

Palliative Care and Discussing Your Wishes with Your Family and the Medical Team



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Learning Objectives:

After This Talk Participants Will Be Able To:



- Understand what palliative care is and when it might benefit them.
- Talk to their doctors about what to expect for their health in the future.
- Think about what is most important to them.
- Talk to their family members about their wishes.
- Choose a health care surrogate.
- Complete a health care surrogate form.
- Complete a living will.
- Share their wishes and their documents with their doctors.

Palliative Care



- Palliate (Latin root) → “To Cloak”



- “Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.”
 - THE WORLD HEALTH ORGANIZATION DEFINITION

What is Palliative Care?



- Specialized medical care for people with serious illnesses.
- *Focuses on providing patients with relief from the symptoms, pain, and stress of a serious illness—whatever the diagnosis.*
- The goal is to improve **quality of life** for both the patient and the family.

Palliative Care Includes



- Pain and symptom management
- Integrates the psychological and spiritual aspects of care
- Support system to patient and family members
- Coordination of care with entire health care team.
- Team approach
- Focus on enhancing quality of life
- Open discussion about understanding illness, treatment options, etc.
- Guidance and counseling regarding treatment options and formulating individualized plan.
- Advance Care Planning and End of Life Planning
- Affirms life and regards dying as natural process

Who is Appropriate for Palliative Care?



- “Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life.”
- Patient’s With Advanced Illness:
 - Cancer
 - Heart Disease
 - Liver Disease
 - COPD / Lung Disease
 - Kidney Disease
 - Brain Disorders

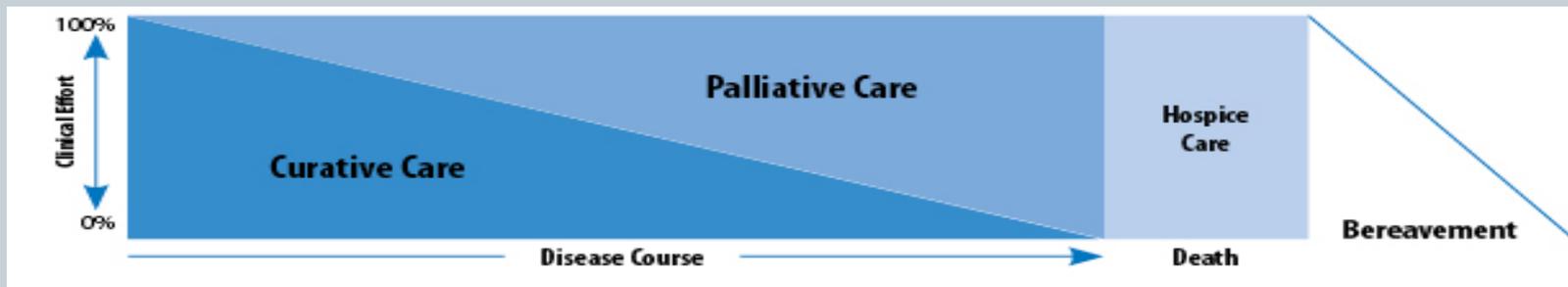
Approach to Health Care For Patients with Chronic Illness



- Old Model



- New Model





More than **90%** of the people think it's important to talk about their loved ones' and their own wishes for end-of-life care.

Less than **30%** of people have discussed what they or their family wants when it comes to end-of-life care. Source: National Survey by The Conversation Project 2013.



60% of people say that making sure their family is not burdened by tough decisions is “extremely important”

56% have not communicated their end-of-life wishes

Source: Survey of Californians by the California HealthCare Foundation (2012)



70% of people say they prefer to die at home

70% die in a hospital, nursing home, or long-term-care facility

Source: Centers for Disease Control (2005)



80% of people say that if seriously ill, they would want to talk to their doctor about end-of-life care

7% report having had an end-of-life conversation with their doctor

Source: Survey of Californians by the California HealthCare Foundation (2012)



82% of people say it's important to put their wishes in writing

23% have actually done it

Source: Survey of Californians by the California HealthCare Foundation (2012)

“Knowledge of and Preferences for Advance Care Planning Adults With Congenital Heart Disease”



- In a study of large adult congenital heart disease clinic only 5% of patients had completed an advance directive.
- 87% of these patients reported they would prefer to have an advance directive available if they were dealing with their own dying and were unable to speak for themselves.

“Facilitators of and Barriers to Advance Care Planning in Adult Congenital Heart Disease”



- Most health care providers for adult patients with congenital heart disease are concerned that patients with good prognoses are not ready to discuss Advance Care Planning.
- Yet, 76% of patients with congenital heart disease **do** want to discuss Advance Care Planning with their doctors.

