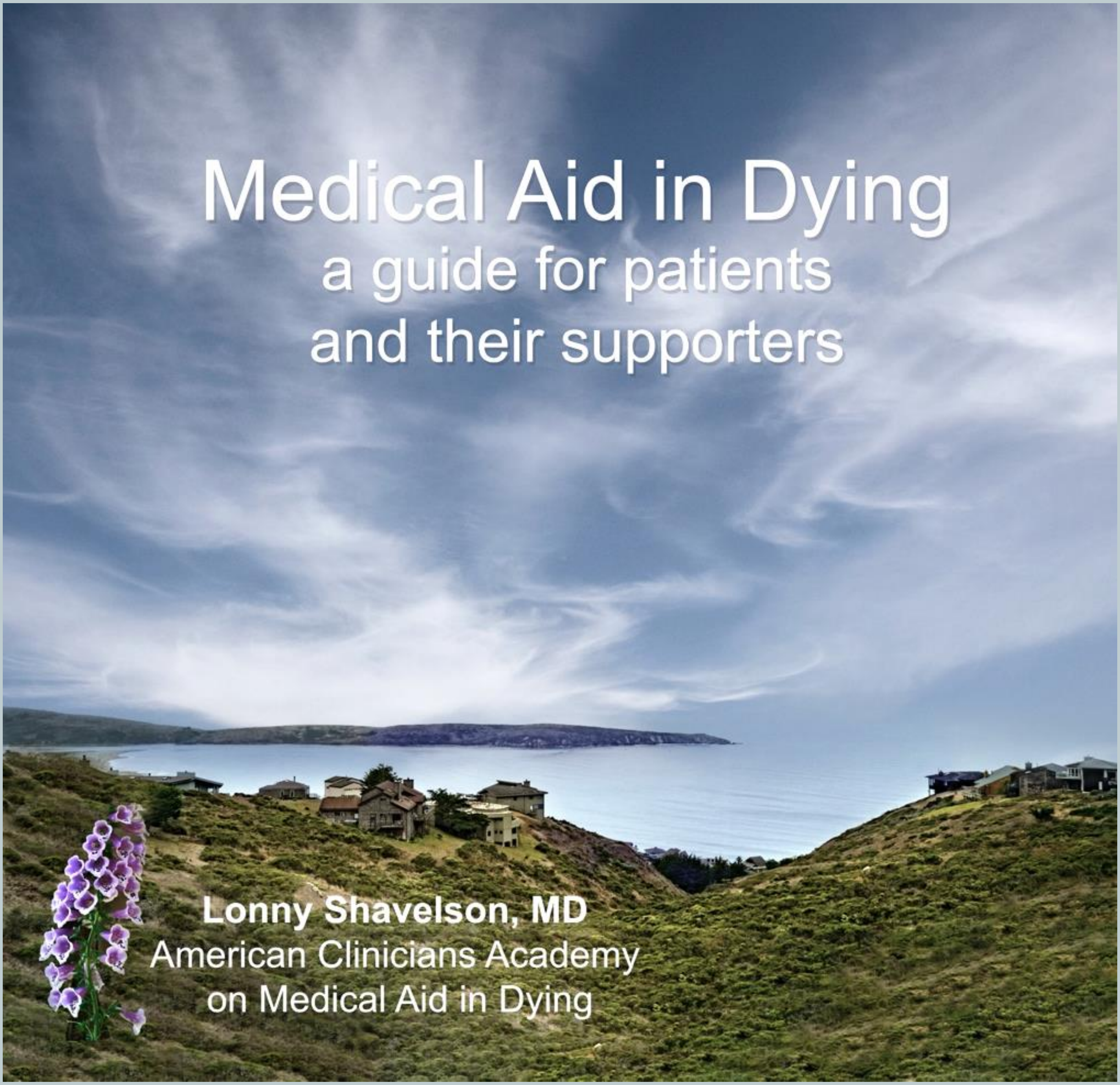


Medical Aid in Dying

a guide for patients
and their supporters

Lonny Shavelson, MD

American Clinicians Academy
on Medical Aid in Dying

Note: For a concise, more practical summary of the many issues related to medical aid in dying discussed in this booklet, please see the companion three-page pamphlet.

