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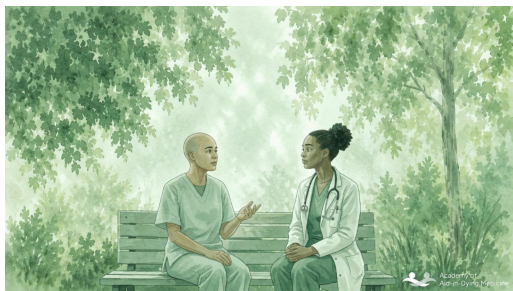
Medical aid in dying: An introduction

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Medical aid in dying: An introduction

- This is a clinical overview of medical aid in dying—what clinicians may need to recognize, discuss, and coordinate.
- Now that aid in dying is legal in your state, the question is not whether it should or shouldn't exist, but how we respond well.
- This talk is about helping you recognize inquiries, respond neutrally, and connect patients to good care.
- I'll leave plenty of time for discussion, because your real-world questions matter.

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Opening clinical scenario

- Let's set the scene: A patient with a life-limiting disease says, "I don't think I can go on like this forever. I want some control over how this ends."
- What are they asking? What do you say next? Who on the team needs to know?
- These questions come up in ordinary clinical encounters, with nurses, social workers, or other frontline staff. Our goal today is to make those conversations easier to recognize and respond to.

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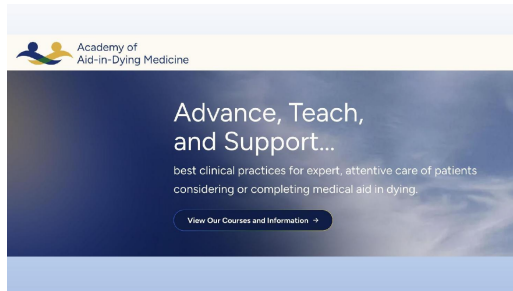
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Mary Sue, RN, CHPN

Presenter introduction

- *Briefly introduce your clinical background and experience with medical aid in dying to establish credibility with the audience.*
- My name is Mary Sue, and I have been a hospice nurse for 15 years. Since New York's Medical Aid in Dying law was enacted, I have had the privilege of caring for more than 20 patients and their families as they navigated this option. I have also completed training through the Academy of Aid in Dying Medicine, and I'm pleased to represent the Academy today."

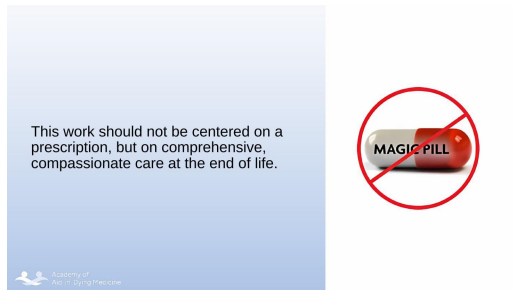
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AADM: Developing and promoting best practices

- The Academy does not take a position for or against medical aid in dying.
- Once laws pass, clinicians will need to know how to take care of these patients.
- Our focus is on good care for patients who are considering or completing aid in dying.
- Our mission is to gather data, develop best practices and teach these to clinicians across the US

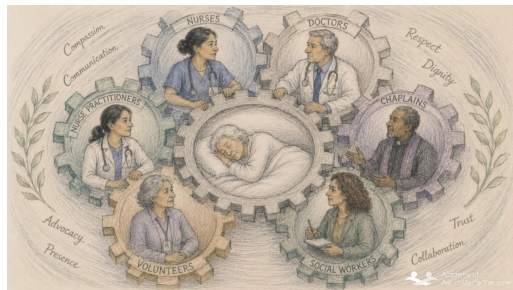
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This is the most important message I hope you take away today.

- Aid in dying is about care at the end of life, not just a prescription.
- It is about walking with patients through their end-of-life trajectory, helping them understand options while continuing to care for them.
- These patients need your expertise, your communication skills, and your guidance no matter how they die.

