Conversations Change Lives:

A Guidebook To Advance Care Planning

LaPOST

Louisiana Physician Orders for Scope of Treatment

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Advance Care Planning:
It All Begins With A Conversation

When you have a serious advanced illness, it may be difficult to discuss what types of medical treatments you do or don't want as your illness progresses. It's a conversation that can be uncomfortable for you and your loved ones, but it is one of the most important conversations you can have. Without it, your family or caregiver may never know your wishes, and you may not receive the kind of care at the end of life that you want.

The advance care planning guidebook is designed to help you prepare your thoughts as you plan this conversation. The guidebook does not provide you with the answers to the many questions you must ask yourself, but it will help you to organize your thoughts.

You do not have to complete it in a single day. Deciding what types of medical care you want is something that requires much thought. Take your time as you complete the guidebook, and remember, you are the expert on your care wishes and preferences.

Step 1:
Preparing for the Conversation

STEP 1

As you prepare to share your wishes for end-of-life care with your loved ones, it may be helpful to know a few facts about advance care planning:

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. 93% report never 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)

Remember, you don't have to talk yet about what you want - you just need to think about it. Start by writing a practice letter to yourself or having a practice conversation with a loved one or friend. These exercises can help you describe your feelings, and may reveal any potential disagreements you and your loved ones may have about the kind of care you want as your illness progresses. It is okay to disagree, but it is important to talk about it now rather than during an emergency situation. Use the following page to make a list of the three most important things you would like to consider or do before you have this conversation with your loved ones.

Ask yourself:

What should I think about and do before having this conversation?

1. _____

2. _____

3. _____

Step 2:
Knowing What You Want

STEP 2

Now consider what types of care you want and don't want at the end of life. Begin by asking yourself what is most important to you.

- *What can you not imagine living without?*
- *What is most valuable to you?*

Finish this sentence:

"What matters to me is

_____ ."

Now consider what is most important to you at the end of life. The exercises below may be helpful to you in identifying your feelings.

As a patient:

- ☐ I only want to know the basics about my condition.
- ☐ I only want to know enough to make informed decisions.
- ☐ I want to know everything about my condition.

After being diagnosed with a serious advanced illness:

- ☐ I don't want to know how long I have left.
- ☐ I want a general idea of how long I have left.
- ☐ I want to know exactly how long I have left.

When it comes to treatment:

- ☐ I want my doctors to do what they think is best for me.
- ☐ I want to have some say in what treatments are given to me.
- ☐ I want to have a say in every decision related to my care.

At the end of life:

- ☐ I want to live independently in my own home for as long as I can.
- ☐ I wouldn't mind receiving care in a nursing facility, if necessary.
- ☐ I want my loved ones to determine what is best for me.

When it comes to health care wishes:

- ☐ I want my wishes followed, even if it makes my loved ones uncomfortable.
- ☐ I want my loved ones to do what brings them peace, even if it goes against my wishes.
- ☐ I want to work with my loved ones to determine my wishes.

As the end of life approaches:

- ☐ I want to live as long as possible, even if it requires extensive life-prolonging treatments and equipment.
- ☐ I want only to be kept as comfortable and pain-free as possible.
- ☐ I want my loved ones to decide which treatments I receive and do not receive.

Now respond to the following statements.

My loved ones know exactly what I want at the end of life.

☐ True ☐ False

I'm worried that I will not receive enough care at the end of life.

☐ True ☐ False

I'm worried that I will receive overly aggressive care at the end of life.

☐ True ☐ False

I just want to be made as comfortable as possible at the end of life.

☐ True ☐ False

Take a few moments to outline your thoughts about what you learned by completing these exercises.

Step 3:
Knowing What Is Available

STEP 3

Now that you've organized your thoughts about what you want at the end of life, it is time to discuss what documents are available to record your wishes.

The Advance Directive, or 'Living Will'

The advance directive, also known as a "living will," is a legal document that provides instructions specifying what kind of treatment should be given to you when you are no longer able to make decisions or speak for yourself. Generally, a living will describes certain life-prolonging treatments. As the declarant, your living will states which treatments you do or do not want in the event you suffer from a terminal illness or are in a vegetative state. It may be very specific or very vague.

