

Start the Conversation

A HANDBOOK FOR CRITICAL HEALTHCARE DECISIONS

Introduction

Good advanced planning for health care decisions is a continuing conversation. This should include discussions about values, things that are important, as well as the meaning and quality of life. To help you in this process, we have produced this Conversation Guide.

The Guide contains worksheets, suggestions, information, and other useful things.

This information will help you think about your values as they relate to medical care decisions. It will also help you to better understand end-of-life care options. Finally, the Guide will help you to discuss your choices with your loved ones and your healthcare surrogate, that is, a person you choose to make healthcare decisions for you in the event that you are no longer able to speak for yourself.

The Ethics Committee at Cleveland Clinic Indian River Hospital understands that it's hard to discuss such a sensitive issue as end-of-life. We are here to make the process easier. With skill, caring, and kindness we help patients and their families face very hard choices. "Start the Conversation" is a public education effort that aims to:

- * Increase the understanding of care options, including hospice and pain-relieving care.
- * Help families talk with each other and their doctor about medical decisions.
- * Encourage the use of an advance directive, that is, a written statement about your wishes regarding medical care should you become too ill to communicate them yourself to your doctor.

Section One

KNOW YOUR CARE OPTIONS

Knowing your options is an important first step in making sure all of your medical care decisions are followed. This section outlines the differences between hospice and pain-relieving care. It clearly describes the benefits of each of these care options.

Section Two

WORKSHEETS TO HELP YOU START THE CONVERSATION

Are some conditions worse than death? This worksheet helps you think about different situations where you would not want medical treatment meant to keep you alive.

Personal and spiritual values important to your medical Decisions. Answer 10 questions about your personal values and beliefs to make sure they are clear to you and to others.

Your personal medical preferences test. This list of questions can give you some idea of how well you have shared your wishes to your family, agent, or doctor. This may lead to a discussion that helps to build understanding.

Your agent's understanding of your medical preferences. Your healthcare surrogate, family member, or doctor completes the same test you have taken. Compare the answers to see how well your wishes have been understood.

Your care plan. This information lists the important steps for making your wishes known. It includes a worksheet to help you decide who the best person is to speak for you regarding a medical problem, in case you cannot speak for yourself.

Know your care options

When faced with decisions about end-of-life care for yourself or someone you love, knowing your options is an important early step. Palliative and hospice care are specialized care options for persons with life-threatening or terminal illnesses. Understanding the benefits of palliative and hospice care is important for all of us so that we can be prepared to find the care we need for ourselves or our loved ones if needed.

PALLIATIVE CARE BENEFITS

Palliative care is comfort care for people with serious illnesses. It focuses on providing relief from the symptoms, pain, and stress of a serious illness. The goal is to improve quality of life for the patient and family. Palliative care is also combined with treatment to help fight disease, depending upon the goals of care.

A wide variety of patients can benefit from palliative care including:

- * Those who have been diagnosed with a serious illness who would like relief from pain or signs of sickness connected with the disease;
- * Those who need to take time to make difficult decisions about how to proceed with care and treatment;
- * Those who need help with communicating concerns related to care and treatment.

The goal of palliative care is to achieve the best quality of life for patients and their families. A patient receiving palliative care may have more (or less) than six months to live. He or she may also continue to look into cure-oriented treatment while receiving palliative care services. This approach is meant to allow people with a life-threatening illness earlier access to the same type of care that hospice patients receive.

Palliative care has been shown to:

- * Reduce painful treatments that are not wanted or needed
- * Increase the ability of patients' families to cope with and care for a loved one
- * Improve how the patient and family feel about their care
- * Improve how patients respond to their treatments

The first step to getting palliative care is to talk to your doctor. Explain to your doctor what quality of life means for you or for your loved one. Also, discuss what treatments and procedures are ahead. Your doctor may handle these requests or make a referral to palliative care. Keep in mind that receiving palliative care does not interrupt your relationship with your primary physician. Palliative care should enhance the effectiveness of the care you receive.

HOSPICE CARE BENEFITS

Hospice provides care, comfort, and support to seriously ill patients and their families, when medical care cannot offer a cure. The hospice team works to make patients comfortable and relieve their symptoms and pain for the entire length of their illness.

