

Your Life Your Priorities

Options for Managing
End-of-Life Decisions



 compassion
& choices
Care and Choice at the End of Life



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INTRODUCTION

Compassion & Choices is the nation's oldest and largest nonprofit organization working to improve care and expand options for the end of life. We support individuals and families, provide information, educate and advocate, locally and nationally.

We believe people — not the healthcare system — should be in charge of their end-of-life decisions. We have developed this booklet to help you in thinking through your own end-of-life wishes, communicating with your family and your loved ones, and ensuring that health providers understand and honor your values and priorities.

You Have Options

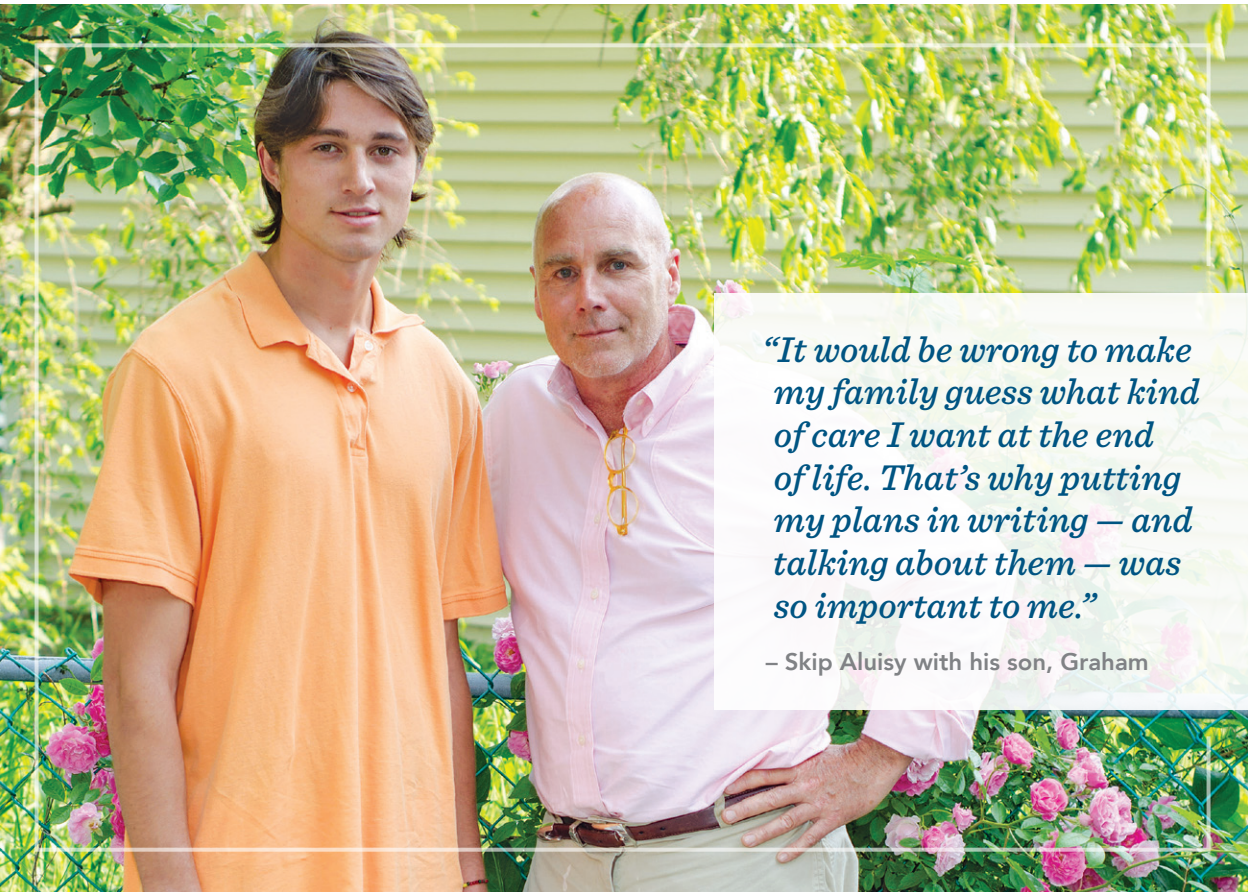
Whatever your stage of life, your values and priorities should guide the healthcare you choose to receive. If you have a terminal illness, it's especially important to be aware of your end-of-life options. You — or your healthcare representative — should decide whether to accept or decline various tests and treatments. Knowledge is power, and with it you and your loved ones can be effective advocates for your wishes.

