

# My End-of-Life Decisions

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An Advance Planning Guide  
and Toolkit



compassion  
& choices

Care and Choice at the End of Life



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To find this guide online or to get information on the full range of end-of-life options, please visit the Compassion & Choices Plan Your Care Resource Center at [CompassionAndChoices.org/end-of-life-planning](https://www.compassionandchoices.org/end-of-life-planning), or call 800.247.7421 to speak with one of our experienced end-of-life consultants.

# ADVANCE PLANNING GUIDE

Death finds us all eventually. We can't prevent that. But we can direct how we'd like our final days to unfold. Advance planning is key — making thoughtful choices now, putting them into a written advance directive and discussing those choices with others. Advance planning helps ensure that we get the care we want and avoid what we don't want, even if we're unable to speak for ourselves.

## **About the Advance Planning Guide**

Like many people, you may have put off making decisions about your end-of-life care. Thinking and talking about end-of-life issues can be difficult, and putting documents in place can seem daunting. That's why we have developed this 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 healthcare 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.



# 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 no hope of 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 by 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 doctor can give you a feeling of authority over your healthcare decisions. If it doesn't, you may want to consider looking for a new doctor.



### In the Toolkit:

Compassion & Choices' **Values Worksheet** has more questions to help you think through your priorities. You'll find it in the Planning Toolkit on Page 17.

# Putting Priorities on Paper: Your Advance Directive

An advance directive is the cornerstone of your advance 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.

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 and are available when you are unable to speak for yourself.



## Medicare Beneficiaries, Please Take Note!

Medicare now reimburses doctors for 30-minute sessions of advance care planning with patients. This service includes conversations before an illness progresses and during the course of treatment. If you are a Medicare beneficiary, you can ask your doctor about adding advance care planning to your annual wellness visit or routine office visit. For more information, see Medicare Coverage of Advance Care Planning, available at [Coalitionccc.org](http://Coalitionccc.org).

## COMPLETING YOUR STATE-SPECIFIC ADVANCE DIRECTIVE

Many states have their own forms with specific guidelines that must be used. They can be found online through your state’s website or through Compassion & Choices’ website. To use our site, go to [CompassionAndChoices.org/\\_\\_\\_\\_\\_](http://CompassionAndChoices.org/) (insert the name of your state after the /). Then click on the box labeled Advance Directive.



*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.*

## COMMUNICATING YOUR ADVANCE DIRECTIVE

Your advance directive can be helpful to your physician and others close to you when they must make choices 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, and take the time to communicate your wishes to that person as fully and clearly as possible.

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

## ADDING OTHER DOCUMENTS

Throughout this guide you will find references to other resources that that can be added to or accompany your advance directive. Documents and links are found in the Planning Toolkit included with this guide and on our website at [CompassionAndChoices.org/end-of-life-planning](https://CompassionAndChoices.org/end-of-life-planning). Some specific medical orders may need to be written by a physician. 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. 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 doctor to keep in your medical record. Review your documents regularly.

### HERE ARE SOME TIPS FOR KEEPING YOUR ADVANCE DIRECTIVE CURRENT:

- » Check to make sure your designated representative is still who you would want to speak for you and that their circumstances haven't changed.
- » 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.
- » Consider keeping a copy with you when you travel or know you will be away from home for a long period of time.



*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.*

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# 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 futile 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 enable breathing, medications to stimulate heart function, 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.

### REQUESTING WITHHOLDING OR WITHDRAWAL OF 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 attending physician will agree on a time-limited trial of life-support therapy, hoping for improvement. If the person does not improve within that time frame, the therapy is stopped.

You can direct your own medical care if you are conscious and capable. This changes once you become unable to speak 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.



*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.*

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## SOME TREATMENTS TO CONSIDER

**Artificial ventilation:** Sometimes called mechanical ventilation, this is often used when patients cannot breathe satisfactorily on their own. A tube is inserted through the mouth into the windpipe, and a machine pushes a precise combination of oxygen and air into the lungs at a controlled speed and pressure. The tube can also be inserted through a hole made in the throat, called a tracheotomy. Some people are given artificial ventilation and then slowly weaned off it, but many others are unlikely to recover the ability to breathe on their own. The longer a person uses artificial ventilation, the less likely recovery becomes.

**Medications to stimulate heart function:** Most people who experience heart failure need to take medication to regulate how their heart works or to restart it if it stops. People who are terminally ill may not want treatment to restart their heart if it would only prolong the dying process.

**Artificial nutrition and hydration:** Nutrition and hydration are provided for people who cannot swallow, cannot swallow sufficient amounts or cannot absorb nutrition through the stomach. For someone who cannot swallow, nutrition and hydration can be provided through a nasogastric (NG) tube, which is inserted through the nose, or a percutaneous endoscopic gastrostomy (PEG) tube, which is surgically inserted through the abdominal wall directly into the stomach.