The hospice team will provide the services below to individuals in the home, wherever they consider home to be:

- manage pain and other symptoms
- offer support for the emotional and spiritual parts of dying
- provide medicine, medical supplies, and equipment
- teach family members skills to help them provide care
- provide special help like speech and physical therapy if needed
- make short-term inpatient care available when pain or other problems become too difficult to take care of at home
- provide support and counseling to family members and loved ones
- provide bereavement care and support for your loved ones

Hospice believes that dying is a natural part of the life course. Every person has the right to live fully with dignity and without pain until a natural death takes place.

Anyone can inquire about hospice services. In Indian River County, hospice is provided by Medicare-certified Visiting Nurse Association; in St. Lucie County, hospice is provided by Medicare-certified Treasure Coast Hospice. You or your loved one can contact your local hospice provider and request services. The hospice team will then contact your physician to determine if a referral to hospice is appropriate. Another way to inquire about hospice is to talk with your physician, and he or she can make a referral to hospice.

Hospice services are available for children and adults. Individuals can be referred to hospice when the goal of treatment changes from cure to comfort, and they have about six months or less to live.

The most common response heard from families following the death of their loved one is, "I wish that I had known about hospice care sooner." It is important that you understand the care that is available for you or your loved one at the end of life.

Hospice is thought to be the model for high-quality, compassionate care for people with a life-limiting illness. The wishes of the patient and family are always at the center of care. Ask about hospice.

Understand Your Care

COMPARING PALLIATIVE AND HOSPICE CARE

Who can receive this care?

P Anyone with a serious illness can receive palliative care. It doesn't matter how long a person is expected to live.

H Someone with an illness with a life expectancy measured in months, not years.

Can I continue to receive treatments to cure my illness?

P You may receive palliative care and curative care at the same time.

H Treatments and medicines to relieve signs of sickness are given by hospice.

Does Medicare pay?

P Some treatments and medications may be covered.

H Medicare pays all charges related to hospice.

Does Medicaid pay?

P Some treatments and medications may be covered.

H Medicaid pays all charges related to hospice.

Does private insurance pay?

P Some treatments and medicines may be covered, but most of the time there is not a 'package' benefit for palliative care.

H Most insurance plans have a hospice benefit.

How long can I receive care?

P This will depend upon your care needs, and the coverage you have through Medicare, Medicaid or private insurance.

H As long as you meet the hospice's criteria of an illness with a life expectancy of months, not years.

PALLIATIVE & HOSPICE CARE

What organization provides these services?

P hospitals, home health, and Hospice agencies

H Visiting Nurse Association and Treasure Coast Hospice

Where are services provided?

P home, assisted living facility, nursing facility, hospital

H home, assisted living facility, nursing facility, hospital, or an in-patient hospice facility

Can I get help from volunteers?

P Volunteers are not offered at present time.

H Trained hospice volunteers provide support for families and patients as needed.

Are medications covered?

P Medicine coverage varies with insurance policy.

H Medicine related to the terminal diagnosis are covered.

Is medical equipment covered?

P Coverage varies with insurance policy and medical need.

H Medical equipment covered related to terminal diagnosis (toilet, hospital bed, etc.).

Is bereavement support provided?

P Usually not covered; exceptions made on an individual basis.

H Bereavement support for family - up to one year following the death.

Are some conditions worse than death?

MEDICAL DIRECTIVES

This worksheet helps you to think about situations in which you would not want medical treatments meant to keep you alive.

Progress in medical technology is changing the way people make decisions about the types of treatment they want. Modern medicine offers choices that require you to make value judgments. These judgments may help you determine if a particular treatment is right for you. In some cases, treatments can keep people alive even if there is no chance you will improve. Ask yourself what you would want in the situations described below if treatment would not reverse or improve your condition.

DIRECTIONS: Circle the number from 1 to 5 that best indicates how you feel about these situations:

- 1 - Definitely want treatments that might keep you alive.
- 2 - Probably would want treatments that might keep you alive.
- 3 - Unsure of what you want.
- 4 - Probably would NOT want treatments that might keep you alive.
- 5 - Definitely do NOT want treatments that might keep you alive.

WHAT IF YOU...

a. No longer can walk but get around in a wheel chair.

1 2 3 4 5

b. No longer can get outside – you spend all day at home.

1 2 3 4 5

c. No longer can contribute to your family's well-being.

1 2 3 4 5

d. Are in severe pain most of the time.

1 2 3 4 5

e. Are in severe discomfort most of the time (nausea, diarrhea).