AT THE END OF LIFE, YOU CAN CHOOSE TO ...

- » Stay in your own home or move to a facility.
- » Control how much and what kind of treatment you receive — at any stage of illness, whether you are terminally ill or not. You may decline any medical treatments.
- » Obtain palliative care to manage your symptoms.
- » Receive hospice care and support wherever you live.
- » Obtain more aggressive management of pain and other symptoms if they are not adequately controlled. Discuss “total sedation” (sedation to unconsciousness) with medical staff if the usual measures do not alleviate your end-of-life suffering.
- » Elect to voluntarily stop eating and drinking (VSED). With appropriate medical oversight and support, VSED permits a natural, peaceful death.
- » Consider medical aid in dying in states where it is authorized, a practice whereby terminally ill, mentally competent adults may choose to self-administer life-ending medication in their final days.

FIRST STEPS

- » Determine your priorities for end-of-life care.
- » Discuss with your loved ones your end-of-life wishes and ask for their support.
- » Explain your priorities to your healthcare providers and secure their commitment to honor your wishes. If your physician won't make that commitment, find one who will.
- » Outline your wishes in an advance directive. Designate someone to advocate for your end-of-life choices if and when you are unable. Include provisions for special circumstances, like dementia or assisted living.



“It would be wrong to make my family guess what kind of care I want at the end of life. That’s why putting my plans in writing — and talking about them — was so important to me.”

– Skip Aluisy with his son, Graham

Plan Your Care Resource Center

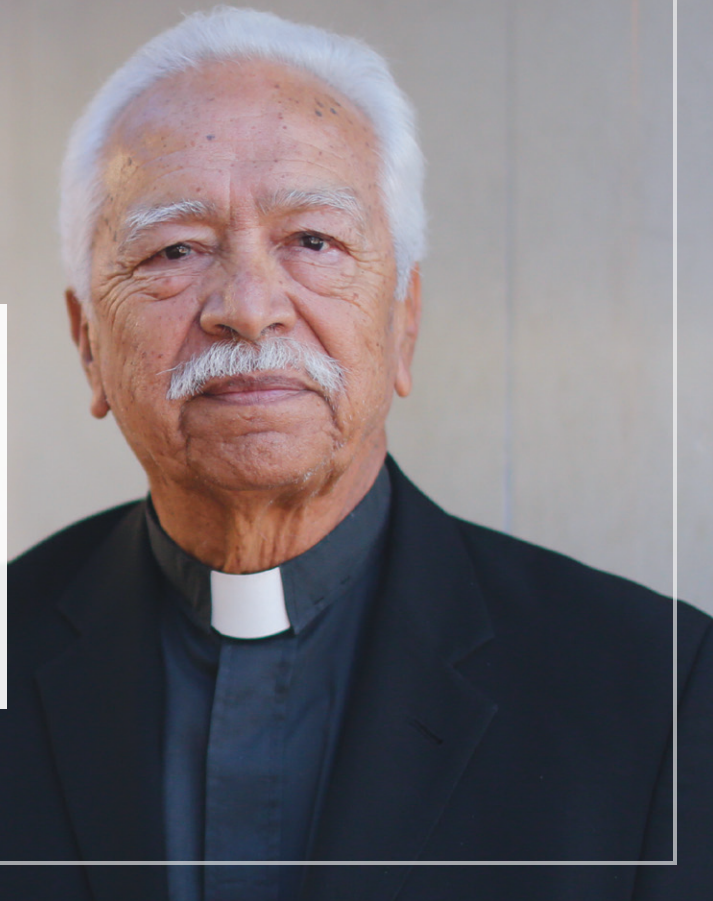
Compassion & Choices is committed to empowering people to get the care they want during a serious illness or at the end of life. One way we do that is by helping people plan well and become good advocates for themselves and their loved ones.



Visit us at CompassionAndChoices.org/plan-your-care to learn more about our advance care planning resources.

“As a minister, I have been blessed to counsel many people as they prepare for life’s end. Most want a peaceful death, without suffering. Advance planning can help them achieve that.”

– Rev. Dr. Ignacio Castuera



OUR ONLINE RESOURCES COVER:

- » Benefits of palliative and hospice care.
- » Completing advance directives.
- » Ways to navigate the healthcare system.
- » How friends and family members can advocate for their loved ones.
- » Asking for effective pain and symptom management.
- » Information about medical aid in dying for terminally ill, mentally capable adults.
- » Other means for attaining a peaceful death, such as voluntarily stopping eating and drinking (VSED), refusing unwanted medical treatment and discontinuing life-sustaining treatment under the care of a physician.
- » Assessing compassionate, patient-centered end-of-life care.

