

## **Preparing for Your Own Death: Instructions and Essential Information**

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The following topics are important for patients who are considering, and may choose to use, the aid-in-dying drug. You should share this with your family too, if they are part of this process with you. We recognize that initiating this process with your physician and the clinical consultant does not necessarily mean that you will use the aid-in-dying medication. Approximately one-third of the patients in other states with a similar law who received a prescription for an aid-in-dying drug did not take the drug. They may not use the drug for a variety of reasons, including never reaching clarity about what to do, changing their minds, deciding to allow the disease process to take its course, adequate symptom control, dying from the disease, or other reasons.

Regardless, there are some important factors to know when considering the use of an aid-in-dying drug.

### **Enrollment in Hospice**

It is important to enroll in hospice. Hospice care is a type of care that focuses on quality of life rather than on prolonging life. Hospice typically helps families provide care to their loved ones in their own homes. We recommend that people with terminal illnesses enroll in hospice. Patients in hospice tend to live with better quality of care, have fewer hospitalizations and are more likely to die at home surrounded by their loved ones. Patients in hospice are likely to have more peaceful deaths with the support that they need. It is helpful to the family, too, as hospice provides help to loved ones and supports them after death. At the time of death, hospice is simpler for families because only one call is needed to the hospice, which will then help coordinate with the funeral home. Hospice is a good option even if you know that at some point you may use the aid-in-dying drug.

### **If Not Enrolled in Hospice**

If you have not enrolled in hospice and you are imminently planning on using the aid-in-dying drug, you may want to make sure that you have made arrangements in advance with a funeral home. Most funeral homes will contact the physician for your family once they have picked up your body. Your family should have contact information available for the funeral home. Your physician will likely sign the death certificate. Your family or attendants do not need to call 911 or the coroner in an expected death, although the coroner will become involved if you have not chosen a mortuary.

## **With Your Physician, Sign a POLST Form and Indicate DNR**

Make certain that you and your physician have recently completed a Physician Orders for Life Sustaining Treatment (POLST) form. The POLST is completed and signed by you, the patient, and your physician. The POLST for patients choosing to use an aid-in-dying drug should clearly indicate “do not attempt to resuscitate” (DNR).

## **Once You Have Qualified for the End of Life Option Act**

Once your physician has indicated that you have qualified to have the prescription, discuss with your physician whether you should have the prescription filled now or at a later time. Some people wait to have the prescription filled and you should discuss the pros and cons of this decision with your physician. Issues to consider include:

- Making sure you have access to it when you need it
- How long the drug will last, as you may not take it for some time
- Whether you are ready to pay for the prescription now (this may involve a consult with your insurance company about paying for the medication)
- How long it takes to get the medication once the prescription is written
- If you do not use the medication, who will have access to it and will they dispose of it properly

If you do decide to have the medication filled, please make certain you review the instructions for consuming the drug as well as all steps leading up to it. The pharmacist should consult with you and provide you with a written handout describing the medications and how they should be used.

Your physician will also prescribe anti-nausea medication to be taken prior to taking the aid-in-dying medication to ensure that you do not vomit the aid-in-dying drug after ingesting it.

## **You Must Have Ability to Ingest and Digest the Medications**

To use the California End of Life Option Act you must ingest the medication yourself. You must be able to either swallow half a cup of liquid, consume applesauce or yogurt with the drug mixed into it, or self-administer the drug into your feeding tube. The mixture containing the lethal dose of medication must be ingested within 1-2 minutes. This is very important, because typically, an individual will fall asleep within 5 minutes of taking the medication. If you have swallowing problems, this could interfere with your ability to successfully use the California End of Life Option Act.

If you have any doubts about your ability to consume/ingest this mixture in 1-2 minutes, we highly recommend that you practice swallowing half a cup of water within 2 minutes or practice self-administering half a cup of water through a feeding tube in the same amount of time before attempting to use the life-ending medication.

## **Where Can You Take the Aid-In Dying Drug?**

You are allowed to take the drugs in the privacy of your own home or yard. You are not allowed to take the drug in any public place including a beach, park or other public area. You are not allowed to take the drug while in the hospital at UCLA and likely not at other hospitals. If you are living in an assisted living facility you will be allowed to take the drug. Nursing facilities may or may not allow you to take the drug. You will have to ask.