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No one discipline can carry this workload alone.

- Frontline nurses, social workers, and chaplains are often the first to field questions, hear hints, and start the conversation.
- The attending, consulting, and mental health providers carry the non-delegable responsibility for evaluation of eligibility.
- The attending or prescriber has the additional responsibility for prescribing and following the patient, in case the route or the dose needs changing.
- So bedside staff can ease the load by frontloading patient education, layering on support for families, and helping patients navigate barriers.
- And all are responsible for ensuring the patient gets attentive palliative care.

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Hand-Offs

- Clinicians who are opposed or hesitant about aid in dying need support and respect.
- For clinicians who opt out, nonparticipation does not end responsibility to the patient.
- All clinicians need to be ready to respond respectfully, using morally neutral language, provide some basic information, and make a timely, handoff to someone who can help.
- Handoffs are part of everyone's role. Care often spans a patient's end-of-life journey, and even participating clinicians may need to transition care.
- Whenever possible, make it a warm handoff. A brief call or message between clinicians can prevent confusion, support continuity, and preserve trust.

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The patient pathway

- patients move from asking questions, to formally requesting, to eligible to planning and then, at some point, to dying.
- It is not a straight line. Someone may only be exploring, may pause, may become ineligible, or may decide not to proceed.

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Identify patients:
Explore, clarify, and translate. Then, offer information.

"It sounds like you may be talking about medical aid in dying, which is legal in our state. Would you like more information?"

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Be open to the conversation.

- Patients usually do not ask directly for medical aid in dying. Most will not even know it is legal.
- In California, less than 25 percent of the older population surveyed knew.
- They may say things like, "I can't go on," "I wish I lived in Oregon," or "I wish this would end."
- Your role is to explore and clarify without jumping to conclusions: "Tell me more."
- Calm, morally neutral language builds trust and can open the door to better care.
- "It sounds like you might be talking about medical aid in dying, which is legal in our state. Would you like more information?"

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Everyone:
Basic information + patient resources

Consider:
one or two trained, designated team experts

Avoid:
Creating another bottleneck

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Providing basic information.

- At this stage, patients often need a simple overview about the legal criteria and the process, not every detail all at once.
- They usually need accurate, steady information over more than one conversation.
- Your role is not to flood them with details, but to orient them.
- Patients and families often arrive with many myths and correcting them early can prevent a lot of upset.

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Refer early — without pressure

Eligibility takes time. Disease progression doesn't wait.

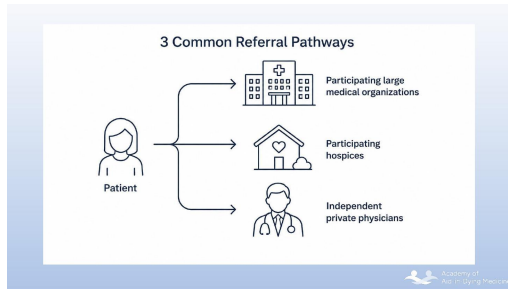
"Starting early keeps your options open."

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Refer promptly

- Early referral matters because the eligibility process takes time, and a patient's condition can change quickly.
- Delays can easily add up and silently disenfranchise patients.
- Urgent aid in dying is not only stressful, it is often not possible.
- A referral does not mean the patient has decided to proceed.
- There are many barriers to consider: limited patient mobility, limited ability to communicate, or limited financial resources.
- Living in a facility or being minimally housed can also throw a wrench into the works.

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Three referral pathways

- Legal access does not necessarily mean easy access.
- The actual pathway varies considerably from one community and organization to another.
- Patients may need help finding participating clinicians and understanding costs.
- Common barriers may also include facility policies.
- The Academy maintains referral resources for patients looking for participating clinicians. In some states, the local aid-in-dying organization may also provide referrals or help patients navigate access.
- • Knowing these referral resources ahead of time can make it much easier to respond when a patient asks.