Your Advance Directive


An advance directive is an important document. It tells healthcare providers and family members what life-sustaining medical treatment you wish to have or not have if you are unable to speak for yourself. It has two parts — a living will (“what I want”) and a medical power of attorney (“who will speak for me”). The specific form varies by state. It is not difficult to complete, and you don’t need a lawyer to do so.

All adults should complete an advance directive, discuss it with loved ones and make sure it is easily accessible. Do this when you are young and healthy to give your loved ones guidance and peace of mind in the event of illness or a serious accident.

In your advance directive, you will designate a representative, or healthcare proxy, to direct your care, should you become incapacitated. Pick someone you trust who will understand your wishes and agree to advocate strongly for them. After reviewing with your medical provider, ask if your doctor will honor your advance directive or ask for a referral to a doctor who will.

It’s not enough just to complete an advance directive; you must share it with others, including family members, doctors, your attorney and your healthcare representative. Keep it in a prominent place. Provide a copy to your doctor(s). Have a copy with you when you are admitted to a healthcare facility to avoid confusion during a crisis.

Medical Orders for Life-Sustaining Treatment (MOLST) or Physician Orders for Life-Sustaining Treatment (POLST) forms are specific physician-signed documents suitable for terminally ill or extremely debilitated individuals. A physician provides a signed copy to be posted in a conspicuous place in your home for quick reference, should emergency medical assistance be called to your home. Your doctor can help you decide whether these forms are appropriate for you.

A close-up portrait of an older Black man with short, graying hair. He is wearing a dark blue suit jacket over a light-colored collared shirt. He is looking slightly to the right of the camera with a thoughtful expression. The background is a soft, out-of-focus green, suggesting an outdoor setting.

“I would recommend that everyone have the conversation and talk with their loved ones about what they want and don’t want, as well as complete an advance directive so their wishes are known.”

– Aris T. Allen Jr.

Access state-specific advance directives and Compassion & Choices’ exclusive resources, including a special provision for dementia: **CompassionAndChoices.org/plan-your-care**

My End-of-Life Decisions Planning Guide and Toolkit

Make sure your wishes are carried out by explaining them clearly to those who will be speaking on your behalf. Use Compassion & Choices' *My End-of-Life Decisions* planning guide and toolkit to define your priorities and get advice on how to start those vital conversations.



Visit CompassionAndChoices.org/my-end-of-life-decisions to read the guide and toolkit and find a downloadable version.

Assisted Living

Assisted-living facilities are designed to provide necessary services in a setting with all the comforts of home. You would expect them to honor any choices you make in the privacy of your home — but that isn't always the case.

If you reside in a long-term care or other facility that is not honoring your treatment preferences or advance directive, you or your representative should contact Compassion & Choices for help in advocating for your choices.



Do you live in or plan to move to an assisted-living facility?
Do you expect to remain there until death?

Download our free Assisted-Living Facility Contract Rider at CompassionAndChoices.org/assisted-living-facility-rider to ensure your new home will honor your wishes.



Armond and Dorothy Rudolph's Story

Armond and Dorothy met resistance from their assisted-living facility when they decided to voluntarily stop eating and drinking. Learn how they overcame eviction and achieved the peaceful ending they sought — and how you can avoid similar obstacles.



CompassionAndChoices.org/Rudolph



The Seven Principles for Patient-Centered End-of-Life Care

1. FOCUS

End-of-life care should focus on the individual's comfort.

Too often, death is seen as a failure of treatment, not a natural event. Physicians sometimes withdraw from patients who are in the terminal stage of illness or encourage them to continue invasive therapies that can make their final days miserable. This deprives people of the opportunity to enter what is sometimes called "the final stage of growth."

You are in charge of your own care. *Set your priorities in advance.*

2. SELF-DETERMINATION

Individual tolerance for pain and suffering varies dramatically.

Only you can determine whether you are suffering too much. You should receive appropriate, state-of-the-art comfort care in accordance with your needs.

Providers should generously prescribe medication for pain and breathlessness, and give patients control over the dose and frequency of administration.

Symptoms such as hiccups, nausea, diarrhea, itching and fatigue can be unbearable and should be taken seriously. Say something if you feel you are being ignored, or empower your healthcare representative to speak on your behalf.

3. AUTONOMY

Decisions about end-of-life care begin and end with the individual.

