

# MEDICAL AID IN DYING

A Guide for Patients and Their Supporters



**Lonny Shavelson, MD**

American Clinicians Academy on Medical Aid in Dying

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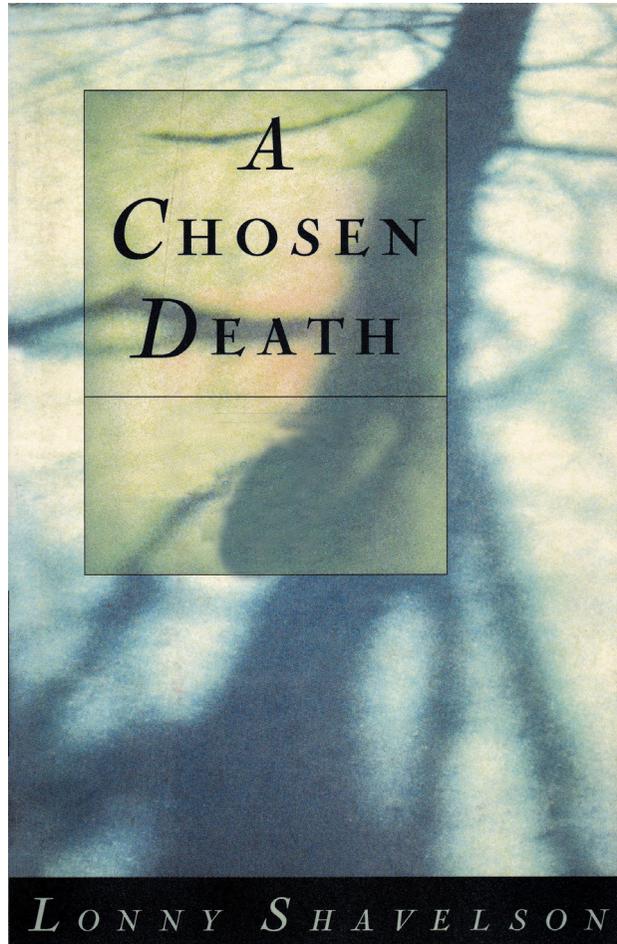


American Clinicians Academy  
on Medical Aid in Dying

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## CONTENTS

About the Author .....	1
About Aid in Dying .....	3
The Language of Aid in Dying .....	7
Is Aid in Dying Right for You? .....	9
The Many Paths to a Dignified Death .....	13
Family, Cultural, and Spiritual Concerns .....	25
The Path to Aid in Dying .....	33
Preparing for Aid in Dying .....	39
You're Ready. What's Next? .....	47
The Three Days Before Your Aid-in-Dying Day .....	57
The Day Before Your Death .....	61
Your Death Day .....	63
After an Aid-in-Dying Death .....	75
Grieving .....	77



## ABOUT THE AUTHOR

Dr. Lonny Shavelson has been deeply interested in issues of end-of-life care for more than thirty years. He wrote the 1994 book *A Chosen Death* and was one of five authors of the 1997 proposed *Guidelines for Physician-Hastened Death* by the Bay Area Network of Ethics Committees.

In 2016, when California's End of Life Option Act (<https://tinyurl.com/CAEOLOA>) legalized medical aid in dying, Dr. Shavelson founded Bay Area End of Life Options, a practice uniquely dedicated to terminally ill patients considering medical aid in dying. In August of 2020, Dr. Shavelson closed his medical practice to new patients and became chair of the newly founded American Clinicians Academy on Medical Aid in Dying ([www.ACAMAID.org](http://www.ACAMAID.org)). His work with the Academy focuses on innovating and advancing clinical knowledge and best practices, teaching, and consulting.

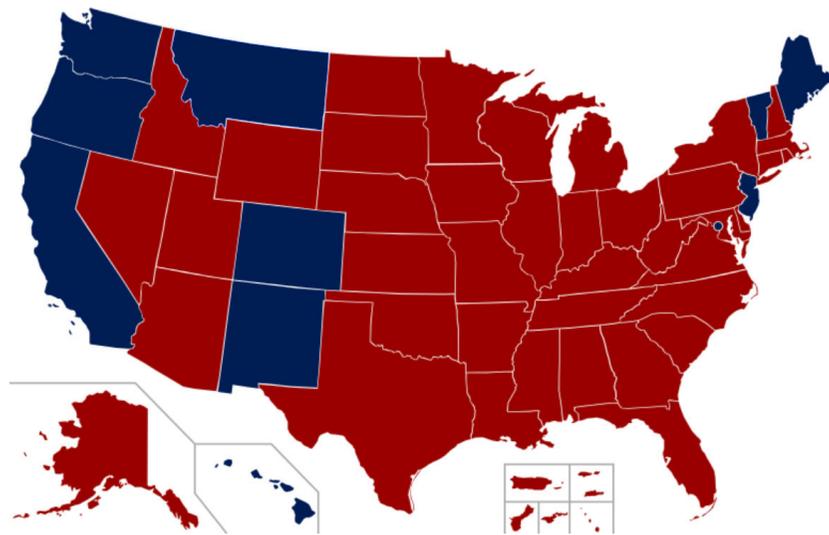
# ABOUT AID IN DYING



This booklet, *Medical Aid in Dying: A Guide for Patients and Their Supporters*, originated from the questions, interests, and needs of dying patients, their families, their loved ones, and the many others who support them. Its goal is to demystify and facilitate the process of medical aid in dying.

The discussions and recommendations in this booklet are the result of my deeply personal experiences evaluating more than a thousand patients who considered taking medications to die, usually at the end of a long terminal illness. Later, in my role as chair of the American Clinicians Academy on Medical Aid in Dying, I talked with hundreds of clinicians about their own experiences in this new field of medicine.

Medical aid in dying hasn't been legal for long in this country. It was born in Oregon in 1997, which implemented the first U.S. law that permitted doctors to provide terminally ill patients with medications they might use to end their lives at the time of their choosing. This right has since expanded to ten states plus Washington DC, covering 22 percent of the U.S. population.



While the laws in most states are similar, please work with your end-of-life clinicians to better understand the potentially unique requirements in your state (<https://tinyurl.com/DWDSStateGuide>).

But just qualifying legally does not provide patients with compassionate and supportive care and information. We at the American Clinicians Academy on Medical Aid in Dying innovate, teach, and advance the best ways to care for patients considering and potentially completing assisted dying.

In this booklet, I'll share what we've learned, so that terminally ill patients can thoroughly understand all of their options. I encourage you to read this booklet in the sequence in which it's written. But also feel free to poke around, jump back and forth, or read only certain sections.

The right for a terminally ill patient to decide how and when to die is both wonderful and complex, filled with awe and anguish. If you are imminently dying, deciding on how you will die is among the most important decisions you'll ever make.



## THE LANGUAGE OF AID IN DYING

- ◆ Straightforward, non-judgmental language helps shape calm, meaningful discussions.
- ◆ *Considering the option* is a helpful expression when talking about your thoughts.
- ◆ *Medical aid in dying* is the most appropriate term today.
- ◆ Medical aid in dying is not suicide.

If you or someone you care about are reading this booklet, it is likely you are terminally ill and considering the option of taking medications to die. I use that expression—*considering the option*—very intentionally, since there are many paths to contemplate as you make plans for your impending death. The first step in your understanding of aid in dying is to consider all of your choices before deciding which route is best for you.

“Medical aid in dying” is now the most common expression for the right of terminally ill patients with less than six months to live to choose the time, place, and manner of their death. But you may have heard other

expressions: death with dignity; right to die; aid in dying; end-of-life option; assisted death.

Some people still use the term *assisted suicide*, but that is both inappropriate and incorrect. Every state's aid-in-dying law explicitly rejects the word *suicide*, and the expression cannot be used in legal documents referring to the process. Later in this booklet, I'll explain why in more detail.



## IS AID IN DYING RIGHT FOR YOU?

- ◆ There is no typical way in which people die.
- ◆ Patients want to know how they are likely to die.
- ◆ Having a “How you die” conversation is essential to making crucial decisions.
- ◆ Encourage your health providers to avoid vague answers.

Many patients have told me they've thought about aid in dying for years. They're certain that when they become terminally ill and their quality of life is severely diminished, they'll take lethal medications to shorten the time and amount of suffering. I always reply, “Well, that was when you were guessing how your death would happen. Now that you're dying and you know the details, let's take another look.”

In this section, let's consider the reasons you might take medications to die, and the reasons you might not.

## The How-You-Die Conversation

There is no typical way in which people die, so it's important you know your own probable path. The manner in which you are likely to die depends on your particular disease, your present condition, and everything from the treatments you've had to the people helping you through your final days. I strongly encourage you to have a "How you die" conversation with your end-of-life clinician. This can be your doctor, nurse, social worker, chaplain, or anyone experienced in clinical end-of-life care.