About the Author

Dr. Lonny Shavelson has been deeply interested in issues about 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. Dr. Shavelson was also involved in the writing of amicus briefs for the Supreme Court when it considered the issue in 1996, Vacco v. Quill.

In 2016, when California's End of Life Option Act 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 2020, he was the lead organizer of the first National Clinicians Conference on Medical Aid in Dying, held at UC Berkeley. In August of that year, Dr. Shavelson closed his medical practice to new patients and became Chair of the newly founded American Clinicians Academy on Medical Aid in Dying. His work with the Academy focuses on innovating and advancing clinical knowledge and best practices, teaching, and consulting.

Before establishing his aid-in-dying practice, Dr. Shavelson was an emergency department doctor for 29 years, then seven as a primary care physician in a clinic for immigrants and refugees.

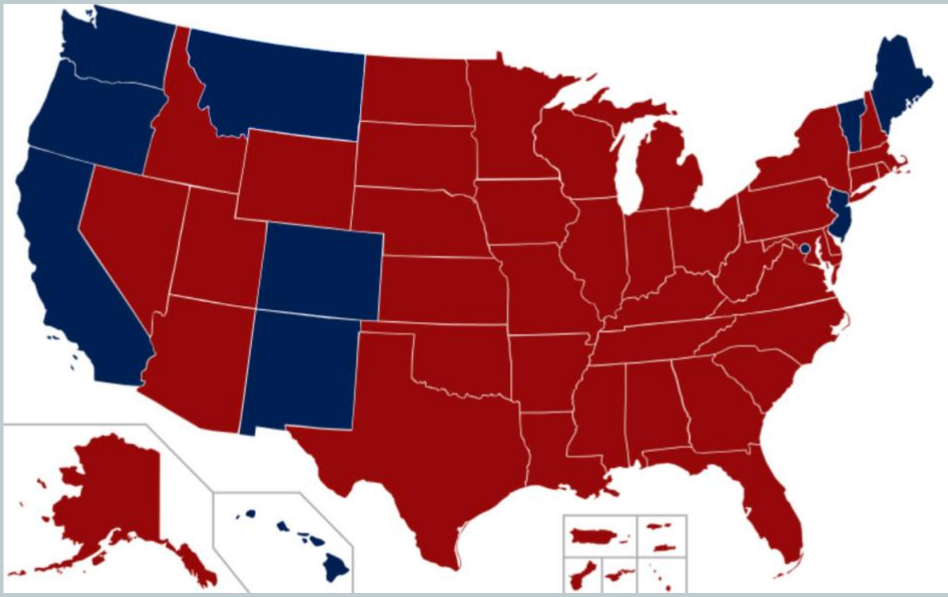
Dr. Shavelson's books include: *I'm Not Crazy, I Just Lost My Glasses*; *Toxic Nation: The Fight to Save Our Communities from Chemical Contamination* (with Fred Setterberg); *Hooked: Five Addicts Challenge Our Misguided Rehab System*; *Under the Dragon: California's New Culture* (with Fred Setterberg). He also filmed and produced the feature documentary, *Three to Infinity: Beyond Two Genders.*

Introduction

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, loved ones and the many others who support them. Its goal is to demystify and facilitate the process of medical aid in dying.

My discussions and recommendations in this booklet are the result of 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 is a baby, well, maybe an adolescent. 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 10 states plus Washington D.C., 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.

But just qualifying legally does not provide terminal patients contemplating an assisted death with the compassionate and supportive care and information they so urgently need. To move past the focus on the legal over the clinical, 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, read only certain sections — and carefully contemplate how what you’re reading may or may not pertain to you and your circumstances.

