

VALUES, CHOICES, AND GOALS

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It's almost impossible to completely predict the choices and hopes you will have when you become so seriously ill or incapacitated that there is no hope of recovery. **How you've lived up until this moment is one of the best predictors of how you'll want to live until you die.** It's vital for you and your advocates to be able to articulate and interpret your values and life goals clearly. Being able to do that will help you avoid what many people say is the worst part of the end of life experience – surprises.

Four things you need to know about end-of-life choices:

1. **Creating a picture of what is important to you as a person is more important than trying to identify medical treatments you may be offered in a future situation.** Technologies designed for short-term intervention for those expected to recover can keep people 'alive' when quality of life is gone. You may or may not want to use them, so it is important to understand how they work.
2. **There are often very vague lines in end-of-life definitions.** Medical personnel may differ in what treatments they think will be helpful or in even defining what 'pain management' or 'dying' means.
3. Choices that you make in **your Living Will** (formally called your Advanced Directive for Medical/Surgical Treatment) **will only come into play when two physicians determine that there is no possibility of recovery.**
4. **Your choices are both medical *and* non-medical.** Your quality of life is as important as your medical treatment options.

This workbook contains three sections. The **First** explores non-medical considerations that help you determine what you consider quality of life. The **Second** explores medical treatment choices you may have. The **Third** translates both of these into instructions on your Living Will.

SECTION ONE: WHAT IS QUALITY OF LIFE TO YOU?

- Do you have any specific directions based on past experiences?
- What are your biggest fears about dying?
- Most people would say "no" to living forever. What would make you say "no"?
- If you knew you were going to die in a month, what would you need to finish?

YOUR PHILOSOPHY OF LIFE

- What gives you the most meaning in your life?
- What are your general beliefs about life and why you are here?
- What are general beliefs about death and what happens to you?
- When are you the happiest and most grateful to be alive?
- How do you like to spend your time?

- What has sustained you through the greatest challenges in your life?
- What does courage mean to you?
- What does independence mean to you?
- What is the one thing you want people to remember you for?
- What religious, spiritual, or meanings do you base your life on?
- Is it important for you to have any unfinished work or dreams continued after your death?

YOUR COMFORT AND ENVIRONMENT

- When you are very sick, where do you want to be, and who do you want to have support you?
- Do you want to be cared for in a hospital if you are terminally ill or dying?
- If possible, do you want to be at home when you are dying?
- Do you want hospice services in your home?
- What are your hopes and concerns about being cared for by your family?
- When you are not feeling well, do you prefer to be alone or visited frequently by family and friends?
- When you envision peacefully dying, what kinds of things do you want to have near you?

VALUES & GOALS: RATE THESE CONDITIONS FROM 1 = NOT VALUABLE TO 5 = VERY VALUABLE

- 1 2 3 4 5 Being able to communicate with my family and friends.
- 1 2 3 4 5 Being able to express my emotions and feelings.
- 1 2 3 4 5 Being mentally alert to be aware of what I'm doing and saying, and to understand the significance of what I am doing and saying, as well as what others are saying to me.
- 1 2 3 4 5 Living with my spouse, family, and/or friends.
- 1 2 3 4 5 Living at home, not a nursing home or long-term care facility.
- 1 2 3 4 5 Being financially independent so I don't have to rely on my family to support my living.
- 1 2 3 4 5 Being able to reflect on life's meaning and to say goodbye to loved ones.
- 1 2 3 4 5 Being independent in bodily care activities so that another person does not have to take me to the bathroom, wash me, brush my teeth, comb my hair, etc.
- 1 2 3 4 5 Maintaining my bodily integrity so there are no tubes, needles, or other things stuck in my body and not having any of my limbs amputated.
- 1 2 3 4 5 Having my spiritual/religious beliefs honored and included as part of my care.
- 1 2 3 4 5 Living long enough for a personal or family milestone such as the birth of a grandchild, graduation, or marriage, or until I achieve a personal goal such as _____.
- 1 2 3 4 5 Living as long as possible using the available medical technologies.
- 1 2 3 4 5 Being kept alive long enough for my family to visit my bedside.

