

Dying Faithfully
Medical and Spiritual Considerations
St Andrew's Episcopal Church
February 9, 2020

Dr. Fredrick Briccetti and Rev. Linda Spinella

Opening Prayer	Rev Linda
Illness and Death	Dr Fred
-cell, biological death	
-being mortal (story)	Rev Linda
The Conversation Project and Goals of Care	
-medical considerations	Dr Fred
Curable vs not curable illness;	
Need for advance directives	
-value based considerations	Rev Linda
patient centered	
Prognosis	
-how determined, time frames, data based	Dr Fred
-prognosis as guideline of service eligibility	Rev Linda
Palliative Care and Hospice Care	
-Medical parameters	Dr Fred
-Spiritual considerations	Rev Linda
Final Thoughts	
-Letting Go	Dr Fred
Closing Poem	Rev Linda
"Otherwise"	

PALLIATIVE MEDICINE AT EXETER HOSPITAL

How we can help

Living with a serious illness can be challenging for you and your family. You may have fears about the future, uncontrolled symptoms, complex medical decisions, your family's concerns about your future, and frequent trips to the doctor's offices, emergency room, or hospital.

Receiving the **best care possible** is not only about addressing your disease, but also about attending to you as a whole person, improving quality of life, controlling symptoms (such as pain, breathlessness, nausea), and addressing your emotional, spiritual and social concerns.

At Exeter Hospital, our palliative medicine specialists aim to personalize care around **what matters most to you**. Just like cardiologists, oncologists, and other specialists, your insurance recognizes us as medical consultants and part of standard medical care.

We are **experts in symptom management**, as well as in helping you and your family ensure **your voice** and preferences are honored as we co-design treatment to align with your goals. Working as part of your care team we identify the right level of in-home medical and nursing support to help you receive the care you want, in the location you want.

Palliative care has long been recognized as an important part of whole-person integrated care, throughout all stages of disease or illness, and is considered a key component of optimal treatment.

"We find that our patients have much better symptom management with the help of palliative medicine providers." – Dr. James Hart,
Hospitalist Physician at Exeter Hospital

"Our palliative medicine program is devoted to helping patients with serious illness live longer and more satisfying lives." - Dr. Panos Fidas,
Director of Medical Oncology

Please ask a member of your care team if you wish to speak with us.

If you are considering Palliative Care, review this Symptom Assessment with your family and/or caregivers, as well as your current doctor.

SYMPTOM ASSESSMENT*

Pain



NO PAIN 0 1 2 3 4 5 6 7 8 9 10 WORST PAIN POSSIBLE

Lack of energy

NORMAL ENERGY 0 1 2 3 4 5 6 7 8 9 10 NO ENERGY

Drowsiness (feeling sleepy)

NO DROWSINESS 0 1 2 3 4 5 6 7 8 9 10 WORST POSSIBLE DROWSINESS

Nausea

NO NAUSEA 0 1 2 3 4 5 6 7 8 9 10 WORST POSSIBLE NAUSEA

Last Bowel Movement

Days ago: 1 2 3 4 5 6 7

Lack of Appetite

NORMAL APPETITE 0 1 2 3 4 5 6 7 8 9 10 NO APPETITE

Shortness of Breath

NO BREATHLESSNESS 0 1 2 3 4 5 6 7 8 9 10 WORST BREATHLESSNESS

Depression

NO DEPRESSION 0 1 2 3 4 5 6 7 8 9 10 WORST POSSIBLE DEPRESSION

Anxiety

NO ANXIETY 0 1 2 3 4 5 6 7 8 9 10 WORST POSSIBLE ANXIETY

Wellbeing

BEST WELLBEING 0 1 2 3 4 5 6 7 8 9 10 WORST POSSIBLE WELLBEING

Other Problem _____

NO _____ 0 1 2 3 4 5 6 7 8 9 10 WORST POSSIBLE _____

**This is the ESASr (Edmonton Symptom Assessment Score revised) Symptom Assessment tool.*



EXETER HOSPITAL

The Art of Wellness

exeterhospital.com



Your Conversation Starter Kit

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



the conversation project

CREATED BY THE CONVERSATION PROJECT AND THE INSTITUTE FOR HEALTHCARE IMPROVEMENT

The Conversation Project is dedicated to helping people talk about their wishes for end-of-life care.

We know that 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.

NAME

DATE

HOW TO USE THE STARTER KIT

This Starter Kit doesn't answer every question, but it will help you get your thoughts together, and then have the conversation with your loved ones.

You can use it whether you are getting ready to tell someone else what you want, or you want to help someone else get ready to share their wishes.