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Legal requirements for eligibility

- Adult (18+) and state resident*
- Request made voluntarily to participating providers
- Confirmed terminal illness (<6-month prognosis)
- Confirmed medical decision-making capacity
- Ability to self-administer prescribed medication

*Residency exceptions: Vermont and Oregon

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Eligibility requirements

- The details vary by state, but these are the core requirements you will see in most aid-in-dying laws.
- For prescribers, diagnosis, prognosis, capacity, voluntariness, and the ability to self-administer all require careful clinical assessment.
- Organizational policies may add steps, so presenters should adapt this section to the state and setting.

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Suffering is not required

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Suffering is not a legal criterion for aid in dying. It is not required.

- Patients do not need to waste precious time and attention trying to prove unbearable suffering in order to be eligible for medical aid in dying.
- Suffering calls for palliation, pronto.

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Having a plan is not required

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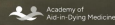
Having a plan is not required

- A patient also does not need to have decided when—or even whether—they would use the medication.
- Some people go through the eligibility process mainly for reassurance that the option will be available.
- Exploring the option is not a commitment, and patients can change their minds.

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Steps towards eligibility

- **First verbal request:** made to a participating provider, who assesses diagnosis, prognosis, capacity, voluntariness, and counsels on all end-of-life options.
- **Consulting/second opinion:** A second clinician independently confirms or denies the patient meets the legal eligibility criteria.
- **Additional capacity evaluation:** Some states, or some cases, require mental health evaluation of decision-making capacity.



Steps toward eligibility, part one

- The eligibility process is structured, although the exact details vary by state.
- The attending clinician evaluates the core eligibility criteria and discusses the full range of end-of-life options.
- A consulting clinician independently confirms—or does not confirm—eligibility.
- in some states, and if either provider has concerns, an additional mental-health evaluation of decision-making capacity is required.

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Capacity to make medical decisions

"the patient must be able to understand information about their condition and proposed interventions, appreciate how it applies to their situation, reason about options, and communicate a stable choice"



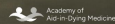
Capacity

- Capacity is specific to the decision at hand, and it can change over time.
- We are looking for the patient's ability to understand the relevant information, appreciate how it applies to them, reason about the options, and communicate a stable choice.
- Depression, anxiety, grief, or distress deserve attention, but their presence alone does not establish incapacity.

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Steps towards eligibility

- **Written request:** Subject to state-specific form, witness, and signing requirements.
- **Second verbal request:** made to the attending/prescriber. State may require an audio or video record placed in the medical record.
- **Waiting period:** In most but not all states, this may be waived in the cases where the provider determines patient is imminently dying.
- **Prescription and dispensing:** If requirements are met, the prescription may be issued and safely held at the pharmacy until it is needed.



Steps toward eligibility, part two

- The remaining steps are more state-specific: written-request requirements, a second verbal request, waiting periods, and documentation.
- Some waiting periods can be waived when a patient is imminently dying.
- Depending on the state and pharmacy, medication may sometimes be held until the patient is ready for it.

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Eligible patients may proceed if and when they decide to ...

... but they are never obligated.



Once eligible, never obliged.

- Eligible patients are never, ever, ever obliged to take the medications.
- It's like having a set of car keys: you can leave them at the door and never use them, but without them, you simply can't drive the car.
- Patients usually change plans, move forward, pause, or change their minds entirely.
- They need to know this is very normal and expected.

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Aid-in-Dying Medications
Safer at the Pharmacy than in the Home.



Prescribing does not equal dispensing

- Patients may want the medications at home “just in case,” but the Academy recommends that the pharmacy safely hold them until the patient is actively planning to proceed. (typically, within a week or so).
- These are lethal medications
- Keeping them at the pharmacy reduces the risk of accidental access and helps avoid a hurried decision during a pain or symptom crisis, which could be treated.
- It also means families don’t have to figure out how to dispose of unused medications.
- Generally, pharmacies can deliver the medications, or make them available for pickup, within a few days.
- Depending on the pharmacy, the patient may also avoid paying for medications that are never dispensed.