Clinicians sometimes hesitate to initiate these essential how-you-die discussions because they fear they'll eliminate the hope that you'll live longer (even though they know, and you know, you're dying). So it may fall to you, the patient, to bring up the topic. That way, you'll enter the dying process knowing your own probable path—and your decisions will be well-informed.

For example, an elderly patient of mine with leukemia asked for medical aid in dying because she feared intractable pain. But significant pain is not a characteristic of leukemia's final stages. Far more common is anemia, weakness, and ultimately a slow fading out of existence. When I told her this, the patient chose gentle comfort measures, and she had the pain-free death she desired. (For those with other illnesses, such as severe cancer that has spread to the bones, pain may be more prominent, although often very treatable.)

From my conversations with dying patients and end-of-life clinicians, I've learned that people *want* to know how they are likely to die—even though they might enter harsh and emotionally troubling terrain during a how-you-die conversation. End-of-life symptoms and experiences vary greatly. Your doctor might tell you about everything from blocked bowels to delirium, bone pain to vomiting. Or, your doctor might explain that you're likely to experience a gradual, gentle fading away from life, with no severe symptoms at all. Having a sense of these possibilities in advance is essential for you to minimize surprises, make specific requests for end-of-life symptom management, and decide among the various possible paths available to you.

Please encourage your health providers to avoid vague answers like, "Your death will come in the way it comes, when it comes. We can't predict the future." Actually, most end-of-life clinicians have a pretty good idea of how your death is likely to occur. They even have a reasonable sense of *when* (especially as death gets closer). Of course, they cannot predict the precise nature and timing of every event leading to your death, nor the *exact* moment of your death. But that doesn't mean that you and they should avoid a detailed conversation about likely scenarios.

# THE MANY PATHS TO A DIGNIFIED DEATH



- ◆ Aid in dying is far from the only route to a dignified death.
- ◆ You define your own dignity.

While many clinicians and patients refer to medical aid in dying as “death with dignity,” that’s a misuse of the word dignity. Dignity is the path that you feel is dignified, for your death, according to your particular beliefs and your individual needs—whether in a hospital ICU fighting for a last few moments of life, receiving comfort care with hospice in your home, or by taking medications to die as death approaches. Your death with dignity is what you say it is.

And while you may have “believed in” medical aid in dying for many years, even advocated for the law in your state, I urge you to take a fresh look at your own death now that it’s approaching. Please remember that your impending death should not be a political statement in favor of aid in dying, but rather the best death for you under your present circumstances.

## Palliative Care

- ◆ Palliative care relieves symptoms and suffering even as a disease gets worse.
- ◆ Palliative care clinicians never use the phrase “Nothing more can be done,” because there is always more that can be done to improve your symptoms.

Chances are you’ve been through many treatments aimed at prolonging your life—sometimes with significant positive results, at times with substantial sacrifices of comfort and quality of life. Many of you will have succeeded, bravely, at gaining extra weeks, months, years, or even decades by these often difficult but life-prolonging efforts.

But at some point, for everyone with a life-threatening illness, treatments become less and less effective, they begin to yield more burden than benefit, and death inevitably approaches. At that time, palliative care, aimed at comfort instead of cure, becomes essential.

A clarification: Palliative care is not just for people who are dying. It can be extremely helpful for those with any serious illness, at any stage. But in this booklet, when I talk about palliative care I’m speaking about how it applies to people who are dying.

End-of-life palliative care refers to treatments that relieve the difficult but common symptoms people

experience as death nears, without focusing on treating the underlying disease or extending life. Palliative care can treat everything from pain to shortness of breath, nausea to constipation, anxiety to depression—even the ubiquitous fatigue that can be overwhelming as death approaches. The overriding goal of palliative care is to improve the quality of your life without necessarily extending it. Palliative care can also improve the quality of your death.

To oversimplify a bit: Palliative care clinicians never use the phrase “Nothing more can be done.” That expression may have applied when your life-prolonging treatments stopped working, but there is always more that can be done to treat your symptoms. In essence: Even as your disease gets worse, palliative care can make you feel better.

### “Where and how do I get palliative care?”

- ◆ Most clinicians have some training and skills in palliative care.
- ◆ When symptoms and suffering increase, specialized palliative care clinicians are needed.
- ◆ Home hospices are the primary providers of end-of-life palliative care.

Palliative care treatments can be provided by any doctor or nurse who is trained in the details of symptom management. This might be your family doctor, oncologist, nurse practitioner or hospice nurse, or any clinician with the skills and willingness to provide such care.

But if and when your symptoms become more complex and difficult to manage, you will likely need the help of palliative care specialists—doctors who often work in teams with nurses, physical therapists, social workers, chaplains, and many others with palliative care skills. They’ve all had extensive training in improving symptoms even as the underlying disease may be getting worse.

You can request a “palliative care consultation” during any hospitalization, or get a referral to an outpatient palliative care team. And if you are already in or about to enroll in home hospice care, hospice doctors and their clinical colleagues are specifically trained in palliative care.

Even if you are determinedly moving toward medical aid in dying, I urge you to strongly consider palliative care during the period before you take the medications to die. There is no reason for you to suffer without expertly managed symptom relief while waiting for your chosen final day.

## Hospice Care

- ◆ Hospice is not a place you go; it’s a service that comes to you, at home.
- ◆ You get to decide how much hospice care you want, how frequently, and when.
- ◆ Hospice teams are the primary source of skilled end-of-life symptom management.
- ◆ When you have a prognosis of less than six months to live, you pay nothing to be in hospice.
- ◆ When you are dying, the sooner you begin hospice care the more it will help you.

In the U.S., hospice is most commonly not a location or facility you go to as you approach death, but rather a type of care that comes to you in your home (or assisted-living or long-term care facility). In fact, less than 2 percent of all hospice care takes place in a specialized in-patient or residential hospice. You don’t go to hospice; hospice comes to you.

Another myth: Home hospice care means that a nurse or attendant moves into your home to take care of you. In fact, hospice staff are almost never in your home for twenty-four hours at a time, and they don’t provide daily bedside care. The hospice team works with you and your support group, educating and helping everyone involved with your day-to-day needs. If you’re



in an assisted-living or nursing facility, their staff plays an essential role in your end-of-life care. Hospice supports and aids their work, but does not replace them.

You can obtain hospice care by contacting a local hospice yourself (<https://tinyurl.com/FindHospice>), or your doctor can make a referral for you. Hospice teams are usually doctors, nurses, home-health aides, social workers, and chaplains. Your own caregivers might include family and other loved ones, friends, paid attendants, volunteers, end-of-life doulas, and others you consider important to your needs who are welcome in your home. Hospices provide medications, equipment (wheelchairs, hospital beds), education, and emotional and spiritual support. Most importantly, hospice teams are your primary source of skilled palliative care.

A common hesitation I hear when I recommend home hospice care to a patient is, "I'm not comfortable having someone other than my family in my home." Well, you set the goals of care, and you set the visit schedule. For safety, though, there is a minimum: A hospice nurse is required to visit at least once every two weeks, to check on the progress of your condition, review your medications, and, if appropriate, consult with your family and caregivers to help them help you. Sometimes the hospice staff will recommend more frequent visits, but that's up to you and not a requirement.

If you live alone and have no available family or other help, hospice teams are not able to provide all

of your daily end-of-life care. The hospice nurse and social worker can help arrange for some assistance, but when you're no longer able to care for yourself they will recommend a skilled nursing facility. That can provide for your safety and comfort as you approach death.

Another myth: "Hospice must be expensive. I'm not sure I can afford it." Hospice is completely covered by Medicare and/or your private insurance. And you don't have to be over sixty-five to get the hospice Medicare benefits—you qualify if you're terminally ill with a less-than-six-months prognosis to live. No age limits apply.

A final myth: "Hospice care is only important for the last few days of my life." Nothing could be further from the truth. Since hospice teams are the best source of palliative care to manage your symptoms and improve the quality of your life, the sooner you begin—even many months before you will die—the better your final months and days will be.

But those are the myths that *aren't* true about hospice. What, exactly, does home hospice provide?

Hospices offer skilled relief of the symptoms of dying. They establish pain control, using everything from medications to massage, better beds to bedside commodes. Hospice care also helps you diminish the angst and anguish of your approaching death. Hospice social workers are skilled at counseling people who are dying, and hospice chaplains address your spiritual concerns. As your palliative care experts, your hospice

clinicians will help you with everything from headaches to nausea, constipation to coughs. Countless symptoms can make dying very uncomfortable, but that doesn't have to be the case.

Hospices also support your caregivers, who suffer in their own ways as you are dying. Then, once you have died, hospices provide grief support for those who will be mourning your loss.

In short, you've probably already been cared for by many medical specialists—oncologists, neurologists, nephrologists, you name it. During your illness, you deserved the best of life-prolonging treatments. Now, you deserve the best clinicians to improve your death. Hospices provide the specialists who care for people who are dying.

"You matter to the last moment of your life,  
and we will do all we can,  
not only to help you die peacefully,  
but to live until you die."