In a growing number of states, the law presumes you would want to be fed and hydrated artificially unless you have a written instruction that specifically rejects this treatment. If you do not want this treatment, you need to record this in your advance directive. If you are terminally ill and choose not to be fed artificially, you can still receive artificial hydration, usually intravenously. Consider including other details about your nutrition decisions in your directive. As an example, keep in mind that spoon-feeding can continue as long you have the ability to chew and swallow, even if you 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.



*Most states' advance directive forms let you indicate your preferences regarding life support in the event of permanent loss of consciousness or terminal illness. You can include additional instructions as well.*

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# 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 physician. Often referred to simply as DNRs, they instruct health-care providers not to attempt to revive you if your heart stops. This option is sometimes selected by people who, for medical reasons, would not benefit from cardiopulmonary resuscitation (CPR). Discuss with your doctor whether such an order is appropriate for you. Some states allow you to include DNR instructions as part of your advance directive. If yours does not, you will need a separate document.

DNR instructions in your advance directive may not apply 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

Out-of-hospital DNRs are written by a physician, usually only for terminally ill, or extremely elderly and frail people who do not want to be revived and only want comfort care. They apply in the event of a medical event anywhere outside of a healthcare facility. If your doctor approves your request for an out-of-hospital DNR, you will be told how to properly display the document, and you may need to wear a bracelet or necklace indicating that you have such an order. Some states require a specific colored-paper copy of your order to be posted on a refrigerator or other conspicuous place in your home.

Out-of-hospital DNRs can be difficult to enforce. Emergency personnel rarely withhold resuscitation, and they are not required to search for out-of-hospital DNR documentation in an emergency. To reject all emergency efforts, you will need to instruct family and neighbors, far ahead of time, not to call 911 if they find you without signs of breathing or heartbeat.

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.

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## 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 are written by a physician. They are a means to translate your advance directive into physician orders to be followed by all medical personnel. Your physician 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.

Currently, only about half of all states have POLST forms available, and the forms have a range of different titles. There is a dedicated website, [Polst.org](http://Polst.org), you can visit to learn more. Or you can speak with your physician about whether or not your state uses a version of POLST.



### In the Toolkit:

You can add **My Particular Wishes** (Page 21) and **Dementia Provision** (Page 23) 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 above. 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.

## ADVANCE DIRECTIVE ADDENDUM: DEMENZA PROVISION

Most advance directives take effect when a person is unable to make healthcare decisions and is either permanently unconscious or terminally ill. Usually advance directives do not include provisions that address when a person is not dying, but has lost decision-making capacity and the ability to self-feed due to severe dementia. You can add a dementia provision to your advance directive to advise physicians and family of your specific wishes about artificial nutrition and hydration, including spoon-feeding. We have provided one in the toolkit. 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 videotaping a statement explaining why you have completed a dementia directive, and making clear that you have made your decision without pressure or coercion.



### Online Dementia Tools:

Compassion & Choices wants to help you and your family prepare and take control of your dementia diagnosis with two interactive online tools:

#### Dementia Decoder

[CompassionAndChoices.org/  
diagnosis-decoder](https://CompassionAndChoices.org/diagnosis-decoder)

#### Dementia Values & Priorities Tool

[CompassionAndChoices.org/  
values-tool](https://CompassionAndChoices.org/values-tool)

# Who Will Speak for Me: Choosing Your Representative

The representative you name in 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 can be anyone you trust who is at least 18 years of age: your next of kin, another family member 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.

Early conversations matter. Talk about your preferences regarding the extreme measures doctors might use to prolong your life. Is your potential representative comfortable with your choices?

## LOOKING BEYOND IMMEDIATE FAMILY

If you're finding it hard to identify an appropriate person 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 nearby friend whom you trust instead of a distant family member.
- » 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.
- » Your local senior services/elder care agency may have a program that provides volunteers for this service. If you are on hospice, discuss this with your hospice provider.
- » Some communities have geriatric case managers who may serve as healthcare representatives for a small fee. Inquire with the Aging Life Care Association for professionals in your area at [Aginglifecare.org](https://aginglifecare.org).
- » Attorneys who specialize in elder law may also be willing to take on this role. Find a list of local attorneys by contacting the National Academy of Elder Law Attorneys at [Naela.org](https://naela.org).

# Putting Plans Into Practice: Ensuring That 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

If your priority is relief of suffering and a peaceful death rather than simply prolonging life, you want to know that your healthcare providers will honor your wishes. Some will support a full range of end-of-life options, including palliative sedation, stopping unwanted medical treatment, voluntarily stopping eating and drinking (VSED) and, where authorized by state law, prescribing medication to end suffering and allow a peaceful death, known as medical aid in dying. Others may not.

