



Caring Conversations[®]



MAKING YOUR HEALTHCARE WISHES KNOWN

Caring Conversations[®]
is designed to guide you, your
family and your friends through the
process of Advance Care Planning.

Name _____ Date _____



History of Advance Care Planning

Advance Care Planning is the ongoing process of discussing values and goals of care, determining and/or executing treatment directives and appointing someone to speak for you when you cannot speak for yourself. Many people are familiar with the names of Karen Ann Quinlan, Nancy Cruzan and Terri Schiavo. The lives of these three young women remind everyone of the importance of making our wishes known for our future healthcare and appointing someone to speak for us when we can no longer speak for ourselves.

The U.S. Supreme Court case of Nancy Cruzan not only changed the path of the Cruzan family; it also resulted in the Patient Self-Determination Act that affirms the rights of adults in the United States regarding their healthcare wishes. Specifically, the case affirms that adults with capacity:

- May choose or refuse any medical or surgical procedure,
- May make advance directives and transfer their decision-making authority.



GUIDANCE AT THE CROSSROADS OF DECISION

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For over a quarter of a century the Center for Practical Bioethics has worked to raise and respond to ethical issues in health and healthcare. The Center has worked with organizations such as the Centers for Disease Control, the Robert Wood Johnson Foundation, AARP, and the National Association of Attorneys General to highlight the importance of Advance Care Planning.

When the Center began its work on this project, less than 10% of adult Americans had discussed their wishes and/or completed any kind of healthcare treatment documents. Today, about 30% of Americans have shared these important discussions and completed documents. Progress has been slow but steady as American society continues to learn the importance of Advance Care Planning.

Reflect, Talk, Appoint, Act

In this workbook you will find information to help you talk with your family and friends about your wishes for your healthcare. **Caring Conversations®** also equips you with the tools you will need to communicate your wishes when you can no longer speak for yourself and advocate on your own behalf. The workbook includes a Durable Power of Attorney for Healthcare Decisions form and a Healthcare Treatment Directive form.

There are two sections in this workbook because there are two important jobs to be done. One is your job, as you begin to think about who you will choose to speak for you when you cannot speak for yourself. The other job is for the person you choose to represent you, the person you appoint as your Agent.

You and the person you wish to speak on your behalf, your Agent, will work together and help each other.

As you begin to think about who you want to speak for you, sections in this workbook will help you:

Reflect – on your personal experiences, values, desires and preferences.

Talk – to the person you are considering as your Agent.

Appoint – the person who will speak for you when you cannot speak for yourself using the Durable Power of Attorney for Healthcare Decisions form.

Act – by sharing your decisions about your healthcare preferences with family, friends, healthcare providers, clergy or attorneys if desired **and** reviewing your preferences on a regular basis.

You will also find information to share with your Agent to help understand what you are asking of him or her and how to act on your behalf. For the person who will be your Agent, you will find information that will help your Agent know:

When – they will have the power to act as your Agent,

How – he or she can be your voice when you cannot speak for yourself, and

What – your Agent needs to know about you, your values and your current health status.

*– When loved ones become seriously ill,
respecting their wishes is a real gift –*

How Caring Conversations Happen

♥ **The Heart** shows you how Caring Conversations can help you share your wishes

You may begin to think about making your future healthcare wishes known when you have a change in life circumstances or a health problem. Or you may begin the conversation when family or friends tell you they want to know how they can help you with future healthcare decisions. These conversations start the process of advance care planning.