—Dr. Cicely Saunders, founder of the first  
modern hospice, St. Christopher's, 1967

## “What does home hospice have to do with me? If I take medications to die, I won’t need hospice.”

- ◆ Hospices are the best source of end-of-life palliative care, especially for patients considering aid in dying.
- ◆ Without hospices assuring quality care, aid in dying would be unethical.

Patients who are contemplating medical aid in dying need hospice care as much as, if not more than, patients who aren’t considering aid in dying.

Remember, you don’t first think of aid in dying on a Sunday and take medications to die that Monday. Almost always, there’s a months-long journey to that final day, during which you’ll discover how your particular death is progressing, including your desires, your timing, your needs and decisions, and how you want to live until the day you will die. So whether your last day will be when your body finally shuts down on its own, or you take medications and shut it down at your own chosen date—hospice clinicians are your best guides.

We at the Academy strongly believe that no patient should take medications to die because they’re receiving inadequate symptom management at the end of their life. Hospice care is a way of assuring that patients aren’t forced to consider aid in dying because of inadequate end-of-life-treatment.

## “But don’t hospices frown on aid in dying?”

- ◆ Hospices have varying policies on their depth of involvement with aid in dying.
- ◆ Most hospices provide non-judgmental conversations about aid in dying.
- ◆ Many hospices provide full aid-in-dying support along with their palliative care.

In part, it’s correct to say that some hospices frown on aid in dying. Certain organizations, especially those with strong religious affiliations, have opted not to actively participate in any way. And a few, sadly, chastise their patients for considering a hastened death.

But most hospices in aid-in-dying states, including those with religious affiliations, now actively support open and non-judgmental discussions with patients considering aid in dying. And they continue to provide devoted hospice care to those patients.

Reports from the various aid-in-dying states show that between 85 and 90 percent of patients who take medications to die are simultaneously accessing home hospice. So there is no uniform conflict between hospices and aid in dying. The goal of the American Clinicians Academy on Medical Aid in Dying is for 100 percent of patients considering aid in dying to also be receiving hospice care.

# FAMILY, CULTURAL, AND SPIRITUAL CONCERNS



“What if I’m sure about taking medications to die, but my loved ones don’t want me to?”

- ◆ Families have vast experience working through challenging disagreements.
- ◆ Mostly, families resolve aid-in-dying disagreements by compromise and understanding.
- ◆ It’s best to avoid distancing statements like, “It’s my decision alone.”
- ◆ When disagreements become abusive, hospices provide help.

If you’re having a disagreement about aid in dying with those you love, one thing is certain: this is not the first time your family has disagreed about a critical issue. So if there’s conflict now about aid in dying, you most likely have the skills to work through the dilemmas and come to a conclusion or compromise. The same wisdom that

carried you through prior conflicts is likely to help you through disagreements about aid in dying.

Summary statements like, “It’s my decision alone,” are oversimplified. You may decide to take into account the wishes and needs of those you love, even if their needs are different than your wishes. And if you consider their opinions and choose to go ahead with aid in dying anyway, loved ones mostly tend to adjust. “Dad has always done what he wants; why should this be different? We don’t agree, but we’ll support his decision.” Or, you may reconsider aid in dying and follow your loved ones’ wishes. There is no uniform answer about how to deal with conflicting thoughts and desires about a hastened death.

But here’s a surprise: Although “What do we do about family conflicts?” is one of the most frequent questions I’m asked, I’m impressed by how rare it is that such conflicts remain unresolved. Mostly, families and loved ones work out an agreement by using the already ingrained family wisdom that has brought them through many years and issues together—maybe not with perfect unity or harmony, but certainly with accepted compromises.

The wisest social workers, therapists, nurses, doctors, and chaplains know that it’s best to step aside and let loved ones work through these issues. These practitioners commonly offer help only when it is requested or clearly needed. At times, direct recommendations may be appropriate. But that is the exception, not the rule.

Remember that should you or your loved ones want

help to resolve conflicts, hospices and other clinical organizations are experienced in and ready to provide such help.

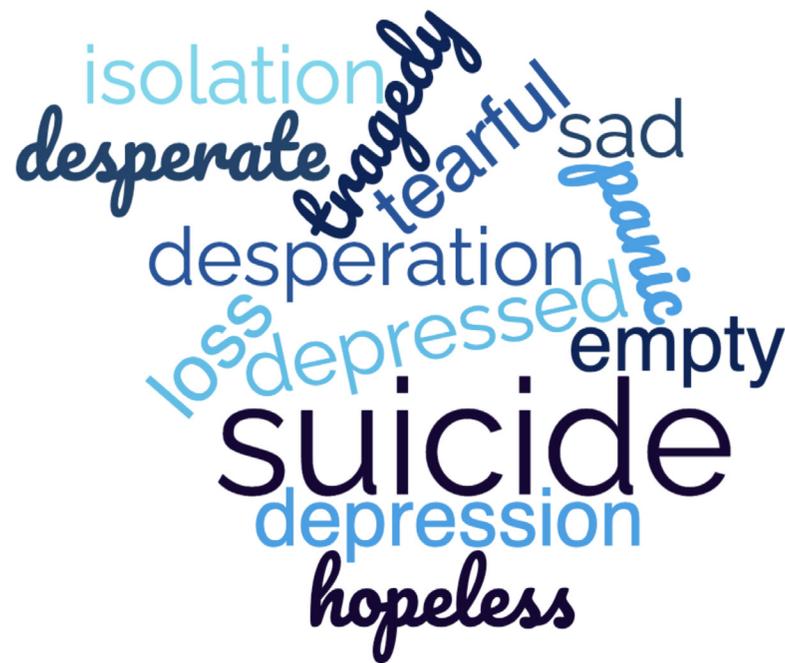
Of course, some families have intense disagreements, even bordering on violence. If your clinicians see signs of abuse or coercion, they are required to step in or report that. This is especially true if the patient is being coerced into taking medications to die, but also if someone is using physical or emotional manipulation to stop a patient from taking medications to die. In that sense, aid-in-dying conflicts resemble many family struggles, and clinicians evaluate each individual circumstance.

### **“But isn’t this suicide? And isn’t suicide wrong?”**

- ◆ Suicide—self-destruction when someone has the possibility of living on—is a tragedy.
- ◆ Patients close to inevitable death by disease do not have the choice of living on.
- ◆ Aid in dying is a decision about how to die, not if to die.

Many family conflicts about aid in dying, especially those involving religious and spiritual concerns, revolve around whether it is “suicide.”

Here’s a point of agreement: Suicide is a tragic event, to be avoided at all costs. Suicide is an often-violent act of desperation by a person experiencing isolation and loss of meaning in their life.



But suicide is when a person has the *possibility of living on*, even the chance that their life will improve—yet they still end their life intentionally.

A person with a terminal illness who qualifies for medical aid in dying, on the other hand, has *no possibility of living on*. The choice of living has, sadly, been taken from them. Their choice is how they will soon die, not if they will soon die. They are not rejecting life, and they've often fought as hard as they could to prolong their life by aggressive medical interventions. Now, they are choosing the route to their rapidly approaching death—unwanted but inevitable. That is not suicide.

For this reason, all aid-in-dying laws clearly state that medical aid in dying is not a suicide—not for life insurance, not on the death certificate, not for medical records, not for any legal or other document.

In fact, the leading organization for the prevention of suicides, the American Association of Suicidology, “recognizes that the practice of physician aid in dying . . . is distinct from the behavior that has been traditionally and ordinarily described as ‘suicide,’ the tragic event our organization works so hard to prevent. . . . Legal physician assisted deaths should not be considered to be cases of suicide.”

Many other major medical organizations agree that the term *suicide* does not apply to medical aid in dying: The American Academy of Hospice and Palliative Medicine; the American Public Health Association;

the American Psychological Association; the American Medical Women's Association; the American Academy of Family Physicians.

Hopefully, then, your families and loved ones will understand that aid in dying and suicide are completely different, and they will not use the word *suicide* in your discussions about medical aid in dying.

### **“Tell me about spiritual or religious concerns.”**

- ◆ Religious positions about aid in dying are as diverse as all spiritual concerns.
- ◆ The Catholic Church is opposed to any procedure that hastens death.
- ◆ Individual spiritual counselors from all religions, including the Catholic Church, tend to respect dying patients' wishes.

Religious and spiritual guidance about aid in dying are as varied as any religious concerns. Some spiritual teachings condemn both suicide and aid in dying, seeing them in the same light. There are also wide-ranging teachings about aid in dying that are independent of whether it is considered a suicide. Some support a patient's right to choose how they will die, some are neutral, and some disapprove or even condemn medical aid in dying.

The Catholic Church considers aid in dying to be suicide, explicitly prohibited in Catholic teachings. Yet

among Catholic priests, I have seen different practices. One patient of mine, dying from lung cancer, was given last rites by his priest on the morning of his aid-in-dying death. When the priest left, a dozen family members gathered around the man, reciting the rosary while he took the aid-in-dying medications. “We don't approve,” one daughter said, “but Poppy will do what he wants anyway. We are at his side to provide support, and pray the rosary at the same time.”