1 2 3 4 5

f. Are on a feeding tube to keep you alive.

1 2 3 4 5

g. Are on a kidney dialysis machine to keep you alive.

1 2 3 4 5

h. Are on a breathing machine to keep you alive.

1 2 3 4 5

i. Need someone to take care of you 24 hours a day.

1 2 3 4 5

j. Can no longer control your bladder or your bowels.

1 2 3 4 5

k. Live in a nursing home.

1 2 3 4 5

l. Can no longer think or talk clearly.

1 2 3 4 5

m. Family or friends cannot be recognized.

1 2 3 4 5

n. Need to be sedated to control your pain.

1 2 3 4 5

Personal and Spiritual Values

AND YOUR MEDICAL DECISIONS

People have personal and spiritual beliefs that affect their medical decisions. This is especially true at the end of life with regard to the use of life-sustaining treatments. To be sure that your values and beliefs are clear to yourself and to others, think about answering the questions below. Use more paper if you need more space.

1. What is most important to you about your physical/mental wellbeing? For example, do you love to do things outside; read; listen to music; be physically active?

2. What gives your life its value, purpose and meaning?

3. What are your fears regarding the end of life?

4. Do you believe life should always be preserved as long as possible?

5. If your treatment had distressing side effects, at what point would you choose hospice or palliative care instead?

6. If you knew you had a life-limiting illness, where would you spend your remaining time, what would you like to be doing, and who would you want to be present?

7. With which family members/friends are you going to start discussing your health care choices?

8. How do you want to be remembered? (If you wrote your obituary or eulogy, what would it say?)

9. Do you have any religious or moral views about medicine or particular medical treatments to prolong life? If so, what are they?

10. What do you want others to know about the spiritual or religious part of your life?

11. Should careful thought be given to cost when making decisions about your medical care? Explain.

12. What do you need for comfort and support as you journey near death? For example, to pray with a member of the clergy? To have others pray for you? To be read to from spiritual or religious texts? To have music playing? To be held?

PERSONAL MEDICAL PREFERENCES TEST

How well does your family, health care surrogate, or doctor know your health care wishes? This short test can give you some idea of how well you have communicated your wishes to them. It may also help you to have a better conversation and understanding with those who care.

DIRECTIONS:

STEP 1: *Answer the 10 questions below using the Personal Medical Preferences.*

STEP 2: *Next, ask your health care agent, family member, or close friend to complete the Agent Understanding of Your Personal Medical Preferences test, also included in this booklet. THE QUESTIONS ARE THE SAME. Don't reveal your answers until after they take the test. They should answer the questions in the way they think you would answer. (Try the same test with your doctor, too.)*

STEP 3: *Grading – Count one point for each question on which you and your agent (or you and your doctor) gave the same answer.*

POINTS GRADE:

10..... You are doing a great job communicating.

8 – 9..... Need some fine-tuning.

6 – 7..... More discussion needed.

5 or below..... You have a lot of talking to do.

PERSONAL MEDICAL PREFERENCES TEST

If you are not sure about any of your choices, you should ask your health care professional to explain the options available to you in more detail.

STEP 1: *Begin here and complete the questions by yourself. Think about how important these situations would be to you.*

Imagine that you had Alzheimer's disease and it had progressed to the point where you could not recognize or converse with your loved ones. When spoon-feeding was no longer possible, would you want to be fed by a tube placed in your stomach?

- a. Yes
- b. No
- c. I am uncertain

Which of the following do you fear most near the end of life?

- a. Being in pain
- b. Losing the ability to think
- c. Being a financial burden on loved ones

Imagine that you are very ill, and doctors recommend a chemotherapy which usually has very severe side effects, such as pain, nausea, vomiting that could last for 2 to 3 months. Would you be willing to endure the side effects if the chance of regaining your current health was less than 5 percent?

- a. Yes
- b. No
- c. I am uncertain

In the same scenario, what if your illness is clearly terminal. Chemotherapy might give you six more months to live. Would you want the chemotherapy even though it has severe side effects (frequent pain, nausea, vomiting, and weakness)?

- a. Yes
- b. No
- c. I am uncertain

If you were terminally ill with a condition that caused much pain, would you want to be calmed with medicine, even to the point of unconsciousness, if it were necessary to control your pain?