REFLECT



TALK



APPOINT



ACT



Continue the Caring Conversations
Review the Caring Conversations

*— The toughest conversations...
are sometimes the most important —*

REFLECT

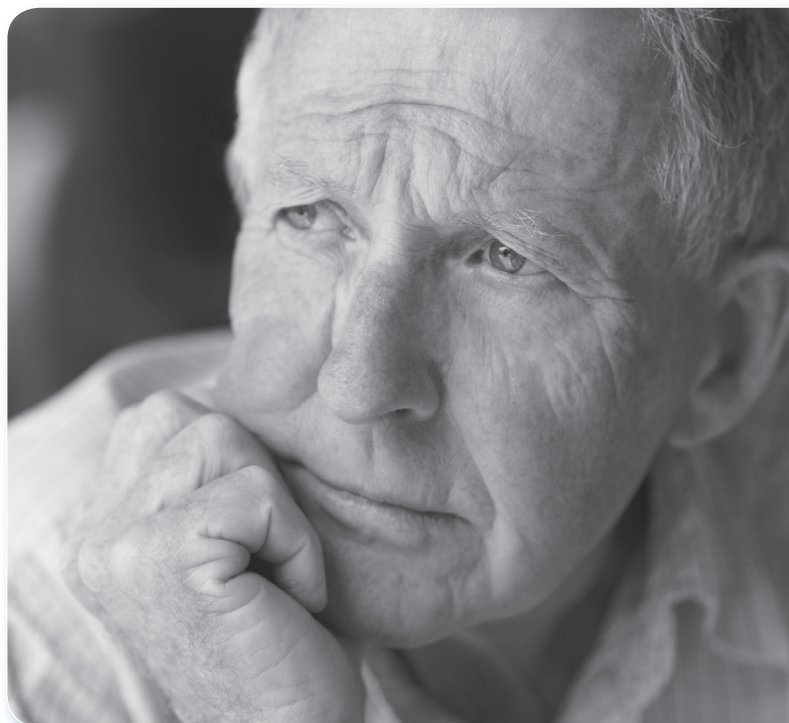
This first section of the workbook is intended to help you think about the importance of making your healthcare wishes known. You may want to read through the questions before you write your responses or before you talk with anyone. There are no “right” or “wrong” answers.

When you are ready, take the time to write out your thoughts. You will find this section helpful when you talk about your ongoing and future healthcare wishes with family and friends.

Acknowledging your beliefs, values and concerns

Imagine that you become seriously ill. This illness may be a call for you to complete unfinished business or a time to reexamine relationships, events, values, decisions and tasks that are important to you.

Your health status will affect the decisions that you will make. You may also wonder who will make the decisions for you when you cannot make them for yourself.



1. What concerns do you have about making decisions for yourself later in your life? Are there certain relationships that concern you? Are you worried about being a burden to someone? How do you feel about others, especially loved ones, caring for you? _____

2. What concerns do you have about your health or future healthcare? _____

3. Where do you want to receive care? What are your preferences and expectations about being cared for at home or another location? _____

4. Who do you want to be with you? Who do you want to talk to? _____

Well Being and Quality of Life

A sense of well being and quality of life include the physical aspects of health and also include connections and shared experiences. Enjoying people you love brings a sense of happiness, satisfaction and fulfillment to your life. You may also have developed spiritual or religious practices along with other rituals or traditions that are very important to you.

If you have a change in your health condition, things that you take for granted can become more important to you. Who are the people most important to you? What relationships and experiences have you shared with them that matter most to you?

Who should be notified if you are ill?

Which group is most like you?

Regardless of their chronological age, when people are seriously ill one of the first considerations they have is whether they will get better or not. Healthcare professionals use the term “reversible condition” if a person is likely to get well. When it is unlikely the person will get well, healthcare professionals will talk about an “irreversible condition.”

People will generally put themselves in one of three groups when there is a discussion about medical intervention. An important consideration of aligning with one group or another is whether a person’s illness is reversible or irreversible.

Group A: Some people say the only way they want to die, even if their condition is irreversible, is with aggressive/maximum medical intervention. (Do everything!)

Group B: Some people say that aggressive intervention is fine but only for reversible conditions. If they were not getting better with a particular intervention they would not want to continue it.

Group C: Some people feel strongly that they do not want any forms of artificial life support under any circumstance.

In which Group (A, B or C) would you put yourself? What do you want your agent and your loved ones to know about your choice?

— How do we know when we are prolonging life or prolonging death? —

Making decisions when you face a serious illness

Along with a sense of well being and quality of life there are two basic areas that are important to think about when considering your future healthcare decisions. One area is breathing and the other area is eating and drinking.

