My End-of-Life Decisions

An Advance Planning Guide and Toolkit

compassion & choices

Revised for 2024-25

Terms Explained

advance directive – Encompasses both living wills and medical durable power of attorney.

advance (care) planning – Involves making decisions based on your personal values, preferences, and discussions with your loved ones about the healthcare you would want to receive if facing a medical crisis, and then documenting those decisions in an advance directive.

diagnosis – Identification of a disease from its signs and symptoms.

hospice – Compassionate and personalized care to support an individual and their loved ones during the final months of life.

life-sustaining measures or life support – Medical interventions that are commonly introduced when biological functions can no longer maintain themselves.

living will – A term commonly substituted for *advance directive*, but referring only to a document of stated wishes, not a document appointing a surrogate decision-maker.

palliative care – A treatment option that focuses on symptom management, pain relief and quality of life for patients with serious advanced illness as well as supporting their families.

palliative sedation – Also referred to as "terminal sedation" or "total sedation," the continuous administration of medication to relieve severe, intractable symptoms that cannot be controlled without rendering a person unconscious. This state is maintained until death occurs.

prognosis – A forecast of the likely course or time to death as a result of a disease or ailment. The term is not used interchangeably with *diagnosis*.

proxy or healthcare proxy – A person named as your healthcare proxy has the power to advocate for your medical wishes and make healthcare decisions for you if you are unable to do so. This person, also called a surrogate or medical power of attorney, is named in your advance directive, a legal document.

terminal – Describes an illness for which the medical expectation is death within six months.

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This guide is available in English and Spanish online and in print format. To find and share this guide or get information on the full range of end-of-life options, please visit the online resource Compassion & Choices' *Tools to Finish Strong* at **CandC.org/tools**, or call 800.247.7421 to speak with one of our experienced end-of-life consultants.

Taking Charge of Your End-of-Life Care

START THINKING:
How do you want to live, through the end of your life?

START TALKING:
"I've been thinking about my future. Can we talk about it together?"

KEEP DISCUSSING:
This is not one conversation. It's many conversations over a lifetime.

ADVANCE PLANNING GUIDE

When we plan for future care, our community, families, loved ones, caregivers, and care team are better prepared to help us navigate our future. Planning for serious illness is an important part of the journey we're on, including when we reach the end of life.

Everyone has unique wants and needs when it comes to discussing their healthcare decisions. Some people want to make these decisions as a family unit, while others want to make them alone. Some people want medical treatments that prolong life, while others do not. Advance planning helps ensure that we get the care we want and avoid what we don't want.

Making thoughtful choices now, having ongoing conversations with those closest to us, and putting them in a written advance directive are all steps we can take to take care of ourselves now and in the future. Let's get started.

About the Advance Planning Guide

The guide will help you think through your priorities for end-of-life care, complete an advance directive and other forms you may need, choose a representative to speak for you if you cannot, and consider common end-of-life medical interventions so you can specify what you want or don't want — right up to the end. And it will guide you in having valuable conversations with your health-care providers and loved ones.

About the Advance Planning Toolkit

Following the guide is a set of planning aids and forms you can tear out and use. They'll help you work through the planning process and add specifics to your advance directive.

Dolores Huerta

Civil Rights icon and Latino Leadership Council member

> “This is a great opportunity for us to reach out to our loved ones and start having those difficult but necessary conversations about advance care planning. Planning equals peace. So why not plan it?”

(see page 5)

Rev. Charles McNeill

Pastor and African American Leadership Council member

> “Advance care planning only works when you do it! When life changes, change your plans. Talking about your end-of-life wishes should be an ongoing conversation with your loved ones and healthcare providers so everyone knows the care you want.”

(see page 6)

Getting Started: What Matters Most to You?

The starting point for your end-of-life plan is your own values and priorities. What's important to you? Picture yourself in an end-of-life situation. What sort of care would you want? Now picture a situation that leaves you unable to care for or speak for yourself. What's most important to you in that kind of scenario? What do you ***not*** want to happen?

AS YOU PICTURE A FEW GENERAL SITUATIONS, CONSIDER:

- **YOUR PERSONAL BELIEFS AND VALUES.** How do your spiritual or religious beliefs affect your attitudes about terminal diseases, treatment decisions, or death and dying? Would you want life-sustaining treatments no matter the circumstance, or do you believe that when there is minimal hope of meaningful recovery, natural death should be allowed?
- **QUALITY-OF-LIFE CONCERNS.** What basic abilities are important to you in order to feel you would want to continue living? For example, do you feel you must be able to recognize loved ones or communicate with others?
- **TYPES OF LIFE-SUSTAINING TREATMENTS.** Are there specific procedures or treatments you *would want* or definitely *not want* if you were diagnosed with a terminal condition?
- **YOUR SUPPORT NETWORK.** Is there a particular doctor you want to help your family direct your care? Is there anyone you do *not* want involved in your healthcare decisions?

The *Advance Planning Toolkit* that follows this guide has a *Values Worksheet* with more questions to help you. You'll also benefit from letting others know your thoughts. Talking with loved ones about end-of-life issues can lead to important discoveries and deeper connections. Speaking to your healthcare provider can give you a feeling of authority over your healthcare decisions. If it doesn't, you may want to consider looking for a new healthcare provider.

In the Toolkit:
Compassion & Choices' **Values Worksheet** has more questions to help you think through your priorities. You'll find it on page 21 in the *Advance Planning Toolkit*.

Putting Priorities on Paper:
Your Advance Directive

An advance directive is the cornerstone of your advance care planning. It makes your end-of-life preferences clear if you are unable to make or communicate medical treatment decisions yourself. Typically an advance directive includes a living will ("what I want") and a medical durable power of attorney ("who will speak for me"). It can also include other documents to spell out your wishes. In most states, a lawyer is not required to complete an advance directive, but legal advice may help ensure your advance directive is valid. Since laws in each area are a little different, an advance directive filled out in one state may not be honored in another state. The best way to ensure wishes are honored is to complete an advance directive for the state in which you live, as well as for any states in which you spend a lot of time or receive medical care.

Your living will specifies what kinds of treatment and care you *would* or *would not* want in order to sustain life. Your durable power of attorney authorizes someone you trust to act as your representative and make medical decisions for you if you cannot make them for yourself. These are healthcare documents and do not include financial, estate, or business concerns. Advance directives are only useful if they are completed before a health crisis, shared with your healthcare team, and available when you are unable to speak for yourself.

COMPLETING YOUR STATE-SPECIFIC ADVANCE DIRECTIVE

Many states have their own forms with specific guidelines that must be used. To find state-specific advance directive forms, visit CaringInfo at **Caringinfo.org/planning/advance-directives.**

COMMUNICATING YOUR ADVANCE DIRECTIVE

Your advance directive can be helpful to your healthcare provider and others close to you when choices are being made on your behalf. However, the documents alone do not guarantee enforcement. That's why it's important to appoint someone who understands and supports your values as your healthcare representative or agent. Take the time to communicate your wishes to that person as fully and clearly as possible and give them a copy for their files.