Establishing an understanding with your doctors 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.

For example, you can ask about their approach to pain control and symptom management, and about the support they will provide if you choose to stop unwanted treatment, voluntarily stop eating and drinking (VSED) or request medical aid in dying.

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

[CompassionAndChoices.org/your-end-of-life-options](https://CompassionAndChoices.org/your-end-of-life-options). 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.

## OBTAINING REFERRALS, IF NEEDED

If your doctor 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. If your healthcare system has policies in place that will not enable your physician to participate, ask them for a referral to another provider outside the system, or seek one yourself.



### In the Toolkit:

The sample **End-of-Life Wishes Letter to Medical Providers** (Page 25) offers a starting point for your own letter to your doctor.

## 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.

## SPECIAL CONSIDERATIONS FOR NONTRADITIONAL FAMILIES

Law and practice may still create difficulties for loved ones who do not fit the traditional definition of a spouse or close family member. Despite the progress made through marriage equality, many same-sex couples continue to have their preferences ignored by relatives and health providers. Decision-making authority that would be automatic in heterosexual relationships may be actively denied. Life partners may be prevented access to one another at the deathbed. At almost every moment in the continuum of care from diagnosis to death, it is advised that same-sex couples take proactive steps to protect their basic healthcare rights.

A detailed advance directive is an important safeguard. Consider including Compassion & Choices' Hospital Visitation Authorization form as an addendum. It ensures that the people you most want to be with you are admitted on a priority basis, whether or not they are family members.



### In the Toolkit:

The **Sectarian Healthcare Directive** addendum (Page 27) helps you avoid unwanted treatment or request a transfer if a hospital's policies conflict with your wishes.

The **Rider to Residential Agreement With Assisted-Living Facility** (Page 29) adds end-of-life stipulations to the contract.

The **Hospital Visitation Authorization** addendum (Page 31) to your advance directive lists those who should be given first preference in visiting you.

# The Best Safeguard: A Continuing Conversation

Studies indicate that the single most powerful thing a person can do to improve their chance for a good death is — simply and directly — to talk about it.

## WHOM TO TALK TO

First and foremost, talk to those who have the greatest impact on your care options — your personal physician, your designated healthcare representative, 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, 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

You may discover that some of those you talk with do not agree with or support your wishes. As noted earlier, you have the right to change physicians or to name a different healthcare representative who supports your desires. 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. Keep in mind that if physicians hear of disagreement among loved ones, they could be justified in continuing unwanted treatment to avoid a possible lawsuit or licensing complaint.

## 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 doctor 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 ... "





# ADVANCE PLANNING TOOLKIT

Whatever your age or current health, it's important to take time NOW to prepare a written record of your end-of-life wishes and share your thoughts. These steps will help ensure that if you cannot speak for yourself your preferences will be honored.

The advance planning tools 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 **Planning 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. We provide links to get you to the right websites quickly.

**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.

# Planning Checklist

Find these and many other end-of-life resources in our online Plan Your Care Resource Center at [CompassionAndChoices.org/end-of-life-planning](https://CompassionAndChoices.org/end-of-life-planning)

- Complete the **Values Worksheet**.
- Complete your state-specific **advance directive — your living will and durable medical power of attorney**. You can locate your state's forms on our website at [CompassionAndChoices.org/](https://CompassionAndChoices.org/) \_\_\_\_\_ (insert the name of your state after the /).
- Complete the **My Particular Wishes** addendum. You can add it to your advance directive to state your wishes regarding specific life-sustaining therapies.
- Review the **Dementia Provision** addendum. You can add it to your advance directive to indicate whether you want to receive/ not receive spoon-feeding if in a state of advanced dementia.
- Visit our dementia online tools to help you and your family prepare and take control of your dementia diagnosis.  
  
Dementia Decoder:  
[CompassionAndChoices.org/diagnosis-decoder](https://CompassionAndChoices.org/diagnosis-decoder)  
  
Dementia Values & Priorities Tool:  
[CompassionAndChoices.org/values-tool](https://CompassionAndChoices.org/values-tool)
- Learn about **Physician Orders for Life-Sustaining Treatment (POLST)** and how they are used in your state. Start with our online DNR/POLST resource. Visit the national POLST website to see your state's form and learn more at [Polst.org/programs-in-your-state](https://Polst.org/programs-in-your-state).
- Plan to talk with your healthcare providers. You can use the **End-of-Life Wishes Letter to Medical Providers** as an outline for conversation with your doctor.
- Review the **Sectarian Healthcare Directive** addendum as a possible addition to your advance directive.
- Review the **Rider to Residential Agreement With Assisted-Living Facility** as a possible addition to an agreement with your residence.
- Complete the **Hospital Visitation Authorization** addendum. This is especially important for visitors who are not traditionally recognized family members.