Regardless of your health condition or any disability you currently live with, these areas are important because they will change with time. (Please see the Pictures of Illness on page 13.) Think about these areas and use the space provided to write your thoughts, feelings and add some of your own personal questions. Reflect on your responses using all you have learned from your many life experiences. Imagine the care you would want if you were weak, frail, or even unconscious.



Breathing

How do you feel about needing mechanical assistance to breathe? Initially when a person cannot breathe medical staff will insert a tube into a person's windpipe to help them breathe. This is called "intubation."

The purpose of inserting the tube into a person's windpipe is to open a passage to get air into the lungs. Then, a machine called a "ventilator" can be used to mechanically help get air into the lungs.

Would you want to be intubated and placed on a ventilator to mechanically help you get air into your lungs?

If you wanted a ventilator to help you breathe, how long would you want this mechanical help?

- Would you want it for a short period of time, that is, short-term?
- Would you want it for a longer period of time, that is, long-term?

Usually staying on a ventilator for over two weeks requires another procedure—a tracheostomy. This is a surgical procedure to place a tube into the windpipe through the neck. It is intended for those who need long-term ventilator support. Knowing that this is a decision with long-term effects, would you want to live supported by a ventilator for a long time?

Eating and Drinking
(Nutrition and Fluids)

Eating and drinking often means more than only having enough food and water. Our daily routines often revolve around meals, and we socialize around food and drink. Eating and drinking also may be one of the most pleasant activities that a person with an illness can still enjoy.

Nonetheless, serious illness often causes problems with normal eating and drinking. You and your family may face questions about artificial feeding and fluids. If you cannot eat on your own, healthcare professionals may discuss the possibility of artificial feeding through a tube (temporarily through the nose or more permanently through the wall of the stomach). These interventions may be helpful to provide short-term support for a person who is expected to recover function and may sustain longer-term survival for a patient in a coma or persistent vegetative state.

Artificial feeding is often assumed to relieve symptoms and prolong life, but the reality is that it causes more symptoms and can shorten life in advanced illness. Tube feedings can cause more symptoms such as pneumonia, bedsores, vomiting, lung congestion and diarrhea. It also shortens survival in most end state diseases. Therefore, it is not the same as eating normally.

Providing IV fluids to someone who is dehydrated may alleviate symptoms in the short term, and fluids are often necessary for temporary support when someone has had surgery or is hospitalized and unable to take anything by mouth. However, IV fluids provided to patients who are dying usually cause more symptoms and do not prolong survival.

The pleasure of good taste and the relief of dry mouth that come from taking a drink of cold water are not available to someone who gets their intake through a feeding tube or an IV. Even patients who have difficulty swallowing can still have comfort feedings to allow them this pleasure.

If you could no longer take in food or water through your mouth, would you want artificially provided nutrition and fluids?

What other thoughts do you want to share about eating and drinking or artificially provided feeding and fluids?

TALK

Sharing the information in your **Caring Conversations®** workbook will allow others to understand and respect your wishes. Remember that conversations about these challenging topics included in this workbook are difficult for many people to face. Expressing your wishes for treatment and care during an illness is a “touchy” subject for many people.

Just as there is not a “right” way to begin this important conversation, there is also no “right” time. Consider the following as starters:

- **Share the story of a friend or colleague:**

“A woman came into the bank and wanted a brand-new \$100 bill for her granddaughter’s eighteenth birthday. Do you know what she told me? She said she wouldn’t let her have her birthday present until she showed her a signed, witnessed and notarized Durable Power of Attorney for Healthcare Decisions. That family is on it! We need to talk about our future healthcare wishes—all of us.”

- **Consider writing a note or making a tape recording of your wishes and sharing it with your loved ones.**

Sometimes it’s easier to initially express what is important to you without having to look someone in the eye—at least it’s a beginning.

- **Blame it on _____** (your church, the library, your book group):

“The book we’re reading in Book Club is about a family who has to make a decision for their daughter, but because she’s an adult, they can’t. It’s a good story but sad. It reminds me I need to tell you what I want as I get older.”

“There was such an interesting speaker at Sunday School yesterday. The subject was Advance Care Planning. We need to start talking about that.”