The newly granted 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 acceptable 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 possibilities to contemplate as you make plans for your impending death. So 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 take medications 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 will 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. So 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 hope (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. You may hear about everything from blocked bowels to delirium, bone pain to vomiting. Or, your doctor may 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 to your death.

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 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 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
- Take a new look at your own death

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.

The option of palliative care

- Palliative care relieves symptoms and suffering even as a disease gets worse
- Palliative care clinicians learn never to use the term, “Nothing more can be done.”

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 serious 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, become essential.

A clarification: Palliative care is not just for people who are dying. It can be extremely helpful for those with all serious illnesses, 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 as death nears, without focusing on treating the underlying disease or extending your life. Palliative care can focus on 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 learn never to use the term, "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. Palliative care's essence is that even as your disease gets worse, palliative care makes 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 and active 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, palliative care is increasingly in the realm 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 out-patient 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.

In short, even if you are strongly considering medical aid in dying, I urge you to obtain 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

If there is any part of medicine that is often misunderstood, it is hospice care. For starters, 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. Hospice care comes to you, rather than you going to hospice.

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 24 hours, and they don't provide daily bedside care. The hospice team works with you and your support group, to educate and help all 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.

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, or anyone 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, 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 will 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 65 to get the hospice Medicare benefits — you qualify if you're terminally ill with a less than six-month 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 days to months 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 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 way 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
- 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.

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

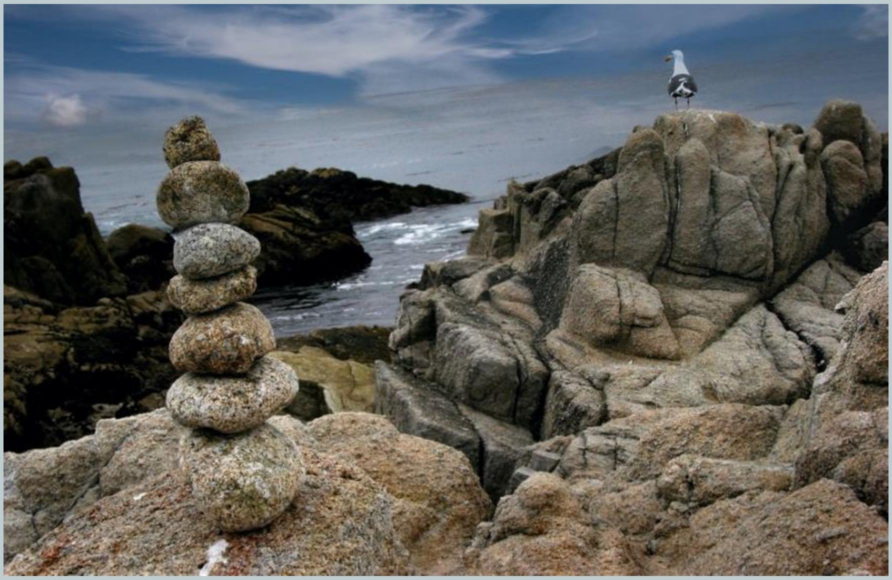
- Hospices have varying policies on their depth of involvement with aid in dying
- Most hospices provide non-judgmental conversations about aid in dying
- Many hospices provide full aid-in-dying support along with their palliative care

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. 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 to work with hospices and patients to reach 100 percent participation.

Here’s another reason why: 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. And the best way to assure that patients considering aid in dying aren’t being forced to that decision by poor end-of-life treatment, is to ensure they’re receiving hospice care.



Family, Cultural, and Spiritual Concerns

“What if I’m sure about taking medications to die, but my family or others I’m close with 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

One thing is certain — this is not the first time you and those you love have 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 family 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 you’d like. And if you consider their opinions and choose to go ahead with aid in dying, anyway, mostly, the family adjusts: “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 the family or 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. Spiritual teachings often revolve around prohibitions against suicide. 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 does consider aid in dying to be suicide, explicitly prohibited in Catholic teachings. Yet even 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, Native American spiritual guides, and representatives of more spiritual faiths than I can name. I’ve also heard of people with terminal illnesses whose spiritual advisors said that God will punish them if they take medications to bring on their deaths.