## Remember:

If you are adding documents to an existing advance directive, it is important to re-sign and update the advance directive with the new documents included.

# 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?

	VERY IMPORTANT				NOT IMPORTANT
Letting nature take its course	4	3	2	1	0
Preserving quality of life	4	3	2	1	0
Staying true to my spiritual beliefs/traditions	4	3	2	1	0
Living as long as possible, regardless of quality of life	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 teaching	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.)?

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*(please turn over)*

**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

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

- » Mechanical breathing (respirator)
- » Cardiopulmonary resuscitation (CPR)
- » Artificial nutrition and hydration
- » Hospital intensive care
- » Pain-relief medication
- » Antibiotics
- » Chemo- or radiation therapy
- » Surgery

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

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

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**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?**

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

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

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*(please turn over)*



**Written directives are an essential part of any end-of-life plan.** The links here will help in locating advance directive documents and other forms that may vary from state to state.

## ADVANCE DIRECTIVE

Once you're comfortable stating your values and priorities, you're ready to complete your advance directive. It clarifies your end-of-life preferences if you become unable to make or communicate medical treatment decisions yourself. Typically the advance directive includes a living will ("what I want") and a medical durable power of attorney ("who will speak for me"). It may also include other documents.

You can locate your state's forms in two places on our website. Scroll down to the state-by-state callout menu at [CompassionAndChoices.org/advance-directive](https://CompassionAndChoices.org/advance-directive) or visit [CompassionAndChoices.org/](https://CompassionAndChoices.org/)\_\_\_\_\_ (insert the name of your state after the /) and click on the advance directive box.

## PHYSICIAN ORDERS FOR LIFE SUSTAINING TREATMENT (POLST)

POLSTs are specific treatment orders that can be written by a physician. To learn more about them, start with our online DNR/POLST resource. ([CompassionAndChoices.org/end-of-life-planning](https://CompassionAndChoices.org/end-of-life-planning)) You can also visit the national POLST website to learn more and see your state's form ([Polst.org/programs-in-your-state](https://Polst.org/programs-in-your-state)). If you feel you need a POLST, you must complete the form with your physician.



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.

### 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, family, those close to me, spiritual advisors and others as I choose.

But the final decision is mine. If I am unable to make decisions only because I am being kept sedated, I would like the sedation lifted so I can rationally consider my situation and decide whether to accept or refuse a particular therapy.

### 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.

*(please turn over)*

## 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
<b>1. Antibiotics if I develop a life-threatening infection of any kind.</b>			
<b>2. Dialysis if my kidneys cease to function, either temporarily or permanently.</b>			
<b>3. Artificial ventilation if I stop breathing.</b>			
<b>4. Electroshock if my heart stops beating.</b>			
<b>5. Heart-regulating drugs including electrolyte replacement if my heartbeat becomes irregular.</b>			
<b>6. Cortisone or other steroid therapy if tissue swelling threatens vital centers in my brain.</b>			
<b>7. Stimulants, diuretics or any other treatment for heart failure if the strength and function of my heart is impaired.</b>			
<b>8. Blood, plasma or replacement fluids if I bleed or lose fluid circulating in my body.</b>			
<b>9. Artificial nutrition.</b>			
<b>10. Artificial hydration.</b>			

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

---

Signature

Date

---

Witness Signature

Date





**The following language can be added to any advance directive.** It advises medical providers, healthcare proxies, caregivers, and loved ones of the wishes of a patient with Alzheimer's Disease or some other form of advanced dementia. Once completed and signed, the addendum should be kept with the advance directive.

## Dementia Provision (Advance Directive Addendum)

I, \_\_\_\_\_, am creating this document because I want my healthcare representatives/agents/proxies, medical providers, family members, caregivers, long-term care providers, and other loved ones to know and honor my wishes regarding the type of care I want to receive if I develop an advanced stage of Alzheimer's Disease or other incurable progressive dementia.<sup>1</sup>

Under the conditions of advanced dementia, including my inability to communicate rationally with loved ones or caregivers, and/or my physical dependence on others for all aspects of bodily care, continuing life would have no value for me. In those conditions, and if my condition is unlikely to improve, I would want to die peacefully and as quickly as legally possible to avoid a drawn-out, prolonged dying that would cause unnecessary suffering.

**For this reason, if I have advanced dementia, and I am unable to feed myself due to advanced dementia, I want the following to apply (initial each option that represents your wishes):**

\_\_\_\_\_ To receive comfort care only, focused on relieving any suffering such as pain, shortness of breath, anxiety or agitation. I would not want any care or treatments that would be likely to extend my life or prolong the dying process. This includes life-sustaining measures like cardiac pacing, cardiopulmonary resuscitation and mechanical ventilation.