It is also a good idea to bring an up-to-date advance directive to your healthcare provider to discuss your healthcare wishes and have the document scanned into your medical records.

An advance directive includes a living will ("what I want") and a medical durable power of attorney ("who will speak for me"). It can also include other documents.

ADDING OTHER DOCUMENTS

Throughout this guide you will find references to other resources that can be added to or accompany your advance directive. Documents and links can be found in the *Advance Planning Toolkit* included with this guide and online at **CandC.org/tools.** Some specific medical orders may need to be signed by a healthcare provider. The more information you can provide to prevent conflicting interpretations of your preferences, the greater the likelihood those preferences will be followed.

STORING AND REVIEWING YOUR ADVANCE DIRECTIVE

To be useful, your advance directive needs to be easily accessible and up to date. Review your advance directive anytime there is a significant life change (death, divorce) or new diagnosis, and, at minimum, every 5-10 years. Give a copy to your designated healthcare representative, keep another in an obvious place at home so your representative or loved ones can find it, and bring one to your primary healthcare provider to keep in your medical records. Review your documents regularly.

TIPS FOR SELECTING YOUR MEDICAL SURROGATE (PROXY) AND REMINDERS FOR YOUR ADVANCE DIRECTIVE:

- A surrogate is the person you name as your healthcare proxy. They have the power to advocate for your medical wishes and make healthcare decisions for you if you are unable to do so. This person is named in your advance directive, a legal document. (See more about selecting a representative on page 14.)
  A good surrogate is someone who:
  - Is willing to take the time to understand what is important to you.
  - Can be trusted to carry out your wishes, even if they differ from their own.
  - Knows how to advocate and will speak up in a crisis.
  - Will be able to make difficult decisions in stressful situations.
  - Will be comfortable navigating family dynamics if needed.
- Discuss your wishes and provide a copy of your advance directive to your surrogate decision-maker, loved ones, and medical team.
- If you update your advance directive (you can, at any time), discard the document you no longer want and replace it with a revised version. Share the revised version and ask others to discard the one you no longer want.
- Review your advance directive annually (or at minimum, every 5-10 years) and update when any one of the "5 Ds" has occurred: **D**eath of a loved one, **D**ivorce, a new **D**iagnosis, **D**ecline in health or you reach a new **D**ecade.
- Keep your advance directive in a place where it will be easily found by your surrogate decision-maker and/or loved ones.
- Make sure your advance directive will be honored in all states in which you receive care or frequently visit.
- Consider keeping a copy with you when you travel or know you will be away from home for a long period of time.
- Talk with your medical team about completing a POLST - Physician Orders for Life Sustaining Treatment (also known as a MOLST - Medical Orders for Life-Sustaining Treatment) form.

An advance directive is a key part of any end-of-life plan. It lets others know "what I want" and "who will speak for me" if you become unable to make or communicate medical treatment decisions for yourself. Complete it early, communicate it fully, and make it easy to find.

What I Want:
Decisions About Life-Sustaining Measures

Without question, the medical industry has made amazing advances in recent decades. But for people whose illness cannot be cured or whose independent functioning cannot be restored, this progress presents a modern dilemma. It requires personal decisions about how much treatment is enough, where the line should be drawn between therapeutic and unwanted treatment, and — the most difficult decision for many — how long life should be prolonged after it has ceased to be "life" as you define it.

Medical interventions are commonly introduced when biological functions can no longer maintain themselves. Also known as "life-sustaining measures" or "life support," these interventions often include artificial ventilation to support breathing, medications to stimulate heart function, dialysis to support failing kidneys, and artificial nutrition and hydration for those who cannot swallow.

Many states' advance directive forms mention at least two scenarios in which life-sustaining interventions could be applied: permanent unconsciousness and terminal illness. You can indicate on the form whether or not you would want continued life support under those circumstances. Often, people who are terminally ill do not want life support because it would only prolong the dying process.

To further personalize the directive, you can cross out and initial any scenarios you don't wish to include, and you can note anything else you feel is important. In making decisions about life support, consider not only terminal illness but catastrophic events such as sudden cardiac arrest or traumatic brain injury.

Some state laws require you to record your preference in writing to have life support withheld. In these states, life support is always initiated unless you have written documents requesting otherwise.

REQUESTING WITHHOLDING OR WITHDRAWING TREATMENT

Life support is considered "withheld" when a person or their representative instructs healthcare providers not to begin a medical therapy to sustain life, and the expected result is that the person will die without it. This option is often selected by people who are terminally ill and have already begun the dying process.

Life support is considered "withdrawn" when a therapy that has been initiated is stopped. Often the person — or their representative or family members — and the healthcare provider will agree on a time-limited trial of life-support therapy, hoping for improvement. If the person does not improve within that timeframe, the therapy is stopped, and a natural dying process is allowed to occur.

You can direct your own medical care if you are conscious and capable. This changes once you become unable to communicate for yourself. Some state laws require you to record in writing your preference to have life support withheld. In these states, life support is always initiated — unless you have written documents requesting otherwise. Even your designated representative cannot change this. If you want life support to be withheld or withdrawn after a certain period (three days, three weeks, three months), you need to indicate this in your advance directive.

SPECIFIC OPTIONS TO CONSIDER

At the end of life you should plan for the care you consider to be most important. The full range of end-of-life options can support those who want little to no care or those who want more care. At the end of life, some people may choose to accept all medical interventions available to them. These options can range from medications and artificial nutrition (feeding tubes) to respiratory support, dialysis, and more. Asking questions and discussing options with your healthcare team will help you determine the best plan for you.

Everyone should have the information they need to make their own decisions with nonjudgmental support for their preferences and values. There are many options available, and some may vary by state. Examples of options for care at end of life include the following:

LIFE-EXTENDING CARE

- **Heart failure support:** Heart failure is a chronic condition where the heart muscle doesn't pump blood as well as it should. As the condition progresses, people may need medication(s) to help their heart pump more effectively. In severe or advanced cases, people may require hospitalization in order to receive continuous IV medications or surgically inserted assistive devices.
- **Respiratory support:** Many disease processes can affect the lungs and the ability to breathe effectively. Options that can help support breathing include oral medications, inhalers, nebulizers, supplemental oxygen through a simple nasal cannula, and CPAPs. Sometimes illness requires a more serious short-term or permanent intervention. This may include a high-flow nasal cannula, BiPAP, Trilogy or mechanical ventilation ("breathing tube"). If mechanical ventilation appears to be needed long-term for more than two weeks, a tracheostomy may be recommended. A tracheostomy is a surgically created hole in the trachea (windpipe) that offers an alternative way to provide oxygen and ventilatory support to the lungs.
- **Artificial nutrition and hydration:** There are a number of reasons why people may need artificial nutrition and hydration, and a variety of ways it can be provided. One way this can be provided is through feeding tubes. Short-term artificial nutrition and hydration can be provided through a nasogastric (NG - nose to stomach) or orogastric (OG - mouth to stomach) tubes. Long-term options can include surgically placed feeding tubes including gastrostomy (PEG, G, or GJ) tubes, which are inserted directly into the stomach. In some specific instances, nutrition can be provided directly into the bloodstream; this is called parenteral nutrition.
- **Supplemental feeding:** Sometimes people need additional calories or more nutrition than they can eat on their own. Sometimes people are able to eat but struggle to get enough calories or nutrition. In this situation, supplemental nutrition can be provided orally, intravenously (through a vein) or through feeding tubes (short-term or long- term). Depending on the disease process, this may not actually prolong life. Spoon-feeding or hand-feeding is an option for those who have the ability to chew and swallow, even if they have lost all cognitive abilities. If such a situation is a concern, you may document that you decline such spoon-feeding as part of your advance directive.