Advance Care Planning



- **Is a Process**
 - ✦ **RATHER THAN A ONE TIME EVENT**

ADVANCED CARE PLANNING STEPS



- Establish baseline
- Future choices
- Think about what others have been through
- Explore values and beliefs
- Think about your care preferences
- Identify a surrogate decision maker
- Document in a living will and health surrogate form.
- Review

Establish the Baseline With Your Doctors



- What is your understanding about your medical situation?
- What do you know about your prognosis?
- How long can you expect continue your current level of activity?
- What will happen as you get older?

Future Choices



- How long will my surgery help me to be active?
- Will surgery help me to feel better?
- Will I need a heart transplant?
- Would I want life support now?
- What circumstances would I not want life support?

Think About What Others Have Been Through



- Have you ever seen someone on a ventilator?
- Have you visited a family member in a hospice?
- Has any one you have known had a heart transplant or an LVAD?
- How did your experience affect how you would like to be cared for?

Explore values and beliefs



- What does it mean for you to “live well”?
- What is most important to you in life?
- What are your main worries about your situation?
- When you think about your future, what do you hope for?

Think About Your Specific Care Preferences



- Who do you want involved in your health care decisions?
- Would you want a heart transplant if you were a candidate?
- If you were to stop breathing, would you want to be on a machine that breathes for you?
 - If you would be interested in a trial of life support, how long would you want doctor's to try for?
 - Under what circumstances should treatment be stopped?
- Would you want to die at home?

Identify a Surrogate Decision-Maker



- **More Detail In Upcoming Presentation**
- If you became unable to tell your clinicians what kind of care they should provide you, who would you want to make medical decisions for you?
- If you became unable to participate in discussions about your care, your surrogate would be called in to tell your doctors what should be done.
- It is best to name a single primary surrogate with alternates rather than naming multiple persons.
- Make sure everyone in your family knows who you have chosen.

Document



- These are important decisions that will impact your care in the future so be sure to get them in writing.
- Living will
 - Specifies which medical treatments you want or don't want at the end of your life, or, if you are no longer able to make decisions on your own (e.g. in a coma).
- Health Care Surrogate
 - Identifies the person you trust to act on your behalf if you are unable to make health care decision or communicate your wishes.
 - Make sure you have many conversations with your surrogate (also called proxy, or agent).

Review



- Review your preferences as your health changes.
- Share your new thoughts with your health care surrogate and your doctors.

Time To Practice and Resources



- HCS forms and Living Wills
- DNR / DNI
- The Conversation Project – Your Conversation Starter Kit
- Five Wishes

The Conversation Project

Conversation Starter Kits

- <https://ufhealth.org/sites/default/files/media/Advance-directives/Starter-Kit-UF-Health-Shands.pdf>
- <http://theconversationproject.org>



Your Conversation Starter Kit

When it comes to end-of-life care, talking matters.



Institute for
Healthcare
Improvement

the conversation project

CREATED BY THE CONVERSATION PROJECT AND THE INSTITUTE FOR HEALTHCARE IMPROVEMENT

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Step 1 Get Ready

You will have many questions as you get ready for the conversation. **Here are two to help you get started:**

? What do you need to think about or do before you feel ready to have the conversation?

? Do you have any particular concerns that you want to be sure to talk about? (For example, making sure finances are in order; or making sure a particular family member is taken care of.)

REMEMBER:

- You don't need to have the conversation just yet. It's okay to just start thinking about it.
- You can start out by writing a letter—to yourself, a loved one, or a friend.
- You might consider having a practice conversation with a friend.
- Having the conversation may reveal that you and your loved ones disagree. That's okay. It's important to simply know this, and to continue talking about it now—not during a medical crisis.
- Having the conversation isn't just a one-time thing. It's the first in a series of conversations over time.

Step 2 Get Set

What's most important to you as you think about how you want to live at the end of your life? What do you value most? **Thinking about this will help you get ready to have the conversation.**

- ? Now finish this sentence: What matters to me at the end of life is...**
(For example, being able to recognize my children; being in the hospital with excellent nursing care; being able to say goodbye to the ones I love.)

Sharing your "what matters to me" statement with your loved ones could be a big help down the road. It could help them communicate to your doctor what abilities are most important to you—what's worth pursuing treatment for, and what isn't.

WHERE I STAND SCALES

Use the scales below to figure out how you want your end-of-life care to be. Select the number that best represents your feelings on the given scenario.