Take your time. This kit is not meant to be completed in one sitting. It's meant to be completed as you need it, throughout many conversations.

TABLE OF CONTENTS

Why talking matters	2
Step 1: Get Ready	3
Step 2: Get Set	4
Step 3: Go	7
Step 4: Keep Going	10

Why talking matters

Sharing your wishes for end-of-life care can bring you closer to the people you love. It's critically important. And you can do it. **Consider the facts:**

90% of people say that talking with their loved ones about end-of-life care is important.

27% have actually done so.

Source: The Conversation Project National Survey (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)

80% of people say that if seriously ill, they would want to talk to their doctor about wishes for medical treatment toward the end of their life.

7% report having had this 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)

One conversation can make all the difference.

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.

How to start

Here are some ways you could break the ice:

"I need your help with something."

"Remember how someone in the family died—was it a 'good' death or a 'hard' death? How will yours be different?"

"I was thinking about what happened to _____, and it made me realize..."

"Even though I'm okay right now, I'm worried that _____, and I want to be prepared."

"I need to think about the future. Will you help me?"

"I just answered some questions about how I want the end of my life to be. I want you to see my answers. And I'm wondering what your answers would be."

What to talk about:

- When you think about the last phase of your life, what's most important to you? How would you like this phase to be?
- Do you have any particular concerns about your health? About the last phase of your life?
- What affairs do you need to get in order, or talk to your loved ones about? (*Personal finances, property, relationships*)
- Who do you want (or not want) to be involved in your care? Who would you like to make decisions on your behalf if you're not able to? (*This person is your health care proxy.*)
- Would you prefer to be actively involved in decisions about your care? Or would you rather have your doctors do what they think is best?
- Are there any disagreements or family tensions that you're concerned about?
- Are there important milestones you'd like to be there for, if possible? (*The birth of your grandchild, your 80th birthday.*)

- 11 Where do you want (or not want) to receive care? (*Home, nursing facility, hospital*)
- 12 Are there kinds of treatment you would want (or not want)? (*Resuscitation if your heart stops, breathing machine, feeding tube*)
- 13 When would it be okay to shift from a focus on curative care to a focus on comfort care alone?

This list doesn't cover everything you may need to think about, but it's a good place to start. Talk to your doctor or nurse if you'd like them to suggest more questions to talk about.

REMEMBER:

- Be patient. Some people may need a little more time to think.
- You don't have to steer the conversation; just let it happen.
- Don't judge. A "good" death means different things to different people.
- Nothing is set in stone. You and your loved ones can always change your minds as circumstances change.
- Every attempt at the conversation is valuable.
- This is the first of many conversations—you don't have to cover everyone or everything right now.

Now, just go for it! Each conversation will empower you and your loved ones. You are getting ready to help each other live and die in a way that you choose.

Step 4 Keep Going

Congratulations! You have had “the conversation” — hopefully, the first of many. You can use the following questions to collect your thoughts about how your first talk went, and to think about what you’d like to talk about in future conversations.

? Is there something you need to clarify that you feel was misunderstood or misinterpreted?

? Who do you want to talk to next time? Are there people who should hear things at the same time (like siblings who tend to disagree)?

? How did this conversation make you feel? What do you want to remember? What do you want your loved ones to remember?

? What do you want to make sure to ask or talk about next time?

Now that you have had the conversation, you're ready to think about **completing two important legal documents** to make sure your wishes are clearly stated — and respected when the time comes.

1 Choose a Health Care Proxy

A health care proxy (also known as a **durable power of attorney for health care**) is a legal document in which you appoint another person (a proxy or agent) to express your wishes and make health care decisions for you if you cannot speak for yourself. Choose someone who knows your wishes well — a person you trust to speak for you if you're not able to speak for yourself.

2 Complete an Advance Directive

An Advance Directive, also known as a **Living Will**, is a legal document in which you state your wishes regarding end-of-life medical care — including the types of treatments you do and do not want — in case you are no longer able to make decisions or communicate your wishes. (Note: This is different from your Last Will and Testament, which is used to distribute assets.)

Every state has its own Advance Directive forms.

See the Medicare website for more information: www.medicare.gov/manage-your-health/advance-directives/advance-directives-and-long-term-care.html

Contact Us

VISIT US

www.theconversationproject.org

E-MAIL US

conversationproject@ihi.org

FOLLOW US ON FACEBOOK AND TWITTER

 @convoproject

 TheConversationProject





How To Talk To Your Doctor

Discussing end-of-life care with your doctor, nurse, or other health care provider.



the conversation project

CREATED BY THE CONVERSATION PROJECT AND THE INSTITUTE FOR HEALTHCARE IMPROVEMENT

The Conversation Project is dedicated to helping people talk about their wishes for end-of-life care.