HOSPICE

Specialized type of care that focuses on compassion and quality of life and care during the final months of life. Hospice care is focused on maintaining or improving quality of life while managing symptoms for someone whose illness or condition is considered terminal or end-stage. Patients and their loved ones are supported by a team of professionals who specialize in end-of-life care and addressing the physical, emotional, and spiritual issues that often accompany terminal illness. Hospice can be provided in the home or in residential facilities such as assisted living, memory care, or skilled nursing.

PALLIATIVE CARE

Specialized medical care for people living with a serious illness. Specialists focus on managing symptoms, coordinating care, and maximizing quality of life. Palliative care is not limited to end of life, but can be provided at any stage of illness, often as an additional layer of care and support in coordination with the patient's existing care team.

SYMPTOM MANAGEMENT

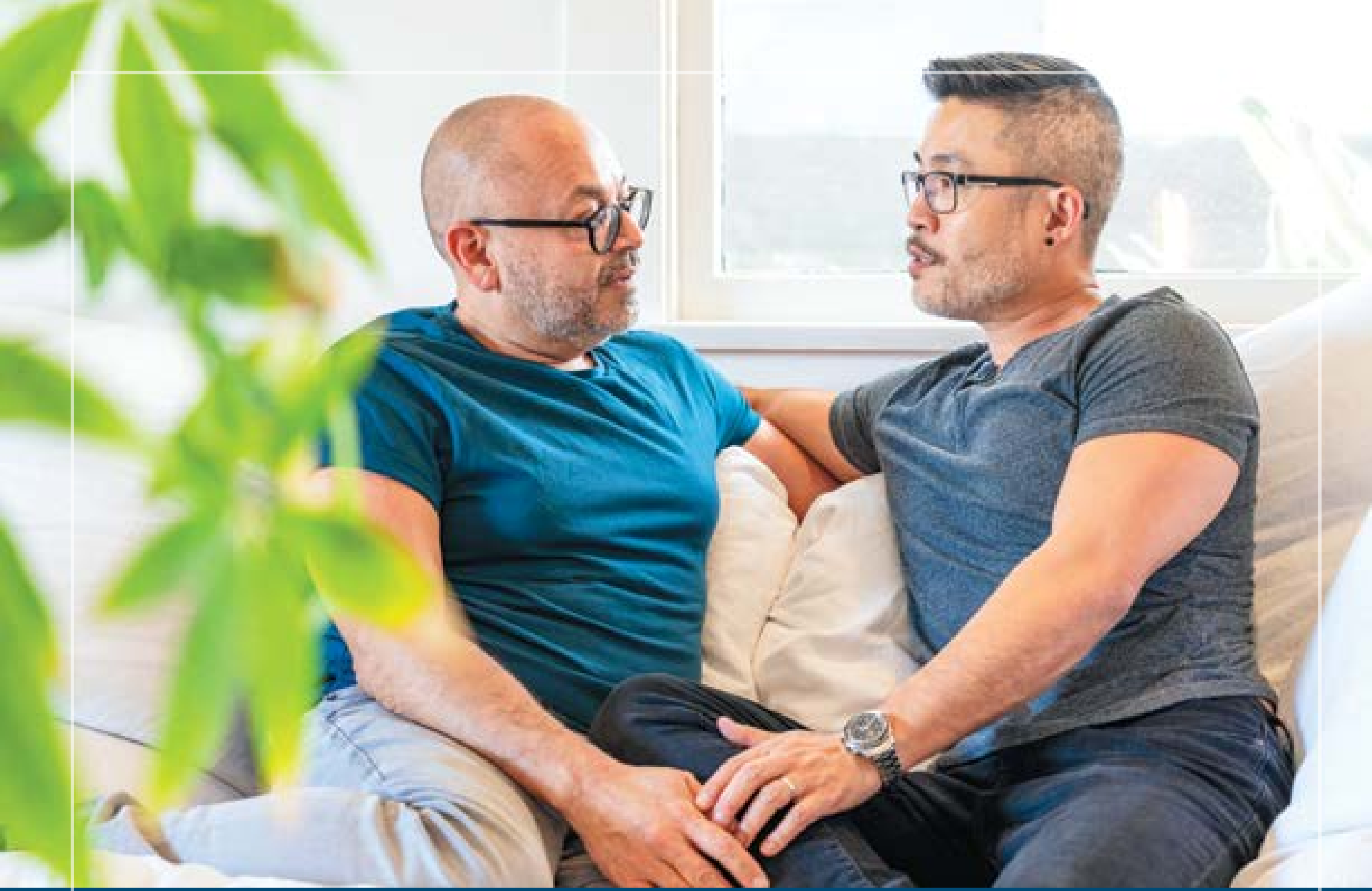
Life with serious and terminal illness is often accompanied by symptoms and side effects that can cause distress and discomfort. Symptoms such as nausea, physical pain, constipation, depression, weakness, appetite changes, and shortness of breath are very common. Managing these symptoms to ensure comfort is the most important part of any care plan. Open communication with the healthcare team is essential for making sure the right medications and proper doses are provided.

PALLIATIVE/TERMINAL SEDATION

Refers to the practice of relieving extreme pain and suffering at the end of life through the use of specific medications that reduce consciousness. While sedated, patients continue to receive comfort care and eventually die as a result of their natural disease process.

VOLUNTARILY STOP EATING AND DRINKING (VSED)

A person may choose to control their dying by making an intentional decision to stop all nutrition and hydration. Sometimes referred to as terminal fasting, VSED is an option for a decisionally capable adult who consciously refuses food and fluids in order to advance the time of their death. VSED is a process that requires support for both the patient and their caregivers.



Allyne Hammer

(1942–2023)

Advocate and LGBTQ+ Leadership Council member

"If you can't speak for yourself, be mindful of who you pick to speak for you. Choose someone you know will support your wishes and is willing to advocate for you."

(see page 14)

Dr. Sudha Royappa

Physician advocate

"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."