HOW MANY OF THESE THINGS AM I WILLING TO COMPROMISE?

WHAT WOULD I FIND INTOLERABLE?

WHEN WOULD I CONSIDER LIFE NOT WORTH LIVING?

YOUR PHYSICAL TOLERANCES

- Is it important to you to be pain-free from illness or any symptoms of the illness (such as nausea, fatigue, shortness of breath, etc.)?
- Under what circumstances would you be willing to endure some pain?
- Do you have specific beliefs around the use of life support technologies to keep you alive when you would otherwise die?
- How much is mental clarity important to you?
- How much is physical incapacitation important to you?
- Is it important for you to seek medical treatments for as long as you can?

END OF LIFE LIMITATIONS & TOLERANCES: RATE FROM 1 = TOLERABLE TO 5 = INTOLERABLE

- 1 2 3 4 5 Being paralyzed. Unable to walk, but can talk, interact, and move around in a wheelchair.
- 1 2 3 4 5 Being unable to interact meaningfully. Cannot speak or respond to requests or commands.
- 1 2 3 4 5 Being unable to care for yourself. Paralyzed and bed bound; unable to wash, feed, or dress.
- 1 2 3 4 5 Tolerating some pain in order to be as alert as possible.
- 1 2 3 4 5 Being pain free but not completely awake. You have pain that can be controlled by meds, but are unconscious or very sleepy or confused most of the time because of the meds.
- 1 2 3 4 5 Being in a coma or persistent vegetative state. You have suffered brain damage and are not conscious and are not aware of your environment in any way.
- 1 2 3 4 5 Dying without trying everything to stay alive as long as possible.
- 1 2 3 4 5 Being mildly demented. You can neither remember things, such as where you are, nor reason clearly. You are not aware that you have these mental impairments. You are capable of speaking with others, although you are not capable of remembering the conversations; you are not capable of washing, feeding, or dressing yourself and are almost totally cared for by others.

HOW MANY OF THESE THINGS AM I WILLING TO COMPROMISE?

WHAT WOULD I FIND INTOLERABLE?

WHEN WOULD I CONSIDER LIFE NOT WORTH LIVING?

SECTION TWO: MEDICAL CONDITIONS AND MEDICAL TREATMENT OPTIONS

In the Colorado Advance Directive for Medical/Surgical Treatment (Living Will), there are two major medical conditions to consider. Please remember that this discussion applies only if you are at the end of life or not expected to recover.

1. **Terminal Condition:** In most states, this is defined as a status that is incurable or irreversible and in which death will occur within a short time. There is no precise, universally accepted definition of “a short time,” but in general it’s considered to be less than a year. (definition, American Hospital Assoc.)
2. **Persistent Vegetative State:** A form of eyes-open permanent unconsciousness in which the patient has periods of wakefulness and physiologic sleep/wake cycles but at no time is aware of themselves or their environment. (definition, American Academy of Neurology)

The group of medical treatments below taken together are considered life-sustaining procedures. Many were designed for short-term interventions with patients who are expected to recover, but they are also used to prolong living and dying. They may be used for months, weeks, or days.

Life Sustaining Procedures are **(artificial substitutions for natural bodily processes)** such as:

Mechanical Ventilation/Respiration: A plastic tube is put down the throat to help breathing. A machine pumps air in and out of the lungs through the tube when a person is no longer able to breathe on their own. If the tube is removed, the person may or may not die soon afterward. Medications and treatments are available to make sure the person is not in pain or distress.

Tube Feeding: On a short-term basis, fluids and liquid nutrients can be given through a tube in the nose that goes into the stomach. For long-term feeding, a tube can be surgically inserted directly into the stomach or the intestines.