\_\_\_\_\_ In the event of an acute infection, I do not wish to be treated with antibiotics and/or antimicrobials in any form but with aggressive pain and symptom relief only, while the illness takes its natural course.

\_\_\_\_\_ If I lose the ability to speak for myself and my advance directive is being taken into consideration as written, I also would like it to be clear that if I am currently receiving any medications or treatments that are likely to extend my life or prolong my dying process, I would like those stopped.

\_\_\_\_\_ I request that food and fluids in any form, including spoon-feeding, be stopped if, because of dementia, any of the following conditions occur:

- » I appear indifferent to food and being fed.
- » I no longer appear to desire to eat or drink.
- » I do not voluntarily open my mouth to accept food without prompting.

*(please turn over)*

- » I turn my head away or try to avoid being fed or given fluids and am clearly repelled by food or fluids.
- » I spit out food or fluids.
- » I cough, gag, choke on, or aspirate (inhale) food or fluids.
- » The negative consequences or symptoms of continued feeding and drinking, as determined by a qualified medical provider, outweigh the benefits.

\_\_\_\_\_ If the above statement regarding food and fluids goes into effect for any of the above listed reasons, and as a result I begin to experience delirium, agitation or hallucinations, then I would like my medical team to provide palliative sedation in order to avoid suffering until death occurs.

I want the instructions in this provision followed even if the person who has the right to make decisions for me and/or my caregivers judge that my quality of life, in their opinion, is satisfactory and I appear to them to be comfortable. No matter what my condition appears to be, I do not want to be cajoled, harassed, or forced to eat or drink. I do not want the reflexive opening of my mouth to be interpreted as giving my consent to being fed or given fluids or misinterpreted as a desire for food or fluids. I have given considerable thought to this decision and want my wishes followed.

Before I am admitted to a long-term care facility, I want that facility to affirm its willingness to honor these instructions. If the long-term care facility where I already reside will not honor these instructions, I want to be transferred to one that will.

Printed Name \_\_\_\_\_ Date of Birth \_\_\_\_\_

Signature \_\_\_\_\_ Date \_\_\_\_\_

*We, whose names are provided below, declare that the person who signed this document is personally known to us, appears to be of sound mind and acting of their own free will, and signed this document (or asked another to sign this document) in our presence.*

**WITNESS 1** Signature \_\_\_\_\_ Date \_\_\_\_\_

Printed Name \_\_\_\_\_ Phone \_\_\_\_\_

Address \_\_\_\_\_

**WITNESS 2** Signature \_\_\_\_\_ Date \_\_\_\_\_

Printed Name \_\_\_\_\_ Phone \_\_\_\_\_

Address \_\_\_\_\_

<sup>1</sup> Defined as Stage 6 or 7, moderately severe to severe dementia, of the Global Deterioration Scale for Assessment of Primary Degenerative Dementia (GDS) and/or the Functional Assessment Staging Tool (FAST) which include severe cognitive decline and the need for extensive assistance for most activities of daily living.



**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 Dr. \_\_\_\_\_ :

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.