MOST IMPORTANT! Share your wishes, values and preferences for healthcare with your Agent. The information you’ve thought about or written down on pages 1-6 of this workbook will help your Agent to speak on your behalf when you cannot speak for yourself.



APPOINT

"Advance directive" is a general term used to describe a **Durable Power of Attorney for Healthcare Decisions** and a **Healthcare Treatment Directive**. It is also used to refer to Living Wills and informal directives people may set down in personal letters or conversations.

A **Durable Power of Attorney for Healthcare Decisions** is a legal document that allows you to name a person to make healthcare decisions for you. It is valid in any state as long as it is signed and witnessed in accordance with state law.

A **Healthcare Treatment Directive** is a legal document that allows you to state in advance your wishes regarding the kind of healthcare treatment you want when you cannot make or communicate these decisions.

As you think about naming a person to be your Agent, look at pages 10-14 in this workbook to learn what your Agent's role and responsibilities will be. This information may help you think about who could best speak for you when you cannot speak for yourself.

A simple question to consider is, "Who can I trust to make the decision I would make for myself?"

Honest and frequent communication is the most important thing you can do to help your Agent make decisions for you that you would make for yourself. That is why we stress the importance of "conversations" and not simply legal documents.

You will not be able to tell your Agent every detail about every circumstance. Medical science moves too fast for anyone to be able to imagine every possibility.

The more you and your Agent talk to each other about what you would want if you were in an advanced stage of illness or near the end of life, the better your Agent will be able to speak for you when you cannot speak for yourself.

Who do you want to make your healthcare decisions when you cannot make them for yourself? Who would be your second choice? _____

— Peace of mind is the gift you give,
when you put your wishes into writing —

Each form follows on the next page.

Durable Power of Attorney for Healthcare Decisions

■ **Take a copy of this with you whenever you go to the hospital or on a trip** ■

It is important to choose someone to make healthcare decisions for you when you cannot make or communicate decisions for yourself. Tell the person you choose what healthcare treatments you want. The person you choose will be your agent. He or she will have the right to make decisions for your healthcare. If you DO NOT choose someone to make decisions for you, write NONE on the line for the agent's name.

I, _____, SS# _____ (optional), appoint the person named in this document to be my agent to make my healthcare decisions.

This document is a Durable Power of Attorney for Healthcare Decisions. My agent's power shall not end if I become incapacitated or if there is uncertainty that I am dead. This document revokes any prior Durable Power of Attorney for Healthcare Decisions. My agent may not appoint anyone else to make decisions for me. My agent and caregivers are protected from any claims based on following this Durable Power of Attorney for Healthcare. My agent shall not be responsible for any costs associated with my care. I give my agent full power to make all decisions for me about my healthcare, including the power to direct the withholding or withdrawal of life-prolonging treatment, including artificially supplied nutrition and hydration/tube feeding. My agent is authorized to

- Consent, refuse, or withdraw consent to any care, procedure, treatment, or service to diagnose, treat, or maintain a physical or mental condition, including artificial nutrition and hydration;
- Permit, refuse, or withdraw permission to participate in federally regulated research related to my condition or disorder
- Make all necessary arrangements for any hospital, psychiatric treatment facility, hospice, nursing home, or other healthcare organization; and, employ or discharge healthcare personnel (any person who is authorized or permitted by the laws of the state to provide healthcare services) as he or she shall deem necessary for my physical, mental, or emotional well-being;
- Request, receive, review, and authorize sending any information regarding my physical or mental health, or my personal affairs, including medical and hospital records; and execute any releases that may be required to obtain such information;
- Move me into or out of any State or institution;
- Take legal action, if needed;
- Make decisions about autopsy, tissue and organ donation, and the disposition of my body in conformity with state law; and
- Become my guardian if one is needed.

In exercising this power, I expect my agent to be guided by my directions as we discussed them prior to this appointment and/or to be guided by my Healthcare Directive (see reverse side).

If you DO NOT want the person (agent) you name to be able to do one or other of the above things, draw a line through the statement and put your initials at the end of the line.