(see page 15)

What I Want:
Other Documents That Spell Out Your Choices

ALLOW NATURAL DEATH AND DO NOT RESUSCITATE ORDERS

Allow natural death (AND) and do not resuscitate (DNR) orders are written by a healthcare provider. A DNR informs medical staff that CPR should not be attempted. This also means other resuscitative measures, such as electric shocks to the heart and breathing support, will also be avoided. DNR orders are useful in preventing unnecessary and unwanted invasive treatment at the end of life. A DNR order does not mean "do not treat." Other treatments like antibiotics, dialysis, and medications that can prolong life may still be provided. DNR instructions in your advance directive may not be effective if you receive emergency care, such as in the event of a sudden collapse. If you do not want resuscitation attempted under any circumstance, you need a form that is separate from your advance directive, sometimes called an "out-of-hospital DNR."

OUT-OF-HOSPITAL DNR ORDERS

All states allow special DNR orders that are effective outside a hospital setting. These are called "out-of-hospital," "pre-hospital, comfort care" or "no CPR" orders. Generally they require the signature of a healthcare provider and the patient (or their authorized surrogate decision-maker).

You may also consider a quick way to convey these wishes by wearing an emergency bracelet or necklace.

First responders are almost always required to initiate life support unless a valid DNR order is in place (meaning it has been signed by a healthcare provider) and is immediately presented to them. To learn more about what you need to do to ensure that paramedics comply with your out-of-hospital DNR, you can call your local ambulance service or fire department.

PHYSICIAN/MEDICAL ORDERS FOR LIFE-SUSTAINING TREATMENT (POLST OR MOLST)

Most often called POLST, but sometimes MOLST, physician or medical orders for life-sustaining treatment is a document that captures the discussion and shared decision-making process between a healthcare provider and person living with advanced or end stage illness. They are a means to translate your advance directive into healthcare provider orders to be followed by all medical personnel. Your healthcare provider may use the POLST form to write orders that reflect the types of life-sustaining treatment, such as CPR or tube-feeding, that you do or do not want given your medical situation.

POLST orders are not for everyone. Only patients with an illness or frailty serious enough that a healthcare professional would not be surprised if they died within one year should have them. For these patients, their current health status indicates the need for standing medical orders. For healthier patients, an advance directive is a more appropriate tool for making future care wishes known.

To learn more, speak with your healthcare provider or visit The National POLST Coalition for the latest information on POLST planning in your state: **Polst.org.**

In the Toolkit:
You can add **My Particular Wishes** (page 25) and **Dementia Advance Directive** (page 28) forms to your advance directive to provide more detail about your preferences regarding specific interventions.

ADVANCE DIRECTIVE ADDENDUM: MY PARTICULAR WISHES FOR THERAPIES THAT COULD SUSTAIN LIFE

You can include more detail about your wishes regarding specific life-sustaining interventions in your advance directive by completing this Compassion & Choices form, included in the toolkit. It lists a range of treatments, including the life-support interventions described previously. For each listed treatment you can check that you consent to the treatment, consent to a trial period, or refuse it. You can also use the form as a basis for discussion.

DEMENTIA ADVANCE DIRECTIVE

The *Dementia Values & Priorities Tool®* is designed to help you communicate your wishes regarding future care if you are living with dementia. After answering a series of questions related to the changes commonly seen in the progression of dementia, you will have a document that can be added to your existing advance directive and shared with others.

The interactive online tool is available in English and Spanish, and a printable version is available in multiple languages. Be aware that not all memory care or long-term care facilities will honor such a directive, so you'll want to explore the issue before you are admitted. To lessen the chance your preferences will be challenged, you may also consider using your phone, tablet, or digital camera to record a statement explaining why you have completed a dementia directive, and making clear that you have made your decision without pressure or coercion. Be sure to share that file with loved ones and/or your medical proxy.

To complete a fully customizable dementia advance directive, visit **CandC.org/dementia-values-tool**.

Who Will Speak for Me:
Choosing Your Representative

The representative you name as your medical power of attorney has the power to advocate for your medical wishes and make healthcare decisions for you if you are unable to do so.

FACTORS TO CONSIDER WHEN CHOOSING A REPRESENTATIVE

Your representative, also known as proxy or medical surrogate, can be anyone you trust who is at least 18 years of age (required in most states), your next of kin, another family member, a friend, or someone else. You cannot, however, appoint your primary care physician or any other healthcare practitioner involved in your care unless they are related to you by blood, marriage, or adoption. You can name an alternative representative to step in if your primary representative is unavailable. Once you've chosen someone, avoid potential conflict by letting others know your choice.

IN SELECTING A REPRESENTATIVE, ASK YOURSELF:

- *Are they assertive?* You want someone who is comfortable speaking with healthcare providers and advocating for you.
- *Are they comfortable talking about death?* They will need to engage with the subject.
- *Do they live nearby?* In a crisis, having someone local can be important.
- *Will they respect my decisions?* They need to understand where you're coming from and be willing to honor your requests.

The most important thing when selecting a representative is discussing your wishes and making sure the person you choose is familiar with your advance directive and what matters most to you.

LOOKING BEYOND IMMEDIATE FAMILY

If you're finding it hard to identify someone to serve as your representative, remember that they do not have to be a family member.

HERE ARE SOME OPTIONS TO CONSIDER:

- In some cases it may be better to ask a friend whom you trust.
- You can consider asking a neighbor or a member of your faith community.
- When discussing your request, let them know there is no financial liability attached to this role.
- End-of-life doulas are available to assist individuals and families throughout the dying process, from choosing a healthcare proxy to bereavement support. Visit **NEDAlliance.org** to learn more.
- The LGBTQ+ community may face challenges in end-of-life healthcare settings, including having their preferences ignored or being prevented from accessing their chosen family member. Consider the *Hospital Visitation Authorization* form on page 39 and an LGBTQ+ specific advance care planning toolkit at **CandC.org/LGBTQtoolkit**
- Some communities have geriatric case managers who may serve as healthcare representatives for a small fee. Inquire with the Aging Life Care Association at **AgingLifeCare.org**.
- Attorneys who specialize in elder law may be willing to take on this role. Find a list of local attorneys through the National Academy of Elder Law Attorneys at **Naela.org**.

Putting Plans Into Practice: Ensuring Medical Providers Honor Your Wishes

Advance directives can go a long way toward making sure you get the type of care you want. There are potential stumbling blocks, however. Difficulties may arise when the values of healthcare providers differ from your own, or when the policies of health systems or care facilities conflict with your instructions. Here are some suggestions to help avoid such problems.

CHOOSING HEALTHCARE PROVIDERS WHO WILL RESPECT YOUR PRIORITIES

Establishing an understanding with your doctors and healthcare team is particularly important. In addition to general concerns (how will they work with you and your loved ones to honor your wishes; will they do their best to fully explain all procedures, treatments, alternatives, and risks; will they be available to answer questions and respond to your needs) you will likely want to explore some specifics. Some examples: choosing to stop unwanted treatment, start VSED, or request medical aid in dying; or choosing to extend life with ventilators, dialysis, or feeding tubes.