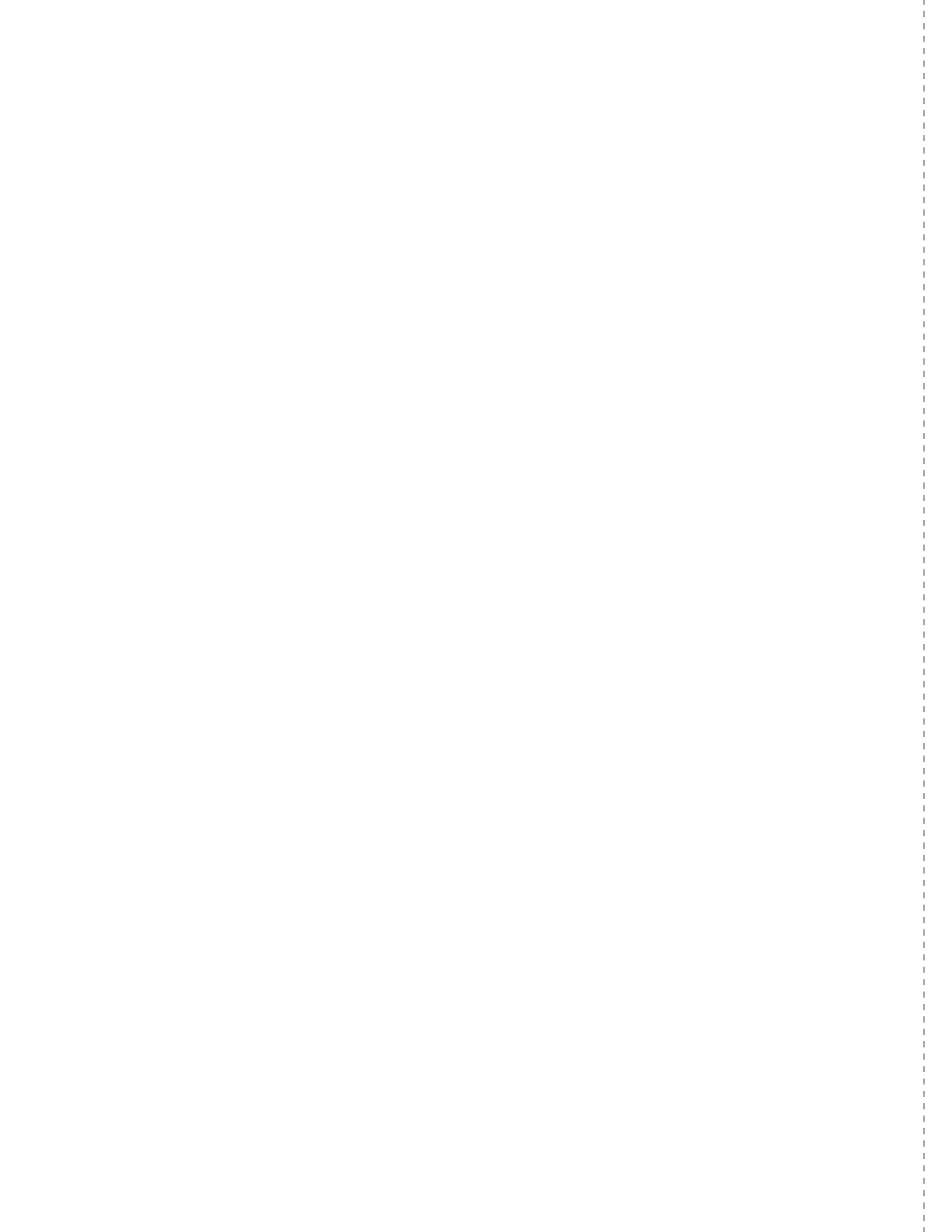
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Signature

Date

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Print Name





**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.

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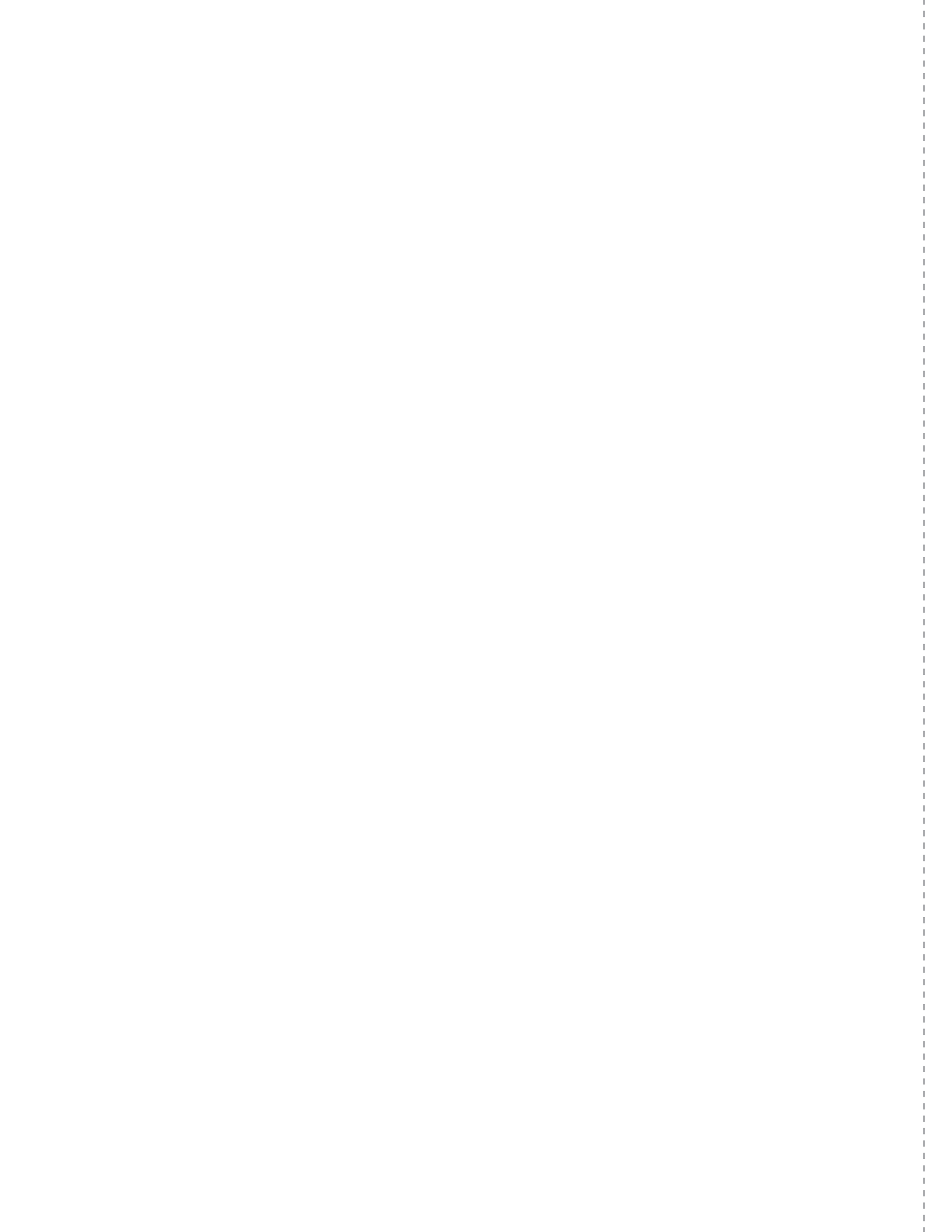
Signature