I have been at aid-in-dying deaths in the presence of rabbis, Buddhist priests, imams, and spiritual guides of diverse Native American cultures—representatives of more spiritual faiths than I can name. I've also cared for people with terminal illnesses whose spiritual advisors told them God would punish them if they took medications to hasten their deaths.

In other words, generalizations simply don't hold up. In order to know how your religion and particular spiritual counselors will or will not work with you as you consider aid in dying, you must ask them.

And remember, your hospice has a chaplain to help with your spiritual concerns and questions.

# THE PATH TO AID IN DYING



You've thought about the many paths that can lead to a dignified death. Now, you've decided that the route to your death will be to take medications to die at the time of your choosing. How do you achieve that goal?

## “What are the legal requirements?”

- ◆ Before considering aid in dying, it is essential to know if you legally qualify.
- ◆ Your decision to hasten your death is about much more than the law.

I believe that information about medical aid in dying too often focuses on the legal requirements, much more than the clinical, social, cultural, and spiritual aspects. That's a mistake, because your decision to take medications to die is about so much more than the law. So I'll outline the legal requirements to be sure you know if you qualify for a physician-assisted death, and then move on to the clinical and social details. You need to know the law, of course—but that's not nearly enough.

In general, all aid-in-dying states require that you:

- ✦ Are over 18 years of age.
- ✦ Live in a state where aid in dying is legal, or you've established residency in that state. (Since each state has different residency requirements, please review your individual state law.)
- ✦ Have a terminal illness with a prognosis of less than six months to live.
- ✦ Have the mental capacity to make your own decisions about your medical care (understand what your disease is, and what the alternatives to medical aid in dying are).
- ✦ Have the physical capacity to take the medications on your own (more about what that means later).
- ✦ Have two doctors who concur that you are qualified, one of whom must agree to be the attending/prescribing physician, the other the consulting/second-opinion doctor.

### **“Okay, I qualify. How do I become eligible for aid in dying?”**

- ✦ Speak with your doctors about working with your wishes.
- ✦ Ask specifically what your doctors mean if they say, “I’ll support you.”

- ✦ If your doctors will not provide aid-in-dying care, contact the Academy for a referral (<https://www.ACAMAID.org/patientintake/>).

First, speak with your present doctors. Tell them you are considering aid in dying and ask specifically if they will be one of the two required doctors. Ask your general doctor and your specialty doctors. Ask your hospice if their doctors participate in aid in dying. If any of these doctors explain that they support your wishes but are not experienced with the process, let them know that the Academy’s physicians will work with them on the details—everything from the law to the medications used. There is no charge for this, and they do not have to be a member of the Academy. If appropriate, please share the Academy’s contact information with your doctors: [ACAMAID@ACAMAID.org](mailto:ACAMAID@ACAMAID.org).

Crucially, be sure you really do have the necessary two aid-in-dying doctors. Even if your doctors have said, “I support your decision to consider taking medications to die,” that doesn’t necessarily indicate they’ll act in the very specific legal roles you will need, which are as follows:

Doctor 1: The attending/prescribing physician. This doctor supervises the aid-in-dying process, from determining if you meet the legal requirements through writing the prescription for life-ending medications and helping you determine if/when you will take them.

Doctor 2: The consulting/second-opinion physician. This doctor meets with you (it can be via telemedicine), reviews your relevant medical records, and agrees (or not) that you are eligible for aid in dying. The consulting physician is not necessarily otherwise directly involved in your aid-in-dying care.

If one of your present doctors will be the attending/prescribing physician for aid in dying, and another the consulting/second-opinion doctor, you're all set to move forward to the next steps.

But it is possible that none of your present doctors will take on those roles. If they work in a healthcare system, please check whether that organization provides referrals to participating doctors. For example, patients in the Kaiser Permanente system in an aid-in-dying state work with a coordinator to find a Kaiser doctor who will evaluate their request and provide physician-assisted dying if appropriate. Many large healthcare structures have similar internal referral systems (in some states they are required to post this on their websites).

If you are still unable to obtain an aid-in-dying evaluation or care, please fill out the form for the Academy's Patient-to-Doctor Referral system and the Academy will help connect you with a participating doctor in your geographic area. You can find the form at <https://www.ACAMAID.org/patientintake/>.

## **“Now that I’m sure I have both doctors lined up, what’s next?”**

- ◆ Each aid-in-dying state but New Mexico requires two verbal requests (New Mexico requires one). Every state requires the patient to sign a form in front of two witnesses, only one of whom can be a family member.
- ◆ There is a variable waiting period between the two verbal requests, so be sure you start the process before you are too ill.

If you haven't already done so, you'll make a “first verbal request.” This starts the waiting period, which varies from state to state (<https://tinyurl.com/DWDStateGuide>). This first request doesn't mean you are committed to taking medications to die. It merely starts the process.

After the defined waiting period, you will make a “second verbal request.” Then you'll sign various forms, such as a “Written Request with Witnesses.” This will vary from state to state, so obtain these forms from your doctor or your state aid-in-dying office.

These are the minimum legal requirements before you can obtain aid-in-dying medications. But remember, in medicine the minimum requirements do not mean you'll receive knowledgeable or compassionate medical care. For clinical best practices, please read on.

# PREPARING FOR AID IN DYING



- ◆ End-of-life care continues while you wait for aid in dying.
- ◆ The decision of if or when to take medications to die is complex. Seek advice.
- ◆ Understand the aid-in-dying medications and how they work.
- ◆ Observe your own unique progression toward death; it's an important guide.

## “Should I change my current end-of-life care?”

Your end-of-life care doesn't end the moment you hear that your attending/prescribing physician will write the prescription for lethal medications, with instructions to “Take them when you're ready.” In fact, “Take the medications when you're ready” is an expression I would like to see stricken from clinicians' language.

The decision of when, or even if, to take medications to end your life is one of the most important and complicated choices you will ever make. Although your own wisdom and intuition will be a powerful guide, you

should also take advantage of opportunities to have deeply honest conversations with family members, your end-of-life support team, your doctors, nurses, social workers, chaplains, therapists, personal spiritual counselors, or whomever you are comfortable with and trust.

Remember that the progression toward your individual death is often your best guide. If you've been expecting severe pain but are not experiencing it, you may be content to slowly fade out of life without taking medications to die. Or if you were sure you'd never tolerate being confined to your bed, you may discover that being in bed surrounded by people you love is an adequate reason to live on for additional days or weeks.

The above are examples of a truism I call "Aid in dying's moving line in the sand." I've often heard patients say, "Once I'm in diapers, I'm out of here!" But they later discover that adult diapers can be "wonderful" (yes, I've heard that word used to describe diapers), since they don't have to struggle to get to the bathroom so often.

Or, the opposite can happen: A patient who is certain she'll wait a few weeks to see close friends who will travel from far away might decide she's endured enough and will take the medications to die before her friends can arrive.

In other words, until you're actually at the moment of a final decision, it's hard to predict what that decision will be. Be patient. I've learned to listen for the words,

"I am so tired. I've had enough. I'm ready." In fact, those are the most common expressions I hear when a patient tells me they're ready to take aid-in-dying medications.

End-of-life clinicians have gained significant experience and wisdom about the "when to die" decision. So stay in touch with them, and don't hesitate to ask for continued guidance as your death gets closer. This is especially important if you are approaching the imminent/active phase of dying, when you have only a few days to a week or so before your body naturally shuts down.

In particular, stay in close touch with your medical providers if you're having trouble with nausea, swallowing, or constipation. Such symptoms might affect the way you'll take medications to end your life, or how well they will work.

*Ongoing expert guidance is essential in making the important decision about if and when to take medications to die.*

**"Before I decide to take these medications, what are they? And how do they work?"**

You may have noticed that we're well into this booklet and I still haven't talked about the medications that can end your life. That's because considering aid in dying is about so much more than simply ingesting lethal medications. By now, I hope you've realized this, so I'll

finally get to the commonly asked question: Just what is the poison potion?

First, here's what it's not (but many people mistakenly think it is): Aid-in-dying medications are not an injection, like what a veterinarian gives your pet. For human beings, it is illegal to inject aid-in-dying medications. The legislators who wrote these laws wanted to be sure that death was entirely voluntary, so they wrote in a "safeguard" stating that patients must take the medications themselves, called "self-administration." Then they added another safeguard, that the medications must be taken by "ingestion" (the actual wording varies from state to state, but that's the essence of it). So, no injections allowed, and the patient must ingest the medications (now defined as anything that involves the gastrointestinal tract; I'll explain more about that in later sections).