It is important that you understand that a living will is restrictive, as it only goes into effect if you have lost the ability to make decisions and are terminally ill. The living will is usually completed in advance of any known illness. Because you complete it yourself, unless there are other known facts, it must be honored. An advance directive does not need to be notarized, but it must be witnessed by two people in order to be valid.

STEP 3

The Health Care Power of Attorney

The health care power of attorney authorizes someone else to make decisions for you when you are no longer able to make decisions or speak for yourself. In Louisiana, there is a specific order of who can make these decisions for you if no written instructions are available.

To become valid, the health care power of attorney document must be witnessed by two people. It is recommended that it be notarized.

The Louisiana Physician Orders for Scope of Treatment (LaPOST)

The Louisiana Physician Orders for Scope of Treatment (LaPOST) document is more than an advance directive or a health care power of attorney. The document is recommended only for patients who have serious advanced illnesses.

The LaPOST document is a physician order that outlines your wishes for medical treatment and goals of care developed when you have a known serious advanced illness. It can also be used to translate a living will into a physician's order when you have a life-limiting and irreversible condition.

STEP 3

The LaPOST document lists some of the medical treatments you can choose to have or not have. Your doctors and health care team can help you decide which treatment options will best help you reach the goals you have for your care at the end of life. When it is completed, it must be honored by all health care professionals.

The document then provides a roadmap for your medical care when you have serious life-limiting illnesses. It can be completed by your personal health care representative if you are no longer able to speak for yourself. The personal health care representative is defined in R.S. 40:1299.64.2 (9) and means a person who has authority in accordance with Louisiana law to act on behalf of an individual who is an adult or emancipated minor in making decisions related to health care because of incapacity.

In order to become valid, the LaPOST document must be discussed by you and/or your health care representatives and be appropriately completed. It must be signed by a physician.

Of the three documents, the LaPOST document is most likely to ensure that you receive the care you want at the end of life because it is a medical order. As such, it travels with you across health care settings, from home to hospital to long-term care facility.

Step 4:
Preparing to have the Conversation

STEP 4

When you are ready to begin the conversation with your loved ones about your end of life wishes, you may find it helpful to first answer the following questions:

Who do I want to talk to about my end-of-life wishes?

Who do I trust to speak for me if I become unable to speak for myself?

When would be a good time to talk to this trusted person?

Where would I feel most comfortable having this conversation?

What are the most important issues I want to address?

STEP 4

What is most important to me as I think about the last phase of my life?

Do I want to be actively involved in decisions about my care?

Are there circumstances that I consider to be worse than death, such as not being able to recognize my loved ones or the long-term need for a breathing machine or feeding tube?

Where do I want, or not want, to receive care at the end of life: home, nursing facility or hospital?

What do I most want my loved ones to know about my wishes?

Step 5:
Beginning the Conversation

STEP 5

Though you have decided what you want at the end of life, it can still be difficult to open the conversation with your loved ones. As you begin to discuss your wishes, remember the following:

- **It is important to be patient. You've had time to think about your wishes, but your loved ones may need a little time to think, too.**
- **You do not have to lead the conversation. Open the discussion and then just let it happen.**
- **Don't become upset if your loved ones' beliefs about end-of-life care do not mirror your own. Be willing to listen and ask them to listen to you, too.**
- **You and your loved ones can always change your minds as your circumstances change. Nothing is carved in stone.**
- **You do not have to discuss everything in a single conversation. This may be the beginning of several conversations.**
- **You are the expert on what you want at the end of life. Don't be afraid to say so.**
- **You can choose when, where, and with whom you want to have this conversation.**
- **Even if the conversation does not go as well as you'd hoped, know that every attempt to discuss your wishes is valuable. You can try again later if needed.**

STEP 5

Having your thoughts organized and your wishes outlined are helpful, but remember that there is no script for this discussion. Below are a few suggestions for ways to open the conversation with your loved ones:

"Even though I'm okay right now, I'm worried that my situation may change, and I'd like to be prepared."

"I'd like your help as I plan for the future."

"I'd like to share my feelings with you about what I do and don't want at the end of life."

"Have you ever thought about what you'd like at the end of life? I'd like to hear your thoughts."

"Life is pleasant. Death is peaceful. It's the transition that's troublesome."

- Isaac Asimov, American author

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