Date

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Witness Signature

Date





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 healthcare 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<sup>1</sup>;
- » Voluntary refusal of food and fluids<sup>2</sup>, with palliative care if needed;
- » Any other option not specifically prohibited by the law of the state in which Facility is located.

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Resident Signature

Date

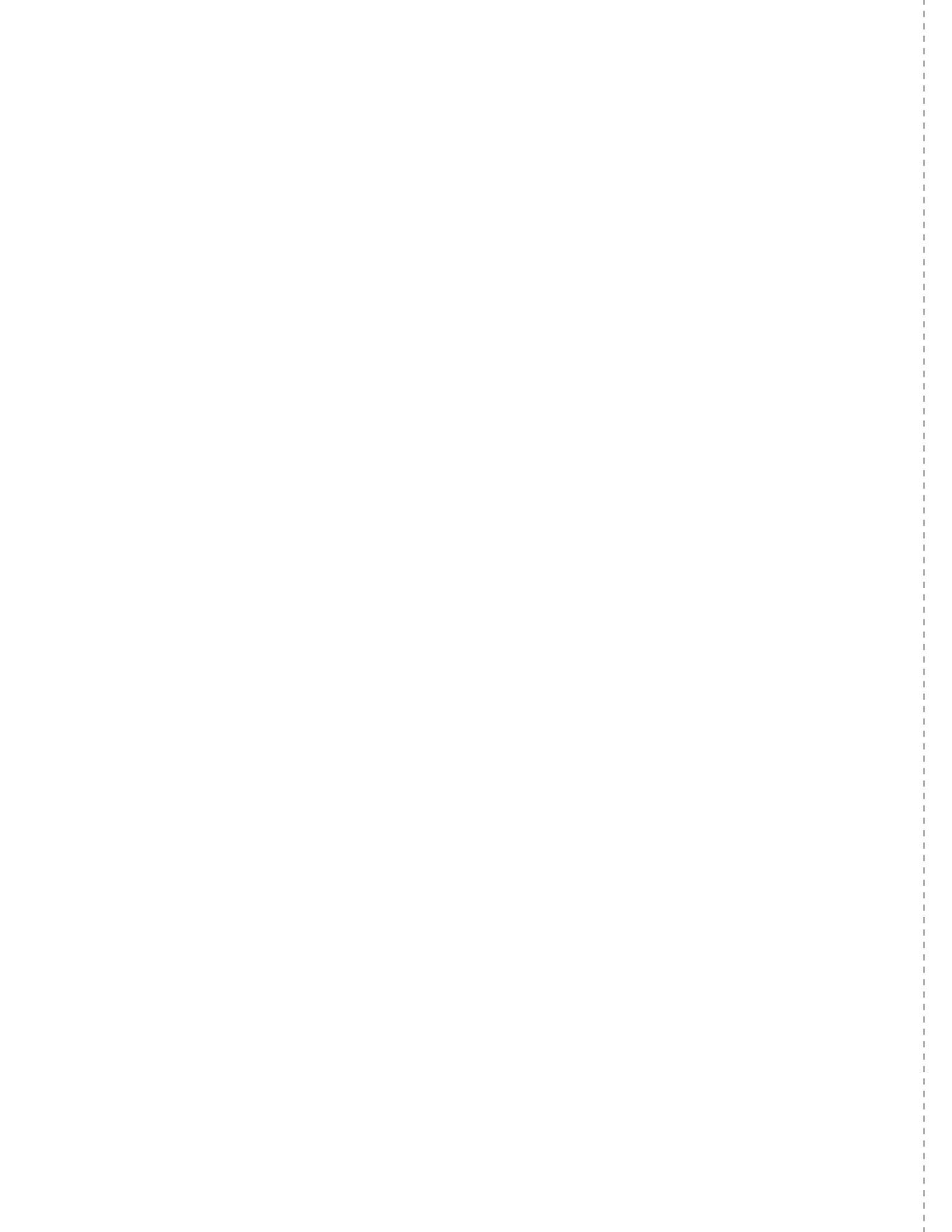
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Facility Representative Signature

