

Planning and Preparing for the Aid-in-Dying Day

Once you are eligible for medical aid in dying, new needs and questions often arise. This handout is intended to help you think through timing, preparation, and what to expect on the aid-in-dying day.

How will I know if and when to proceed?

- **Stay in close contact with your care team**

Please stay in close contact with your prescribing provider and your hospice or palliative care team for support and guidance. Patients are never obligated to take their aid-in-dying medication, and it is entirely normal to change one's mind. Many people are surprised to find that their natural dying process is more peaceful than expected, especially with quality hospice care. In these cases, patients often continue on their natural course and die without using the prescribed medication.

- **Understanding your “window of opportunity”**

There is a specific window of opportunity for aid in dying. It opens once a patient is determined eligible and closes if the patient permanently loses decision-making capacity or the ability to safely ingest and absorb the medication. Your attending prescribing provider, working closely with the hospice or palliative care team, can help guide you about whether and when to proceed. While no clinician can predict exactly when a person will begin to die, clinical updates can help you stay informed about your condition and timing considerations. When patients become weaker, bedbound, sleep most of the time, lose appetite, show changes in alertness or vital signs, or experience worsening symptoms, these may be signs that the body is preparing for death and that the opportunity for aid in dying may be closing soon.

- **Managing symptoms so you do not feel rushed**

Any uncomfortable symptoms can and should be well managed, so that the decision to proceed with aid in dying is not driven by unmanaged discomfort. Hospice or palliative care teams can help ensure that symptoms such as pain, nausea, or shortness of breath are well controlled. Some hospices fully train and support their staff to provide attentive care for patients considering aid in dying. For referrals, please fill out our intake form at this link.

- **Your reasons are your own**

Patients are not required to justify their decision or prove that they are suffering. While it is important to discuss your thoughts with a trusted provider, your reasons for proceeding may be entirely private and personal.

How do I prepare?

- **Planning for all possibilities**

It is important to have detailed plans and good bedside care, such as hospice, in case you lose the mental capacity or physical ability to safely proceed with aid in dying. If needed, your loved ones or other bedside attendants should be prepared to provide comfort and vigil care, including repositioning, cleaning, and giving comfort medications. Ask your hospice team or healthcare provider to help you develop this plan.

- **Arranging bedside support for the aid-in-dying day**

This can be a very tender and stressful day, and having the right support can make it easier for everyone. The patient must be able to self-administer the aid-in-dying medication, but others can still help with the surrounding tasks. End-of-life doulas or trained aid-in-dying volunteers can often provide bedside support when hospice or facility staff are unable to be present, including preparing the medications and remaining at the bedside to support your loved ones. Typically, state end-of-life choice organizations can help refer patients to these helpers, and some hospices may also offer or coordinate this support.

- **Medications and symptoms in the days before the aid-in-dying day**
Constipation, diarrhea, nausea, and vomiting should be thoroughly managed, ideally with non-sedating medications, to help maintain alertness and decision-making capacity. However, comfort medications should never be withheld, and all distressing symptoms should be well controlled. Stay in close contact with your prescriber with any questions or concerns.
- **Keep the aid-in-dying medication safely at the pharmacy**
For safety, the aid-in-dying medication should be kept at the pharmacy until your plans are finalized, and the date is near, typically just a few days beforehand. This helps ensure the medication does not pose a risk in your home and prevents loved ones from having to dispose of it. Pharmacies can typically deliver the medication promptly when needed, and you will not be charged while it is being securely held.
- **If you live in a facility**
Make sure that facility staff or caregivers are sufficiently informed in advance. Skilled nursing facilities may legally prohibit aid in dying on their premises, while other facilities may have different requirements.
- **If you need an alternate location for the aid in dying day**
If the patient intends to use a short-term rental, the owner or operator should be informed, at a minimum, that the patient is seriously ill and very likely to die on the premises. A friend's or family member's home may be a workable alternative if needed.
- **Practice swallowing or using non-oral routes**
Once your plans are set, practice swallowing two to four ounces of a slightly thickened liquid, such as a smoothie, each day. This helps ensure that you can swallow comfortably when the time comes. If you plan to use a non-oral route, practice pressing the plunger and emptying a 60 mL or 100 mL syringe filled with water into a bowl. This practice can help you feel more confident and prepared for the aid-in-dying day.
- **The day before and the morning of the procedure**
Scheduling the procedure in the morning can help ensure there is adequate time for attendance and support. Consider saying goodbye to loved ones in the days leading up to the planned day, while keeping only your closest companions nearby for your final moments. The night before, stop taking all solid food after midnight and consume only clear liquids afterward. Many patients choose to wear an incontinence brief for comfort, although passing stool is uncommon.