Agent's name _____ Phone _____ Email _____
Address _____

*If you do **not** want to name an alternate, write "none."*

Alternate Agent's name _____ Phone _____ Email _____
Address _____

Execution and Effective Date of Appointment

My agent's authority is effective immediately for the limited purpose of having full access to my medical records and to confer with my healthcare providers and me about my condition. My agent's authority to make all healthcare and related decisions for me is effective when and only when I cannot make my own healthcare decisions.

SIGN HERE for the Durable Power of Attorney and/or Healthcare Directive forms. Many states require notarization. It is recommended for the residents of all states. Please ask two persons to witness your signature who are not related to you or financially connected to your estate.

Signature _____ Date _____

Witness _____ Date _____ Witness _____ Date _____

Notarization:

On this _____ day of _____, in the year of _____, personally appeared before me the person signing, known by me to be the person who completed this document and acknowledged it as his/her free act and deed. IN WITNESS WHEREOF, I have set my hand and affixed my official seal in the County of _____, State of _____, on the date written above.

Notary Public _____

Commission Expires _____

Healthcare Treatment Directive

I, _____, SS# _____ want everyone who cares for me to know what healthcare I want.
(optional)

I always expect to be given care and treatment for pain or discomfort even if such care may affect how I sleep, eat, or breathe.

I want my dying to be as natural as possible. Therefore, I direct that no treatment (including food or water by tube) be given just to keep my body functioning when I have

- a condition that will cause me to die soon, or
- a condition so bad (including substantial brain damage or brain disease) that I have no reasonable hope of achieving a quality of life that is acceptable to me.

An acceptable quality of life to me is one that includes the following capacities and values. (Describe here the things that are most important to you when you are making decisions to choose or refuse life-sustaining treatments.)

Examples:	• recognize family or friends	• make decisions	• communicate
	• feed myself	• take care of myself	• be responsive to my environment

I want my doctor to try treatments on a time-limited basis when the goal is to restore my health or help me experience a life in a way consistent with my values and wishes. I want such treatments withdrawn when they cannot achieve this goal or become too burdensome to me.

Among the time-limited treatments I would not agree to under any circumstances are the following: _____

Examples:	• resuscitation (CPR)	• dialysis	• ventilator
	• food or water by tube	• chemotherapy	• transfusions
	• antibiotics	• surgery	

In facing the end of my life, I expect my agent (if I have one) and my caregivers to honor my wishes, values, and directives.

Be sure to sign the reverse side of this page even if you do not wish to appoint a Durable Power of Attorney for Healthcare Decisions

If you only want to name a Durable Power of Attorney for Healthcare Decisions, draw a large X through this page.

Talk about this form and your ideas about your healthcare with the person you have chosen to make decisions for you, your doctors, family, friends, and clergy. Give each of them a completed copy.

You may cancel or change this form at any time. You should review it often. Each time you review it, put your initials and the date here. _____

This document is provided as a service by the Center for Practical Bioethics.
For more information, call the Center for Practical Bioethics 816-221-1100
E-mail – bioethic@practicalbioethics.org • Web site – www.practicalbioethics.org

ACT

Continue Caring Conversations®

Many people in your life have different roles and help you in many different ways. Begin to list those who need to know about your **Caring Conversations®** workbook. Other family members and all of your healthcare providers need to be aware of your advance care planning and who you have appointed as your Agent. You also might include a special friend, your clergy or an attorney if you have these relationships. Write down their names.

You may have other people in your life who would want to know if you were ill or faced with new healthcare challenges such as your hair stylist, your favorite card partner, people in your golf foursome, the folks you meet for coffee, or your fellow church members. List their names with contact information and share this information with your Agent.

One of your neighbors may notice an ambulance in your driveway! Let your neighbors know that if you experience a healthcare problem your Agent needs to be contacted. Share your Agent's name and contact information with your neighbors.

Review Your Caring Conversations®

One of the best things you can do for yourself, your family and your friends is to do your advance care planning **early** and **often**, before a healthcare crisis arises.

Planning **early** is important because you can be more thoughtful and reflective, before a healthcare crisis arises. You never know when you may face an unexpected illness.