Then, there's the "poison pill" rumor. I'm not sure where this started, but it has never been true. Since the beginnings of aid in dying in Oregon in 1997, the lethal medications have been a complex liquid suspension of medications, not a pill. Originally, they were an enormous dose of a single sedative, secobarbital. The patient (or an assistant) had to tediously open one hundred capsules of secobarbital, gather the powders together, mix them with water, juice, or apple sauce, and swallow the concoction. For a variety of reasons, we haven't done that for years. But that's what people remember hearing about.

In recent times, a consortium of clinicians (I'm one

of them) has innovated newer and better medication combinations and methods, sharing data and recipes until we've improved and perfected the speed and reliability of bringing on a comfortable death.

Here's how it works: There are five components to the lethal mixture, which is taken as a two- to four-ounce suspension of powders:

Morphine, diazepam (Valium), and phenobarbital: These potent sedatives put you to sleep within three to ten minutes of taking them. You then rapidly enter a deep coma. As the brain turns off many patients stop breathing (they don't feel this) and die within thirty to sixty minutes. But some patients continue breathing at a low level and can live on for many hours (while still unconscious). For this reason, the medication cocktail also includes . . .

Digoxin and amitriptyline: These are highly toxic to the heart. So if the patient continues breathing even while in a deep coma, these medicines will bring on a comfortable death in a few hours.

We refer to this prescription by its initials: DDMAPh. Thousands of patients have taken DDMAPh and we have data from the Academy and multiple states that back up the safety, efficacy, and reliability of this protocol. And we're always working on improvements. Updates can be found on the Academy's website at <https://tinyurl.com/AidInDyingRx>.

Those are the basics of aid-in-dying pharmacology.

There are many more details on preparing and ingesting the medications in the sections that follow.

### “Who should be with me on the aid-in-dying day?”

- ✦ It is common to be anxious on the aid-in-dying day.
- ✦ Having a skilled clinician’s help allows you and your loved ones to focus on being loving and supportive, rather than on the technical aspects of your death.

You can choose whomever you wish to be with you on the day of your death. But I have some recommendations.

First, aid-in-dying laws and the Academy all strongly recommend that you don’t take these medications alone. There’s nothing illegal about that, but it’s a terrible idea. You’re probably quite ill and very weak, so mixing and taking the medications without assistance will be mechanically difficult and potentially unsafe. Also, from my point of view as an end-of-life clinician, it seems fundamentally sad to die alone, even if you’ve been a highly independent person all of your life.

If there is no one you know who can be with you, talk with your hospice staff and clinicians about whether they can be there on the day you’ll die. If that doesn’t work, fill out the Academy’s “Attendant Referral Form” (<https://tinyurl.com/MAIDattendant>), and they’ll find a

skilled aid-in-dying volunteer or end-of-life doula to be with you.

You may plan for loved ones or other caregivers to be with you on the aid-in-dying day. But I still strongly recommend that you include someone who is skilled and knowledgeable about aid in dying. This might be your doctor, nurse, hospice chaplain, social worker, aid-in-dying trained volunteer, or end-of-life doula—anyone who has specific experience with the process and procedures.

The major advantage of having an experienced attendant is that it frees you and your loved ones from the distractions of the technical details of the day. On the day of your death, loved ones should be loving, rather than worried about whether you and they are correctly following detailed medical instructions. Even the strongest, most dedicated and supportive families are anxious and concerned about how everything will go on the day of your death. So it’s helpful to have someone there who knows exactly what to do. And if any questions come up, they’re right there to answer them.

When knowledgeable clinicians are present, patients have more peaceful and less complicated deaths. And their loved ones have less complex grief. Family members and others who don’t have to manage medications or make clinical decisions on the aid-in-dying day can focus their attention on you and each other during these tender final moments.



## YOU'RE READY. WHAT'S NEXT?

- ◆ Be sure your doctor has prescribed the most recently recommended medications.
- ◆ Have a final, quick check-in with your prescribing doctor.
- ◆ Check with your supporters to be sure you've maintained the mental and physical capacity to proceed.
- ◆ Practice swallowing two to four ounces of liquid in two minutes (if you can't swallow, see below).

If you are ready to make a specific plan, here are some pragmatics.

If possible, have a brief, final check-in with the doctor who prescribed your aid-in-dying medications. This can be via phone, telemedicine, an in-person visit at your home, or, if you can get there, a visit to the doctor's office. If the doctor isn't available for a brief discussion, talk with your hospice nurses or other clinicians about your decision to take medications to die, and the timing of your plan. Ask them about whether, given your present condition, it is safe to proceed.

## Getting the Medications

First, you'll need the medications. While most doctors don't send these medications to you long in advance of the aid-in-dying day, some may have sent you the medications early. If you already have the medicines, check with your doctor to be sure they're the most up-to-date recommendation. The field of aid in dying is advancing rapidly, and you can find the most recently endorsed medications at <https://tinyurl.com/AidInDyingRx>. Feel free to share that link with your doctor.

If you don't yet have the medications, let your attending/prescribing physician know that you've set a date, and it's time for the medicines to be shipped to you immediately.\* Take advantage of that conversation to update your doctor about any changes in your condition since you last spoke, particularly any changes in your swallowing ability, digestive/intestinal function, or the dosage of medicines you've been taking for pain or anxiety.

Aid-in-dying prescriptions are for enormous doses of compounded and restricted medications. Most chain pharmacies can't fill these prescriptions, nor can some small private pharmacies. Your doctor is probably

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\* In New Jersey, the medications must be picked up at the pharmacy. They cannot be shipped. In Washington state, the medications cannot be shipped, but can be delivered directly by the pharmacy to the patient's home or picked up at the pharmacy. In most other states, the medications are shipped from the pharmacy, by next-day UPS or FedEx, if needed.

familiar with an aid-in-dying-experienced compounding pharmacy that will rapidly ship these medicines to you. If there are any difficulties in finding a participating pharmacy, feel free to contact the Academy for a recommendation, at [ACAMAID@ACAMAID.org](mailto:ACAMAID@ACAMAID.org).

The medications should arrive as a bottle of powders, to be mixed into a liquid suspension on the day you take them. Some pharmacists provide the medications as a liquid suspension, but that is uncommon. The medications in pre-mixed suspensions expire within weeks, there is an increased risk of spillage, and the powdery suspension can get clumpy in the bottle and become difficult to resuspend. Talk with your pharmacist, and if they plan to send the medications in liquid suspension form, you should ask for the powders instead.

Once you receive the medications, simply store them in a cool, dry, and safe place. Do not keep them open to view—these are enormous amounts of dangerous medications, including opiates, and you don't want someone other than you to die by taking them.

## Decision-Making Capacity

Before taking these lethal medications, you must again confirm that you:

- ✦ Know the illness you are dying from.

- ✦ Realize you can obtain or continue with aggressive palliative/hospice care instead of taking medications to die.
- ✦ Comprehend that you can change your mind at any time.
- ✦ *Understand that by taking these medications you will quickly die.*

When patients cannot communicate verbally, they can establish the above by head nods, writing, or other adaptive means traditionally used for consent to medical procedures. But they must be conscious and aware of what they are communicating.

On the day of aid in dying, only you can make the final decision. If you lose the mental ability to communicate your continued choice to take medications to die, no one else can make the decision to go forward—not your spouse, loved ones, or even your power of attorney.

This next part is crucial: If you are becoming increasingly confused as you get closer to your chosen day of death, be sure a family member or one of your clinicians is frequently evaluating your level of confusion, to let you know if you still qualify for aid in dying and how long that may last. If you are gradually losing the ability to make and communicate your decisions, you might want to move the selected day forward while you are still capable. Or, you might choose to call off the aid in dying and have a comfortable, supported hospice death.

## Preparing to Take the Medications

The lethal medications must be “self-administered”—whether by swallowing or physically self-administering the medications into a feeding tube, ostomy, or rectal catheter. I’ll discuss details of the non-swallowing methods in a following section.

If you’ll be swallowing the medications, it is essential to rehearse a day or two before the aid-in-dying day. On that day, you’ll be drinking two to four ounces of a thick, bitter-tasting liquid in two minutes. For a detailed explanation of two- vs. four-ounce mixing, see <https://www.ACAMAID.org/mixinginstructions/>. To get used to the swallowing and timing, it’s crucial to practice in advance with a nontoxic drink of similar consistency (nutrition drinks like Ensure will suffice). That way, you’ll be familiar and comfortable with the procedure before taking the medications on the day of your death.

The reason you must completely swallow all of the medications within two minutes is that they act so quickly that if you take longer you might fall asleep mid-dose and not get it all down. If there’s any doubt about your swallowing ability, talk with your prescribing physician or another clinician about taking the medications by another route (discussed below).