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Eligible patients and their families will have many questions



Once they are finally eligible, after a big sigh of relief, new questions will come up.

- How will I know if or when to proceed? What's it like? How long does it take? Will it be peaceful? Who will be there to help my family?
- Again, your expertise and guidance are essential.
- Let's answer a few.

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There is a window of opportunity



When to proceed? There is a window of opportunity.

- Aid in dying has a window of opportunity.
- It opens when the patient becomes eligible and closes if the patient permanently loses capacity or the ability to self-administer safely.
- Patients need honest guidance about where they are in their illness and whether that window of opportunity may be narrowing.
- Good, informed consent includes frank, ongoing conversations

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Contingency planning is essential

- Every patient needs a good end-of-life plan that does not depend on medical aid in dying.
- aid in dying does sometimes slip away as an option.
- Decline can happen quickly and catch patients and families off guard.
- Patients who had to fight to get aid in dying can really resist a change in course.
- So please, early and often, discuss making a detailed plan for a non-aid-in-dying death. From the very beginning of the discussion!

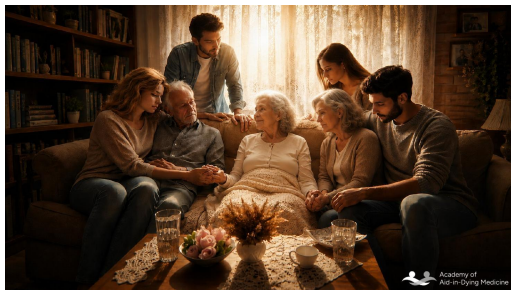
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Decision point

- After some time, the patient may decide it's time.
- They may not fully be able to explain it. Often, they've just had it and don't want to go on.
- Aid in dying is not a failure of palliative care; it is just part of it.
- Families may feel sadness, relief, conflict, gratitude, or all of those at once.

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The day itself requires preparation.

- Families need to know who will be present, who can help them, and what to expect.
- It can be a very stressful day.
- The Academy highly recommends, and data supports, that patients who have an experienced clinician prepare the medications and remain bedside for support have smoother, more peaceful deaths.
- This clinical bedside care frees the grieving family to focus on each other rather than the medical details.
- If hospice or palliative care staff cannot provide this care, volunteers or end-of-life doulas are available to help.

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A safe and peaceful aid-in-dying procedure requires:

- Intact cognition
- Ability to ingest the medications into their gastrointestinal tract
- A functional, absorptive gastrointestinal tract
- receptive brain receptors



Yes, there is such a thing as a safe death. It's not as easy as it looks.

- A peaceful aid-in-dying process depends on some important clinical factors.
- The patient needs to have intact cognition and the strength to swallow or push the meds through a PEG or other catheter.
- They also must have a functional absorptive gut and receptive brain receptors.
- This is why following the patient all the way through their trajectory is so important.
- The route or dose may need to be changed by the prescriber.

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The medications are mega doses of three sedatives and two cardiotoxins



Patients and families need to know about the medications.

- The meds are mega doses of three sedatives — morphine, valium, and phenobarbital — and two medications that are toxic to the heart, digitalis and amitriptyline.
- It is mixed into 2-4 oz of clear filtered apple juice.
- Sadly, they taste super bad, so we recommend a popsicle before and after.
- This is another example of why bedside teaching and preparation matter so much. Patients do better when they know things like this.

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The journey of the medications, part 1: first they have to get in.

- By swallowing or using a feeding tube, ostomy, or rectal catheter.
- What could go wrong here?
- Patients often get weaker at the end of life, so best practice is to have them practice.
- Can they swallow 2 ounces within two minutes without choking?
- Can they depress the plunger on a feeding syringe? No feeding pumps — they clog.