## **Who Should Be Present At Your Death?**

This is a deeply personal decision. Some people have their close friends and family members present while others opt to have just one person. You may also choose a caregiver to be present. Whomever you choose, you should determine if the person is comfortable with being there and not someone who is likely to panic and decide to call 911.

Most people are looking for a peaceful death; therefore, the choice of which person you have present may be very important in ensuring that it is peaceful. You may ask someone from your medical team to be present; however, if they are not comfortable being present or do not support your decision, this is not a good idea. Ideally you want someone who supports your decision.

Whoever is present should be someone who wants to be helpful by creating the environment that you want. Once you have decided whom you would like to have present and tend to you during the process, you may want to have a conversation and reflect about more personal considerations and desires. Here is a checklist of things to consider and guide you through a deeper reflection and conversation:

- Whom would you want to be present?
- Would you want to be held, caressed or touched?
- What kind of atmosphere would you want?
- Are there photos, special objects or animal companions you would want nearby?
- Particular flowers, candles, or scents?
- Would you prefer silence, or a particular piece of music played?
- Would you want a particular poem or prayer read?
- Would you want loved ones to reminisce and share stories as if it were a party, or just carry on as if it were an ordinary day?

There are no right answers to any of these questions – except what you would want.

Those attending will also need to help make sure you stay awake and take the medication quickly, and help you to sit upright for the first 20 minutes after you have taken the medication.

## **The Dying Process**

Your attendants/loved ones will need to make sure you stay awake and take the medication quickly (within 1-2 minutes) to avoid falling asleep before ingesting all of the medication. Your attendants/loved ones will also need to help you to sit upright for the first 20 minutes after taking the medication.

Usually within a very few minutes you will appear to be sleeping. How long it takes an individual to die can vary and every individual is different. In other states that have used aid-in-dying medications, people tend to die quickly, but every individual is different. How much time passes before death can vary, and there have been reports of it taking from 10-to-20 minutes to hours. The factors that affect the length of time can include how sick you are (overall condition) and how easily your body absorbs the medication. Be assured that once you are in a non-responsive state (usually takes 5-10 minutes after taking the medication), you will not experience any suffering.

## **Once the Death Occurs**

In your packet you will find a companion document called, "Preparing for Death: Guidelines for Family, Loved Ones or Caregivers." There are explicit guidelines and instructions for your loved ones and caregivers on what needs to take place in a logistical way, as well as guidelines and suggestions to fulfill your requests and create the most meaningful and peaceful experience possible.

Your survivors will likely need to tend to a host of legal documents and to the settling of your estate and affairs. By law, using aid-in-dying medication is not suicide. The underlying diagnosis will be listed as the cause of death on the death certificate. Making the choice to use the aid-in-dying medication does not affect your life insurance, health insurance, accident insurance or annuity policies.

## **Disposing of Unused Medications**

Disposing of unused medications is very important and must be done safely and properly. The U.S. Drug Enforcement Agency has developed guidelines for disposing of medications. It is not uncommon for patients near end of life to have many medications left over. It is important that these medications are safely handled and they cannot be used by someone else. If you choose not to use the aid-in-dying medication, please safeguard this medication from others until you can dispose of it properly.

- The aid-in-dying medication is a controlled substance and is not accepted at every location that accepts medications.
- Never flush unused medications of any kind down a toilet or drain and do not throw it into the trash.

- The best disposal method is to use a designated drop-off facility.
- The Los Angeles County Sheriff's Department, along with the Los Angeles County Departments of Public Health and Public Works, has created the Safe Drop-Off Program. There is a handout in the patient packet that lists the Safe Drug Drop-Off locations.
- The Santa Monica Police Department has a drop-off box located outside the police station, at 333 Olympic Blvd, Santa Monica, CA 90401. For questions, call (310) 395-9931.
- Many cities have special days designated as "Take Back" days in order to safely remove old drugs and controlled substances from the street.
- To find a facility that accepts controlled substance medications, visit: **[nodrugsdownthedrain.org/NoDrugs](http://nodrugsdownthedrain.org/NoDrugs)**. Be aware that the location needs to say that it accepts "CONTROLLED SUBSTANCES," not just medications.
- A statewide recycling program called CalRecycle can also help you find a place near you. They can be reached at (800) 732-9253. Make sure that when you call, you specify that you need to dispose of a controlled substance so that they do not misdirect you. They can assist with other recycling issues as well, such as needles (sharps) or other medications.