## “What if I can’t swallow?”

There are various reasons why a patient may not be able to take aid-in-dying medications by swallowing:

- ✦ Blockage of the mouth or esophagus.
- ✦ Too weak or short of breath to swallow all of the medications within the two-minute safety goal.
- ✦ Severe nausea or vomiting, creating a significant possibility of vomiting the aid-in-dying medications.
- ✦ Patients with bowel obstructions might be able to swallow the medications, but their blocked bowels might not be able to move the medications from the stomach to the intestines, where they are absorbed into the bloodstream.
- ✦ Patients with neurological diseases (like ALS, Parkinson’s, multiple sclerosis, and others) can lose their ability to safely swallow.
- ✦ Some people have such an aversion to bitter tastes that they can’t swallow the particularly bitter aid-in-dying medications.

Fortunately, self-administration of aid-in-dying medications is still possible for patients who can’t swallow, by a variety of routes and methods. For information about all non-swallowing methods of self-administration of

aid-in-dying medications, please see <https://tinyurl.com/Non-oralAdministration>.

**Feeding Tubes (PEG or J Tubes):** Many patients who are unable to swallow safely have had thin feeding tubes placed into their stomach or high in the intestinal tract. Mostly, these patients are still able to use their hands to self-administer aid-in-dying medications into their feeding tubes. For details, please view the Academy’s feeding tube video or written instructions at <https://tinyurl.com/Non-oralAdministration>.

**Nasogastric (NG) Tubes:** Less common than direct-to-stomach feeding tubes, these are thin tubes placed through a patient’s nose into their stomach. If the tubes have been used to feed the patient, they can also be used to self-administer aid-in-dying medications. The method is the same as for other feeding tubes, so follow the video link above for details.

**But beware:** Many nasogastric tubes are intended only or mostly for suction, to relieve the pressure from a bowel obstruction (also called “venting” or “sump” tubes). These venting tubes cannot be used for aid in dying.

**Ostomies:** Some patients with a history of bowel obstructions or other intestinal diseases have had ostomies surgically created, a direct opening from the intestines to a bag attached to the outside wall of the

belly. As long as an ostomy is functioning, it can be used for the self-administration of aid-in-dying medications. If there is any doubt about whether an ostomy is safe for medication administration, consult with the surgeon who constructed the ostomy, and/or your aid-in-dying physician. For details, see <https://tinyurl.com/Non-oralAdministration>.

**Rectal Catheters (enemas):** This is the most common non-swallowing method of self-administration of aid-in-dying medications, similar in many ways to administering an enema. While this may sound unpleasant, it is remarkably comfortable for the vast majority of patients who require this route. In fact, some clinicians have been so impressed by the ease and comfort of the rectal catheter they're even offering it to patients who can swallow the medications—to avoid the bitter taste, uncertainties of swallowing for weakened patients, and the possibility of vomiting the medicines.



Briefly, a clinician (most commonly a nurse) inserts a thin catheter into the rectum, then attaches a medication-filled syringe to the catheter and hands the syringe to the patient—who then pushes the plunger to self-administer the medicines. For details, please see <https://tinyurl.com/Non-oralAdministration>.

If you are using an enema, feeding tube, or ostomy

for self-administration, be sure you and a knowledgeable assistant have gone through the details thoroughly in the days before aid in dying, including a rehearsal. Do not leave these details for the day of your death.

### **A specific note for patients with ALS or other potentially paralyzing neurologic diseases:**

Patients with ALS and other potentially paralyzing neurologic illnesses who have reached terminal stages can face unique dilemmas for aid in dying.

Some (but far from all) ALS patients not only lose their ability to safely swallow, but also the ability to use their hands (or other movements) to self-administer the medications into a feeding tube or rectal catheter. Since most aid-in-dying states (New Mexico is an exception) prohibit any “assistance” in the self-administration process, this can render some ALS patients ineligible to take life-ending medications.

At the present time there is no remedy for this difficulty. So some ALS patients must decide to take the medications sooner than they would otherwise choose, before they lose the ability to self-administer the medications. When an ALS patient loses swallowing and all other movement abilities, they are no longer eligible for aid in dying. This does not eliminate the possibility of a comfortable hospice death by heavy sedation (sometimes called “palliative sedation,” but there are many variations, so speak with your hospice clinicians about this).



## THE THREE DAYS BEFORE YOUR AID-IN-DYING DAY

Since most patients and their supporters have never been at a clinician-assisted death, the Academy has produced a short video, with actors, showing an aid-in-dying day (<https://www.ACAMAID.org/video-enactment/>). I recommend that you and those who will be there for your death watch the video, to decrease the anxiety of an unfamiliar event and have a better idea of how your death will unfold.

### Preparing Your Digestive Tract

- ◆ For aid-in-dying medications to work, your stomach and intestinal tract must be functioning.
- ◆ Follow these instructions to help your intestines absorb the medications.

**Eating:** If you can, I encourage you to eat small amounts of food with some nutritional quality in the days to weeks before your death. Don't force yourself; if you really don't

feel like eating, it's fine not to. But if you can eat even small amounts, that's likely to improve your intestinal function, which will help the transport and absorption of the aid-in-dying medications. The better the condition your gut is in, the better the absorption of the medications.

**Bowel Care:** Whether you're swallowing or taking the medications by enema, you'll need a bit of a bowel tune-up before the aid-in-dying day. Constipation, common with many illnesses, is our enemy. Significant constipation risks delaying the absorption of the medications, or even making you vomit after you take them. Talk with your hospice nurse or another clinician about working with you to assure your bowels are functioning. If you have a bowel movement within a day or two before aid in dying, that should suffice. If not, you should receive medications or an enema to relieve the constipation pressure. If you're taking the medications by a rectal catheter, I recommend an enema that morning to empty stool from the rectum.

### Planning the Timing of Aid in Dying

The best time of day to take aid-in-dying medications is around 11:00 a.m. or noon. That gives you and your loved ones some time together before you die. I don't recommend taking the medications in the late afternoon or evening because, rarely, it can take your heart many hours to stop (you are unconscious during that interval).

If you start too late in the day the process can go into the wee hours of the morning, which is hard on those who are waiting.

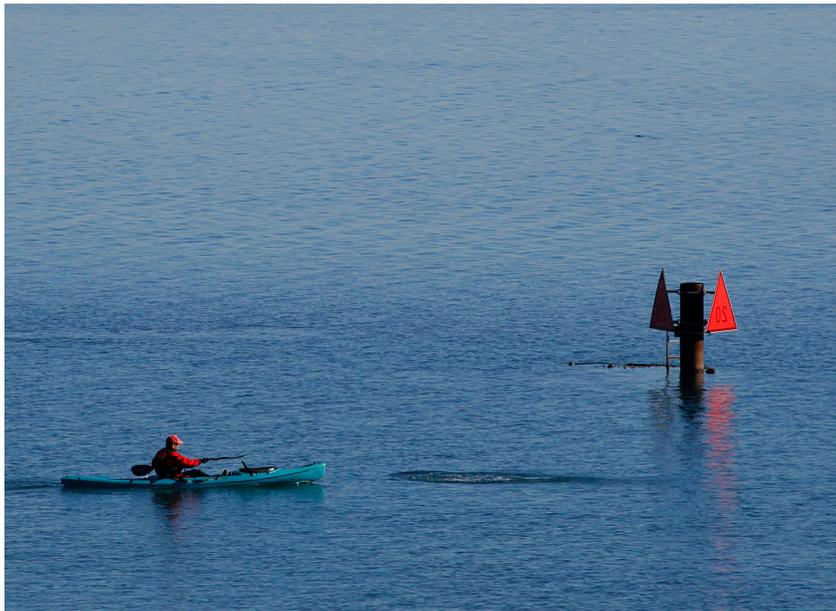
### Planning for After You've Died

**Arrangements for Your Body:** If you haven't done so already, this is a good time to make preparations with a funeral home or other organization to take your body away. Ask your hospice social worker to help with these plans.

This is also a good time for your family to decide how long to wait before your body is taken away. Some wish to stay with you until the next day (ice is often needed). Others want a few hours to adjust to your death before your remains are removed, and others want the funeral home to come as soon as possible. There is no correct timing, but it's best for your family to talk about this before you die.

**The Death Certificate:** Your regular doctor, hospice doctor, or aid-in-dying physician will sign your death certificate. The legal cause of death is your underlying illness; aid in dying is not listed (although it can be included after your disease if you request that). Additionally, it is not legal to use the term *suicide* on your death certificate. Insurance policies and any other legal/financial circumstances are not affected by an aid-in-dying death.

# THE DAY BEFORE YOUR DEATH



- ◆ Gather the materials for the procedure.
- ◆ Prepare your body before you take medications to die.

**Juice and Popsicles:** Purchase at least eight ounces of clear apple juice (no pulp, and avoid acidic juices like orange/pineapple/Gatorade) and some fat-free popsicles or sorbet (details in the section “Your Death Day”).

**Medications:** Continue all of your usual medications unless you receive specific instructions from hospice or your attending/prescribing doctor to stop or adjust those medications.

**Food:** Feel free to eat anything you’d like until about midnight the night before aid in dying, then stop all solid foods and take in only clear liquids until you ingest the medications the next morning. If you are (against my advice) planning a late afternoon or evening death, stop eating solids at least eight hours before you take the

medications, then stick to clear liquids in small amounts to keep from becoming too thirsty.

