

# Your Life Your Priorities

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Options for Managing Your  
End-of-Life Decisions



 **compassion  
& choices**  
Care and Choice at the End of Life



# INTRODUCTION

Compassion & Choices is the nation's oldest and largest nonprofit organization working to improve care and expand choice at the end of life through support of individuals and families, education, and advocacy at the local and national levels.

We believe people — not the healthcare system — should be in charge of their healthcare decisions. We aim to empower you with tools and information to control your own end-of-life experience. This booklet will help you, your family and your loved ones state and honor your values and priorities.

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# You Have Options

As an informed individual, you and/or your healthcare representative should be in charge of your own healthcare at every stage of life. You should decide whether to accept or decline various tests and treatments. If you have a terminal illness, it's especially important to be fully aware of your end-of-life options. Knowledge is power; with it, you and your loved ones can be effective advocates.

## FIRST STEPS

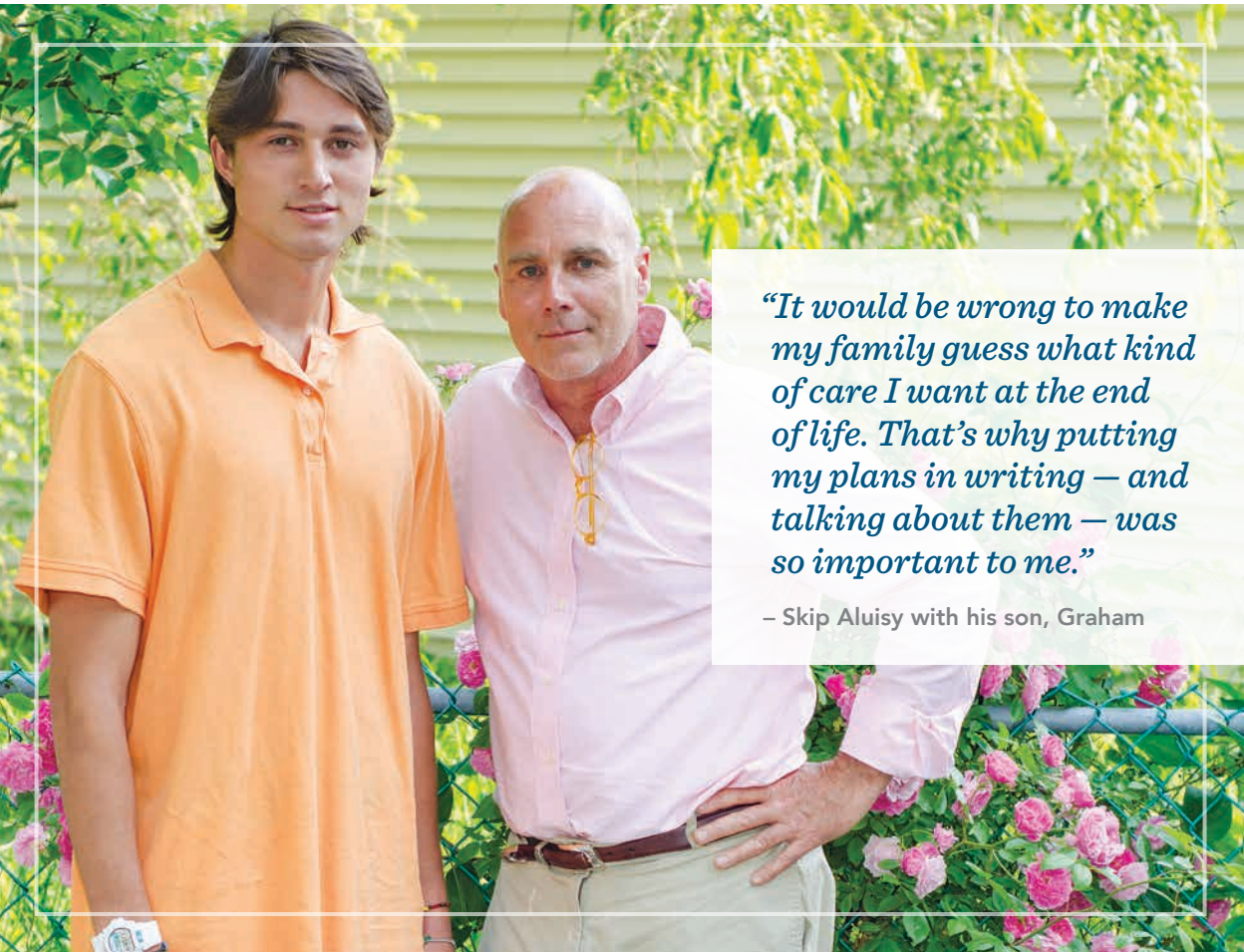
- » Determine your priorities for end-of-life care.
- » Discuss with your loved ones your end-of-life wishes and ask for their support.
- » Explain your priorities to your healthcare providers and secure their commitment to honor your wishes. If your physician won't make that commitment, find one who 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.