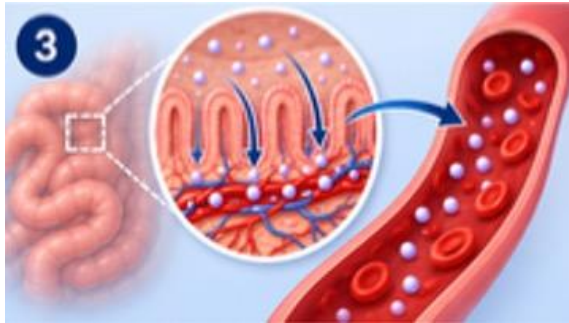
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The journey of the medications, part 2: then they have to stay in.

- The meds have to get to the stomach. Here a bit of the phenobarbital is absorbed, which is why patients go to sleep quickly and easily.
- What could go wrong here?
- Nausea and vomiting need to be very well controlled.
- Gastroparesis can be silent and problematic. That's where the stomach is paralyzed or weak and just does not empty. Usually, patients with gastroparesis have some nausea and are really not tolerating any food.
- P.S. Dexamethasone can be very helpful for nausea and vomiting; it is not sedating, and in low doses it can help patients feel much better.

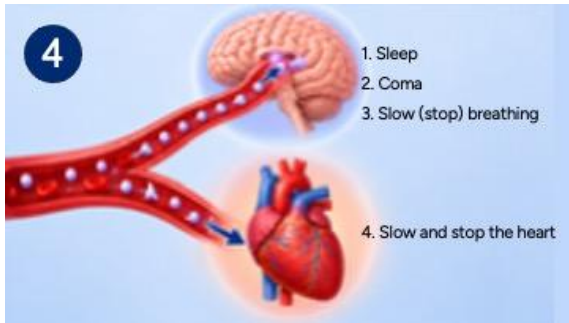
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The journey of the medications, part 3: the meds have to get absorbed through the gut into the blood.

- Once they get out of the stomach, the meds move into the intestines.
- This is really where the action happens. The villi absorb the meds through to the bloodstream.
- What could go wrong here?
- Sick patients are often thin and eating very little. Their villi are withered, and their GI tracts are slowing down, less perfused with blood, and thinner.
- Malabsorption, cachexia, and ascites can all interfere.

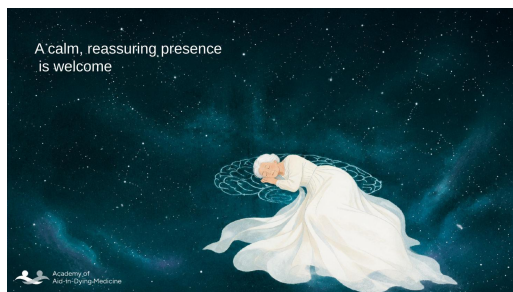
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The journey of the medications, part 4: the meds have to meet brain receptors and heart receptors.

- The sedatives must reach and effectively dock on their receptors in the brain to bring on sleep and then coma.
- This is really what patients want: to go comfortably to sleep and die peacefully in their sleep. This is what their families want too.
- Patients who are on high doses of opioids or sedatives may have many saturated receptors, which is why we use megapharmacology to overwhelm that system, and sometimes, if indicated, we use even higher doses.
- From 30 years of data, using various cocktails, we know that sedatives alone do not always work to suppress respiration.
- So the cardio-toxins are a kind of backup, and they take time.

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Calm reassurance is welcome. Help families know what to expect.

- Patients generally fall asleep and are comatose within 10-15 minutes.
- Most patients die within two hours, but patients with slow absorption can take longer, up to a day, so it is best to prepare families and staff for a range of possibilities.
- Aid in dying does not erase all the normal signs and symptoms of dying. Death is death.
- Many patients will have color changes, stiffening and relaxing of the body, and sudden agonal breaths that may stabilize for a while before dying.
- Families need to know that comatose patients will remain comfortable. They will not experience those symptoms.
- Having an experienced, knowledgeable presence can significantly reduce fear and stress for loved ones.

