American Clinicians Academy on Medical Aid in Dying www.ACAMAID.org

Preparation and Instructions for the Aid in Dying Procedure

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Planning: Once you have completed the process and become eligible for medical aid in dying, ask your medical providers (the attending/prescribing doctor who wrote your prescription, and your hospice nurse or doctor) for continued guidance, planning, and monitoring about if or when to take the medications. This is especially important if you are approaching the imminent/active phase of dying or have any trouble with nausea, swallowing or constipation. Ongoing expert guidance is essential in making this important decision.

The Aid in dying procedure can only proceed if the patient has:

- Capacity to make medical decisions for themselves. You must be able to communicate that you
 understand what your terminal disease is, know what your various options are (including just
 continuing with hospice/palliative care until you die), and understand that taking aid-in-dying
 medications results in death.
- The ability to self-administer the medications by swallowing, or by using a feeding (PEG) tube or rectal catheter. Someone other than the patient, however, can legally mix and prepare the aid-in-dying medications, and bring them to the patient. The patient must self-administer the medications by swallowing them, or pushing a syringe plunger if using a feeding tube or rectal catheter.
- The ability to physically absorb the medications. Patients with bowel obstructions or other stomach and intestinal issues cannot safely absorb aid-in-dying medications. If you think this may apply to you, talk with your doctor before taking aid-in-dying medications.

The Prescription: Please be sure that your doctor has the most current prescribing information, as there are older and less effective versions of prescriptions that sometimes are mistakenly used. Please do not hesitate to contact or have your doctor contact the Academy (<u>ACAMAID@ACAMAID.org</u>) for further information, or refer to our Pharmacology Information link https://www.acamaid.org/pharmacologyinfoupdates/

Medication delivery: A pharmacist will call and arrange for payment and delivery of medications. We suggest you ask the pharmacy to hold the prescription until the week you plan to use it. This will keep these dangerous medications safely out of reach and prevent the disposal of medications and charges for them if they are not used.

Skilled attendance on the aid in dying day: Having good support for yourself and your loved ones on the day of aid in dying is very important. It frees your loved ones to do what they do best – love you, instead of worrying about this medical procedure. Many hospices will allow their staff to be present before and after taking the medications. Your hospice nurse, social worker or chaplain can be an essential source of comfort and experience at the time of aid in dying. Privately hired nurses or end-of-life doulas can be helpful on the aid-in-dying day, and experienced volunteers are available in some states. If your hospice or other organization does not provide someone to be there for the aid-in-dying day, please feel free to contact the Academy and we will work on finding a qualified person to be there for you and your family.

One week before taking aid in dying medications:

Notify your care providers – Let hospice and your attending/prescribing doctor know that you are planning to take aid-in-dying medications, and when you plan to do this.

*It is especially important to notify your attending doctor promptly if you are having any difficulty with swallowing, any nausea or vomiting or significant constipation. These issues may need to be managed before you take aid-in-dying medications.

Practice swallowing – Daily, practice swallowing 4 ounces (1/2 cup) of slightly thickened liquids, in two minutes (so that you don't fall asleep before you complete the dose), from a short glass cup; tall glasses may be difficult to tip and empty, and plastic can bind the medications. You may need to use a straw. The medications have the consistency of *Ensure* and taste bitter. Practice can help you feel confident that you will be able to easily swallow all the aid-in-dying medications within the required two minutes. You will be able to have a popsicle or some sorbet after you finish swallowing all the medications, to help clear the bitter taste and any burning from the medications.

Bowel care – make sure your bowels are moving easily and regularly, at least every other day, even if you are eating very little. If needed, gently increase your laxatives. It is also recommended that you try to continue to eat at least small amounts of food 2-3 times a day or take small amounts of *Ensure* or another dietary supplement. This helps your digestive tract continue to move and be able to absorb the aid-in-dying medications.

Medications – Continue all of your usual medications unless you receive specific instructions from hospice or your attending/prescribing doctor.

Finalize plans for your remains – let your loved ones and providers know what you want done with your remains. You should contact a local mortuary and make arrangements. Your death certificate will cite your underlying disease as the cause of your death and will make no mention of medical aid in dying. The death certificate will be available from the mortuary or institution after being signed by your doctor.