What happens during the procedure?

- **Support on the day of death**
The aid-in-dying procedure is generally very peaceful when you and your loved ones know what to expect and feel well supported. Having knowledgeable hospice staff, an experienced clinician, an end-of-life doula, or a trained aid-in-dying volunteer at your bedside can help ensure a calm process and allow your loved ones to focus on being with you.

- **Preparing the medications**

The medications come in powder form and must be carefully mixed with clear, filtered apple juice. For detailed step-by-step instructions, please see our handout “Preparing the Aid-in-Dying Medications.” The Academy strongly recommends having an experienced clinician or skilled attendant manage this preparation, which can reduce stress during this tender time and minimize the amount of medical detail your loved ones have to handle.

- **Taste and physical sensations**

When swallowed, the medication may cause a burning sensation or a bitter taste. This can be soothed by a non-fat popsicle or a few teaspoons of non-fat sorbet before and after taking it. Sitting upright during swallowing can help prevent coughing, and it is best to remain upright until sedation begins to take effect.

- **If you cannot swallow the medication**

Some patients are unable to swallow but can self-administer the medication by pushing it into the GI tract through a tube, such as a PEG, ostomy, or small rectal catheter. Non-oral routes require significant clinical support. If you need a provider who can manage a non-oral route, please fill out our referral form at this link.

- **What to expect after taking the medications**

After taking the medication, most people become sleepy within five to ten minutes and then enter a comfortable coma. Their breathing may slow and seem to pause, and their skin color may change; they may also take a few very deep, sudden breaths that can look alarming, but they will not be aware of these changes and will not feel discomfort. For many, breathing and the heart slow down and stop over the next two hours; for some, this can take longer if their body absorbs the medication more slowly. They will remain comfortable during this time. Once there have been no breaths for 10 minutes and there is no heartbeat in their neck, the patient has died.

What about my loved ones after I die?

- **What your loved ones should do right after death**

Loved ones or bedside attendants should call hospice or the attending provider once no breaths or neck pulse have been detected for at least 10 minutes.

- **Death certificate and life insurance**

According to the law, the death certificate will officially list the patient’s underlying medical condition as the cause of death, not medical aid in dying. Life insurance companies are legally prohibited from canceling policies for patients who pursue aid in dying.

- **Grief support**

In general, families are not at higher risk of complex grief simply because their terminally ill loved one took aid-in-dying medication and died. Hospices and various nonprofits offer specialized grief support for families. Contact us for details.

For patients traveling from out of state

- **Plan extra time for evaluation and support**

If you decide to travel to another state and choose to proceed, arriving at least three to seven days in advance of your planned death is strongly recommended. A patient’s condition is very likely to deteriorate,

which may mean increased fragility and the need for more care. Arriving early allows time for thorough evaluation and preparation, helps minimize risks of adverse outcomes, and supports a more peaceful experience for both you and your loved ones.

The Academy of Aid-in-Dying Medicine is a national 501(c)(3) nonprofit. Our mission is to develop and promote best practices for the care of patients considering or completing medical aid in dying, so patients and families receive safe, compassionate, evidence-based support at the end of life. We are able to offer education and guidance because of the generosity of patients, families, and clinicians who value this care. To learn more or to donate, please visit us at AADM.org