American Clinicians Academy on Medical Aid in Dying
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Nursing Best Practices for the Care of Patients Considering Aid in Dying

~tips for nurses~

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Nursing care for patients considering medical aid in dying is most practically thought of in phases:

- Establishing eligibility
- Continued evaluations and care
- The aid-in-dying day

ESTABLISHING ELIGIBILITY

- **Legal requirements**:
  - >18 years old
  - Live in a state where aid in dying is legal
  - Terminally ill with <6-month prognosis
  - Mental capacity to make their own medical decisions
  - Physical capacity to self-administer the medications
  - The above must be confirmed by two physicians

- **Not required**:
  - Proof of "suffering"
  - Mandatory psychiatric evaluations
  - Ability to swallow (see below)

- **Sequence of events for eligibility** (this does not commit a patient to take medications to die):

  - Take any request from a patient considering aid in dying seriously, even if the patient has no firm plan or is just thinking about the possibility. Use open ended questions to clarify and translate vague language, i.e. "I want that dignity death." Identify requests for aid in dying early.

  - Connect with aid-in-dying participating doctors: Some hospices allow their doctors to prescribe and/or consult, some do not. Assist in finding doctors who participate. The patient must work with two participating physicians.

- Attending" (prescribing) physician: Will write the prescription and follow the patient through the process.
- "Consulting" (confirming) doctor: Confirm the patient's eligibility.

- **Referral systems:** Many organizations have aid-in-dying referral systems, including Kaiser and Sutter Health.
  - The American Clinicians Academy on Medical Aid in Dying has a Patient to Doctor Referral System. Here is their intake form.

- **First verbal request:** The patient has a discussion with and gives a first verbal request to *any* doctor, who is legally required to document it in the chart. This is not a request for the medications, rather a request to start the eligibility process. It begins the mandated waiting period (48 hours in California, varies in other states).

- **Enter the waiting period:** (Varies from state to state)
  a. Do not delay the eligibility process because the patient "isn't that sick yet." Accomplishing all the required steps takes time, and rushing through the process makes for a frantic and anxious period, when peace is most desired.
     i. If your state has a short waiting period, do not use that as an excuse to delay beginning because you can move quickly later. The process of eligibility often takes longer than these short waiting periods.
     ii. If your state has a longer (15-20 day) waiting period, all the more reason to get started quickly. Terminally ill patients can deteriorate with surprising speed.

- **During the waiting period:**
  - Gather medical records (a summary is often adequate) and send them to the attending (prescribing) and consulting (confirming) doctors.
  - Obtain the patient's signature on the required written request for aid in dying (again, there is no commitment if they sign this form).
    - Two witnesses must be present: One can be a family member, the second someone with no vested interest in the patient's estate.

- **Evaluate the patient's ability to self-administer the medications:**
  - Swallowing: Must be able to swallow 4 ounces of thick liquid medications within 2 minutes (if they take longer, they may fall asleep mid-dose).
  - PEG tube, ostomy, or rectal catheter: For patients who cannot safely swallow 4 ounces in 2 minutes, a 60ml syringe can be attached to a PEG, ostomy or rectal tube and the patient must be able to depress the plunger to administer the medications.
    - About 1 in 5 aid-in-dying patients now use rectal self-administration. For details, see this link)

CONTINUED EVALUATIONS AND CARE

- **Openly discuss disease processes and palliative measures.** Patients need to understand their disease trajectory and possible palliative interventions in order to make informed decisions. These sometime difficult discussions are often a relief to many patients, and supports their decision making.

- Identify and communicate how close to death the patient appears to be (months, weeks, days). This frank discussion will help the patient decide whether to continue the aid-in-dying process or not, and to evaluate their timing.

- **Hospice hospice hospice!** Hospice care provides crucial palliation and improved quality of life for terminally ill patients, especially for those who are considering aid in dying. Hospice also provides valuable support for loved ones. Encourage patients to interview a few hospices and choose one that is actively engaged with and supportive of aid in dying patients. Before patients choose among hospices, the organizations should clearly state what they allow their doctors and nurses to do, or not to do, before and during the aid-in-dying procedure.

- **Review the aid-in-dying day and procedure***:* You and/or they can watch the Academy's video on the Aid-in-dying Day at https://www.acamaid.org/video-enactment/

- **Prepare a Plan B:** Patients and families need contingency plans should aid in dying become impossible**.** If aid in dying is off the table, these patients may desire an assertively palliated death, even to the point of sedation.

- **Plan for an attended death, if possible:** The Academy highly recommends that someone with aid-in-dying experience be with the patient and family on the aid-in-dying day. On that day, loved ones should be free to be loving, not aid-in-dying technicians.
  - Attendant options can include:
    - hospice nurse or social worker (a chaplain may also attend, but not for technical guidance of the death)
      - Hospice policies vary widely; some do not allow their staff to mix meds or be present during ingestion
    - doctor
    - a paid end-of-life doula (if they have specific aid-in-dying training)
    - an aid-in-dying trained volunteer
    - if none of the above are readily available, the Academy will help find a skilled attendant for the patient, at this link.