Date

<sup>1</sup> 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

<sup>2</sup> *Compassion & Choices, Voluntary Stopping Eating and Drinking*, [CompassionAndChoices.org/wp-content/uploads/2016/10/VSED-FINAL-2.17.17.pdf](https://www.compassionandchoices.org/wp-content/uploads/2016/10/VSED-FINAL-2.17.17.pdf)







**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

Date

## WITNESS SIGNATURES:

### WITNESS 1

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Address

\_\_\_\_\_  
Date

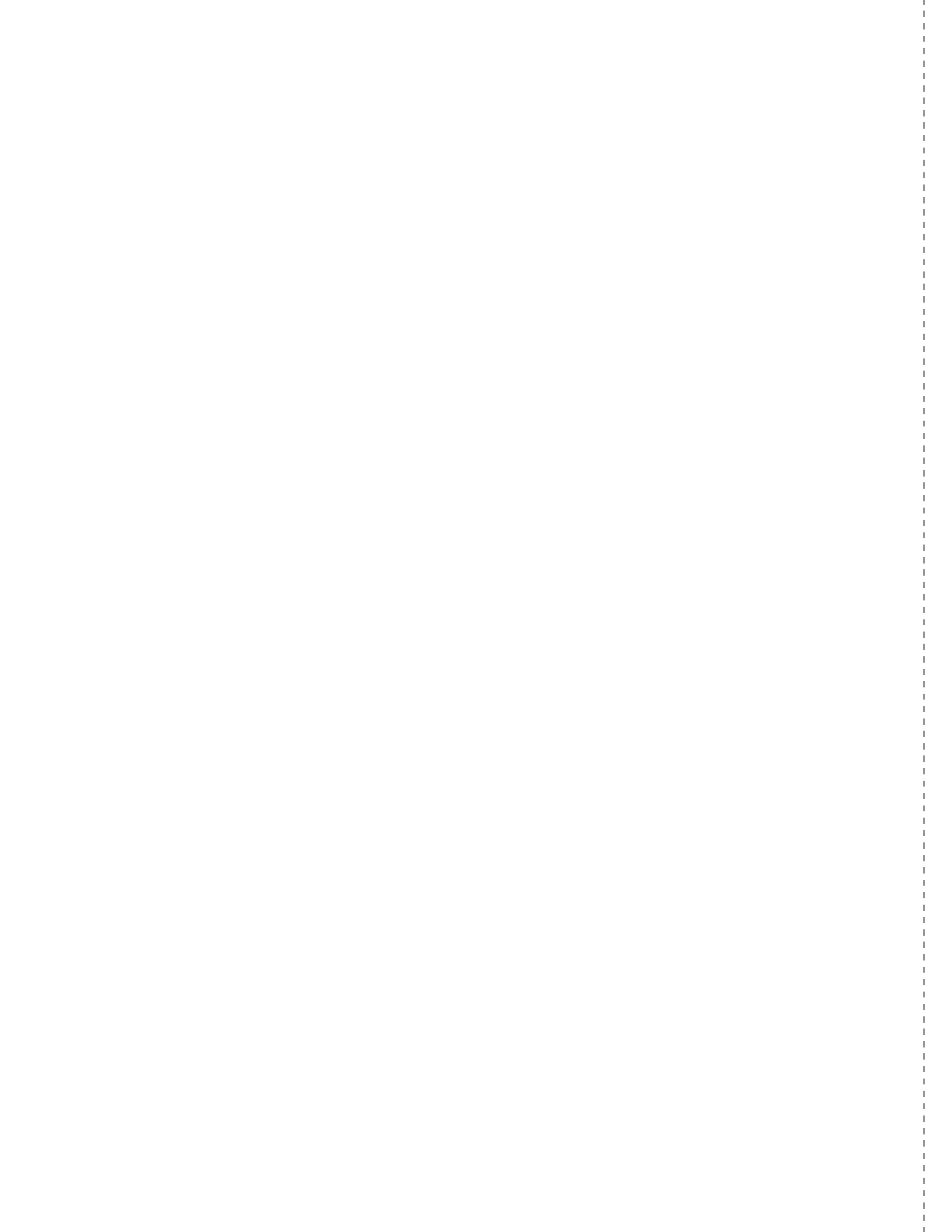
### WITNESS 2

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Address

\_\_\_\_\_  
Date

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





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

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## **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 the booklet or donate online at [CompassionAndChoices.org/donate](https://CompassionAndChoices.org/donate). Together we can ensure more comfort, autonomy and options are within reach of everyone.



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& choices

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