Do not take in any fatty foods or liquids for at least eight hours before taking aid-in-dying medications. Any fat delays the emptying of your stomach into the intestines, and can delay the absorption of the medications.

On the morning of your death: If you're used to drinking coffee or tea, feel free to do so. Adding sugar or sweetener is fine, but don't add any cream or milk. Clear juices are also fine, but in small amounts—leave enough room in your stomach for the aid-in-dying medications.



## YOUR DEATH DAY

- ◆ Know who will mix the medications, and how (if your clinician will not do so).
- ◆ Handle these dangerous medications safely (hint, control your pets).
- ◆ Understand the best ways to ingest the medications.

### Mixing and Preparing the Medications

You will have received the medications as powder in a bottle (usually a four-ounce bottle, but check). The powder will be mixed with water or clear apple juice to a final volume of two or four ounces of a thick liquid that you can drink. For details about mixing aid-in-dying medications, see <https://www.ACAMAID.org/mixinginstructions/>.

I recommend clear apple juice over water. The sweet juice improves the taste, and theoretically the sodium, potassium, and sugar in apple juice help the intestines absorb the medications. But many have used water without difficulties, so it's really your choice. I do not recommend that you mix the medications with your favorite alcoholic drink. There is no truth to the myth

that alcohol increases the sedative effect of the aid-in-dying medications, and alcohol may increase burning and bitterness.

Other juices are fine, but only if they have absolutely no pulp or other fibrous matter. Pear juice, for example, is not acceptable. I also don't recommend orange or other citric juices because they are acidic and may increase the burning sensation from the medications.

Anyone can mix the medications, whether it's the patient (unusual), a family or other support-team member, or a clinician/attendant present that day. Some hospices do not let their staff mix the medications. Check with your hospice to see if this is the case. (There is nothing in any aid-in-dying law that prohibits hospice staff from mixing these medications or handing the mixture to you. It's a decision made by each hospice.)

I recommend that the medications be mixed just a few minutes before they are taken, and promptly brought to the bedside. The powdered medicines do not dissolve in the liquid, but rather become suspended. So if you mix the medications even thirty minutes before they are taken, the powders will settle to the bottom of the drinking glass (or bottle). Then you'll have to shake or stir the liquid vigorously to again suspend the powders in the liquid, and sometimes that causes them to clump. Again, please see the Academy's video about mixing the medications at <https://www.ACAMAID.org/mixinginstructions/>.

You can take the medications in a small favorite drinking glass or from the bottle itself, but the glass seems a bit easier (and familiar). It is perfectly fine for whoever mixes the medications to hand them directly to you. They can also place a straw in the glass or bottle and place the straw in your mouth—as long as you do the actual swallowing.

**A note of caution:** When someone is walking from the kitchen to your bedroom carrying a glass of lethal medications, be sure that all pets and children are completely under control. I have nightmares about someone tripping over a cat, spilling the medications, and then the cat laps up the medicines and dies while the patient stays alive. Another way to avoid accidents is for the person who mixes the medications to do so in the bottle, then cap the bottle securely and bring it and a glass to your bedside. Then, while sitting calmly at a bedside table, they can pour the medications into the glass and hand it to you. Please make sure you have the glass completely in your hands before they let go.

Take the medications while sitting up as much as you can. It's easier to swallow in that position, and gravity helps the medications get to your stomach. You can sit in your favorite comfortable chair or in bed, torso inclined upward from the hips. If you're sitting up in bed, maintain that position until you are unconscious, then someone can gently lay you down (although it's fine to just leave you sitting or inclined). But if you're sitting

in a chair to take the medications, don't then try to walk to your bed—you're highly likely to pass out and fall during the maneuvering. If you take the medications while sitting in a chair, just stay there.

### **“What does it feel like to take the medications?”**

These medications have a bitter taste, and they occasionally cause a burning sensation of the mouth and esophagus (felt in the middle of the chest).

Clinicians and family members: It is crucial that the patient is fully informed of this possibility, so they anticipate it and are not surprised or shocked and think something has gone wrong. Patients can panic if they have unexpected symptoms, so advance warning is essential.

Here's how you and your loved ones can improve the taste, avoid the burning, and help you get the medicines down:

- ✦ Sorbet and/or popsicles (the flavored-ice kind, with no fat in them; no Creamsicles or Dream-sicles): By sucking on a popsicle or sorbet just *before* taking the aid-in-dying medications, you'll cool your mouth down and be less sensitive to bitter tastes and burning. Then, *after* swallowing the medications, additional small bites of a popsicle and/or sorbet cool

the mouth further and provide a sweet taste to counter the bitterness. Designate one person to hold and provide the popsicle or spoons of sorbet—it's a sweet, final kindness on the part of a loved one.

- ✦ Those around the patient should become something of a cheerleading squad to achieve the two-minute goal of swallowing the medications. If the patient feels the bitterness or burning and slows down or pauses drinking, that prolongs the bitterness and delays getting the soothing sweet sorbet or popsicles once all of the liquid is down. Encourage your loved one to keep swallowing; you're right there waiting with the sorbet as soon as they finish. But don't rush them so much that they start gagging or choking. Two minutes is more time than it seems, and nearly all patients have no problem getting the medications down in that amount of time.
- ✦ If after finishing the medicines the patient is bothered by bitterness or burning, reassure them in a calm, loving voice that the discomfort will be very brief; the enormous dose of sedatives swiftly decreases pain. And they'll be unconscious within three to five minutes, so

while the burning is occasionally intense, it is mercifully brief. Your loved one will be comforted by the serene, reassuring voice of someone they know and trust.

### “What happens after I take the medications?”

- ◆ How long will it take me to die?
- ◆ For those around me, what will my death look like?

Immediately after taking the aid-in-dying medications, you can get a bit euphoric (high). I advise moving into the feeling—a pleasant sensation of floating just before you lose consciousness. In fact, “Oh, wow,” are common last words for an aid-in-dying patient.

Once the euphoria comes on, you will quickly feel an uncontrollable urge to sleep. You’ll then drift gently into unconsciousness. That’s usually only three to five minutes after taking the medications, occasionally up to ten minutes, very rarely longer than that.

During that short interval, you might have some twitching movements. You won’t feel these at all, but they can be upsetting to loved ones and are sometimes mistaken for seizures. The twitching is a sign that your brain is shutting down, like the typical twitches people experience just before falling asleep.

Many patients also scratch their noses just before

falling asleep. That’s the effect of the medicines, which can cause itching.

Then, the wait begins—for your loved ones, not for you. Your brain turns off soon after you take the medications. To the best of medical knowledge, you have no further earthly feelings. Where you are during that interval when your brain is switched off but your heart is still beating is a spiritual question, not a medical one. From a medical standpoint, you will remain unconscious until your heart stops and you are formally declared dead.

Seizures are very rare during aid in dying, happening mostly to patients with brain disease (from strokes to tumors). If a seizure does occur, you’ll be unconscious and won’t feel it. But it can be upsetting to whomever is with you. These rare seizures pass within minutes. Nothing needs to be done by anyone in the room other than wait for the seizure to pass.

I’ll switch to addressing your loved ones now; once you are unconscious, we shift our attention to the others in the room. They need care and full explanations while they’re waiting for your heart to stop.

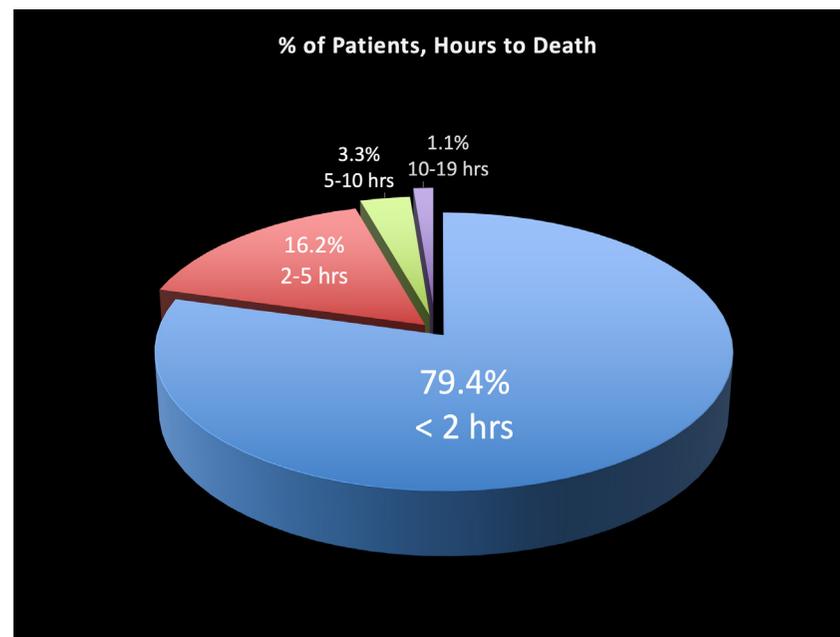
Death comes on by one of two routes. Many patients completely stop breathing once they are unconscious, and the lack of oxygen stops the heart—usually within ten to thirty minutes of taking the medications. But a significant number of patients keep breathing slowly and shallowly even though they’re unconscious. That is why the aid-in-dying formula includes medications to

stop the heart even if the patient keeps breathing. Those deaths take a bit longer.