Planning **often** is important because your life circumstances and relationships may change and influence your wishes and preferences.



You and Your Agent



This second section in your **Caring Conversations®** workbook is for you and the person who is accepting the responsibility to speak on your behalf when you cannot speak for yourself. While all of your loved one may advocate on your behalf, your Agent (appointed under a Durable Power of Attorney for Healthcare Decisions) is the person who is in the best position to advocate for you and to express your wishes when you cannot advocate for yourself.

Most states have rules about who can or cannot be appointed as an Agent. Many times the healthcare professionals who are treating you cannot be your Agent. Also if you are in a care facility one of the employees cannot be your Agent, unless your relative is employed at the care facility. Generally, there are very few requirements to be an Agent, but an Agent must be a minimum of 18 years old.

What is most important is that you appoint the Agent who you trust to speak on your behalf and express your decision about healthcare as you would if you were able to speak for yourself.



“There is no greater act of love or respect than to make healthcare decisions for those who can no longer decide for themselves, but it is not an easy duty. **Caring Conversations®** will help you be prepared.”

Myra Christopher holds the Kathleen M. Foley Chair in Pain and Palliative Care at the Center for Practical Bioethics. Prior to December 2011, Ms. Christopher was President and Chief Executive Office of the Center since its inception in 1984. She contributed to drafting the Patient Self-Determination Act that became law in 1990.

For three decades Ms. Christopher has devoted her professional career to improving care for seriously ill people and their families.

When

On the Durable Power of Attorney for Healthcare Decisions form that is provided in this workbook, you will see a section labeled “Execution and Effective Date of Appointment.” Some of the words in that section are, “... effective when and only when I cannot make my own healthcare decisions.” You may want to change the wording of that paragraph to make your Durable Power of Attorney document effective immediately or leave it as it is.

The words, “when I cannot make my own healthcare decisions” can be confusing because it’s difficult to know with certainty when you reach that point. You and your Agent will hear people talking about “capacity” or “decision-making capacity.” When you hear these words, someone may be questioning whether or not you can make your own decisions or if it is time for your Agent to make your decisions. The determination of “capacity” is difficult because it changes from person to person, depending on the different circumstances and what the decision is about.

Having “capacity” to make healthcare decisions is different from being “competent” to make decisions. Usually, the word “competency” is a legal term and requires a court proceeding during which a judge will make the decision to appoint a guardian and/or conservator.

There is a lot to learn about how to determine capacity and it is important for you and your Agent to have the same information and understanding. To begin, use the Glossary at the back of this workbook to compare the definitions of “capacity” and “competency” and discuss them with your Agent.

How

You have read many times throughout this workbook that your Agent will speak for you when you cannot speak for yourself. That’s true. How will your Agent speak for you? Your agent can be your voice for your healthcare decisions and advocate for you in two different ways.

1. Your Agent will make the healthcare decisions that you would have made if you could speak for yourself. This is the best way.
2. If your Agent doesn’t know the decisions you would have made for yourself, your Agent will be asked to make a decision that is in your “best interest,” that is, what does he or she think is best for you, using advice from your medical team.

— Your Agent cannot know your values, wishes and preferences without good communication! —

What Your Agent Needs to Know

Your Agent's job begins when he or she accepts the responsibility of speaking for you. Even though it may not (yet) be time to step into your shoes, it is time for your Agent (and you) to learn more about your healthcare wishes and gather medical information.

What does your Agent need to know about you?

A good starting point for your Agent to learn about your future healthcare preferences is on pages 1-6 of this workbook. If you have written responses in the workbook, the conversations you have with your Agent may be more relaxed and comfortable.

What does your Agent need to know about your current health condition?