As a patient, I'd like to know...

- 1 2 3 4 5
- Only the basics about my condition and my treatment
-
- All the details about my condition and my treatment

As doctors treat me, I would like...

- 1 2 3 4 5
- My doctors to do what they think is best
- To have a say in every decision

Step 3 Go

When you're ready to have the conversation, think about the basics.

MARK ALL THAT APPLY:

? WHO do you want to talk to?

- | | |
|---|---|
| <input type="checkbox"/> Mom | <input type="checkbox"/> Faith leader (Minister, Priest, Rabbi, Imam, etc.) |
| <input type="checkbox"/> Dad | <input type="checkbox"/> Friend |
| <input type="checkbox"/> Child/Children | <input type="checkbox"/> Doctor |
| <input type="checkbox"/> Partner/Spouse | <input type="checkbox"/> Caregiver |
| <input type="checkbox"/> Sister/Brother | <input type="checkbox"/> Other: <input type="text"/> |

? WHEN would be a good time to talk?

- | | |
|--|---|
| <input type="checkbox"/> The next holiday | <input type="checkbox"/> Before the baby arrives |
| <input type="checkbox"/> Before my child goes to college | <input type="checkbox"/> The next time I visit my parents/ adult children |
| <input type="checkbox"/> Before my next trip | <input type="checkbox"/> At the next family gathering |
| <input type="checkbox"/> Before I get sick again | <input type="checkbox"/> Other: <input type="text"/> |

? WHERE would you feel comfortable talking?

- | | |
|---|--|
| <input type="checkbox"/> At the kitchen table | <input type="checkbox"/> Sitting in a park |
| <input type="checkbox"/> At a favorite restaurant | <input type="checkbox"/> At my place of worship |
| <input type="checkbox"/> In the car | <input type="checkbox"/> Other: <input type="text"/> |
| <input type="checkbox"/> On a walk | |

? WHAT do you want to be sure to say?

If you wrote down your three most important things at the end of Step 2, you can use those here.

If I had a terminal illness, I would prefer to...

- 1 2 3 4 5

Not know how quickly
it is progressing

Know my doctors best
estimation for how
long I have to live

? Look at your answers.

What kind of role do you want to have in the decision-making process?

How long do you want to receive medical care?

- 1 2 3 4 5

Indefinitely, no matter
how uncomfortable
treatments are

Quality of life is
more important to
me than quantity

.....
What are your concerns about treatment?

- 1 2 3 4 5

I'm worried that I won't
get enough care

I'm worried that I'll get
overly aggressive care

.....
What are your preferences about where you want to be?

- 1 2 3 4 5

I wouldn't mind spending my
last days in a health care facility

I want to spend my
last days at home

? Look at your answers.

What do you notice about the kind of care you want to receive?

How Involved do you want your loved ones to be?

1 2 3 4 5

I want my loved ones to do exactly what I've said, even if it makes them a little uncomfortable

I want my loved ones to do what brings them peace, even if it goes against what I've said

When It comes to your privacy...

1 2 3 4 5

When the time comes, I want to be alone

I want to be surrounded by my loved ones

When It comes to sharing Information...

1 2 3 4 5

I don't want my loved ones to know everything about my health

I am comfortable with those close to me knowing everything about my health

? Look at your answers.

What role do you want your loved ones to play? Do you think that your loved ones know what you want, or do you think they have no idea?

? What do you feel are the three most important things that you want your friends, family, and/or doctors to understand about your wishes and preferences for end-of-life care?

1.
2.
3.

Step 4 Keep Going

Congratulations! Now that you have had the conversation, here are some legal and medical documents you should know about. Use them to record your wishes so they can be honored when the time comes.

- **Advance Care Planning (ACP)**
The process of planning for your future care—exactly what you have been working on here.
- **Advance Directive (AD)**
A document that describes your wishes.
- **Health Care Proxy (HCP)**
Identifies your health care agent (often called a “proxy”), the person you trust to act on your behalf if you are unable to make health care decisions or communicate your wishes. In some states, this is called the Durable Power of Attorney for Health Care. This is probably the most important document. Make sure you have many conversations with your proxy.
- **Living Will**
Specifies which medical treatments you want or don't want at the end of your life, or if you are no longer able to make decisions on your own (e.g., in a coma).

You can find more information about these documents from the link in the “Keep Going” section of the website Starter Kit at: www.theconversationproject.org.

Remember, this was the first of many conversations. You can use the questions on the following page to collect your thoughts about how your first talk went, and then look back to them when you prepare for future conversations.

Questions?

