

California End of Life Option Act

Information, Suggestions and Options for Patients

What is the California End of Life Option Act?

The California End of Life Option Act allows physicians to prescribe an aid-in-dying drug for individuals who qualify under the Act. One goal of this act is to allow specific types of terminally ill patients, those with six months or less to live, to bring about the end to their lives in a peaceful way at a time of their choosing.

What makes you eligible for the medical aid-in-dying drug in California?

The California End of Life Option Act has specific criteria that define which patients can access the aid-in-dying medication. You can qualify if you are:

- An adult (18 years of age or older)
- Terminally ill with a prognosis of six months or less to live, as determined by two physicians (your attending physician and a consulting physician)
- Mentally capable of making your own healthcare decisions without a psychiatric impairment that might interfere with this capacity
- Able to prove that you are a California resident
- Acting voluntarily
- Making an informed decision that includes having information about other end-of-life options that may be helpful to you
- Aware that you may choose to obtain the aid-in-dying drug but not take it
- Capable of self-administering and ingesting the aid-in-dying drug, without assistance from another person
- Willing and able to comply with all procedures, as required by the law

How do you obtain the aid-in-dying drug at UCLA?

- The process begins when you express a request for the aid-in-dying drug to your physician. There is no commitment that you use the drug by making the request. Your request starts a process in which you can obtain more information and your eligibility is determined. You decide if you want to take the next steps.

- If you think you might want an aid-in-dying drug and/or would like more information, you should tell your physician.
- If your physician is a participating physician (meaning he or she chooses to participate in the provision of aid-in-dying drugs as permitted by the Act), he or she will refer you to a clinical consultant who will help you and your physician comply with the law. Your advocate will also provide you with the opportunity to explore your thoughts and needs.
- If your physician is not a participating physician, he or she is not obligated by the law to act upon your request. You may choose to go to a different physician who is voluntarily willing to prescribe an aid-in-dying drug.
- If your physician does not prescribe the aid-in-dying drug, you can ask members of your medical team to connect you with a clinical consultant who will provide you with more information. No member of the UCLA medical team is obligated by law to participate, and thus, only medical professionals and staff who are voluntarily participating will assist you.

What are the responsibilities of the patient under the law to obtain the aid-in-dying drug?

Requests

- A total of three requests must be made.
 - Make two oral requests, 15 days apart, directly to your doctor. Neither of these requests can come from anyone else; they must be initiated by you and made voluntarily.
 - These requests can only be made to your doctor, and cannot be relayed to your doctor by a resident, fellow, nurse, nurse practitioner or any other medical employee.
 - Make a third written request, which can be done on the same day as the second oral request or at a later time. The written request must be made on the Request for an Aid-in-Dying Drug to End My Life in a Humane and Dignified Manner form. This form is available on the Medical Board of California website:
mbc.ca.gov/Forms/Licensees/aid-in-dying_request.pdf.

You can also ask your UCLA clinical consultant for a copy of the form.

Witnesses

- Your written request form must be signed by you and two adult witnesses.
- The two witnesses attest that to the best of their knowledge and belief, you are:
 - The person requesting the drug
 - Known to them or have provided proof of identity
 - Voluntarily signing the request in their presence
 - Appearing to be of sound mind and not under duress, fraud or undue influence

- There are also specific rules about who can be a witness, including the following:
 - Only one of the two witnesses to the written request may be related to you by blood, marriage, registered domestic partnership, adoption or be entitled to a portion of your estate upon your death.
 - Only one of the two witnesses may own, operate or be employed at a healthcare facility where you are receiving medical treatment, including a health facility where you reside.
 - A witness may NOT be your attending physician, a consulting physician, a mental health specialist or your clinical consultant.

Proof of Residency

- You must provide proof of residency in the state of California. Residency may be proved with one of the following:
 - A driver's license or other identification issued by the state of California
 - Registration to vote in California
 - Evidence that you own or lease property in California
 - Filing of a California tax return for the most recent tax year

Informed Decision

- You must make an informed decision that is based on an understanding and acknowledgment of relevant facts.
- These relevant facts must come from your physician and include:
 - Your medical diagnosis and prognosis
 - Potential risks associated with taking the aid-in dying drug
 - Taking the prescribed drug will likely aid your dying
 - The possibility that you may choose not to obtain the drug
 - The possibility that you may change your mind and decide not to take it
 - The availability of other feasible alternatives or additional treatment opportunities including, but not limited to, comfort care, hospice care, palliative care (symptom management) and pain control
- You may withdraw the request for an aid-in-dying drug at any time.
- You can decide that you do not want to ingest the drug at any time.