- a. Yes
- b. No
- c. I am uncertain

Imagine that you have medium-level mental illness causing mental confusion. About half the time, you recognize and interact with friends and loved ones on a simple level. You also have circulation problems, which caused one leg to be removed. Now, the other leg develops a condition and the doctor recommends removal because the condition could be deadly. Would you want the operation?

- a. Yes
- b. No
- c. I am uncertain

Is it more important for you to: (a) have your treatment decisions followed at the end of life even if family members or friends disagree, or (b) have family and friends all agree and feel comfortable with whatever decision is made?

- a. Have specific decisions followed, even if there is disagreement
- b. Have family and friends all in agreement
- c. I am uncertain

Imagine that you are physically weak and need help with simple tasks such as dressing, washing, eating, and using the toilet. You live in a nursing home, your mind is fairly clear and capable most of the time, but you have had pneumonia or other lung infections four times in the last year. Each time you became confused and had to be placed in the hospital for several days and given antibiotics through an IV tube. The next time you get pneumonia, do you want antibiotic treatment again or just comfort (palliative) care until death comes?

- a. Antibiotic treatment
- b. Comfort care
- c. I am uncertain

Imagine that you are in a permanent coma, and you have to rely on a tube placed into your stomach for food and water. Would it be important to you that decisions about your care be guided by your religious beliefs or spiritual values?

- a. Yes
- b. No
- c. I am uncertain

If your heart, kidneys, pancreas, lungs and liver could all be used in transplant operations to save lives, would you want to donate them at death?

- a. Yes
- b. No
- c. I am uncertain

YOUR HEALTH CARE SURROGATE'S UNDERSTANDING OF YOUR MEDICAL PREFERENCES

STEP 2: *Your named health care surrogate, family member, close friend, or physician should complete the same test as you have taken. See how close the answers compare.*

Instructions: Answer the following questions in the way you think "N" (name:) would answer and how important these situations are to your family/friend/doctor.

Imagine that N had Alzheimer's disease and had progressed to the point where he/she could not recognize or converse with loved ones. When spoon-feeding was no longer possible, would he/she want to be fed by the insertion of a tube placed in the stomach?

- a. Yes
- b. No
- c. N would be uncertain

Which of the following do you think N fears most near the end of life?

- a. Being in pain
- b. Losing the ability to think
- c. Being a financial burden on loved ones

Imagine that N is very ill, and doctors recommend a chemotherapy which usually has very severe side effects, such as pain, nausea, vomiting, weakness that could last for 2-3 months. Would N be willing to endure the side effects if the chance of regaining his/her current health was less than 5 percent?

- a. Yes
- b. No
- c. N would be uncertain

In the same scenario, what if his/her condition is clearly terminal. Chemotherapy might give N 6 more months to live. Would N want the chemotherapy even though it has severe side effects (frequent pain, nausea, vomiting, and weakness)?

- a. Yes
- b. No
- c. N would be uncertain

If N were terminally ill with a condition that caused much pain, would N want to be calmed with medicine, even to the point of unconsciousness, if it were necessary to control the pain?

- a. Yes
- b. No
- c. N would be uncertain

Imagine that N has medium-level mental illness causing mental confusion. About half the time, N recognizes and interacts with friends and loved ones on a simple level. N also has circulation problems, which caused one leg to be removed. Now, the other leg develops a condition and the doctor recommends removal because the condition could be deadly. Would N want the operation?

- a. Yes
- b. No
- c. N would be uncertain

Is it more important for N to: (a) have his/her treatment decisions followed at the end of life even if family members or friends disagree, or (b) have family and friends all agree and feel comfortable with whatever decision is made?

- a. Have specific preferences followed, even if there is disagreement
- b. Have family and friends all in agreement
- c. N would be uncertain

8. Imagine that N is physically weak and needs help with simple tasks such as dressing, washing, eating, and using the toilet. N lives in a nursing home, has a fairly clear mind and is capable most of the time, but he/she had pneumonia or other lung infections four times in the last year. Each time N had to be placed in the hospital for several days and given antibiotics through an I-V tube. The next time N gets pneumonia, do you think he/she would want antibiotic treatment again or just comfort (palliative) care until death comes?

- a. Antibiotic treatment
- b. Comfort care
- c. N would be uncertain

Imagine that N is in a permanent coma, and has to rely on a tube placed into his/her stomach for food and water. Would it be important to N that decisions about N's care be guided by religious beliefs or spiritual values held by N?