Intravenous (IV) Fluids: A small plastic tube is inserted directly into the vein and fluids are administered through the tube. Typically, IV fluids are given on a short-term basis.

Cardiopulmonary Resuscitation (CPR): Attempts to restart breathing and the heartbeat of a person with no heartbeat or who has stopped breathing. Typically involves “mouth-to-mouth” and forceful pressure on the chest to restart the heart but may also involve electric shock or drugs. A plastic tube may be inserted down the throat into the windpipe to assist breathing.

Kidney Dialysis: Using a machine to clean waste products from blood when failed or damaged kidneys cannot do so. A catheter is placed in a vein and blood is filtered through a machine before being returned to the body. Acute dialysis treatments are often 2-4 times a week, several hours each time. (definitions from www.polst.org, Physician Orders for Life-Sustaining Treatments Paradigm)

These and other treatments may be provided (1) *for comfort only* or (b) *in an attempt to prolong life*. Discussions about which goal is being pursued are most effective at the time of decision so they can reflect your needs at that time. These treatments include:

- Antibiotics treat some infections (such as pneumonia) that can develop when a person is seriously ill. Antibiotics may also treat symptoms such as the discomfort from a urinary tract infection, although that treatment will not affect the course of the primary disease.
- Diagnostic tests which will not change the course of the illness but have been standard markers in the past; these are tests that can help diagnose problems that may help with comfort care. The tests may or may not be uncomfortable.
- Drugs to treat uncomfortable symptoms, such as nausea, headaches, etc.
- Blood transfusions.
- Minor surgeries.
- Invasive Diagnostic Tests, such as using a flexible tube to look into the stomach.
- Major Surgery, such as removing the gall bladder or amputating a limb.
- Chemotherapy, using drugs to fight cancer.
- Complementary Therapies, such as aromatherapy or massage, which may help with comfort care.

We make the best choices we can right now.

We may change those to match new understandings and needs as time goes on.

Use the next two pages to summarize your goals of care and attach the sheet to your Advance Directive for Medical/Surgical Treatment (Living Will). We suggest also attaching it to your Medical Durable Power of Attorney form, so that those instructions are always available to your Health Care Agent when they need to know how to advocate for your care in your voice.

Note on your Living Will that you have “attached other directions.”

**OTHER DIRECTIONS
TO BE ATTACHED TO MY LIVING WILL**

Date of Living Will: _____

SECTION ONE: MY QUALITY OF LIFE

I, _____, have given careful consideration to the values and choices that are the most important to me as I am nearing the end of my life. While I cannot consider all of the decisions I will face at that time, these are the things I want you to know about my overall care.

My philosophy of life and the guiding principles I have lived by are written below. Please use these to make decisions about how I am treated if I am unable to participate in my own care. Even if I am conscious, there may be times when it is difficult for me to keep all of these things in mind, so please advocate for my dignity and priorities.

My environment and comfort will affect how I can respond, react, and focus my attention. These are things that are important for me to have, when it is possible:

This is my best assessment about what my limitations and tolerances might be. I know that I may feel differently about these conditions when I am faced with them, but these also include my values, so please align the two considerations as much as possible.

SECTION TWO: MEDICAL TREATMENTS I DO OR DON'T WANT

My Living Will sets out my life support preferences and I understand that, in the future, my decisions about other medical treatments may differ from the choices below. Please follow the instructions below unless I say so at the time or unless I have given my Health Care Agent authorization to make different choices for me.

	YES	NO	FOR COMFORT ONLY	I WANT MY DOCTOR AND HEALTH CARE AGENT TO DECIDE	I AM NOT SURE
Dialysis					
Tube Feeding					
Mechanical Ventilation					
Artificial Nutrition & Hydration					
Antibiotics					
Diagnostic Tests					
Drugs					
Blood Transfusions					
Minor Surgery					
Major Surgery					
Chemotherapy					
Complementary Therapies					