Required Form to Complete Before Using the Drug

- California state law requires that you complete a Final Attestation for an Aid-in-Dying Drug to End My Life in a Humane and Dignified Manner form 48 hours prior to ingesting the aid-in-dying-drug.

- This form restates your intent to take the drug and your awareness of the consequences. Even if you complete this form, you are not obligated to take the drug and can choose not to take the drug.
- You also need to identify someone who can deliver the final attestation form to your attending physician after your death. The form may be delivered by a family member, your healthcare provider (e.g., hospice) or another representative that you designate.

How does your family/caregiver fit into this process?

- You will be counseled by your physician and the clinical consultant about notifying a family member, if you have one, regarding your request for an aid-in-dying drug.
- You will not be denied access to the drug if you do not notify your next of kin or family member, although we at UCLA strongly encourage patients to discuss this important action with family members and/or those you identify as closest to you.
- Your physician and clinical consultant will also provide counseling on the importance of having another person present when you take the drug, although this does not have to be a family member. One important reason for this is that the drug must be ingested in a short period of time (two minutes) so that you do not fall asleep before taking the full dose.
- Your clinical consultant may be helpful in identifying how and what to tell your family members and if you deem it appropriate for them to participate in counseling sessions that would allow you and your family to talk about this action together.
- We recommend that you think about the impact that this action may have on your family members. End of life can be a particularly meaningful time for you and those who love and care about you. Shortening this phase could leave out the possibility for specific meaningful events and healing. There could be positive effects of shortening this phase and some unintended ones too. If you make the choice to proceed with the aid-in-dying drug, you might want to prepare those closest to you for your impending death. We encourage this for all of our patients as they face serious illness, but as the disease progresses, these communications are even more important.
- The people that love and care for you will miss you and grieve your absence in their lives. This is true whether you die from your illness or from ingesting an aid-in-dying drug. Sometimes, loved ones need time to talk about the loss and think about what it will mean to live without you. Families that approach end of life with open lines of communication are often more prepared and the survivors typically manage the grief process better than families that do not discuss the impending loss.

- End of life also provides an opportunity to express one's wishes and feelings such as sadness and grief. We encourage patients and families to take some time to think about the ways they may want to express themselves to each other. It can be a time to heal relationships, express and feel love, recount accomplishments, and share life histories. We encourage individuals to take this time to be thoughtful about their current situation and to make self-directed choices.
- Your clinical consultant will talk to you about whether there are any letters, videos or notes that you may wish to leave to specific people as legacies. Legacies can be last gifts of your words and feelings expressed to your loved ones. These can help facilitate healing through the grief process. (See article on legacies and ethical wills for more information.)

What are the responsibilities of the physician under the End of Life Option Act?

Attending Physician

- Your attending physician is one of your doctors who has primary responsibility for your healthcare. This will most likely be the physician who is caring for your disease (e.g., your oncologist, neurologist, cardiologist), but it could also be your primary-care physician or a palliative-care physician.
- Your attending physician, if he/she is participating in this act, is the one that will be responsible for writing the prescription for the aid-in-dying drug. Some patients may need to be referred to an additional attending physician that will participate and write the prescription. It is common for patients with complex medical conditions to have multiple attending physicians who care for them.

Examination

- The physician must examine you and determine if he/she believes that you have a terminal diagnosis with six or less months to live; he/she must document these findings in your chart.
- The physician must document both of your required oral requests for an aid-in-dying drug in your medical chart, and he/she must make sure that the requests are at least 15 days apart.
- The physician must put the completed Request for an Aid-in-Dying Drug to End My Life in a Humane and Dignified Manner form into your medical record. This form should be your third request (this is your only required written request).