Compassion & Choices has a fact sheet, *How to Talk to Your Doctor About Your End-of-Life Options*, that you can review for ideas. Find it at CandC.org/tools. The toolkit that is within this guide contains a sample *End-of-Life Wishes Letter to Medical Providers* you can use as a starting point for your own letter or conversation.

In the Toolkit:
The sample **End-of-Life Wishes Letter to Medical Providers** (page 33) offers a starting point for your own letter to your doctor.

OBTAINING REFERRALS, IF NEEDED

If your healthcare provider cannot support your end-of-life decisions or does not wish to manage your care, you always have the right to seek care from another source. You can and should be referred to someone else.

If your insurance company will only pay for services provided by a contracted healthcare system or group of physicians, you can contact your insurance company for a list of contracted providers.

AVOIDING PROBLEMS IF AN INSTITUTION'S POLICIES CONFLICT WITH YOUR WISHES

It's possible that in an emergency you could be admitted to a hospital whose policies conflict with wishes stated in your advance directive. Compassion & Choices offers a *Sectarian Healthcare Directive* as a possible addendum to your advance directive. It states that admittance does not imply consent to unwanted treatment and requests transfer if warranted.

Another situation worth guarding against is the possibility that an assisted-living facility's policies would be in conflict with a resident's wishes for a peaceful death. Adding a rider to the contract will clarify the resident's expectations and the facility's agreement. *Our Advance Planning Toolkit* includes such a rider for you to review.

The Best Safeguard: A Continuing Conversation

Studies indicate that the single most powerful thing a person can do to ensure their wishes are honored is to talk about it.

WHOM TO INCLUDE IN THE CONVERSATION

First and foremost, talk to those who have the greatest impact on your care options — your personal healthcare provider, your designated healthcare representative (healthcare surrogate or proxy), and your family or other loved ones. Additional people who need to know about your end-of-life concerns and wishes include your estate attorney, caregivers, and friends.

WHAT TO TALK ABOUT

You'll want to talk about the topics covered in this guide: your values, your wishes for end-of-life care, your designated representative, and other elements of your advance directive. You may want to bring up other topics as well, such as your financial plans and plans for care of your body after your death. And a single conversation will likely not be enough. Your situation and your wishes may change over time.

AVOIDING FUTURE CONFLICT

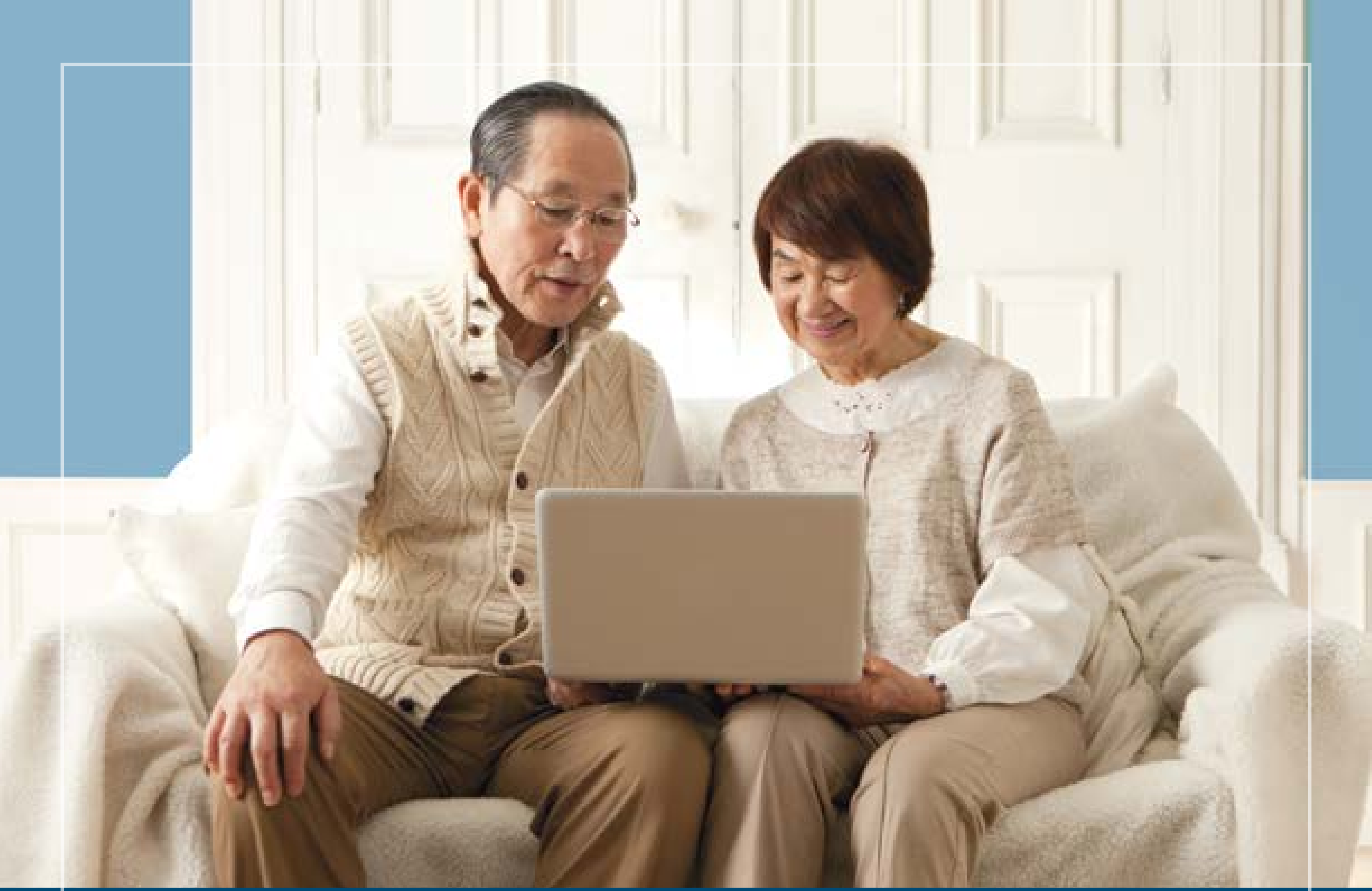
Some of those you talk with may not agree with or support your wishes. As noted earlier, you have the right to change healthcare providers or to name a different healthcare representative who supports your desires and plans. If you anticipate that other family members may strongly disagree with your preferences, communicate directly — verbally and in writing — with them, and be clear that if they cannot support your wishes, you do not want them involved in your healthcare decision-making.

