

Preparing for Death: Guidelines for Your Family, Loved Ones or Caregivers

Once your loved one has chosen to take this step, and make use of the aid-in-dying drug, you may be the one — or one of several — who has been asked to tend to this process and be a witness. This is intended to briefly give you a sense of what to expect — before, during and after — as well as some practical information and guidelines.

While you have been asked or chosen to tend to this process for your loved one, it is quite possible that you may have your own hesitations or conflicts in participating as a matter of conscience. You may honor your loved one's choice and want to support him or her, but still have your own reservations or struggles. Take the time you need to reflect on your possibly competing values so that you can arrive at a plan you can live with. Upon reflection, have that conversation with your loved one. A heart-felt truth-telling may offer guidance and clarity for each of you.

We all know that death is a part of life and that each of us will likely face it at some point either as a witness, or ultimately at the end of our own physical life. Some people have no direct experience with the dying process, and may know death only through images in the media. Our cultures have moved us away from helping us process this as a part of everyday life. If we have witnessed death, depending on the circumstances, it may have been something beautiful and peaceful or something far from that.

Nothing prepares a person for being present at the death of a loved one, other than experience — and many of us do not have that history. Even if one did have a particular experience, it still wasn't with *this* loved one. Even a "planned death" will stir emotions that we may not have anticipated. After all, the disease that leads up to this moment was not planned.

We know that deaths that allow time for preparation often can be helpful for the survivors because there has been time to prepare, anticipate, talk, forgive, share, and make arrangements. Our hope is that this deeply personal choice will afford the opportunity to make such preparations, have those conversations, and ultimately find a deeper meaning and sense of peace.

Being present and tending to someone in their last moments when someone has made this personal choice is an act of courage and a demonstration of great love and service. Don't forget to breathe and go easy on yourself.

In Preparation for the Process

You will likely have had a conversation with your family member or loved one about when and where the drug will be taken and what his or her wishes are with respect to many things. Remember that the drug cannot be ingested in a public place. That is against the law.

If that conversation has not happened, or has not been finished, you may want to initiate and facilitate such a conversation and these questions might help guide you:

- Whom does he/she want present?
- Would he/she want to be held, caressed or touched?
- What kind of atmosphere would he/she want?
- Are there photos, special objects or animal companions he/she would want nearby? Particular flowers, candles, or scents?
- Would he/she prefer silence, or a particular piece of music played?
- Would he/she want a particular poem or prayer read?
- Would he/she 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 he or she wants.

There are some additional things you need to know:

- Is your loved one enrolled in hospice? Be sure to have the name and phone number of the hospice available to you.
- Has he/she signed 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?
- What is the name of the physician who wrote the prescription? This attestation needs to be returned to the physician, and the physician will then be able to sign the death certificate.

If the patient is in hospice, the decision may be made for hospice attendants to be present in the house when the patient takes the drug. If that is the case, such attendants may choose to step outside of the room. Participation in this law is voluntary, and some individuals may not be in agreement with facilitating a death with an aid-in-dying drug. That does not mean that they will not be with you or attend to your or your loved one's needs, but they may choose to be out of the room at the time the drug is ingested and return to attend to the person dying if needed. They will also help with the body once the death has occurred. It may be important to clarify with the hospice attendant just how he/she will be present.

If the patient is in hospice and a hospice attendant is not present, it may be important to discuss in advance if he or she would like to have the hospice nurse or social worker notified should there be an extended dying process. Identifying who communicates with hospice is important. It may be the patient's legal surrogate decision-maker or a family member.

The Dying Process

The instructions for taking the drugs will have been provided. You will need to make sure your loved one stays awake and takes the drug quickly (within 1-2 minutes) to avoid falling asleep before ingesting the entire dose. You will also need to help your loved one sit upright for the first 20 minutes after taking the drug.

Usually within a few minutes, the person will appear to be sleeping. How long it takes an individual to die can vary and every individual is different. We have learned from other states that already have experience with this medication that people tend to die quickly, but every individual is different. How much time passes varies, and there have been reports of it taking from minutes (approximately 10-20 minutes) to hours. The factors that affect the amount of time can be how sick the person is (overall condition) and how easily his or her body absorbs the drug. Be assured that once the person is non-responsive (usually 5-10 minutes after taking the drug), he or she will not experience any suffering. If he or she does not die as soon as you expect, do not panic. Do not call 911. Do not attempt to resuscitate your loved one. This is a time of waiting, much as when someone's disease has progressed and natural death is near. It may be helpful to think about any additional time of waiting as a vigil, which often occurs during the last hours of a person's life during a natural death.

