

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 an emotionally challenging experience for you and those close to you. The Academy is here to offer support as you explore the option of medical aid in dying. Navigating the healthcare system to find providers who support and can guide you through the process can be unexpectedly complicated. We hope to provide comprehensive information to help you make a well-informed choice that aligns with your values and wishes.

The Academy of Aid-in-Dying Medicine 501(c)(3) offers more information and free patient referrals on its website, AADM.org.

Becoming eligible requires patients to meet several requirements. Patients must independently and voluntarily request this option from two participating providers, who then assess their eligibility based on the legal requirements. To qualify, individuals must be adult residents of the state with a terminal diagnosis and prognosis of six months or less, have the mental capacity to make their own medical decisions, and be physically able to self-administer the prescribed liquid medications either by swallowing or by pushing them into their GI tract through a feeding syringe and tube via PEG, ostomy or small rectal catheter.

To initiate the process for medical aid in dying, you must first make a direct 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 witnessed by two others. Patients who require translation will have to complete an additional form. The attending/prescribing provider, if they agree you meet the legal criteria, takes a second verbal request 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, so starting the process early is advisable to avoid unnecessary stress or urgency. Being deemed eligible does not obligate you to use the medications; it simply provides you with the option.

If you are found ineligible, you may be reevaluated later if your condition changes.

The fees for aid-in-dying care vary. If your medical organization or hospice allows their MDs to act as prescribing physicians, then there is no further cost other than paying for the medications (about \$600 to \$800 - hospices cannot cover this). If your hospice or medical organization doesn't allow their MDs to participate, they may be able to refer you to outside independent physicians, some who can bill insurance or work voluntarily, and some who work for fees based on a sliding scale.

We strongly recommend that you consider (and carefully choose!) hospice care, regardless of how your end-of-life journey unfolds. Good contingency plans and supportive care at the end of life are essential. Hospice services offer expert pain management, comprehensive symptom control, support for your loved ones, and comfort care, no matter how your end-of-life proceeds. To ensure you receive care that supports all your end-of-life options, interview a few hospices before deciding. While most hospices provide some support for patients considering or using medical aid in dying, policies and care can vary significantly. It's crucial to ask about the specific aid in dying

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care their MDs and RNs can and cannot offer. Some hospices do not allow their MDs to participate in aid-in-dying, others allow their doctors to act as prescribers or consultants, and some only permit them to act as consultants. Some hospices permit their nurses to monitor patients, prepare these dangerous medications, manage non-oral routes, and remain at your bedside during ingestion through to your death, while others do not.

If you live in a facility, be sure to ask about their policies as well. Skilled nursing facilities may legally not permit 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, but policies can vary at different types of facilities.

If you cannot proceed with aid in dying in your current location, alternative plans, such as going to a friend or family member's home for the day, are reasonable options. Short-term rentals or hotels may also be an option, but they require prior permission from their owners.

If your condition requires a non-oral route of self-administration, especially via a rectal catheter or ostomy, a medical presence (MD or RN) to monitor, prepare, and attend to the procedure helps ensure a safe and peaceful process. Many independent MDs, some hospices, and private-duty nurses can provide this care.

Some patients may decide to move to states where aid in dying is legal so they can have aid-in-dying as an option. Bear in mind that the evaluation process and the self-administration of aid-in-dying medication must occur within that state's borders. Transporting lethal medications across state lines is not legal and could potentially be considered "assisting a suicide" in states where aid-in-dying laws are not in place.

We recommend a few 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 clear and the date approaches, usually within a few days. Then, they can be promptly delivered. If you decide to take the medication to die, we strongly suggest you have 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 take care of the medical details, freeing 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 offer this essential support.

The procedure is generally very peaceful when you and your loved ones know what to expect and are well-supported. As a reminder, patients must have mental capacity and the ability to self-ingest on the day they take the medications to die. The medications come in a powder mixed with 2 oz clear filtered apple juice. The suspension tastes bitter and can cause a burning sensation, which can be soothed by a popsicle before and after ingestion and fades quickly as the sedation begins. Typically, after you take the medications, deep sleep and then a coma occur in about 5-10 minutes, and the majority of deaths occur within 5 hours. Some patients' illnesses cause medications to be absorbed more slowly, and those deaths can take longer. But remember, you will be comfortably unconscious during that entire time.

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.

The Academy offers more information and free patient referrals on our website at AADM.org.

You'll find more comprehensive information in our booklet - free to download or for a small fee from Amazon.



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

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