WHEN TO TALK

Death can be a difficult topic to bring up, but the time to talk is now. One approach is to set aside time to initiate a conversation about it. You might select a family gathering or a time when illness and medical visits provide an opening. Or you could prepare to introduce the topic when a particular subject arises, such as concerns about losing various aspects of your independence. Decide whether individual conversations with specific family members or a group discussion would work best. Perhaps begin by giving family members a copy of your advance directive.

HERE ARE SOME WAYS TO START THE DISCUSSION:

- "It's important to me to be able to talk honestly with you about my concerns and wishes if I ever become seriously ill or unable to speak for myself … "
- "My doctor/attorney says I need to go over my advance directive … "
- "I want to make sure that I get the best care possible and the type of care that I want, so there are things we should talk about … "
- "I'd like it to be as easy as possible for my family to make medical decisions on my behalf if I ever become incapable of communicating my wishes … "
- "If you are ever in a position where you need to make healthcare decisions for me, it will be helpful for you to know what I really want ... "



Ashley Johnson

Death doula and end-of-life educator

> "End-of-life care for those with dementia is about more than medical decisions. It's about ensuring comfort, preserving dignity, and creating moments of peace and connection."

(see page 13)

Rabbi Ariel Stone

End-of-life options advocate

> "Every day of life is a gift. Life should have delight in it. Life should have the opportunity to connect with others in it. Life should have satisfaction in it. Life should feel like a gift. As much as it is a gift to be alive, it is a gift to be able to let go of life in a way that feels right to the individual."

(see page 21)

ADVANCE PLANNING TOOLKIT

Taking the time to prepare a written record of your end-of-life wishes is important. Advance directives are recommended for adults over 18 and especially encouraged for anyone living with chronic or serious illness. These steps will help ensure that if you cannot speak for yourself your preferences will be honored.

The advance planning tools found here will help you clarify your priorities, inform the people you have chosen to support you, and document and communicate your decisions. You can use the *End-of-Life Panning Checklist* on the following page to keep track of your progress as you review the other materials. We suggest you start by completing the *Values Worksheet*.

Not included here are two essential forms that are the basis for any advance directive regarding end-of-life care: a living will (“what I want”) and a durable medical power of attorney (“who can speak for me”). These forms differ significantly from state to state, so you will need to obtain the correct state-specific forms online, or from a state-specific resource or an estate planning attorney.

One more thing: Keep copies of your state-specific advance directive and other completed forms together in an easy-to-find place, and provide copies to family members, your doctor and the representative you designate. That way they’ll be available when needed. Complete the *Values Worksheet.*

The following documents are not intended as legal advice. Your state may have specific laws about how these documents should be completed. Consult local counsel for advice specific to your situation.

End-of-Life Planning Checklist

Please visit the Compassion & Choices website for more resources at CandC.org/plan.

Many people postpone making arrangements for healthcare at the end of life. Planning ahead allows individuals to spend their final days with friends and family while focusing on the present. Informing loved ones of wishes ahead of time relieves them of the possible burden of making decisions about your final arrangements.

PLEASE CONSIDER WHETHER ANY OF THE FOLLOWING ARE APPROPRIATE FOR YOUR SITUATION:

- ☐ Discuss your wishes with family and loved ones.
- ☐ Discuss your wishes with your healthcare surrogate.
  - ☐ Make sure they are comfortable making decisions on your behalf.
  - ☐ Make sure they know where important documents (see list below) can be found.
  - ☐ Provide them with a copy of your Advance Directive.
- ☐ Discuss your wishes with your provider(s) and healthcare team.
- ☐ Create and/or locate important documents.
  - ☐ Advance Directive or Living Will
  - ☐ Durable Power of Attorney for healthcare
  - ☐ Durable Power of Attorney for finances
  - ☐ Last Will and Testament - Compassion & Choices has partnered with FreeWill to offer this documentation at no cost, available at CandC.link/free-will
  - ☐ Living Trust
  - ☐ Life insurance policies (with beneficiary information)
  - ☐ Information for financial accounts, assets, and property
  - ☐ Information for final arrangements, funeral plans, pre-paid services
- ☐ Ensure important documents are up to date and reflect your current wishes. Provide a copy of your current Advance Directive to:
  - ☐ Healthcare provider(s)
  - ☐ Surrogate decision-maker
  - ☐ Hospice team (if applicable)
- ☐ Name a guardian for children, pets.
- ☐ Talk with the guardian about wishes and plans.

Values Worksheet

Below are some questions to consider as you make decisions about your healthcare preferences. You may want to write down your answers and provide copies to your family members and healthcare providers, or simply use the questions as "food for thought" and a basis for discussion.

HOW IMPORTANT TO YOU ARE THE FOLLOWING ITEMS?

click one number ranging from 4 to 0 for each statement

	VERY IMPORTANT				NOT IMPORTANT
Allowing death without life-prolonging medical interventions	4	3	2	1	0
Preserving quality of life	4	3	2	1	0
Staying true to my faith or spirituality	4	3	2	1	0
Extending my life as long as possible with life-sustaining interventions	4	3	2	1	0
Being independent	4	3	2	1	0
Being comfortable and as pain-free as possible	4	3	2	1	0
Leaving good memories for my family and friends	4	3	2	1	0
Making a contribution to medical research or donating my remains to science	4	3	2	1	0
Being able to relate to family and friends	4	3	2	1	0
Being free of physical limitations	4	3	2	1	0
Being mentally alert and competent	4	3	2	1	0
Being able to leave money to family, friends, or charity	4	3	2	1	0
Dying more quickly rather than lingering	4	3	2	1	0
Avoiding expensive care	4	3	2	1	0

WHAT ARE YOUR VALUES AND WISHES IN THE FOLLOWING AREAS:

1. **What will be important to you when you are dying (e.g. physical comfort, no pain, family members present, etc.)?**

2. How do you feel about the use of the life-sustaining measures in the following situations?

- Terminal illness
- Permanent coma
- Irreversible chronic illness
- Dementia

3. Do you have strong feelings about particular medical procedures?

- Ventilator breathing (breathing assistance)
- Cardiopulmonary resuscitation (CPR)
- Artificial nutrition and hydration
- Hospital intensive care
- Pain-relief medication
- Antibiotics
- Chemo- or radiation therapy
- Surgery
- Dialysis

4. What limitations to your physical or mental health would affect the healthcare decisions you would make?

5. Would you want to be placed in a nursing home or care facility indefinitely if your condition warranted?

6. Would you prefer hospice care, with the goal of keeping you comfortable in your home during the final period of your life, as an alternative to hospitalization if you are eligible?

7. In general, do you wish to participate or share in making decisions about your healthcare and treatment?

8. Would you always want to know the truth about your condition, treatment options, and the chance of success of treatments?

9. What rituals, traditions, and observations do you want to be honored at the end of life?

The following document can be added to any advance directive to provide guidance regarding consent to or refusal of certain therapies. Once completed, signed, and witnessed, it should be kept with the advance directive.