Talking with your loved ones openly and honestly, before a medical crisis happens, gives everyone a shared understanding about what matters most to you at the end of life. (See the [Conversation Starter Kit](#) for help taking that first step. It's available for free at theconversationproject.org.)

After you've had the conversation with your loved ones, the next step is talking to your health care team about your wishes. Again, don't wait for a medical crisis; talking with your doctor or nurse now makes it easier to make medical decisions when the time comes.

NAME

DATE

HOW TO USE THIS GUIDE

You can use this guide as a workbook to make notes of what to tell your health care team — whether you're getting ready to discuss your own wishes, or you're helping someone else get ready to discuss theirs.

TABLE OF CONTENTS

Step 1: Get Ready	2
Step 2: Get Set	3
Step 3: Go	6
Step 4: Keep Going	9

This document does not seek to provide legal advice. ©2017 The Conversation Project. All rights reserved.

Step 1 Get Ready

Okay — so you've had the conversation with your loved ones. **Congratulations! You've already taken the most important step.**

Note: If you haven't yet had the conversation with your loved ones, see the [Conversation Starter Kit](#) for help taking that first step. It's available for free at theconversationproject.org.

The next step is to have a conversation with your health care team:

- **Ask your care team to explain where things stand with your health today, and what the future may hold.** Your care team can explain the available treatment options — and the chances of certain treatment options working. Be sure to ask questions if anything is unclear. (Note: It's important to understand that even for the care team there is often a lot of uncertainty — both about the course of your illness, and about how different treatment options will work.)
- **Also, let your care team know your goals and preferences, especially regarding end-of-life care.** You're the expert about what matters most to you.

Then together, you and your care team can decide which treatment options are right for you — especially if you or your loved one experience a dramatic change in health.

Note: Medicare Part B (Medical Insurance) covers voluntary Advance Care Planning as part of your Yearly "Wellness" visit. This is planning for care you'd want to get if you become unable to speak for yourself.

Step 2 Get Set

When you're ready to talk to your health care team (or help someone else get ready to talk to theirs), **start by thinking about the basics.**

MARK ALL THAT APPLY:

? WHO do you want to talk to?

- Your primary care doctor
- Your nurse, nurse practitioner, or physician's assistant
- Your specialist, if you have a chronic condition (heart doctor, lung doctor, etc.)
- Your therapist, social worker, psychologist, or psychiatrist
- Your case manager
- Your admitting team, if you are hospitalized
- The staff physician or nurse at your nursing home or assisted living facility
- Your palliative care specialist
- Other: _____

Choose someone you're comfortable talking to — if possible, someone who knows you and your health status.

? WHEN would be a good time to talk?

- At your next annual physical
- At your next routine follow-up visit
- After an urgent care visit
- After a visit to the emergency room
- When you're admitted to the hospital
- If you have a new diagnosis (for example, cancer, chronic heart or lung disease)
- Other: _____

Even if you're in good health, it's still important to make sure your health care team knows your wishes, since anyone's health status can change suddenly. It's particularly important to have this conversation if you or a loved one has a chronic illness.

You'll probably have several conversations over time, and each one will be a little different depending on the context. But every conversation will help your health care team understand what matters to you.

Most importantly — don't wait until there's a crisis. And don't wait for your doctor to bring it up. As we say in *The Conversation Project*, "It's always too soon... until it's too late."

How else can you prepare yourself for the conversation?

Here are some common medical terms that might come up:

- **Advance Care Planning:** Making plans now for the care you want when you have a serious illness. Part of planning could include giving guidance about decisions regarding end-of-life care and choosing a representative ("proxy" or "agent") to make decisions if you are unable to do so (Note: See [*How To Choose a Health Care Proxy & How to Be a Health Care Proxy*](#).)
- **Hospice Care:** Focuses on providing the person with serious illness and their family with comfort, pain relief, support services, and spiritual care when they are expected to live six months or less.
- **Palliative Care:** Care to help people get relief from pain, distress, psycho-social and spiritual distress, and other symptoms that can occur during an illness. A person can receive palliative care at any stage of a serious illness, including when getting treatment.
- **Shared Decision-Making:** A process in which clinicians and patients work together to make decisions and select tests, treatments, and care plans based on clinical evidence that balances risks and expected outcomes with patient preferences and values.

Remember, your job is not to come up with a list of treatment options; that's your care team's job. Your role is to help your doctor or nurse understand what matters most to you. Then they can explain and discuss treatment options in the context of your current health status and your wishes. Then you can make the decision that's right for you.

