of care may change over the course of your illness.
- Knowledge about your disease progression and the natural dying process gives you and your loved ones some control in your plan of care.





Remember...not talking about Advanced Care Planning can make it more difficult for your loved ones who may be left wondering what they should do in certain situations.

In addition to your close friends and family, Advance Care Planning can be discussed with your:

- Primary Care Provider
- Pastor or other member of your faith community
- Family lawyer
- Nurse Care Coordinator
- Resource staff listed in this presentation



Thank you



Resources to start the conversation

Many films deal with physical decline and death in a sympathetic and life-affirming way, including *The Bucket List*, *Steel Magnolias*, and *Still Alice*. (The Huffington Post has a list at huff.to/28NvUZD.)

<https://www.marylandattorneygeneral.gov/Pages/HealthPolicy/AdvanceDirectives.aspx>

<https://marylandmolst.org/docs/MOLST%20MM3%202013%20FINAL%20PROPOSED%2072613%20POSTED%2021714-no-instructions.pdf>

Health Care Decision Making Worksheet Instructions

<https://marylandmolst.org/docs/Health%20Care%20Decision%20Making%20Worksheet.pdf>

Gawande A. Letting go. *The New Yorker*. August 2, 2010. <https://www.newyorker.com/magazine/2010/08/02/letting-go-2>.

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

Your Conversation Starter Guide How to talk about what matters to you and have a say in your health care.

<https://theconversationproject.org/get-started>

What Matters to WORKBOOK A Guide to Serious Illness Conversations <https://theconversationproject.org/wp-content/uploads/2020/12/WhatMattersToMeWorkbook.pdf>

For Caregivers of People with Alzheimer's or Other Forms of Dementia <https://theconversationproject.org/wp-content/uploads/2020/12/DementiaGuide.pdf>

<https://www.dhss.delaware.gov/dsaapd/files/advancedirective.pdf>

Resources

<https://fivewishes.org/docs/default-source/default-document-library/product-samples/fwsample.pdf?sfvrsn=2>
www.agingwithdignity.org

<https://www.mettlehealth.com> Online palliative consultations
in whatever place you call home

<https://youtu.be/IGEVH4N1DyQ> DR BJ Miller- Palliative Care & and
Dying Well

https://www.ted.com/talks/bj_miller_what_really_matters_at_the_end_of_life?utm_campaign=tedsread&utm_medium=referral&utm_source=tedcomshare
(What really matters at the end-of-life Ted Talk)

<https://youtu.be/K8FDhIAUmkl>
A beginner's guide to the End of Life

<https://youtu.be/IQhI3Jb7vMg> Being Mortal

MD Advance Directives forms: <https://www.marylandattorneygeneral.gov/Health%20Policy%20Documents/adirective.pdf>

DE Advance Directives forms: <https://www.dhss.delaware.gov/dsaapd/files/advancedirective.pdf>

References

- DiJulio B, Hamel L, Wu B, Brodie M. *Serious Illness in Late Life: The Public's View and Experiences*. Menlo Park, California: Kaiser Family Foundation; November 2017. <https://www.kff.org/other/report/serious-illness-in-late-life-the-publics-views-and-experiences/>
- Gaande A. Letting go. *The New Yorker*. August 2, 2010. <https://www.newyorker.com/magazine/2010/08/02/letting-go-2>.
- U.S. Department of Health and Human Services. *Health, United States, 2016*. Centers for Disease Control and Prevention; May 2017. <https://www.cdc.gov/nchs/data/hus/hus16.pdf>.
- Gross J. ['How many of you expect to die?'](#) *The New York Times*. July 8, 2008.
- New survey reveals 'conversation disconnect' [press release]. Cambridge, Massachusetts: The Conversation Project; September 18, 2013 http://theconversationproject.org/wp-content/uploads/2013/09/TCP-Survey-Release_FINAL-9-18-13.pdf Accessed November 1, 2017.
- McCutcheon Adams K, Kabcenell A, Little K, Sokol-Hessner L. *"Conversation Ready": A Framework for Improving End-of-Life Care*. IHI White Paper. Cambridge, Massachusetts: Institute for Healthcare Improvement;2015. <http://www.ihl.org/resources/Pages/IHIWhitePapers/ConversationReadyEndofLifeCare.aspx> Accessed November 3, 2017.