My Particular Wishes for Therapies That Could Sustain Life

(Advance Directive Addendum)

This document is meant to inform my physician, nurse, or other care provider of my consent to or refusal of certain specific therapies. It also guides my family or any other person I name in making healthcare decisions for me if I cannot articulate these decisions myself.

I hope this document helps those who must make difficult choices to proceed with confidence. By following these instructions they know they are acting in my best interests and are consenting or refusing certain therapies just as I would if I could hear, understand, and speak or communicate them myself.

DECISIONS WHILE I AM CAPABLE

So long as I am able to understand my condition, the nature of any proposed therapy, and the consequences of accepting or refusing the therapy, I want to make these decisions myself. I will consult my doctor or healthcare provider, family, those close to me, spiritual advisors, and others as I choose. But the final decision is mine.

COMFORT CARE

I want any and all therapies to maintain my comfort and dignity. If following the instructions in this document causes uncomfortable symptoms, such as pain or breathlessness, I want those symptoms relieved. I desire vigorous treatment of my discomfort, even if the treatment unintentionally causes or advances the time of my death.

DECISIONS FOR SPECIFIC THERAPIES

(Note: If you are unsure of the purpose of any of the following medical therapies, please speak with a health professional for clarification.)

If my mental or physical state has deteriorated, the prognosis is grave, and there is little chance that I will ever regain mental or physical function, I would like the following:

		YES	TRIAL PERIOD*	NO
1.	**Antibiotics if I develop a life-threatening infection of any kind**			
2.	**Dialysis if my kidneys cease to function, either temporarily or permanently**			
3.	**Artificial ventilation if I stop breathing**			
4.	**Electroshock if my heart stops beating**			
5.	**Heart-regulating drugs including electrolyte replacement if my heartbeat becomes irregular**			
6.	**Cortisone or other steroid therapy if tissue swelling threatens vital centers in my brain**			
7.	**Stimulants, diuretics, or any other treatment for heart failure if the strength and function of my heart is impaired**			
8.	**Blood, plasma, or replacement fluids if I bleed or lose fluid circulating in my body**			
9.	**Artificial nutrition**			
10.	**Artificial hydration**			

** Doctors may see whether the therapy quickly reverses my condition. If it does not, I want it discontinued.*

Signature *(Please print this document and sign with a pen.)* Date

Witness Signature *(Please print this document and sign with a pen.)* Date

Important note: Laws regarding witness signatures and what makes a document valid vary from state to state. This tool does not meet every state's specific requirements. If you have questions or want to ensure you have taken all necessary steps, share your completed document with an attorney licensed in your state.

For more information or to complete an electronic version of the Dementia Values & Priorities Tool®, visit CandC.org/dementia-values-tool.

Dementia Values & Priorities Tool®

Every end-of-life plan should start with thinking about your values and wishes. For example, what will be most important to you in the final weeks or days of life? What does "quality of life" mean to you? How do you feel about the use of life-sustaining treatments (such as artificial nutrition, breathing assistance, medications) if diagnosed with a terminal illness? What if you are living with dementia? The *Dementia Values & Priorities Tool®* is designed to help you communicate your wishes regarding future care if you are living with dementia.

Instructions:

1. Take your time to answer the questions on the following pages, providing as much detail as you wish.
2. Sign and date your completed document. It is recommended you sign in the presence of a witness.
3. Share your completed document and discuss your wishes with your surrogate decision-maker(s), and healthcare provider(s).
4. Save a copy of your completed document with your existing advance directive.

Dementia Advance Directive

I, ____, am completing this document because I want my surrogate decision-maker(s), physicians and healthcare team, family, caregivers, and loved ones to know my wishes regarding the type of care I want if I am living with dementia.

CARE PREFERENCES

For the questions below, select one of three options to indicate your desired care preferences.

Live as Long as Possible - My goal is to live as long as possible and receive aggressive medical care and life-saving treatments. This could include calling 911, going to the hospital, CPR, nutrition support, artificial hydration or breathing assistance if needed.

Treat Me but Not Aggressively - I want to continue medication for chronic health conditions (e.g. diabetes, heart disease) and treatment for illness (e.g. pneumonia and infections). I want to avoid surgery, long-term feeding tubes, aggressive treatment and other life-prolonging care.

Allow a Natural Death – Focus on comfort care, avoiding medications and treatments that prolong life. This could include stopping dialysis or blood transfusions, avoiding surgery, turning off a pace-maker or withdrawing treatment for heart disease, diabetes and other health conditions.

	CARE PREFERENCES		
If my physician or healthcare provider has determined my dementia has progressed to advanced or late stage, then I want	Live as Long as Possible ○	Treat Me but Not Aggressively ○	Allow a Natural Death ○
If I require around-the-clock (24-hour) assistance and supervision, then I want	Live as Long as Possible ○	Treat Me but Not Aggressively ○	Allow a Natural Death ○
If I no longer recognize my loved ones, then I want	Live as Long as Possible ○	Treat Me but Not Aggressively ○	Allow a Natural Death ○

	CARE PREFERENCES		
If I am unable to walk or move safely without assistance from a caregiver, then I want	Live as Long as Possible ○	Treat Me but Not Aggressively ○	Allow a Natural Death ○
If I am unable to bathe and clean myself without assistance from a caregiver, then I want	Live as Long as Possible ○	Treat Me but Not Aggressively ○	Allow a Natural Death ○
If I am unable to remain at home and have to live in a nursing facility, then I want	Live as Long as Possible ○	Treat Me but Not Aggressively ○	Allow a Natural Death ○
If I no longer have control of my bladder (urinary incontinence) or bowels (bowel or fecal incontinence), then I want	Live as Long as Possible ○	Treat Me but Not Aggressively ○	Allow a Natural Death ○
If I am no longer aware of my surroundings (where I am, the date/year, who is with me), then I want	Live as Long as Possible ○	Treat Me but Not Aggressively ○	Allow a Natural Death ○
If I am unable to clearly communicate my thoughts or needs (words and phrases do not make sense), then I want	Live as Long as Possible ○	Treat Me but Not Aggressively ○	Allow a Natural Death ○

INTEREST IN HOSPICE CARE

If my physician or healthcare provider determines I have six months or less to live, then	I am interested in hospice care to support me and my loved ones. I would like to enroll as soon as I am eligible. ○	I am not interested in hospice. ○	I am unsure at this time. My surrogate can make that decision on my behalf when the time comes. ○

FOOD AND DRINK

If the changes caused by dementia result in any of the following: » I no longer appear to desire food or drink, turn my head or otherwise avoid being fed or giving fluids. » I do not open my mouth to accept food or drink without prompting and all food or drink must be provided by a caregiver (hand or spoon-feeding). » I am unable to safely swallow food or drink (cough, choke or aspirate/inhale). » The negative consequences of continued food or drink, as determined by a medical provider, outweigh the benefits. **Then I request all food and drink be stopped, including nutrition support and hydration.**	yes ○	no ○

FLEXIBILITY FOR SURROGATE

This document will help guide my medical team and surrogate decision-maker(s). I authorize them to be flexible and make decisions based on what they feel is in my best interest. ○	**This document should serve as clear and precise direction to my medical team and surrogate decision-maker(s). My wishes should be followed as much as possible, even if they would personally prefer another option.** ○

ADDITIONAL INFORMATION IMPORTANT TO YOU

For example, do you have additional wishes that were not included? Is there any person you would not want to be consulted about your care? Are you interested in clinical trials (if eligible)? Would you want your representative to advocate for hospice and the possibility of palliative sedation if you are experiencing severe distress or pain?