And here are brief explanations of some of the treatment options your care team might mention:

- **Intubation/Mechanical Ventilation:** When you can't breathe on your own, a breathing tube is placed in your throat and into your lungs, connecting you to a machine that can breathe for you. Can be used short-term or long-term, depending on your needs and preferences.
- **Artificial Nutrition and Hydration:** When you can't eat or drink on your own, fluid and nutrients are delivered in an IV or through a tube in your nose or stomach. (This is sometimes called a "PEG tube" — an abbreviation for "percutaneous endoscopic gastrostomy.") Can be used short-term or long-term, depending on your needs and preferences.
- **CPR (Cardiopulmonary Resuscitation):** If your heart stops, attempts are made to restart your heart with chest compressions or electricity.
- **Comfort Care:** When curative care is no longer likely to help, medication or other non-invasive options are used solely to keep you comfortable.
- **A Time-Limited Trial of Aggressive Care:** A short-term trial (usually days) of all possible life-saving medical care, with the understanding that if it is not successful and it appears that your chances of survival are low, or that your quality of life will be inconsistent with your preferences, you would discontinue aggressive care and focus solely on comfort.

Step 3 Go

Sometimes the hardest part is knowing how to begin. When you're ready to talk to your doctor (or any member of your health care team), **here are some ways you could break the ice.**

Call or email your doctor's office before your visit.

- It helps your doctor and health care team if they know in advance that you want to take time during your visit to discuss your wishes regarding end-of-life care. That way, they can make sure to set aside time for this important conversation.

"Could you please tell Dr. Jones that I want to talk about my end-of-life care wishes during my visit on Friday?"

Prepare your opening line.

- When you meet with your doctor, tell it like it is.

"I want to have a conversation about my wishes for end-of-life care."

- Bring in your Starter Kit and share your "three most important things I'd like people to know about my end-of-life wishes" or your answers to the "Where I Stand" scales (both found in Step 2: Get Set).

"Have you heard about The Conversation Project? It's a campaign to help people talk about their wishes for end-of-life care. Here's what I've thought about so far."

- Share your reflections about deaths that you or your loved ones have witnessed.

"My friend's sister recently died in the hospital after weeks of aggressive care. I don't want that. I think I might prefer to die at home."

"I think I'd feel more comfortable if I died in the hospital. They take such good care of me."

- Tell your doctor about important milestones you hope to make.

“My granddaughter is getting married in a year and I’d really like to be there — can you help me understand what I might need to do to make it to the wedding?”

- Bring your health care proxy (the person you’ve chosen to make medical decisions for you if you aren’t able to) and/or a friend or family member to the visit. Ask them to take notes.

“I brought my sister with me today, because I want to talk to you about my health care wishes and she’s my proxy. I want her to be part of this.”

Here are some questions you can ask to help you understand your or your loved one’s medical problems.

- In fact, it’s pretty hard to make decisions about the care you want to receive without a good understanding of the answers to these questions.

“Can you tell me what I can expect from this illness? What is my life likely to look like 6 months from now, 1 year from now, and 5 years from now?”

“What can I expect about my ability to function independently?”

“What are some possible big changes in my health that my family and I should be prepared for?”

“What can I expect to improve (or not improve) if I choose this course of treatment, or another course of treatment?”

“What can I expect if I decide to do nothing?”

Make sure to ask your doctor or health care team to document your discussion, and your wishes, in your medical record.
Things to remember and other things it's okay to say:

- Ask a lot of questions.

"I don't understand—can you explain it in a different way?"

- You don't have to decide about anything right away.

"I'd like to talk this over with a friend — can we have another conversation in a couple of weeks?"

"Would you write this down for me?"

- Ask for numbers and statistics if it helps you, but also realize that in many cases, there is a lot of uncertainty.

- You may want to have a private conversation with your doctor. It can be hard to do this, especially if your loved one always accompanies you. Leave your doctor a message prior to the appointment. They are accustomed to facilitating this in a way that will not make your loved one feel uncomfortable.

"Could you please tell Dr. Jones that, when I come in for my visit on Friday, I'd like a chance to talk to him alone about my wishes for end-of-life care?"

Step 4 Keep Going

It's important to have follow-up conversations to revisit the issues that come up in these conversations. Your preferences may change as time passes. Your health care team may ask you to consider treatment options that you'd like some time to think about. **And sometimes, these conversations don't go as planned.**

Here are some scenarios that may require you to have the conversation again with your health care team, or to revisit the conversation with your loved ones.

My health care provider doesn't want to talk about it.

- It is your right to talk about this — you can insist on it. (“Yes, I am doing well now, but things can change at any moment and I want us both to be prepared.”)
- If there isn't enough time, suggest scheduling another appointment specifically to focus on this conversation.
- If you continue to feel resistance, you may need to consider seeking another health care provider.