Your Agent will be able to represent you with confidence if you include him or her in discussions about your health status starting now. When you experience a serious illness, your Agent will be better prepared to speak for you if he or she knows your medical history as well as what is new or of immediate concern. You and your Agent should ask the following questions of your healthcare providers based on the most current health information that is available:

1. What is your diagnosis (disease or illness) in terms you and your Agent can understand?
2. What is your expected prognosis (course of the illness) in the short-term and the long-term?
3. Considering the diagnosis and the prognosis, what is the "best case" and what is the "worst case" that you will experience?
4. What are your healthcare providers trying to achieve for you, i.e. treatment goals? (Are the treatment goals consistent with your personal values?)
5. What are the treatment options – and how will they affect your prognosis? (Better? Worse?)
6. How will treatment options affect your well being and your day-to-day life?
7. What does your healthcare provider recommend be done next?
8. If you decide to do nothing – what will happen next?

An important question to ask your healthcare provider is this: "If this was your diagnosis and prognosis, what would you do?"

Ask questions until you hear an answer you and your Agent understand. You may not like the diagnosis, the prognosis, the treatment options or the treatment goals. However, you must understand what is happening to make good choices.

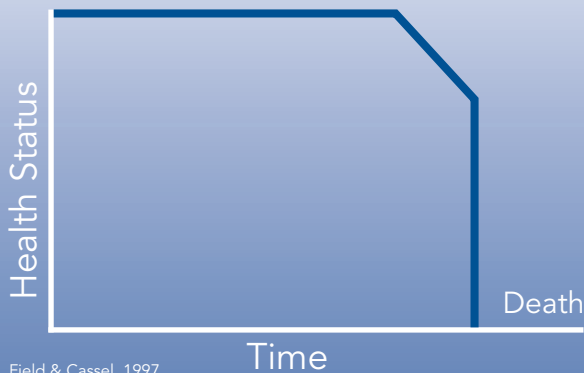
*– Advance Care Planning is not an event,
it is a Process –*

Pictures of Illness

How you experience a serious health condition will be based on your illness or disease as well as your unique health factors. Below are pictures of four of the basic ways a person might experience an illness or serious health condition. Look at the pictures below and think about which one looks like the path of your illness or disease. The path of a disease is referred to as a "trajectory." If you are unsure, show these pictures to your healthcare provider and ask which looks most like the picture of the path or trajectory of your illness or disease.*

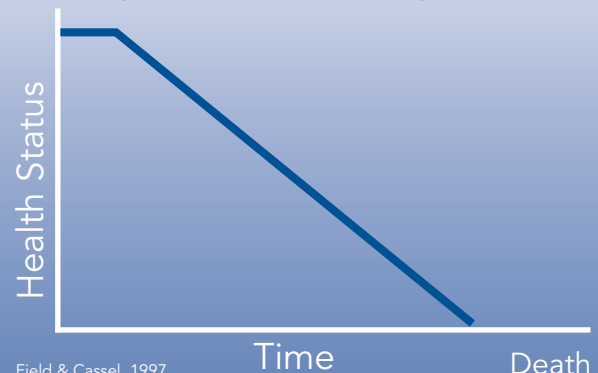
Illness Trajectory - #1

Sudden death – unexpected cause
(E.g., heart attack, traumatic event, etc.)



Illness Trajectory - #2

Steady decline – short terminal phase
(E.g., advanced cancer diagnosis)



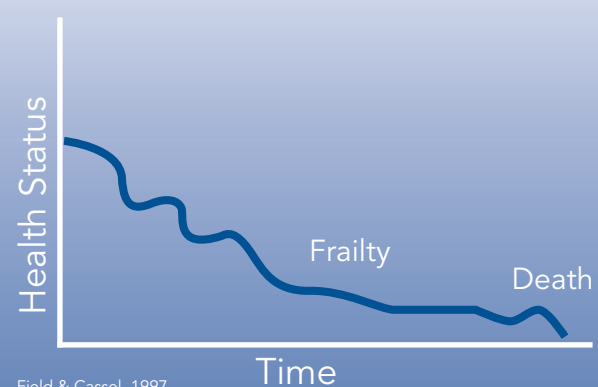
Illness Trajectory - #3

Slow decline – periodic crisis - death
(E.g., progressive heart and lung disease)



Illness Trajectory - #4

Lingering, Expected Death
(E.g., advanced multiple chronic diseases)



* Adapted from Field, M. J. & Cassel, C. K. (Ed.). (1997) *Approaching Death: Improving care at the end of life*. Division of Health Care Services. Institute of Medicine. Washington D.C.: National Academy Press.