## 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 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.

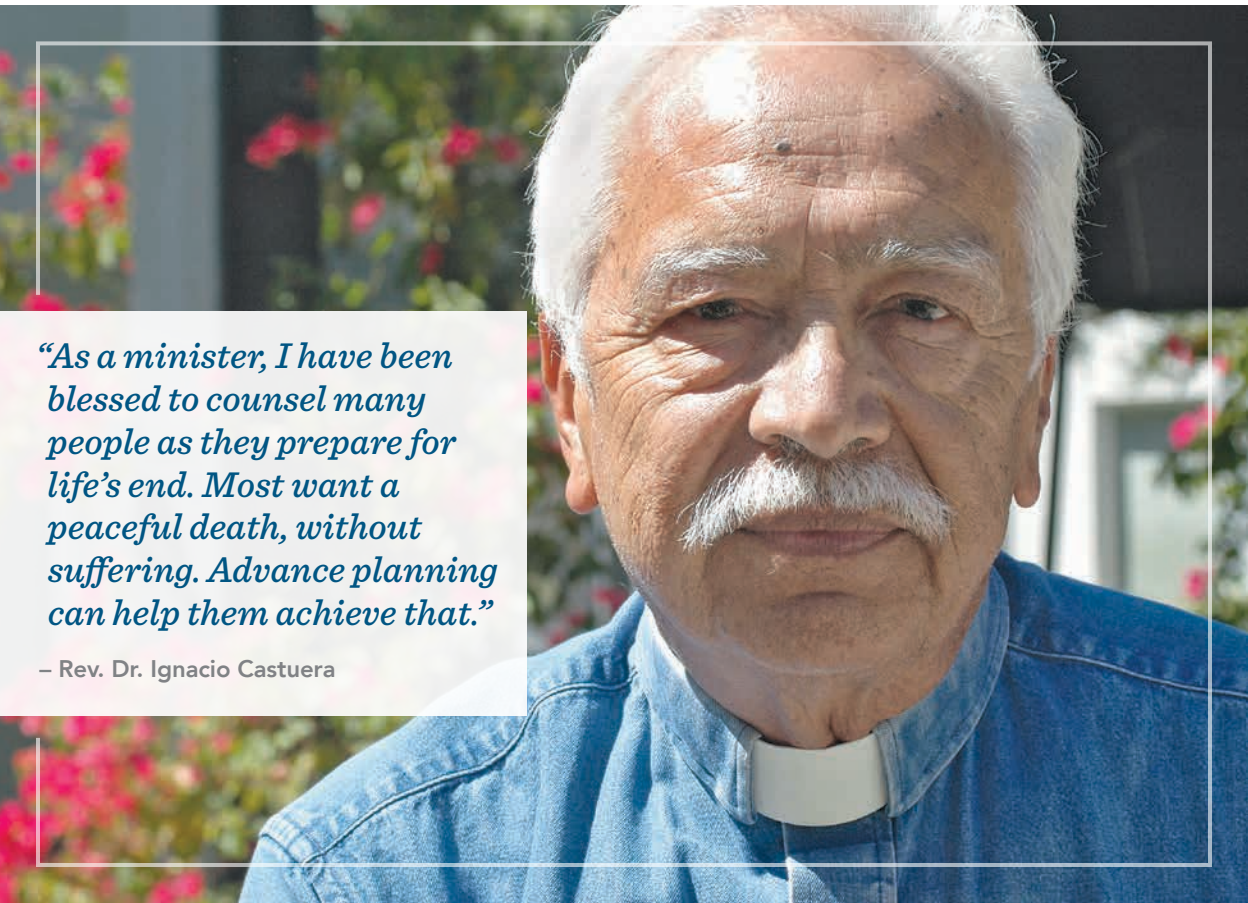


*“It would be wrong to make my family guess what kind of care I want at the end of life. That’s why putting my plans in writing – and talking about them – was so important to me.”*

– Skip Aluisi with his son, Graham

# C&C's End-of-Life Consultation Program

Compassion & Choices' End-of-Life Consultation Program offers confidential, professional support to people facing the end of life or planning ahead. Trained consultants are available to talk through your options with you no matter where you live — absolutely free of charge.



*“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

## WE OFFER:

- » Guidance in all aspects of end-of-life decision-making, including advance directives and special riders, such as our dementia provision.
- » Help navigating the healthcare system, including hospice or palliative care providers, pain specialists, social service agencies, support groups, and other local resources.
- » Education for friends and family members on how to advocate for loved ones.
- » Education about effective pain and symptom management.
- » Advocacy for residents of long-term care facilities or other institutions who may be receiving inadequate end-of-life care or ineffective symptom management.
- » Support for healthcare professionals seeking information about compassionate, patient-centered, end-of-life care.
- » Expertise from physicians, counselors, social workers, pharmacists, and other healthcare professionals.
- » Information about aid in dying for terminally ill, mentally capable adults.
- » Referrals to trained client-support volunteers who can provide telephone or in-person support. Volunteers work in conjunction with professional staff. Volunteer availability is dependent on location and scheduling.



Visit us at [CompassionAndChoices.org/information](https://www.compassionandchoices.org/information) to learn more about our end-of-life planning resources.

# Your Advance Directive

An advance directive is an important document that tells healthcare providers and family members what medical treatment you wish to have or forgo. It comes into effect if you can't speak for yourself. It allows you to choose in advance whether to accept or refuse life-sustaining treatments under certain circumstances.

The advance directive encompasses a person's living will and varies by state. It is not difficult to complete, and you don't need a lawyer to do so.