My loved one has dementia and it's not possible to discuss what matters.

- Can you remember a conversation with your loved one about the death of someone close? Did she or he ever comment on the experience someone else had at the hospital? Use these observations to guide the conversation with the care team and the decisions that are made. (Note: See our [*Conversation Starter Kit for Families and Loved Ones of People with Alzheimer's Disease or Other Forms of Dementia.*](#))

I am a health care proxy for a loved one, and I disagree with his or her wishes.

- A health care proxy should act on a loved one's behalf using "substituted judgment" — in other words, making the decision your loved one would make if he or she could. If you feel that you cannot carry out your loved one's wishes, then it's a good idea to say so. They might want to choose an alternate health care proxy. If you have never had a conversation with the person for whom you're a proxy, then you will need to do your best to act in your loved one's best interest, guided by their health care team. (Note: See [How to Choose a Health Care Proxy & How to Be a Health Care Proxy.](#))

I am a health care proxy for my parent, but my siblings disagree with my parent's expressed wishes.

- See the answer above. Your obligation as a health care proxy is to make decisions according to your loved one's wishes.
- There are teams of people in the medical community (often called ethics committees) that can help clarify these kinds of situations, but sometimes it just takes time for family members to come to terms with their loved one's expressed wishes.

My doctor doesn't agree with my choices and has his/her own strong opinion.

- First, explore why. Maybe your doctor fears that aggressive therapy will buy you a little time, but little quality of life. Or maybe your doctor believes that a time-limited trial of aggressive therapy may mean that you can be back enjoying your life again. If it's still challenging to find common ground, you may need to seek a second opinion. Remember, you are the expert on your desired quality of life.

I got two different opinions from two of my doctors.

- Get them in same room at the same time and talk! We do this with painters and contractors, and here the stakes are much higher. Sure, it can be logistically difficult — but it is your right.
- If you're not comfortable bringing together two of your doctors who disagree, tell one of your doctors (or another member of your team) that you've received two different opinions and you'd like help understanding the difference.

We invite you to talk back.

Was your health care team “Conversation Ready”? Were they ready to listen? We invite you to share your experience talking to your doctor by visiting theconversationproject.org and clicking on “*Your Stories*.”

We hope you will share this document with others.

Every time people talk to their doctors (or any member of their care team) about their end-of-life wishes, it helps ensure that their wishes will be properly respected.

Contact Us

VISIT US

www.theconversationproject.org

E-MAIL US

conversationproject@ihi.org

FOLLOW US ON FACEBOOK AND TWITTER

 @convoproject

 TheConversationProject

PALLIATIVE CARE

When you have a serious illness, symptoms can include pain and emotional distress. A special type of care called palliative care is available to help you get relief from these and other symptoms. You can receive palliative care at any stage of your serious illness, including when you are getting treatment.

Palliative care (pronounced pal-lee-uh-tiv) is specialized medical care for people with serious illness. It focuses on providing relief from the symptoms and stress of the illness and aims to improve quality of life for the patient and the family. Palliative care is provided by a specially-trained team of doctors, nurses, and specialists who work together to provide an extra layer of support. It is appropriate at any age and at any stage of an illness, and it can be provided along with curative treatment.

The goal of palliative care is to improve the quality of life for people with serious illnesses and their families. "Family" can be people related to us and those we choose to call family.

Palliative care can prevent or provide relief from symptoms such as pain, shortness of breath, fatigue, nausea, loss of appetite, problems with sleep, and emotional and spiritual distress. Another purpose of palliative care is to improve connections and communication among family members and providers of care. Palliative care can improve your quality of life when you are seriously ill.

Palliative care can be helpful if you:

- Suffer symptoms due to any serious illness of any length
- Experience physical or emotional pain that is not under control
- Need help understanding your situation and coordinating care

PALLIATIVE CARE

Often a team of specialists provides palliative care. The team usually includes:

- Palliative care doctors and nurses
- Social workers and chaplains
- Pharmacists and nutritionists
- Counselors and others

This team works with your doctor and other health care providers to offer an extra layer of support by helping to control symptoms related to your illness and its treatment.

You can ask for palliative care and do not have to give up your primary health care provider or efforts to cure your illness.

Medicare, Medicaid, Veterans Health Administration benefits, and private health insurance cover many palliative care services. Many hospitals provide palliative care, and it can be provided in nursing homes and in your home as well.