Referral to a Clinical Consultant

- UCLA Policy requires that your physician also refer you to a clinical consultant.
- The advocate will:
 - Familiarize you with the law and what is required of you and your physicians
 - Discuss your understanding of your current medical condition and the meaning that having an aid-in-dying drug has for you
 - Provide you with appropriate referrals to additional resources that might be helpful to you
 - Facilitate a referral to an independent consulting physician, which is required by the law
 - Answer questions and help you, and potentially your loved ones, think through your thoughts, concerns and feelings as you go through this process
 - Advocate for you when appropriate and develop a plan to ensure that your needs have been met, and that you have made this decision on your own and have not been pressured by others.
 - The clinical consultant's goal is to ensure that a uniform practice is used here at UCLA, taking into consideration the needs of each individual patient

Counseling by Your Physician

- Your physician is obligated to discuss the following with you prior to writing a prescription for an aid-in-dying drug:
 - Explain and make sure you understand your medical diagnosis and prognosis and clarify any misunderstandings
 - Tell you about the potential risks associated with taking the aid-in dying drug
 - Inform you of the likely result of taking the prescribed aid-in-dying drug: the hastening of the dying process
 - Inform you that you may choose not to obtain the drug
 - Inform you that you may change your mind and decide not to take it at any time
 - Offer you other feasible alternatives or additional treatment opportunities, including, but not limited to, comfort care, hospice care, palliative care (symptom management) and pain control
 - Suggest to you the importance of telling your family and/or next of kin
 - Inform you that by law, you must take the aid-in-dying drug in a private place, and that it may never be consumed in a public place (beach, park, etc.)
 - Inform you to store the drug in a safe location where other people, such as children or vulnerable individuals, cannot access it
 - Inform you and your loved ones where to return this drug if there is any remaining or if you choose not to use it
- Your physician will request that you have someone involved with your care (a family member or friend) return your Final Attestation for an Aid-in-Dying Drug to End My Life in a Humane and Dignified Manner form to the prescribing physician.

Other Obligations on the Part of Your Physician

- Determine that you have mental capacity to make healthcare decisions
- Refer you to a mental health specialist (psychologist or psychiatrist) if he/she is uncertain of your capacity to make healthcare decisions or if there are indications that you have a mental disorder
- Make certain that you have seen a consulting physician to confirm that you have a diagnosis with an expectation of six months or less to live
- Ask you if you have changed your mind prior to writing the prescription
- Mail or hand deliver the prescription to the designated pharmacy (the physician cannot give you the prescription)
- Make sure that you are a California resident, as defined above
- Complete a checklist to make certain that all steps are followed
- At UCLA, your physician must complete a Physician Orders for Life-Sustaining Treatment (POLST) with you; this form reviews important issues such as Do Not Attempt Resuscitation (DNAR) requests. The POLST is described in more detail below.
- If at any point you are determined ineligible for this act, your physician who accepted the request and referred you to the clinical consultant must inform you of disqualifying reasons
- Your physician cannot prescribe this drug solely based on age or a disability
- Within 30 calendar days of writing a prescription for an aid-in-dying drug, the attending physician must submit a copy of your written request (the Request for an Aid-in-Dying Drug to End My Life in a Humane and Dignified Manner form) to the California Department of Public Health (CDPH) through the Office of Regulatory Affairs at UCLA
- Your physician will also be required to submit additional mandatory forms to the CDPH, as required by the End of Life Option Act

What are the responsibilities of the consulting physician under the End of Life Option Act?

- The consulting physician must examine you and determine if you have a terminal diagnosis with six or less months to live; he or she must document these findings in your medical chart
- Determine that you have mental capacity to make healthcare decisions
- Refer you to a mental health specialist (psychologist or psychiatrist) if there are indications that you have a mental disorder

What are the responsibilities of the mental health specialist (if you are referred to one) under the End of Life Option Act?

- The mental health specialist can be a psychologist or psychiatrist.
- The mental health specialist, through one or more appointments with you, will determine in his/her best professional judgment whether you have capacity — as defined by the Act — to make this decision and that you are not suffering from impaired judgment due to a mental disorder.

What can you expect from the pharmacist at UCLA under the End of Life Option Act?

- The pharmacist will fill the prescription and provide it to you or to an individual you have designated to pick up the drug.
- The pharmacist will educate you and provide information about the best way to ingest this drug.
- The pharmacist will educate you about an antiemetic (anti-nausea) medication and how to take it.
- The pharmacist will educate you about a timeline of eating, drinking and how to achieve the desired outcome of the drug while reducing the chance of other effects.

What other resources are available to me?