In other words, 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. Generalizations simply don’t hold up.

And remember, your hospice has a chaplain to guide you in 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 by taking medications to die at the time of your choosing. How do you achieve that goal?

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/2nd-opinion doctor.

“OK, I qualify. How do I begin the process toward 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.

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

Crucially, be sure you really do have the necessary two aid-in-dying doctors. Even if your doctor has said, “I support your decision to consider taking medications to die,” that may mean they support the idea, but it doesn’t necessarily indicate they’ll act in the very specific legal roles of:

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/2nd-opinion physician. This doctor meets with you (it can be by telemedicine), reviews your relevant medical records, and agrees (or not) that you are eligible for aid in dying. The consulting physician is not 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/2nd-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 that on their web sites).

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 they will help connect you with a participating doctor in your geographic area. You can find the form here, at https://www.acamaid.org/patientintake/.

"Now that I'm sure I have both doctors lined up, what's next?"

- There are usually two verbal requests and some forms to sign (varies in each state)
- There is a variable waiting period, so be sure you start 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."

- 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.

The items above 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 those clinical “best practices,” please read on.

Preparing for the Aid-in-Dying Day

- 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. Obtain advice
- Observe your own unique progression toward death, it’s an important guide

First, continue your end-of-life palliative care.

Your clinical 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 major factor, you should also take advantage of deeply honest conversations with selected family members, your end-of-life support team, your doctors, nurses, social workers, chaplains, therapists, personal spiritual counselors, or whoever you are comfortable with and trust.

But remember — waiting to see how your individual death is evolving is often your best guide. If you’ve expected to have severe pain but are not experiencing that, 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 adequate 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 have too 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 for diapers), since they don't have to struggle to get out of bed to the bathroom so often or so suddenly.

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, or why, or when. Be patient. I've learned to listen for the words, "I am so tired, I've had enough. I'm ready." In fact, that's the most common expression 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.

"I've decided to take the medications to die. Soon. Now what?"

- Check in with your attending/prescribing physician before you proceed.

If you've considered the various themes discussed above and 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 by phone, telehealth, 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.

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

- The day you die is often filled with anxiety and worries
- 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

Every option about who should be with you on the day of your death is possible. 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, we’d rather you don’t die alone, even if you’ve been a highly independent person all of your life.

If you have no one to 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, feel free to contact the Academy at ACAMAID@ACAMAID.org. They have contacts nationally and can likely recommend someone to be with you. Or, fill out their “Attendant Referral Form” here, 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 have plans for family, loved ones, friends or other caregivers to be with you on the aid-in-dying day. But I still strongly recommend that someone who is specifically skilled and knowledgeable about aid in dying also be there. 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.

Patients who have knowledgeable clinicians present 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.

I’m 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 2- to 4-ounces in 2 minutes (if you can’t swallow, see below)

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 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.

*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.

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 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.

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.

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 four ounces of a thick, bitter-tasting liquid in two minutes. Or, you'll rapidly swallow two ounces of medications, followed by two ounces of a clear liquid (water or juice). 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 non-toxic 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 may 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 may 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.

- 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 still have the ability 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 www.acamaid.org/PEGTubes.

- Nasogastric (NG) tubes: Less commonly than direct-to-stomach feeding tubes, some patients have had thin tubes placed through their nose and 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 www.ACAMAID.org/ostomies.

- Rectal catheter (enema):

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 www.ACAMAID.org/rectalmeds.

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.

- Many but not all patients with paralyzing illnesses can still participate in aid in dying
- Legal restrictions about self-administration can prevent some paralyzed patients from taking aid-in-dying medications

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 3 Days Before Your Aid-in-Dying Day

Since most patients and their supporters have never been at an aid-in-dying death, the Academy has produced a short video, with actors, showing an aid-in-dying day. 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. https://www.acamaid.org/video-enactment/.

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 intestinal function, which will help the transport and absorption of the aid-in-dying medications. The better 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 assuring that 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.