Resources

Palliative Care, The Relief You Need When You're Experiencing the Symptoms of Serious Illness

National Institute for Nursing Research at the National Institutes of Health

English and Spanish Brochures:

<https://www.ninr.nih.gov/newsandinformation/publications/palliative-care-brochure>

GetPalliativeCare.org

Center to Advance Palliative Care

Information for consumers

<http://www.getpalliativecare.org/>

Hospital-based palliative care teams

Tool to locate hospital-based palliative care teams, which may also provide community-based care

<http://www.getpalliativecare.org/howtoget>

Home and Community Based Services for Veterans

U.S. Department of Veterans Affairs

Information on palliative care and hospice services available to veterans

http://www.va.gov/GERIATRICS/Guide/LongTermCare/Home_and_Community_Based_Services.asp

ADVANCE CARE PLANNING

FOR SERIOUS ILLNESS



Making plans for the health care you want during a serious illness is called "advance care planning." Planning involves learning about your illness, understanding choices for treatment and care, talking with family and health care providers, and completing written documentation about care choices, choosing someone to make choices if you cannot. "Family" can be people related to us or those we choose to call family.

Communicate Your Wishes Talk about health care decisions with your family and health care providers. Be clear about the type of care you want. Think about what you feel would make you comfortable during the last stages of your life.

Medicare covers voluntary planning discussions with your health care professional during the *Welcome to Medicare* preventive visit, your *Annual Wellness Visit*, and at other times when you need to have this discussion as part of your medical care. You may want to discuss planning documents, like a durable power of attorney for health care, or medical care decisions and their impact on your life.

Written directions. There are two types of written legal documents, also called advance directives:

- **A living will** spells out your decisions for treatments and life-sustaining measures such as mechanical breathing (respiration and ventilation), tube feeding, or resuscitation.
- **A durable power of attorney** for health care names a health care proxy, who is the person who makes choices for you when you cannot. If you do not name a health care proxy, states generally have rules about how families can make care decisions for you.

Health care providers and insurance companies need your permission to share personal information with the health care proxy.



ADVANCE CARE PLANNING FOR SERIOUS ILLNESS



POLST You may ask your health care providers to discuss and complete a **Physician Orders for Life-Sustaining Treatment** or POLST form (name may vary by state). This is an option for people with a serious illness that is likely to get worse over time or people with frailty—such as advanced heart or lung disease—whose health care professionals would not be surprised if they died within a year.

- A POLST makes sure that decisions about care at the end of life are written as medical orders that health care providers must follow.
- The POLST should list the medical care people do or do not want, given their current health condition. It should include decisions for cardiopulmonary resuscitation (CPR) if your heart stops or if you stop breathing.

Without a POLST, emergency care providers generally must provide such medical treatment to keep people alive. Not every state has POLST, and some states have similar forms that go by different names.

Remember You may change your mind about care as you get older or if you become ill, so it is important to review your advance directives or POLST regularly. States' rules and regulations differ, so it is important to make sure your documents work in your home state and others where you spend a lot of time.

Resources

**Advance Care Planning
National Institute on Aging at
the National Institutes of Health**
Basic information on this topic and
helpful links
[http://www.nia.nih.gov/health/
publication/advance-care-
planning](http://www.nia.nih.gov/health/publication/advance-care-planning)

**Give Peace of Mind: Advance
Care Planning
Centers for Disease Control and
Prevention**
Provides basic information on this
topic and helpful links
[http://www.cdc.gov/aging/
advancecareplanning](http://www.cdc.gov/aging/advancecareplanning)

**Caring Connections
National Hospice and Palliative
Care Organization**
Links to every state's advance care
directive forms
[http://www.caringinfo.org/i4a/
pages/index.cfm?pageid=3289](http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3289)

The National POLST Paradigm
Shows which states have POLST
and how to get more information
about their forms
[http://www.polst.org/programs-
in-your-state](http://www.polst.org/programs-in-your-state)

HOSPICE CARE



Hospice offers a special type of care that focuses on providing you and your family with comfort, pain relief, and support services when you are expected to live six months or less. "Family" can be people related to you or those we choose to call family.



About Hospice Care

- Provides pain and symptom relief tailored to your needs and wishes, as well as emotional and spiritual support
- Open to people of all ages and all types of diseases, such as Alzheimer's disease, cancer, heart disease, kidney disease, stroke, HIV/AIDS, and other illnesses
- Can be provided in your home, nursing homes, assisted living facilities, hospitals, hospice centers, or other places where you live
- May include respite support as well as grief counseling and other types of counseling for family members

Hospice care includes doctor and nurse services; medicines; therapies; social work and clergy services; dietary and medical supplies and equipment; respite care; and management of pain and other symptoms. For community hospices, a member of the hospice team is available 24 hours a day, seven days a week, to provide support and care. Hospice generally does not cover room and board in a facility, unless the person needs specialized short-term inpatient or respite care related to the terminal diagnosis. You can stop hospice at any time.