Psychological Support

- Having a serious illness is upsetting and it can cause feelings of sadness, depression, anxiety, loss, and fear. These feelings are normal under the circumstances. Many patients who experience these feelings benefit from someone that they can talk to about their worries and concerns.
- One role of the clinical consultant is to help address these issues and provide you with recommendations that may be helpful.
- Many times, patients benefit from both psychological counseling — especially by individuals who understand your disease — and appropriate anti-anxiety and anti-depressant medications; together, these interventions can help improve the quality of your life even though the disease may still be progressing.
- We want you to live as well as you can despite the limitations of the disease and even if you decide that using an aid-in-dying drug is the best option for you near the end of your life.
- Receiving psychological support, and/or taking anti-anxiety or anti-depressant medications, can be part of your end-of-life care, regardless of whether or not you choose to have an aid-in-dying drug available to you.

Palliative Care

- Palliative care focuses on symptoms such as pain, shortness of breath, fatigue, constipation, nausea, loss of appetite, difficulty sleeping, anxiety and depression. It also helps you gain the strength to carry on with daily life.
- Palliative care can and should occur throughout the entire continuum of care for cancer and other serious illness. It is more often associated with more advanced stages of the disease and is an important component of quality end-of-life care.
- Anyone receiving an aid-in-dying drug should be receiving palliative care for symptoms throughout their care.
- For patients who are considering an aid-in-dying drug, it is important that you have been given the opportunity to make certain that your symptoms have been well managed.
- You can arrange an appointment with a palliative-care physician to make certain that your symptoms have been addressed to the best capabilities of modern day medicine.
- In some clinics, there is a palliative-care nurse practitioner that can assist with these same types of symptoms.

Hospice Care

- Cicely Saunders, considered the founder of hospice, stated: "You matter because of who you are. You matter to the last moment of your life, and we will do all we can, not only to help you die peacefully, but also to live until you die."
- Hospice care focuses on quality of life rather than prolonging life.
- Hospice care focuses on employing medical care that alleviates symptoms, reduces suffering and improves quality of life. It is usually utilized in the final stage of care in a serious illness.
- Hospice care emphasizes the treatment/alleviation of physical discomforts, as well as psychological and spiritual discomforts, during a time when a life nears its end - although the timeframe may be somewhat uncertain.
- Hospice care is an option for humane and compassionate care when a disease cannot be stopped and comfort is the highest priority.
- Hospice is not necessarily a place, but a type of treatment. Hospice care can be done in the home or in a skilled nursing facility. There are few hospice programs that are actual free-standing facilities.
- The focus is on the patient and the family as a unit.
- Patients are best served on hospice when they have had some time to stop invasive medical treatments, which can cause additional discomforts.

- Too often, referrals to hospice care occur just days before a death, and this is often traumatic for everyone involved. Sometimes, hospice is not brought up by families or physicians, or there is a concern that entering hospice care means you are “giving up.” Another way to frame this is that hospice care is the best care available for the phase of the disease that you are dealing with at this time.
- Hospice does not provide all the caregiving that a patient needs, but hospice does provide assistance to the family in making good decisions around pain medications and reduction of symptoms such as nausea or constipation. Hospice companies always have a 24-hour on-call nurse and a telephone number for assistance. This allows patients to stay in their own environment rather than be rushed to a hospital to address symptoms.
- It is a reasonable choice to have hospice care, even if you ultimately decide that you would like to use the aid-in-dying drug. One option does not exclude the other.

Physician Orders for Life-Sustaining Treatment (POLST)

- This form, usually printed on bright pink paper, states what kind of medical treatment patients want toward the end of their lives. It is placed in your medical records and usually placed on the back of a door or at the foot of your bed in your home in the event the paramedics are called.
- Any patient with a serious disease should have a discussion with his/her physician around goals of care. A patient requesting or considering an aid-in-dying drug must discuss issues such as what quality of life is acceptable to you and what you are hoping to be able to do in the time you have left.
- The POLST form is completed and signed by both the patient and a physician. POLST gives seriously ill patients more control over their end-of-life care. It is a document you will keep with you at all times, and copies should be made for your healthcare providers so they can honor it.
- For a patient seeking an aid-in-dying drug, a POLST should be completed. This will prevent unwanted treatments or procedures if the patient is not in the hospital and a medical professional (e.g. paramedics) are present.
- A POLST communicates information about resuscitation, artificial nutrition, hydration, other treatments, and comfort care. It also indicates the name of your healthcare power of attorney.
- A POLST is very important for patients seeking an aid-in-dying drug because it also allows you and your physician to indicate that you want to die naturally or by means of the aid-in-dying drug and that you do not want anyone to attempt to bring you back when the likelihood is that you will not survive anyway.