Here's how long it takes to die after taking aid-in-dying medications:

(The information below applies to the recommended combination of digitalis, diazepam, morphine, amitriptyline and phenobarbital, DDMAPh. If your doctor has prescribed different medications, ask them to explain the expected timing to you.)

Around 80 percent of patients die within two hours. Another 16 percent die before five hours are up. So, 96 percent of patients die within five hours. Within that range, there is no way to predict the specific timing for any individual patient. But for an additional 3 percent, their hearts keep beating for five to ten hours. And about



1 in 100 patients live on for up to about twenty hours. In reports of many thousands of aid-in-dying deaths, there have been extremely rare cases of awakenings—due to severe mistakes in the prescribing, or errors in the ingestion of the medications. These are so rare, I comfortably tell patients they are guaranteed to remain unconscious and die (but the timing may vary).

There are specific risk factors that can lead to a prolonged time to death. So we can often, but not always, predict which patients may take longer to die. Ask your clinicians if you have any or many of those risk factors, and what they mean. (They, or you, can check the Academy's Red Flag Checklist for Potentially Prolonged or Complicated Deaths: <https://www.ACAMAID.org/redflagchecklist/>).

Why are these timing details important? Because aid in dying is a medical procedure and you and your family deserve to know what may happen, if for no other reason than to be prepared for a possible wait. Knowing of these possible times to death, families are less worried if you don't die as quickly as they or you expected. While nothing is impossible, once a patient is unconscious they virtually never recover any sensations, feelings, or thought processes before they die. And the best way to keep this at "virtually never" is for your prescribing physician to review the warning signs (<https://www.ACAMAID.org/redflagchecklist/>), to prevent prolonged deaths or complications.

## **“What happens to my body while I’m unconscious, but before I die?”**

This part, of course, is for those at your bedside, since you’ll be unconscious and unaware of anything else that happens.

The first thing your loved ones will see is that you are completely comfortable and at peace—often for the first time in many months. Frequently this is their time to take a deep breath and understand the reality and significance of your rapidly approaching death. It is commonly a somber moment, and tearful. Often, loved ones will lie at your side and hold you gently. They may tell stories about your life, and of theirs with you. The air fills with intimacy and love. This is the first moment of their healing from your illness and death.

These are the physical events they’ll see:

Soon after aid-in-dying patients are unconscious, it’s common for them to stop breathing. Their face may turn a deep blue color, the sign of a lack of oxygen. As death gets closer and the circulation of blood fails, the color will change to ashen gray.

Some patients, however, stop breathing for only a few minutes (even up to fifteen or more) and then take a sudden, deep gasp and begin to breathe again. This can be frightening if those present don’t know it can happen, so they should be prepared for the possibility.

Long pauses in breathing are an indication that death

is very near, but not quite there yet. The general pattern is for breathing to gradually slow and become shallower during the wait for the patient to die. They may make snoring or grunting noises. You may hear the infamous “death rattle” as saliva pools in the back of the throat. There may be occasional sudden, loud, gasping breaths, called agonal breaths.

The patient is completely unaware of these physical events and feels no discomfort. They are all part of the normal process of dying. The aid-in-dying medications do not prevent these events as death approaches, but they do speed up the process.

Finally, the patient will stop breathing entirely. This transition is easier to sense than you might think. But even when breathing seems to stop, wait a bit longer before concluding they have died.

Once you have seen no breathing at all for fifteen minutes, you can be sure your loved one has died. If you are so inclined, you can check for a neck pulse, but if you’re not experienced at this you might not feel a pulse even if there is one. That’s why I recommend waiting for the absence of breathing for fifteen minutes. Then you can take a deep breath of your own and experience the reality and intensity of your loss. Many people begin to weep at this moment, from the final realization that someone they have deeply loved has now died.

## AFTER AN AID-IN-DYING DEATH

- ◆ Your loved ones will pause and take a moment for themselves.
- ◆ Hospice staff will help with the next steps.



The events that follow an aid-in-dying death aren't that different from those that follow other at-home deaths. The first thing to do is pause and realize there is no rush for the next steps.

If there are clinicians with you—hospice staff, aid-in-dying volunteers, end-of-life doulas, spiritual counselors, or others—allow them to be your guides. They are experienced with the immediate aftermath of a death and can help you move through the next steps.

If your loved one has been in hospice, as I hope they have been, and no one from hospice was present at the death, call the hospice number to let them know their patient has died. They'll instruct you from there, often sending a hospice nurse to the home to confirm the death and aid the family. They'll also call the funeral home and arrange for transport of the body. If hospice has not been involved, a family member should call the funeral home

or agency responsible for the body. They will talk you through the procedures to follow.

One thing I've noticed that is slightly different for aid-in-dying deaths than for other kinds of deaths is that sometimes loved ones have been so focused on the preparations that they've been unable to fully process their loss. So once the assisted death is over, take some time to acknowledge what has happened.

I wish I could say that aid-in-dying deaths are “better” deaths, but there is no “better” when someone you loved dearly has died. Aid in Dying does not change loss, deep sadness, or mourning.

I've heard rumors that an aid-in-dying death can be a “celebration of life.” But I've very rarely seen this happen. By the time I leave the patient's home, someone crucial to the lives of many people has died. While there may be some relief in the comfort, quickness, and even the mercy of an aid-in-dying death, I haven't seen it become a cause for celebration. So you may be disappointed if that's what you've expected. No matter how death happens, the enormity and intensity of the loss remains.

## GRIEVING

- ◆ Grieving an aid-in-dying death is very similar to grieving other expected deaths.

We don't know very much about how grieving an aid-in-dying death differs, if at all, from other expected deaths. The best study, conducted through By the Bay Hospice, surveyed families who experienced aid-in-dying deaths compared to those whose loved ones had more typical hospice deaths. The majority (55 percent) of families who experienced their loved one's assisted deaths described an easier grieving process—more ability to say goodbye while the patient was still conscious; a less painful and more dignified death; and “the patient was able to die on their own terms.” Another 28 percent had an experience similar to other hospice deaths.

Only 17 percent of aid-in-dying families reported a more problematic grief process. Mostly, these survey respondents described difficulties due to ambivalent feelings about assisted deaths, or anger that the patient ended their life while quality still seemed to remain.

Interestingly, the study authors concluded that many of the difficulties after an aid-in-dying death were

“disenfranchised grief” due to the persistent stigma around aid in dying. Some families were reluctant to admit to others that their loved ones had taken medications to die, in fear of being judged or criticized for allowing it. Those mourners felt isolated—disenfranchised—and unable to share their experiences.

All hospices offer bereavement counseling, as do most religious/spiritual organizations. Don’t hesitate to ask them for information or help.

There is one type of grieving that is unique to the families of patients who deeply desired aid in dying but couldn’t achieve it. This may have been because they couldn’t connect with a participating doctor, or because the patient died or lost mental competence during the waiting period. In my experience, the guilt and unrelenting grief for loved ones after a desired but inaccessible aid-in-dying death can be extremely complex and profound. One daughter told me, “That’s the last thing my mom wanted, and I couldn’t get it for her. I failed her when it mattered so much.” From my point of view after caring for hundreds of patients and families considering medical aid in dying, that grief is the most difficult—the grief of failing to satisfy the final wishes of someone you deeply love.

Which is one of the reasons I’ve written this booklet. If this has been a helpful guide for you and your loved ones as you consider medical aid in dying, I thank you.

Lonny Shavelson, MD

Chair

American Clinicians Academy on Medical Aid in Dying

[www.ACAMAID.org](http://www.ACAMAID.org)

**THIS BOOKLET IS** available to patients and families who are considering medical aid in dying. You can request a printed copy at <https://www.ACAMAID.org/patientbooklet>. Organizations and medical practitioners working with patients considering aid in dying can obtain multiple copies at the same URL.

The Academy welcomes donations to support our crucial work (<https://www.ACAMAID.org/donateonline/>). Your gift will:

- ✦ Improve access to and knowledge about medical aid in dying.
- ✦ Provide an opportunity for clinicians to participate in discussions and explorations critical to end-of-life care.
- ✦ Increase evidence-based knowledge to inform the care of all terminally ill patients considering medical aid in dying.
- ✦ Sponsor conferences and trainings.
- ✦ Continue our unique Patient-to-Doctor Referral System.
- ✦ Provide clinical consultations by aid-in-dying experts.
- ✦ Continue investigations and data collection.
- ✦ Inform patients and their loved ones about aid in dying.