The answer to the question, *"Who should decide?"* is "YOU."

Even very ill people usually retain the capacity to make decisions. Loved ones and providers should take care not to usurp that authority when communication becomes difficult.

If you are no longer capable of making decisions, your known wishes (as detailed in your advance directive) still dictate the level of care you receive. Ensure clarity by completing a dementia provision.

4. PERSONAL VALUES

You have the right to make decisions based on your own deeply held values and beliefs, without fear of moral condemnation or political interference.

Dying patients should not be subject to subtle or overt suggestions that their choices are wrong or immoral. A provider's beliefs should never supersede the patient's. Providers who withhold vital information about treatment options must be held accountable. Compassion & Choices advocates for laws and policies that protect your rights.

5. INFORMED CONSENT


You have the right to comprehensive, candid information to enable you to make valid decisions and give informed consent.

Compassion & Choices encourages you to assess your situation using the following “BRAIN” exercise. Before consenting to procedures and treatment, assess the **B**enefits, **R**isks, **A**lternatives, **I**nsight into what these mean to you, and consequences of doing **N**othing.

Ask the doctor these crucial questions as you consider disease-specific treatment:

- » What is the chance it will prolong my life? By how much?
- » What are the side effects?
- » How will it affect my quality of life?
- » What are the alternatives?

Providers should never withhold information about legal alternatives. Doing so deprives you of the information you need to give informed consent.



“Autonomy is an incredibly important value to me. I would like to have as much control over the conditions under which I leave this life as possible.”

– Dustin Hankinson

6. BALANCE

You must be empowered to make decisions based on your own assessment of the balance between quantity and quality of life.

You may reject treatment because of unacceptable side effects. Saying “no” to burdensome treatment may improve your quality of life and give you more opportunities to experience joy in the time you have left.

7. NOTICE

You as the patient have the right to early, forthright and complete notice of institutional or personal policies or beliefs that could impact your end-of-life wishes.

People who are dying often discover too late that the beliefs and values of their healthcare provider limit their personal end-of-life options.

Health-plan marketing materials and enrollment documents should prominently spell out any such limitations in a clear, forthright manner. Hospitals, clinics, pharmacies and other healthcare institutions should publicly display information about restrictive policies of a religious or moral nature. Again, you and your representative should verify that your providers will adhere to your wishes.

Vicky York's Story

Vicky York, dying of ovarian cancer, used Oregon's Death with Dignity Act in August 2014. She told Compassion & Choices this about her experience:



“Even now, at the very end, we’re able to have joy and humor, and go places and eat out ... This is the way I want to go, just like this.”

– Vicky York with her son, Rick

Pain Care

Managing symptoms is often the most critical aspect of end-of-life care. It is important that you, your representative and your caregivers advocate assertively for good symptom management. At the end of life, the proper dose is whatever is necessary to keep you comfortable. You may need more pain medication as your disease progresses, so don't wait until it becomes severe to begin treatment. If your disease is progressive or incurable and your highest priority is comfort, make this clear to your doctor and everyone around you. Keep a list of your medications and your prescribers, make sure you have enough medication for weekends and holidays, and be sure you know who is on call when your physician is not available and how to reach that person.

Medical Aid in Dying

Medical aid in dying is an end-of-life option now authorized in several states. It allows terminally ill, mentally capable adults with six months or less to live to request a prescription from their doctor for medication that they could decide to take in their final days or weeks to end unbearable suffering and die peacefully. Each state has included safeguards to guard against abuse. For example, an individual must be able to personally ingest the medication; no one else can administer it. A decision to request medical aid in dying is one that family members and other loved ones will want to weigh in on and understand. An early conversation is important.

Your Physician's Role

Along with your family members, your physicians play an important role in your care. Be honest and forthright with your physician(s) about your desires and concerns about your own dying. Share your priorities with them, and let them know that you expect honest and forthright communication about your prognosis. If you feel you are not being heard or your choices are not respected, find another physician who will be able to support your end-of-life preferences.

“I find it helpful to discuss end-of-life issues with my patients while they are still healthy. This can help minimize their fear and anxiety, and bring them peace and comfort when they are faced with tough decisions.”

– Dr. Sudha Royappa





PEACE AT LIFE'S END, ANYWHERE.

No one should suffer needlessly at life's end. Throughout the nation, people at the end of life have the right, supported in law and medicine, to receive information and care that meets their needs and conforms to their values. We hope the advice and resources in this handbook help you receive the care that you want at the end of life.



4th edition

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