- The POLST should indicate “Do Not Attempt Resuscitation” (DNAR). If you previously completed a POLST, but did not indicate DNAR, you should complete a new one prior to ingesting the aid-in-dying drug.
- Your clinical consultant can help you prepare a POLST that you can take to your physician to discuss further and finalize.

What if I am not an English speaker?

- If you are not an English speaker, you may still request the aid-in-dying drug; however, you must use a trained interpreter when your healthcare provider does not speak the same language as you do. The UCLA Health Interpreter/Translation and Deaf Services Program is available to our patients and families.
- The interpreter may not be related to you by blood, marriage, registered domestic partnership, adoption or be entitled to a portion of your estate upon your death.
- An interpreter must meet the standard put forth by the California Healthcare Interpreting Association or the National Council on Interpreting in Health Care or other standard accepted by the deemed acceptable by CDPH. The interpreter may read the Request for an Aid-in-Dying Drug to End My Life in a Humane and Dignified Manner form to you and verify your agreement with this document by making an additional declaration about their fluency.
- If you do not speak English, you will need an interpreter to engage in all formal counseling and attestations. This can be arranged for you with your clinical consultant. Our interpreter team can also be reached at (310) 267-8001.

What can your physician not do under the Act?

- Your physician cannot administer a medication through injection or IV that is intended to end your life. This act only allows the physician to prescribe a life-ending medication that you ingest yourself if you have a terminal illness and are expected to live less than six months.

Can I take the aid-in-dying drug while an inpatient in the hospital?

- No, you cannot take the aid-in-dying drug in a UCLA hospital.
- At UCLA, you may make a request for the aid-in-dying drug while an inpatient, but you cannot bring the drug to the hospital and take it as an inpatient.

What will be listed on my death certificate as the cause of death?

- The physician will comply with the law, which states that the cause of death on the death certificate will not be listed as suicide. No actions taken in accordance with the End of Life Option Act constitute suicide, assisted suicide, homicide or elder abuse. The physician will list the underlying disease as the cause of death, as recommended by the CDPH.

Will using the End of Life Option Act affect my will or insurance?

- The End of Life Option Act specifically mandates that you should not be negatively affected by making this choice.
- The law states that wills, insurance, contracts, and annuities are not affected if a qualified individual shortens their time before dying by taking an aid-in-dying drug that was prescribed to him/her by his/her physician.

What is the drug that I will be prescribed?

- There is more than one drug or combination of drugs that may be used as an aid-in-dying medication. Discuss this with your physician and pharmacist.
- Your doctor should prescribe a medication (antiemetic) that is used to reduce the likelihood of you becoming nauseated or vomiting the drug.

Are there other states where a law like the California End of Life Option Act has been used?

- Yes. Oregon, Vermont and Washington have similar laws that allow for patients to ingest a prescribed drug when they have a terminal illness.
- These states have a documented history of using this process.
- Oregon and Washington have published their data and outcomes, which were reviewed here at UCLA prior to our own implementation.
- While a small number of qualified individuals have utilized these acts, there have been positive effects on end of life, including increased discussion among patients and physicians, higher use of palliative care and hospice, and fewer deaths in hospitals.

Informational Resources

- To read the full law - California End of Life Option Act (ABX2-15) - visit: leginfo.legislature.ca.gov/faces/billTextClient.xhtml?bill_id=201520162AB15
- Compassion & Choices is an organization that has supported the passage of these bills. The organization also has educational materials on their website: compassionandchoices.org

Checklist of things to do before taking the drug

- Complete the Final Attestation for an Aid-in-Dying Drug to End My Life in a Humane and Dignified Manner form 48 hours prior to ingesting the drug; this is to be returned to your physician.
- Review the step-by-step instructions for taking the drug given to you by your pharmacist and follow them precisely.
- Have someone with you when you take the drug.
- Make sure whoever is with you understands that you DO NOT WANT ANYONE TO ATTEMPT RESUSCITATION.