Finalize your (and your family’s) after-death plans

- Establish the timing of your aid-in-dying day
- Plan now for what will happen right after you die

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 the 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, or to tell the funeral home to come as soon as possible. There is no correct timing, but it’s best for the 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.

Plan the timing of the aid-in-dying day: The best time of day to take aid-in-dying medications is around 11AM or noon. 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.

The Day Before Your Death

- ❖ Gather the materials for the procedure
- ❖ Eating, and other preparations before you take medications to die

- **Juice:** Purchase at least 8 ounces of clear apple juice (not the unfiltered, thicker kind) and some fat-free popsicles or sorbet (details below).

- **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 8 hours before you take the medications, then stick to clear liquids in small amounts to keep from being 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 bind 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)
- How to handle these dangerous medications safely (hint, control your pets)
- The best ways to ingest the medications

Some technical details

You will have received the medications as powder in a bottle (usually a 4-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 alcohol 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 the patient (unusual), a family or other support-team member, or a clinician/attendant present on that day. Some hospices do not let their staff mix the medications. Check with your hospice to see if this is the case.

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 become a suspension of the powders. 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've had nightmares of 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, 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.

This is essential: 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.

There are three crucial methods of improving the taste and avoiding burning:

- Sorbet and/or popsicles (the flavored-ice kind, with no fat in them; no Creamsicles or Dreamsicles): 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 2-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 3 to 5 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.

An interesting observation: Immediately after taking the aid-in-dying medications, the patient can get a bit euphoric (high). I tell them about this, and advise them to move into the feeling — it's a pleasant sensation of floating just before they lose consciousness. In fact, "Oh, wow," are common last words for an aid-in-dying patient.

You might also notice that patients scratch their noses just before falling asleep. That's the effect of the medicines, a good indication they're starting to work.

"What happens after I take the medications?"

- How do the medications work?
- What will I feel when I take them?
- How long will it take me to die?
- For those around me, what will my death look like?

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 3 to 5 minutes after taking the medications, occasionally up to 10 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 the family 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.

Then, the wait begins — for your family, 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.

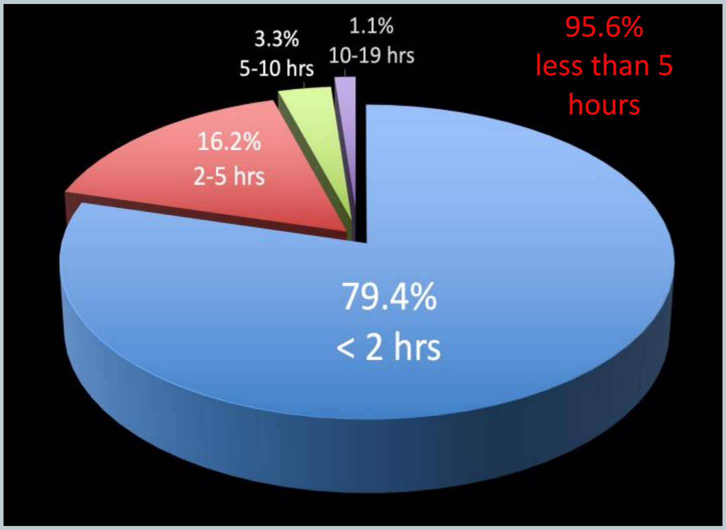
Seizures are very rare during aid in dying, typically for patients with brain disease (from strokes to tumors). If a seizure does occur, you'll be unconscious and won't feel it. But it can be upsetting to whoever is with you. These rare seizures pass within minutes. Nothing needs to be done by anyone 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 10 to 30 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: (This 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 5 hours are up. So, 96 percent of patients die within 5 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 5 to 10 hours. And about 1 in 100 patients live on for up to about 20 hours.

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 live that long. 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": 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 at www.acamaid.org/redflagchecklist/, to prevent prolonged deaths or complications.