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Enactment video

- This is an enactment, and everyone you will see is an actor. It may still be emotional to watch.
- As you watch, notice the communication, pacing, and practical support at the bedside.
- Also think about how this might look within your own organization's policies and the boundaries of your professional role.
- The enactment runs about eight minutes.

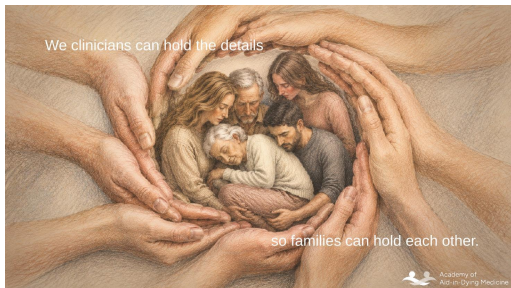
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Even when death is peaceful, it is rarely emotionally simple.

- Aid in dying is still dying. It's usually sad.
- Families do not always know what to do. We do not really have the rituals worked out.
- We typically advise patients to make their goodbyes to their broader community in the days before a planned death, and to reserve the aid-in-dying day for the innermost circle of people, so it is easier to focus.
- Staff may also feel the emotional impact, and that deserves acknowledgment. Debriefing can give space for thoughts and feelings and even for improved care.

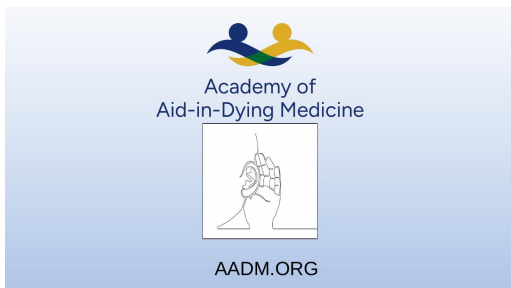
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Clinicians play a special role for families.

- If there is one thing I hope you leave with today, it's that aid in dying does not sit outside palliative care — it depends on the same clinical honesty, assertive symptom management, cohesive family support, and continuity you already provide every day.

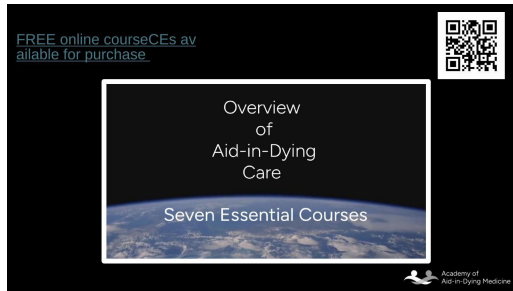
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Closing

- If there are a few things to take away, they are these: recognize the question, respond without judgment, know the referral pathway, and do not wait too long to begin the conversation.
- Professional neutrality does not require every clinician to participate. It does mean that patients' questions deserve a clear and respectful response.
- Invite questions and discussion.

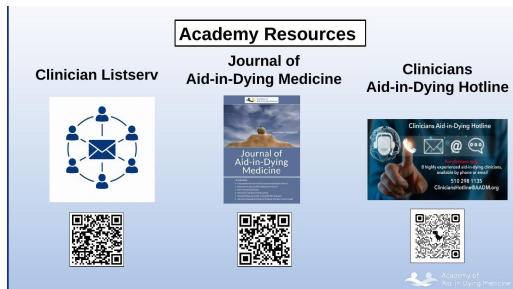
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Training and Academy resources

- This overview is a starting point.
- We offer free online content in our series, “Overview of Aid-in-Dying Care: Seven Essential Courses.”

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More resources

- The Academy has additional training and practical resources, a clinician Listserv, Journal of Aid-in-Dying Medicine, and Clinicians Aid-in-Dying Hotline.
- Point participants to the QR codes or handout for the resources most useful to them.