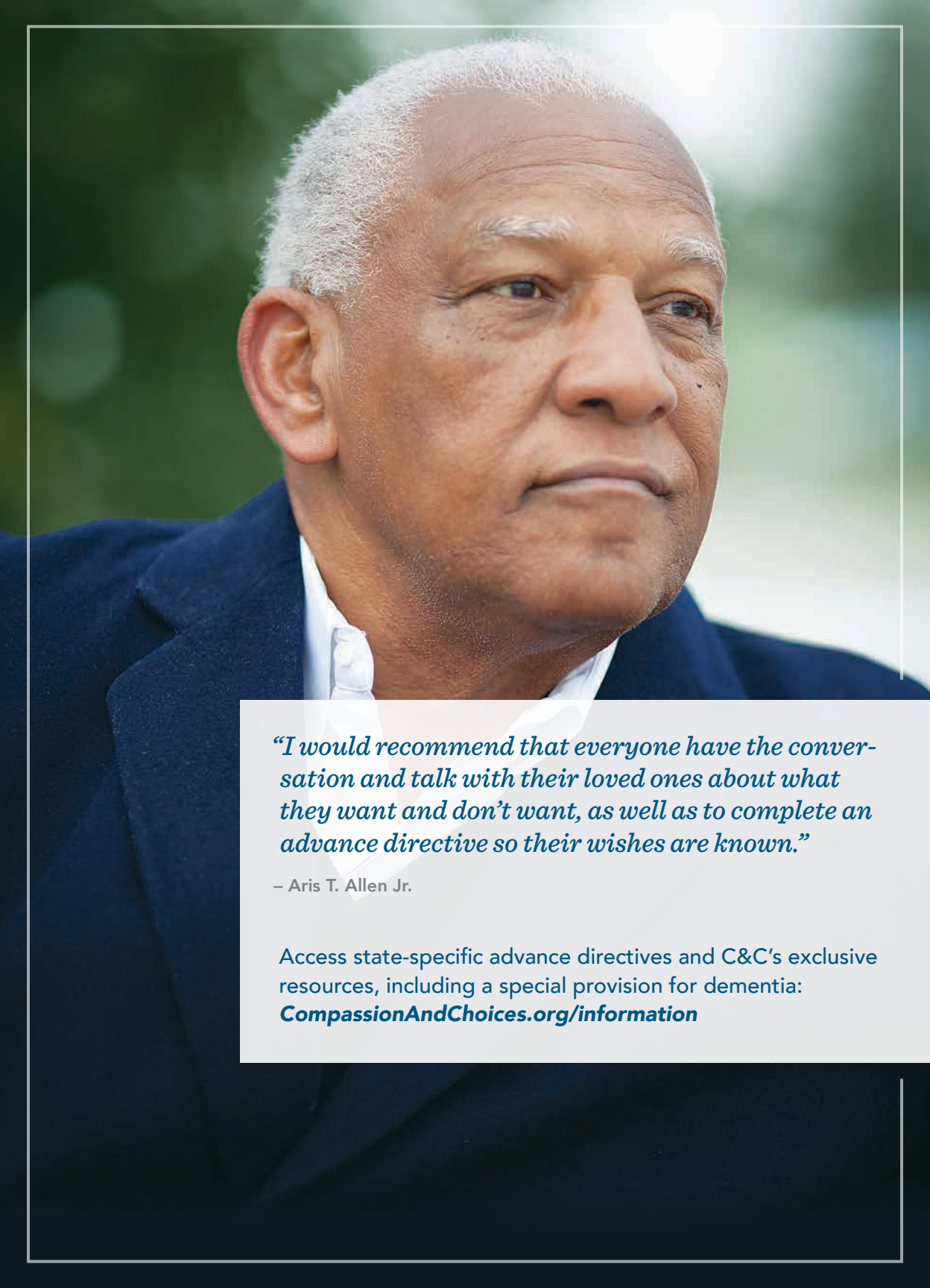
All adults should complete an advance directive, discuss priorities with loved ones, and make sure it is easily accessible. Do this when you are young and healthy to give your loved ones guidance and peace of mind in the event of illness or a serious accident.

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, such as on your refrigerator or a bathroom mirror. 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. Your doctor can help you decide whether these forms are appropriate for you. Your 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.



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 with trees.

*“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 to complete an advance directive so their wishes are known.”*

– Aris T. Allen Jr.

Access state-specific advance directives and C&C’s exclusive resources, including a special provision for dementia:

**[CompassionAndChoices.org/information](https://CompassionAndChoices.org/information)**

# Good-to-Go Resource 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' Good-to-Go Resource Guide and Toolkit to define your priorities and get advice on how to start those vital conversations.



Visit us at [CompassionAndChoices.org/information](https://CompassionAndChoices.org/information) to learn more about these resources.

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## 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 healthcare 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/information](https://CompassionAndChoices.org/information) to ensure your new home will honor your wishes.



## Armond & 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](https://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 hiccoughs, nausea, diarrhea, itching and fatigue can be oppressive 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 choices.

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.

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## 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.



# Physician Resources

Many physicians hesitate to initiate end-of-life conversations. To promote those conversations, Compassion & Choices provides practicing physicians readily available, free, and confidential telephone consultation with one of our seasoned medical directors, each with years of experience in end-of-life medical care. They offer advice on hospice, palliative care, and effective pain and symptom management — among other end-of-life options.

*“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.



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**CompassionAndChoices.org**