24-hours before taking aid-in-dying medications:

- Continue all of your usual medications unless you've received specific other instructions.
- Starting after dinner, the night before you take aid-in-dying medications: Do not eat any solid foods. Water and other clear, non-fatty fluids are fine, but don't take in large volumes of liquid.
- Continue to not eat any solid foods on the aid-in-dying day. No breakfast or lunch on that day, only clear liquids.
- NOTE: The best time to begin taking the medications is about 11 AM. That provides the patient with some time with their family and assures that death will be achieved during the daytime while family and others are not exhausted, and hospices and funeral homes are readily available.

On the day of aid in dying: Please see the Academy video – <u>Enactment of Aid in Dying at the Bedside</u>. <u>https://vimeo.com/388148923</u>

Medication Preparations:



*Please see the Academy video – Instructions for Mixing Aid-in-Dying Medications

- Choose a secure, well lit, uncluttered surface to mix the medications. Any people present should be
 encouraged to stay away from the area while preparations are in process. These are dangerous
 medications. Pets should be secured, and children closely supervised.
- Cover the surface with a layer of paper towel. Medical gloves may be helpful but are not required.
 Have all supplies ready, including clear filtered apple juice, not the unfiltered variety, (water can be used, but apple juice is preferred), a measuring cup with spout, a short glass cup, spoon, and a sealed plastic container or bag for garbage.
- Before opening the bottle, gently tap the bottom so that the powder settles away from the lid.
- Open the bottle, away from your face, and slowly fill it roughly halfway with the apple juice. Put the lid back on the bottle and shake vigorously. Finally, fill the bottle up to the neck, being careful not to overfill, and secure the lid. Again, shake the bottle vigorously to suspend all the powder particles. Check the bottom of the bottle to be sure there is no remaining dry powder.
- Once the medication has been mixed, it can be brought to the patient's bedside in the capped bottle.
 Shake the medications thoroughly one more time, then carefully pour the liquid suspension into the short glass cup just before the patient ingests the medications.
- Be sure the patient is settled comfortably in bed or a safe chair before they take the aid-in-dying medications. It is not safe for them to walk to another location once they have swallowed these medicines.

After the procedure, as soon as you reasonable can, thoroughly clean the used short glass cup, spoon
and the bottles. Dispose of the emptied and cleaned bottles in a sealed plastic bag or container
directly into garbage bin.

Procedure for taking aid-in-dying medications:

Step 1. Anti-nausea pills: take these tablets at least 30 to 60 minutes before the actual aid-in-dying medications. These anti-nausea medications, typically Zofran/ondansetron and Reglan/metoclopramide, do not cause sedation, and their anti-nausea effects last 8 to 12 hours.

Step 2. Wait at least 30 to 60 minutes after the anti-nausea medications and then take the final aid-indying medications, sitting somewhat upright if possible. These final medications are bitter and can cause a burning sensation and mild coughing. This thoroughly resolves within the few minutes it takes to fall asleep. Small sips of clear juice, small spoonfuls of (fat free) sorbet or a (fat free) popsicle can significantly help any burning sensation and change the bitter taste in the patient's mouth to a sweet one.

Common signs and symptoms of dying:

Aid-in-dying medications quickly cause deep sleep, within 3 to 10 minutes, soon followed by coma, and then respiratory suppression and death.

*While in a coma but still breathing, the anesthetized patient has no conscious awareness and is not suffering.

It is very common for patients to have sudden deep, gasping breaths before dying. These are reflexes and the patient does not feel discomfort from these breaths, but the family should be prepared so as not to be surprised or concerned. Snoring or gurgling sounds, temporarily stiffened limbs, as well as changes in facial color (blue or pale), are also extremely common and will not be felt by the comatose patient. These normal symptoms of dying do not indicate discomfort. If breathing does not stop completely in the first hour from the huge dose of sedatives in the aid-in-dying medications, then the cardiac medications in the mixture will soon stop the heart, usually within 2 to 5 hours of ingestion.

*If any concerns arise, a call to your hospice or other provider can be very reassuring.

After Death

- Families should call hospice and the mortuary to notify them of the death. If the patient is not cared for by hospice, the attending physician who wrote the prescription should be contacted.
- Mortuaries commonly come within 30 to 90 minutes to collect remains, and will need basic
 information (name, address, birth date, weight, height, stairs into the home, name of hospice). (For
 other variations in "home funerals" and alternative burial/cremation plans, please check your local and
 state resources and laws.)
- Hospices offer a nursing visit for support after a loved one dies, and to instruct about disposal of medications. Hospices also offer ongoing bereavement support, free of charge.

[~] Please promptly call your hospice or your attending/prescribing doctor with any concerns or questions.