SIGNATURE

Signature *(Please print this document and sign with a pen.)*

Date Signed

Print Full Name

Date of Birth

WITNESS 1

Signature *(Please print this document and sign with a pen.)*

Date

Print Full Name

Relation

WITNESS 2

Signature *(Please print this document and sign with a pen.)*

Date

Print Full Name

Relation

This sample letter sets forth end-of-life wishes. It can serve as a starting point for a personal statement based on an individual's own planning decisions.

End-of-Life Wishes Letter To Medical Providers

Dear ______________________________ .

It is important to me to have excellent and compassionate care, and to stay as healthy and active as possible over the course of my life. At the end of life, in keeping with my personal values and beliefs, I want treatment to alleviate suffering. Most importantly, I want to ensure that if death becomes imminent, the experience can be peaceful for my family and me.

If there are measures available that may extend my life, I would like to know their chances of success and their impact on the quality of my life. If I choose not to take those measures, I ask for your continued support even if that choice goes against medical advice.

If my condition becomes incurable and death the only predictable outcome, I would prefer not to suffer, but rather to die in a humane and dignified manner. I would like your reassurance that:

- If I am able to speak for myself, my wishes will be honored. If not, the requests from my healthcare representative and my advance directive will be honored.
- You will make a referral to hospice as soon as I am eligible, should I request it.
- You will support me with all options for a gentle death. These include palliative sedation and, if medical aid in dying is authorized in my state, providing a prescription for medications that I can self-administer to help my death be peaceful and dignified.

I am not requesting that you do anything unethical while I am in your care, but I hope for your reassurance that you would support my personal end-of-life care choices as listed above.

I hope you will accept this statement as a fully considered decision and an expression of my deeply held views. If you feel you would not be able to honor my requests, please let me know now while I am able to make choices about my care based on that knowledge.

______________________________ ______________

Signature *(Please print this document and sign with a pen.)* Date

____

Print Name

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The following language can be added to any advance directive. It helps ensure that a patient's instructions will be respected in a situation where institutional policy conflicts with those instructions and that — depending on state law — the provider will assist with the transfer. The signed addendum should be kept with the advance directive.

Sectarian Healthcare Directive

(Advance Directive Addendum)

I understand that circumstances beyond my control may cause me to be admitted to a healthcare institution whose religious or moral policy conflicts with instructions in my advance directive.

My consent to admission shall not constitute implied consent to procedures or courses of treatment mandated by ethical, religious, or other policies of the institution if those procedures or courses of treatment conflict with this advance directive.

Furthermore, I direct that if the healthcare institution in which I am a patient declines to follow my wishes as set out in my advance directive, I am to be transferred promptly to a hospital, nursing home, or other institution that will agree to honor the instructions set forth in this advance directive.

My preferred choices of medical facility to which I'd like to be admitted or transferred are:

1.
2.
3.

I hereby incorporate this provision into my advance directive and into any other previously executed documents to guide healthcare decisions.

Signature *(Please print this document and sign with a pen.)* Date

Witness Signature *(Please print this document and sign with a pen.)* Date

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Having this rider in place helps ensure that an assisted-living facility will respect a resident's wishes for end-of-life care.

Rider to Residential Agreement With Assisted-Living Facility

Resident and Facility agree that Facility will be the Resident's "home," with the dignity and privacy that concept implies. Resident hopes to remain in this home for the duration of their life.

Facility will respect Resident's end-of-life choices and will not delay, interfere with, nor impede any lawful option of treatment or nontreatment freely chosen by Resident or Resident's authorized health-care proxy or similar representative, including any of the following end-of-life options:

- Hospice or palliative care services in the home.
- Forgoing or directing the withdrawal of life-prolonging treatments.
- Aggressive pain and/or symptom management, including palliative sedation.[1]
- Voluntary refusal of food and fluids,[2] with palliative care if needed.
- Any other option not specifically prohibited by the law of the state in which Facility is located.

Resident Signature *(Please print this document and sign with a pen.)* Date

Facility Representative Signature *(Please print this document and sign with a pen.)* Date

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[1] *Khader and Mrayyan, The Use of Palliative Sedation for Terminally Ill Patients: Review of the Literature and an Argumentative Essay, J Palliat Care Med 2015, 5:4*

[2] *Compassion & Choices, Voluntary Stopping Eating and Drinking, CompassionAndChoices.org/our-issues/vsed*

This form enables people not traditionally recognized as family members to gain priority visitation rights. Once completed and signed, it should be kept with the advance directive.

Hospital Visitation Authorization

(Advance Directive Addendum)

I, ______________________________,

residing at ____________________ in ____________________

County, state of ____________________, do hereby give notice and authorization that if I should become ill or incapacitated through any cause that necessitates my hospitalization, treatment, or long-term care in a medical facility, it is my wish that the following person(s),

______________________________,

be given first preference in visiting me in such medical or treatment facility, whether or not they are parties related to me by blood or law, unless or until I freely give contrary instructions to medical personnel on the premises involved.

Executed this __________ day of __________ (month), __________(year)

at (location of signing) ______________________________

by: ______________________________ __________

Signature *(Please print this document and sign with a pen.)* Date

WITNESS SIGNATURES:

Witness 1	**Witness 2**
Signature *(Please print this document and sign with a pen.)*	Signature *(Please print this document and sign with a pen.)*
Address	Address
Date	Date

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This guide is available in English and Spanish online and in print format. To find and share this guide or to get information on the full range of end-of-life options, please visit the online resource Compassion & Choices' *Tools to Finish Strong* at **CandC.org/tools**, or call 800.247.7421 to speak with one of our experienced end-of-life consultants.

Compassion & Choices improves care, expands options and empowers everyone to chart their end-of-life journey.

Leading the Movement for Change

For over three decades, Compassion & Choices has led the end-of-life choice movement. All our work, from political advocacy to professional consultation to legal representation, is provided to the public free of charge. Our efforts are funded entirely through donations from people like you who share our vision for a patient-driven healthcare system that honors an individual's values, beliefs, and preferences.

Please consider making a gift to Compassion & Choices by using the remit envelope in the center of this booklet, or donate online at **CompassionAndChoices.org/donate**. Together we can ensure more comfort, autonomy, and options are within reach for everyone.

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