HOSPICE CARE



Hospice care is possible if you are likely to die within six months if your illness goes as expected and you have a desire for your care to focus on comfort. For most health insurers, including Medicare and Medicaid, a doctor must certify a life expectancy of six months or less. If necessary, a doctor can continue to certify that a person needs hospice, even if the person lives longer than six months. All but a few state Medicaid programs cover hospice. The Veterans Health Administration covers hospice.

People often choose hospice care late in the course of illness. Many others could benefit from the physical and emotional comfort that hospice care can provide.

Many who have lost family members wish they had asked for hospice sooner.



Resources

Hospice and Respite Care Centers for Medicare & Medicaid Services
Information on this benefit and how to use it
<http://www.medicare.gov/coverage/hospice-and-respite-care.html>

Medicaid beneficiaries need to consult their state's Medicaid program about hospice coverage. Find contact information for state programs at <http://www.medicare.gov/coverage/hospice-and-respite-care.html>

CaringInfo National Hospice and Palliative Care Organization
Offers a variety of resources
www.caringinfo.org/i4a/pages/index.cfm

Home and Community Based Services for Veterans
Information on hospice services available to veterans
http://www.va.gov/GERIATRICS/Guide/LongTermCare/Home_and_Community_Based_Services.asp

HIPAA PERMITS DISCLOSURE TO HEALTH PROFESSIONALS INVOLVED IN THE PATIENT'S CARE

<p>Provider Orders for Life-Sustaining Treatment (POLST)</p> <p>This is a Physician/APRN Order Sheet. <u>First</u> follow these orders, <u>then</u> contact physician or APRN. These medical orders are based on the patient's current medical condition and preferences. Any section not completed does not invalidate the form and implies full treatment for that section.</p>	<p>Patient Last Name _____</p> <hr/> <p>Patient First Name/Middle Initial _____</p> <hr/> <p>Date of Birth (mm/dd/yyyy) _____ Gender _____</p>
--	--

<p>Section A Check One</p>	<p>Cardiopulmonary Resuscitation (CPR): Patient has no pulse <u>and/or</u> is not breathing.</p> <p><input type="checkbox"/> YES, Attempt CPR</p> <p><input type="checkbox"/> NO, Do Not Attempt Resuscitation/DNR Follow orders in B, C and D when not in cardiopulmonary arrest.</p> <p>This will constitute a DNR order, and no separate DNR Order will be required.</p>
---------------------------------------	---

<p>Section B Check One</p>	<p>Interventions:</p> <p><input type="checkbox"/> Full Treatment – Includes treatment described below, use intubation, advanced airway interventions, mechanical ventilation, and cardioversion as indicated. Transfer to hospital if indicated. Includes intensive care. Treatment Plan: Full treatment including life support measures in the intensive care unit.</p> <p><input type="checkbox"/> Selective Interventions – Includes treatments described below. Use medical treatment, IV fluids and cardiac monitor as indicated. Do not use intubation, advanced airway interventions, or mechanical ventilation. Transfer to hospital level of treatment to meet need, if indicated. Avoid intensive care. Treatment Plan: Provide basic medical treatments.</p> <p><input type="checkbox"/> Comfort-focused Care – Use medication by any route, positioning, wound care, oxygen, and other measures to relieve pain and discomfort. Patient prefers no transfer to hospital for life-sustaining treatment. Transfer only if comfort needs cannot be met in current location. Treatment Plan: Maximize comfort through symptom management.</p>
---------------------------------------	--

Other Orders (e.g. time limited treatment, hospice evaluation, etc.):

<p>Section C Check Only One in Each Column</p>	<p>Medically Administered Fluids and Nutrition. Oral fluids and nutrition must be offered if medically feasible and consistent with patient's goals of care.</p> <table style="width:100%;"> <tr> <td><input type="checkbox"/> IV fluids long-term for hydration and nutrition</td> <td><input type="checkbox"/> Feeding tube long-term</td> </tr> <tr> <td><input type="checkbox"/> IV fluids for a defined trial period</td> <td><input type="checkbox"/> Feeding tube for a defined trial period</td> </tr> <tr> <td><input type="checkbox"/> No IV Fluids for hydration and nutrition</td> <td><input type="checkbox"/> No feeding tube</td> </tr> </table>	<input type="checkbox"/> IV fluids long-term for hydration and nutrition	<input type="checkbox"/> Feeding tube long-term	<input type="checkbox"/> IV fluids for a defined trial period	<input type="checkbox"/> Feeding tube for a defined trial period	<input type="checkbox"/> No IV Fluids for hydration and nutrition	<input type="checkbox"/> No feeding tube
<input type="checkbox"/> IV fluids long-term for hydration and nutrition	<input type="checkbox"/> Feeding tube long-term						
<input type="checkbox"/> IV fluids for a defined trial period	<input type="checkbox"/> Feeding tube for a defined trial period						
<input type="checkbox"/> No IV Fluids for hydration and nutrition	<input type="checkbox"/> No feeding tube						