Your Agent: Help or Hinder

As you face a serious illness, you will begin to recognize the importance of the partnership between you and your Agent. This partnership will be helped by some circumstances and hindered by others. The following chart will help you and your Agent talk about things that might “help” or “hinder” your Agent in the future. *

Remember that from time-to-time there may be changes in your life as well as in the life of your Agent.

What Can HELP	What Might HINDER
Agent’s Characteristics and Life Experiences	
Previous experience as an Agent Good coping strategies Religious community support Spiritual beliefs	Competing responsibilities Agent’s own health problems Physical distance Financial barriers
Agent’s Social Network	
Support from family and friends Conversation with family and friends Working toward consensus	Family conflict
Relationship and Communication Between Loved One and Agent	
Knowing wishes and preferences Keeping a promise to your loved one Decision will result in “good” outcome Being involved in medical condition	Confusion about preferences Overcome by emotion Balancing preference and quality of life
Relationship and Communication Between Agent and Care Providers	
Care provider availability Frank information from care provider Recommendations from care provider Positive reinforcement for decision-making Respect from care providers	Too many care providers involved Not knowing “who is in-charge”

Glossary



Advance Care Planning*: The process of discussing, determining and/or executing treatment directives, appointing a proxy decision maker, and periodically reviewing those plans.

Advance Directive*: A written health care directive and/or appointment of an agent, or a written refusal to appoint an agent or execute a directive.

Agent*: An individual designated in a legal document known as a **power of attorney** for health care to make a health care decision for the individual granting the power; also referred to in some statutes as **durable power of attorney for health care** (DPAHC), attorney in fact, proxy, or health care representative.

Best Interest: The Agent, surrogate or proxy makes the healthcare decision that will allow for the best possible outcome for the patient, in the particular circumstances, when the patient's wishes are not specifically known. Along with the medical information, the values of the patient are taken into consideration.

Family: Traditionally defined as a group of people related by blood and/or marriage, the twenty-first century "family" may expand to include other people who share intimate relationships, similar values and common memories.

Capacity to Make a Healthcare Decision*: An individual's ability to understand the significant benefits, risks, and alternatives to proposed health care and to make and communicate a health care decision. The term is frequently used interchangeably with "competency" but it is not the same. "Competency" is often distinguished as a legal status imposed by the court, although most states have dropped the term in favor of "legal incapacity." (see below)

Competency: If a person appears to not be able to make some or any decisions for him or herself (and has not done any advance planning for healthcare or financial and property matters), a court will step in when necessary and determine the "competency" of a person and appoint a guardian and/or conservator.

Palliative Care*: Also called "comfort care," a comprehensive approach to treating serious illness that focuses on the physical, psychological, and spiritual needs of the patient. Its goal is to achieve the best quality of life available to the patient by relieving suffering, controlling pain and symptoms, and enabling the patient to achieve maximum functional capacity. Respect for the patient's culture, beliefs, and values is an essential component.

Substituted Judgment: The Agent, surrogate or proxy makes the healthcare decision the patient would make for him or herself if the patient had capacity to make a healthcare decision and was able to communicate.

Surrogate*: A person who, by default, becomes the decision maker for an individual who has no appointed proxy.

* As defined in the Uniform Health Care Decisions Act and the Patient Self-Determination Act (Source: Report to Congress 2008).

The Center for Practical Bioethics

Vision

Ethical discourse and action advance the health
and dignity of all persons.

Mission

To raise and respond to ethical issues in
health and healthcare.

Our Core Value

Respect for human dignity.

We believe that all persons have intrinsic worth.

We promote and protect the interests of those
who can and cannot speak for themselves.

We commit to the just delivery of healthcare.

We welcome your interest in **Caring Conversations**® program. For more
information about **Caring Conversations**® or the Center for Practical Bioethics,
please contact us at 816-221-1100, visit our website www.PracticalBioethics.org,
or e-mail us at bioethic@PracticalBioethics.org.