"What happens 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 lay at your side and hold you gently to them. Soon after, the family 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 15 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. After that deep gasp, 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. Aid in dying does not prevent these events as death approaches, but it does speed up the process.

Finally, your loved one 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. I've seen patients not take a breath and have no pulse for up to five minutes and then start breathing again and their pulse returns. This can be frightening if you don’t know it may happen.

These long pauses in breathing are an indication that death is very near, but not quite there yet. Once you have seen no breathing at all for ten 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 one is there. That’s why I recommend waiting for the absence of breathing for ten 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

- What happens soon after I die?
- Your family will pause, 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 than other at-home deaths. The first thing to do is pause, 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 than other deaths is that sometimes close family members have been so focused on the method of death and all of the preparations that they’ve lost track of the significance of 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. There’s a deep sadness and mourning, and aid in dying does not change that.

I’ve heard rumors that an aid-in-dying death can be a “celebration of life.” But I’ve yet to see that 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 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

- Is grieving after an aid-in-dying death different than other grieving?

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 difficult grief process, mostly from ambivalent feelings about assisted deaths, or anger that the patient ended their life while quality still seemed to remain.

Interestingly, though, the study authors concluded that many grief 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 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.

We at the American Clinicians Academy on Medical Aid in Dying have had a number of requests to form specific support groups for loved ones grieving after an assisted death. We're working to form such groups, so if that interests you please write to the Academy at ACAMAID@ACAMAID.org to get updates.

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

There's one type of grieving that is unique to aid in dying, for families and supporters of a patient who deeply desired a physician-assisted death, but couldn't achieve that goal. That may have been because they couldn't connect with a participating doctor, or 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. "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 — from failing to satisfy the final wishes of someone you deeply love.

Which is one reason I've written this booklet. If this has been a helpful guide for you and your family as you consider medical aid in dying, I thank you.

Lonny Shavelson, MD
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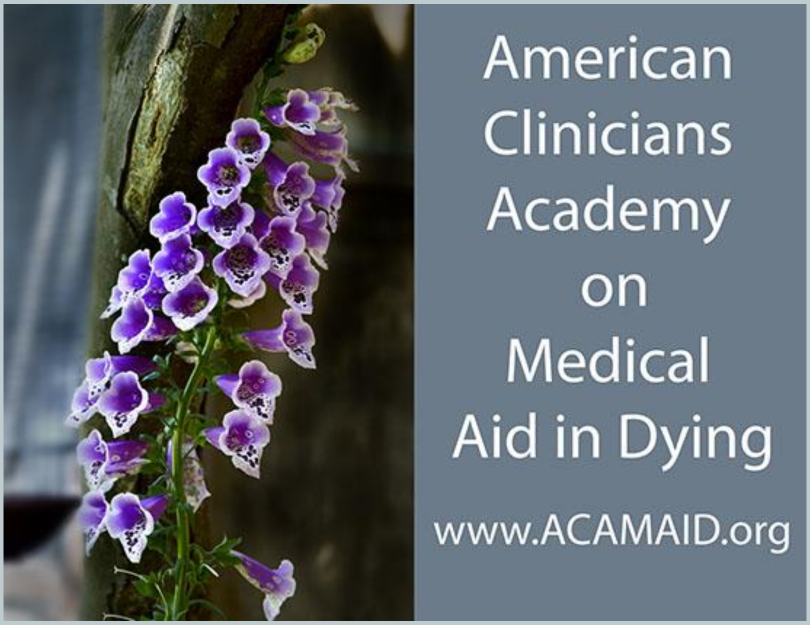
American Clinicians Academy on Medical Aid in Dying



Photographs by Lonny Shavelson

This booklet is provided without charge to patients and families who are considering medical aid in dying. You can request a copy at www.ACAMAID.org/patientbooklet. Organizations working with patients considering aid in dying can obtain multiple copies at the same URL.

The Academy welcomes donations to help with these and other expenses at https://www.acamaid.org/donateonline/. Please support our continued work to educate clinicians, patients, and families about medical aid in dying.