  - The ample experience of academy clinicians has shown that having an experienced clinician at the bedside is crucial, so that the family can safely focus on their loved one and process their own experiences. (See this link to a video and free CEs about the significance of attending aid-in-dying deaths.)

- **Support and maintain GI function**, to enable absorption of the medications.
  - Ideally, patients should have an easily passed bowel movement at least every three days, even if they are not eating (the shedding of GI mucosa continues and produces a small amount of stool); slowly increase laxatives as needed. Treat diarrhea as well, especially if it is frequent.
  - Encourage patients to eat at least a small amount twice a day to maintain intestinal villi, which will help absorb aid-in-dying medications.
  - *Control any nausea and vomiting:* The most common cause of vomiting aid-in-dying medications is nausea and vomiting before taking aid-in-dying medications. Do not proceed with aid in dying if the patient is nauseated or vomiting. Consider using non-sedating anti-nausea drugs such as Ondansetron, so the patient's mental capacity is maintained.

Dexamethasone (started 2-3 days before the aid-in-dying day, if possible) is the most effective anti-emetic and also increases mood, energy, and appetite.

- **Practice swallowing 4 oz in 2 minutes**: Swallowing ability can change over time, so even if the patient's initial assessment showed they can complete the task, continue to practice and test swallowing ability. This also reassures the patients, who are often anxious about not being able to properly swallow the medications. (If swallowing is impaired, consider rectal administration: https://tinyurl.com/RectalAdmin .

    - **Remind patients about the bitter taste and possible burning** (see below for details). Acquire sorbet or popsicles for the aid-in-dying day.

- **Advise about acquiring aid-in-dying medications:** Three sedating and two cardiotoxic medications are provided as a powdered mix. They are typically not covered by insurance, require a compounding pharmacy, and cost around $700. (See this link for details about the pharmacology of aid in dying.)

THE AID-IN-DYING DAY

- **Please see this video** for An Enactment of an Aid-in-Dying Day .

- **Orchestrate the room:** Patients and families are sometimes intimidated by the procedure, so they formally maintain their distance. Encourage loved ones to be relaxed, close and settled. Remember that the patient may not die for a few hours after an attendant arrives, so everyone should get comfortable.

- **Review what to expect after medication ingestion:**
    - 3 to 10 minutes to deep sleep and coma
    - 2 to 5 hours to death (96% of cases).
    - The key to a comfortable, peaceful death is sedation. Reassure patients and families that the three sedating medications ensure deep and maintained unconsciousness. The time to death is less predictable, but even if prolonged, the patient has no conscious awareness or discomfort.
    - Families have less anxiety and better emotional outcomes if they are prepared and supported through the normal signs and symptoms of dying, including sudden agonal gasping, purple or grey discoloration, twitching movements, etc.

- **Mix the medications carefully:** If no clinical support is present, advise the family of safe mixing, and share the video below.

    - Anyone may legally mix the medications including nurses, doulas, physicians or loved ones. (See this link to California's End of Life Option Act.

    - View this 3 minute video about properly mixing aid-in-dying medications
        - Use a barrier (paper towels) and gloves.
        - Fill the bottle halfway with 2oz of water or clear apple juice, cap and shake.
        - Then fill to 4 oz.
        - Take the capped bottle to the bedside

    - Decant the medications into the glass that the patient practiced with

- **Bitterness and burning:** Provide popsicles or small spoonfulls of sorbet just before and after the ingestion to help manage any bitter taste or burning sensation. Loved ones can do this as a final sweet gesture.

- **Your calm presence and gentle explanations will be welcomed**. Maintaining a composed, encouraging demeanor will comfort the family during the potentially disturbing signs and symptoms of dying.

- **Wait an appropriate time before declaring the patient dead:** Breathing should be absent for ten minutes before you declare the patient dead, to avoid sudden surprises with recurrence of breathing or sudden agonal breaths. It can be difficult for even experienced clinicians to know exactly when a patient's heart has stopped (lack of pulses is elusive). Knowing the exact moment is not as important as being sure the patient has died before you tell the family.

- **Aid in dying deaths do not *require* coroner involvement:**

    - Call hospice and/or the mortuary, as you would for any anticipated death.
    - Reassure the family that the death certificate will list the patient's underlying disease as the cause of death, not aid in dying.
    - Notify the prescribing physician about the time to sleep and the time to death. (This can be done during routine hours.)
    - Please fill out the Academy's Death Data Form, to improve information and care. No specific patient information is gathered.

Please feel free to contact us with any questions or concerns: ACAMAID@ACAMAID.ORG

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