

501(c)(3) supporting best practices for the care of patients considering or completing aid in dying

Initial information for patients considering aid in dying

We recognize that contemplating end-of-life decisions can be challenging. The Academy is here to offer support as you explore the option of medical aid in dying. Navigating healthcare systems, finding providers, and managing the process can be unexpectedly complicated. We hope to provide comprehensive information to help you make well-informed choices that align with your values and wishes.

Becoming eligible requires patients to meet several legal criteria. You must be an adult resident of a state where medical aid in dying is legal, have a medical diagnosis with a prognosis of six months or less, possess the mental capacity to make your medical decisions, and be physically able to self-administer the prescribed liquid medications, either by swallowing or by pushing them into your GI tract through a feeding tube or catheter (rectal or ostomy). Patients must voluntarily and independently request evaluation for this option from two participating providers. Suffering or having a verified plan is not required, and patients are never obligated to take the medications to die.

The process to become eligible for medical aid in dying formally begins when you make a direct verbal request to a participating provider who agrees to serve as your "attending" or prescribing clinician. This clinician will document your request in your medical chart and begin the evaluation and counseling process. A "consulting" or second clinician must also review your records and confirm your eligibility. If there are questions about your capacity to make your own medical decisions, an additional capacity evaluation may be required by a mental health professional. In some states, you must complete a written request form that two other individuals must witness. Patients who require translation will have to complete an additional form. The attending/prescribing provider, if they agree that you meet the legal criteria, may take a second verbal request at any time after a mandated waiting period, which varies from 2 to 15 days in different US states. This completes the eligibility process.

Verifying eligibility may take considerably longer than the mandated waiting period. If you think you may want this option at some point in your dying process, starting the process early can prevent unnecessary stress or urgency. Being deemed eligible does not require you to take the medications to die; it simply provides you with the option to do so.

If you are found ineligible, you may be reevaluated later if your condition changes. Ask your provider for guidance about when this might be indicated.

The costs for aid-in-dying care can vary. If your medical organization or hospice permits its providers to participate, there is no additional out-of-pocket expense for this service. Independent doctors who offer this care usually charge a fee based on a sliding scale, although some can bill insurance, while others volunteer their services. The medications are seldom covered and generally cost around \$700.

We strongly recommend that you consider (and carefully choose!) hospice care, regardless of how your end-of-life journey unfolds. Hospice services provide expert symptom management, support for your loved ones, and comfort care, regardless of how your situation evolves. Your condition may change quickly or unexpectedly, so it's important to have solid backup plans and to prepare your caregivers for all contingencies.

While most hospices will provide "support" to patients considering or using medical aid in dying, the actual care can vary greatly. Ask about the specific aid-in-dying services their staff can and cannot provide. Some hospices prohibit any participation in aid-in-dying; others allow their providers to act as attending prescribers or consultants, while some only permit them to serve as consultants. Some hospices train their bedside staff to coordinate care with

prescribers and manage non-oral routes. Some allow nurses to prepare the medications and stay with you when you take them, right up to your death. Others do not allow staff to prepare the medicines and require them to step away before you take them, leaving you and your loved ones to handle this stressful process on your own.

Transferring from one hospice to another that provides aid in dying care is an option, although it takes time to become an established patient, involves a new care team, and sometimes requires switching medical equipment.

If you live in a facility, make sure to ask about their policies as well. Skilled nursing facilities may legally "opt out" and not allow aid in dying on their premises. Other facilities, such as assisted living, must allow you to do what you choose in your own apartment or room, though medications might need to be delivered to a family member. Policies and practices can vary among different types of facilities.

If you cannot proceed with aid in dying in your current location, consider alternative options, such as staying with a friend or family member for the day. You might also use a short-term rental or hotel, but it is important and ethical to notify the property owners beforehand about the possibility of a death happening on-site. This helps prevent unexpected legal or coroner-related issues that could occur afterward.

If your condition requires a non-oral route of self-administration, especially via a rectal catheter or ostomy, having a medical professional present to monitor, prepare, and attend to the procedure helps ensure a safe and smooth process. Independent providers, some hospices, and private-duty nurses can provide this care.

Some patients may choose to relocate to states where aid in dying is legal so they can access it as an option. Keep in mind that the evaluation process and taking the prescribed medication to die must happen within that state's borders. Transporting lethal medications across state lines is generally not legal and could be considered "assisting a suicide" in states without aid-in-dying laws. Residency requirements and waiting periods vary. We recommend careful consideration of the financial and emotional burdens involved in moving across state lines for aid-in-dying. It is often very hard for a sick patient to leave familiar surroundings and loved ones, and they may decline rapidly as a result.

We recommend several key preparations to ensure a safe and peaceful process. For safety, the aid-in-dying medications should be kept at the pharmacy until your plans are finalized and the date is approaching. If you decide to take the medication to die, we strongly advise having an experienced clinician—such as a hospice nurse, end-of-life doula, or volunteer—at your bedside to help manage the procedure. The aid-in-dying day can be very emotional and stressful. An experienced clinician can handle the medical details, allowing you and your loved ones to focus on each other. If your hospice staff cannot provide the attentive bedside care you and your family need, privately hired end-of-life doulas or volunteers from various non-profit organizations can provide this vital support.

The procedure is generally very peaceful when you and your loved ones know what to expect and have good support. As a reminder, to proceed, you must have mental capacity and be able to take the medications without assistance. The medicine comes in a powder mixed with 2 ounces (1/4 cup) of clear, filtered apple juice. The suspension tastes bitter and may cause a burning sensation, which a popsicle can soothe and that fades quickly as sedation begins. Typically, after taking the medications, deep sleep and then a coma occur within about 5-10 minutes, and most deaths happen within 2 hours. Some patients' conditions lead to slower absorption of the medications, and in these cases, death may take longer, sometimes up to a day. But remember, the patient will remain comfortably unconscious throughout the entire process.

After your death, according to law, your death certificate will officially list your underlying medical condition as the cause of death, not medical aid in dying. Notably, life insurance companies are legally prohibited from canceling policies for patients who pursue aid in dying. Hospices and various nonprofits offer specialized grief support for families.

We hope our information and support is helpful. Please consider donating to AADM.org.