- a. Yes
- b. No
- c. N would be uncertain

If N's heart, kidneys, pancreas, lungs, and liver could all be used in transplant operations to save lives, would he/she want to donate them at death?

- a. Yes
- b. No
- c. N would be uncertain

Making your care plan

Planning for end-of-life care is as important as all the other life plans you have made. Having a plan in place, before it becomes a worry, makes it easier for you, your doctor, and your loved ones if you are unable to tell them your health care choices because of an injury or serious illness.

The best way to make sure that your wishes are known and honored is to complete an advance directive. It is also important to talk to members of your family, close friends and health care providers about your preferences for care and treatment.

WHAT IS AN ADVANCE DIRECTIVE?

An advance directive is a legal document. It spells out your wishes and names someone to make decisions for you if you become unable to do so yourself. It is a written letter from you, properly signed and witnessed, that explains your future wishes and decisions about treatment.

Because advance directives express your personal values, they give the best possible guidance to those who will make decisions about your care when needed. Completing an advance directive also allows you to assign a health care surrogate, a person of your choosing who can make decisions for you in the event that you are no longer able to speak for yourself.

As you begin your advance directive, here are some important things to know:

- You have the right to consent to or refuse any medical treatment.
- You have the right to appoint a surrogate to make decisions for you.
- You do not need a lawyer to complete an advance directive.
- You can change your advance directive at any time.

HOW CAN I PREPARE MY ADVANCE DIRECTIVE?

Any advance directive form that is properly signed and witnessed is legal in Florida. It can be as long or as short as you wish.

<https://www.indianrivermedicalcenter.com/wpcontent/uploads/2015/02/IRMCadvdir1page02172014.pdf>

You may use a prepared form or write your own; you may also edit (both removing certain sections you don't want and adding specific language you do want) a prepared form. To be legal in Florida, the advance directive must be signed and dated by you. You must have your signature witnessed by two other people (one of whom cannot be related to you). It is not required to have the advance directive notarized, nor drawn up by an attorney. You may also change an advance directive at any time by attaching an addendum (signed, dated and witnessed). You may also cancel the previous form by creating a new advance directive. After completing an advance directive, be sure to discuss it with your family, and also give a copy to your doctor(s). IRMC will keep a copy of your advance directive in your electronic medical health record if you bring it to the hospital.

Health Care Surrogate

HOW TO SELECT YOUR HEALTH CARE SURROGATE

When you decide to pick someone to speak for you in a medical crisis, in case you cannot speak for yourself, there are several things to think about. This worksheet will help you decide who the best person is. Usually it is best to name one person to serve at a time, with at least one back-up person, in case the first person is not available when needed. Who would you wish your surrogate to be?

Name #1: _____

Name #2: _____

Name #3: _____

Keep in mind that the above names are only those of people you would consider to be your surrogate. Whom you decide to select must be named in your advance directive.

Consider the following when you appoint your surrogate:
A surrogate should be someone

- 18 years old or older who can serve as your surrogate.
- You can trust to make sure your wishes are carried out.
- Who could manage the responsibility and be comfortable speaking for you.
- Who lives close by or could travel to be at your side.
- Who knows you and understands what's important to you.
- Who will talk with you now about sensitive issues and will listen to your wishes.
- Who will likely be available long into the future.
- Who would be able to handle conflicting opinions between family, friends and medical care staff.
- Who can be a strong advocate in the face of an unresponsive doctor or institution.

MORE ABOUT SELECTING A HEALTH CARE SURROGATE

- Ask the person you choose as your surrogate for his or her permission.
- Discuss your health care wishes, values and fears.
- Make sure your surrogate gets a copy of your advance directive.
- Tell family members and close friends whom you picked.

Hospice Providers

Visiting Nurse Association and Hospice
1110 35th Lane
Vero Beach, FL 32960
772.567.5551
www.vnadc.com

Treasure Coast Hospice
Mayes Center for Hope
1201 SE Indian Street,
Stuart FL 34997
www.tchospice.org

William and Helen Thomas Counseling Center
5000 Dunn Road,
Ft. Pierce FL 34981
800-299-4677
www.tchospice.org

To find a hospice or palliative care provider in other areas, go to the
National Hospice and Palliative Care Organization www.nhpco.org

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Planning for Critical
Health Care Decisions (13th ed., 2011)*