<p>Section D Check One</p>	<p><input type="checkbox"/> Antibiotics if life prolonging <input type="checkbox"/> No antibiotics <input type="checkbox"/> Antibiotics only if likely to contribute to comfort</p>
---------------------------------------	---

<p>Section E Check All That Apply</p>	<p>The basis for these orders is:</p> <table style="width:100%;"> <tr> <td><input type="checkbox"/> Patient</td> <td><input type="checkbox"/> Parent(s) of minor</td> </tr> <tr> <td><input type="checkbox"/> DPOAH agent</td> <td><input type="checkbox"/> Surrogate</td> </tr> <tr> <td><input type="checkbox"/> Court-appointed guardian</td> <td><input type="checkbox"/> Other (specify): _____</td> </tr> </table> <p>This order has been discussed with the patient named above (or agent, guardian, or parent named below), who has given consent as evidenced by signature below.</p>	<input type="checkbox"/> Patient	<input type="checkbox"/> Parent(s) of minor	<input type="checkbox"/> DPOAH agent	<input type="checkbox"/> Surrogate	<input type="checkbox"/> Court-appointed guardian	<input type="checkbox"/> Other (specify): _____
<input type="checkbox"/> Patient	<input type="checkbox"/> Parent(s) of minor						
<input type="checkbox"/> DPOAH agent	<input type="checkbox"/> Surrogate						
<input type="checkbox"/> Court-appointed guardian	<input type="checkbox"/> Other (specify): _____						

Documentation of discussion is located in medical chart at:	Date of Discussion:
---	---------------------

Mandatory Signature of Patient or Activated DPOAH, Guardian, Surrogate or Parent of Minor, and Physician/APRN			
Name (Print)	Signature (Mandatory)	Date	Relationship (write "self" if patient)
Physician/APRN Name: (Print)	Physician/APRN Phone Number:	Physician/APRN State License Number:	
Physician/APRN Signature: (Mandatory)		Date: (Mandatory)	

HIPAA PERMITS DISCLOSURE TO HEALTH PROFESSIONALS INVOLVED IN THE PATIENT'S CARE
Information for Patient Named on this form – Patient's Name (print):

This voluntary form records your preferences for life-sustaining treatment in your current state of health. It can be reviewed and updated by you and your health care professional at any time if your preferences change. If you are unable to make your own health care decisions, the orders should reflect your preferences as best understood by your DPOAH, Guardian or by your written Advance Care Plan.

(Optional) Contact Information for DPOAH, Guardian or Parent of Minor

Name:	Relationship:	Phone Number:	Address:

(Optional) Health Care Professional Preparing Form

Name:	Preparer Title:	Phone Number:
		Date Prepared:

Directions for Health Care Professionals

Completing POLST

- Encourage completion of an Advance Directive.
- Should reflect current preferences of patient with serious illness or frailty whose death within the next year would not surprise you.
- Verbal/phone orders are acceptable with follow-up signature by physician/APRN in accordance with facility policy.
- Use original form if patient is transferred/discharged.

Reviewing POLST

This POLST should be reviewed periodically and if:

- The patient is transferred from one care setting or care level to another, or
- There is a substantial change in the patient's health status, or
- The patient's treatment preferences change.

Voiding POLST

- A patient with capacity, or the activated DPOAH or Court appointed Guardian of a patient without capacity, can void the form and request alternative treatment.
- Draw line through sections A through E and write "VOID" in large letters if POLST is replaced or becomes invalid if in a Health Care facility.
- At any time a patient at home or agent or guardian may revoke this POLST by destroying it.

Review of this POLST Form

Review Date	Reviewer	Location of Review	Signature

Review Outcome: No Change Form Voided New form completed

Review Date	Reviewer	Location of Review	Signature

Review Outcome: No Change Form Voided New form completed

Review Date	Reviewer	Location of Review	Signature

Review Outcome: No Change Form Voided New form completed

ORIGINAL TO ACCOMPANY PATIENT IF TRANSFERRED / DISCHARGED.
FAX OR PHOTOCOPY SHALL BE REGARDED AS VALID IF CONSISTENT WITH
FACILITY OR AGENCY POLICY.