Although there is not any specific activity you need to do, this can be an important time to create the atmosphere that you have talked about with your loved one regarding his or her desires – perhaps reading a poem, saying a prayer, singing a special song, caressing a hand, stroking a forehead, sharing tender feelings, offering reassurance, or simply holding the space of calm in stillness.

Caregivers may also administer any of the medications that they have been using or may have been provided by the physician or hospice if there are any symptoms that ordinarily would be treated. For example, atropine may be used under the tongue when excessive oral fluids seem present, and morphine or other pain medications may continue to be administered if the patient seems to be in pain. Medications for pain and agitation can be taken in advance as well if these have been part of the patient's regimen of symptom management.

Those present at the death will witness some or all of the following changes that frequently occur during the natural dying process: snoring, gurgling noises, changes in rate of breathing (sometimes slower, sometimes faster), increased paleness or grayness of the skin, and coolness of the skin. One might also observe release of bowel and bladder, no response,

eyelids slightly open, pupils enlarged, eyes fixed on a certain spot, no blinking, jaw relaxed and mouth slightly open. Lowering the person to a semi-upright position and turning the person onto his or her right side, a position that may also improve absorption of the drug, may alleviate snoring and gurgling noises. Generally, there are no physical movements or signs of distress, although it is not uncommon for people to twitch or make sounds after death has occurred. Death has occurred when breathing has stopped for five minutes and no pulse or heartbeat can be felt.

As a witness, you might experience the moment of death in any number of ways. It might be an intensely meaningful or even spiritual encounter. Or it may seem surprisingly ordinary, even anti-climactic. You may feel instant grief. You may feel numb. You may feel relief. Or you may be angry. There are no correct feelings or responses — only yours.

After Death Occurs

There is no hurry to notify anyone or have the body removed. Nothing has to be done right away. Some people want to stay in the room with the body; others prefer to leave. Take as long as you like to observe any cultural or spiritual traditions, gather family together, reminisce, mourn, or celebrate life. It is not unusual and can be healing for some to tend to the body in a tactile, physical way — apply lotion or fragrant oils, bathe the body, or comb the hair; others will not opt to do this. You might ask a member of your religious community or a spiritual counselor to come. If you have a list of people to notify, this is the time to call those who might want to come and see the body before it is moved. Very often the mouth will open — placing a rolled up towel under the chin can close the mouth. It is not necessary to do this, but often people are distressed by the open-mouth appearance.

We recommend that either you or others in attendance make sure the body is lying flat as the joints can become stiff after death and cannot be moved. This stiffness is called “rigor mortis” and begins sometime during the first hours after death.

If hospice is involved, a plan for what happens after death is already in place. You only need to make the one call to hospice.

If your loved one is not enrolled in hospice, please contact the funeral home with which you have pre-arranged pick up. Most funeral homes will contact the physician for you, but you may want to have that contact information available. The physician for your loved one will likely sign the death certificate. You 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. In the patient packet that was given, you will find resources about mortuaries, burial and cremation. Ideally, these issues will be worked out in advance of the ingestion of the drug.

Disposal of Aid-in-Dying Drug

Disposing of unused drugs 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 cannot be used by someone else. If your loved one died before having the opportunity to use the aid-in-dying drug, please safeguard this drug from others until you can dispose of it properly.

- The aid-in-dying drug is a controlled substance and is not accepted at every location that takes medications.
- Never flush unused medications of any kind down a toilet or drain or throw them into the trash.
- The best disposal method is to use a designated facility:
 - The Los Angeles County Sheriff's Departments, along with the Los Angeles County Departments of Public Health and Public Works, have 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. You may call them at (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. Be aware that the location needs to say it takes "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.

Next Steps

When you witness and tend to such an event, you will experience feelings of grief and personal loss, but you may also feel disconnected from people, places or things. It can feel as if you are walking in a fog, without your bearings in the "real world." This can be especially difficult when you are thrown into the intensity of making funeral/memorial arrangements.

These are profound events — the death and the witnessing of the death. Life will never quite be the same again. How could it be? It would only make sense that you may feel disconnected or strange. It may be hard to understand your feelings yourself, let alone explain them to others, especially to those who have never witnessed a death.

Over the following weeks and months, some may experience emotional and spiritual rawness that stirs up feelings of anger as well as grief and even guilt. For others, it can be truly liberating. We only really know what we need to deal with as we move into and through our grieving process, step-by-step, day-by-day.

There are a number of ways to find support as you learn to carry this experience and loss — including bereavement groups and individual counseling. In the patient packet that was given, you will find specific resources on grief support groups. Some feel a need for solitude and retreat from everyday life for a while. It may take a false start or two. Be kind to yourself and find what serves you. You have given someone a great gift beyond measure.