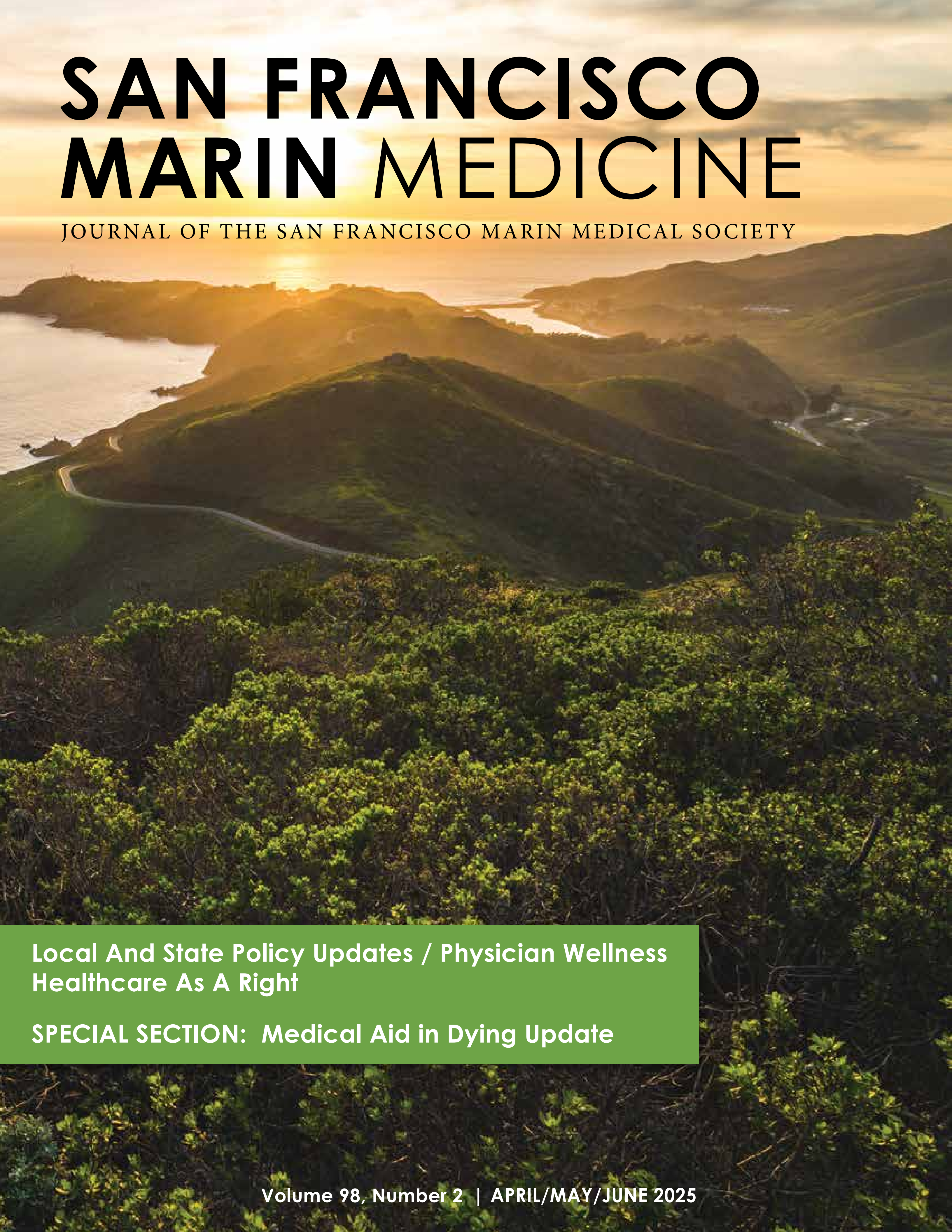


SAN FRANCISCO MARIN MEDICINE

JOURNAL OF THE SAN FRANCISCO MARIN MEDICAL SOCIETY

Local And State Policy Updates / Physician Wellness
Healthcare As A Right

SPECIAL SECTION: Medical Aid in Dying Update

Volume 98, Number 2 | APRIL/MAY/JUNE 2025

Advances in Aid-in-Dying Clinical Care:

AN UPDATE FROM THE ACADEMY OF AID-IN-DYING MEDICINE

Lonny Shavelson, MD, and Thalia DeWolf, RN, CHPN

Legal medical aid in dying — allowing terminally ill patients with decision-making capacity to take medications to die at the time of their choice — was born in Oregon in 1997, had a 23-year adolescence growing from legal rules to bedside care, and on February 14, 2020 it matured. Now, in 2025 — with 22% of the U.S. population living in aid-in-dying states — medical aid in dying is an increasingly wise adult, guided by evidence-based best clinical practices.

February, 14, 2020: A sunny winter morning on the Clark Kerr campus at UC Berkeley; more than 300 aid-in-dying clinicians from across the country gathered for the *first National Clinicians Conference on Medical Aid in Dying.* Prior to that day, they'd been working in relative seclusion, isolated by small numbers and the newness of aid-in-dying clinical care. The intense camaraderie at the conference formed a new medical community, and gave birth to the Academy of Aid-in-Dying Medicine. Clinical practice guidelines have rapidly evolved.

Clarifying and expanding the definition of medical aid in dying

Uniformly, in the lay press and medical literature, aid in dying was defined as variations of *"(the) medical practice wherein a health care provider prescribes medication to a qualified individual who may self-administer that medication to bring about a peaceful death."* But quality patient care, we all know, should never be narrowly focused on just writing prescriptions. Yet it wasn't until 2023 that the major clinical-practice resource UpToDate updated its prescription-focused definition of aid in dying to, *"...the legal practice where a clinician cares for a terminally ill patient who considers and potentially follows through with hastening their imminent death..."* The two major concept changes in that definition are (1) cares for a terminally ill patient, and (2) considers aid in dying.

Considering aid in dying has become the state-of-art term, acknowledging that terminally ill patients — novices at the dying process — are reviewing options, not just requesting lethal medications. Considering aid in dying is the all-encompassing term, from awareness of the option and simply wanting more information, through their journey in continued end-of-life care, ending only with death, whether by lethal medications or not. The aid-in-dying provider, then, is an end-of-life clinician who also offers aid in dying, if that's how the patient chooses to die.

This opened the nascent field of *aid-in-dying* medicine to include providing everything from information to life-ending medications, and all care in between. In fact, helping patients through the *if*, and *if so*, when dilemma is a major focus of compassionate aid-in-dying care, independent of whether the patient takes medications to die.

These conceptual advances led to our teaching about "interval care" — between contemplation and death. Terminally ill patients physiologic and psychosocial circumstances change as they get closer to dying; the patient's condition at the beginning of the process is often very different by the end. The attending/prescribing provider, then, doesn't operate at a moment in time (qualifying the patient and giving them a prescription), but over a spectrum of evolving events and circumstances.

Hospices and nurses are central to aid-in-dying care

Each year, around 50% of terminally ill patients receive hospice care. For those who utilize aid in dying, hospice enrollment rates are remarkably high, in the 90% range. By now, virtually every hospice in states where aid in dying is legal has cared for patients who have considered or completed aid in dying. Hospice staff, then, play a vital role in supporting these patients, independent of outcome. As a result, policies and procedures have evolved.

Since aid-in-dying laws permit any clinician or organization not to participate in the practice, the range of care has been described as "opt-in" or "opt-out." But that binary choice rapidly proved to be uninformative as a variety of care models developed. Similarly, non-specific but common expressions such as "We support aid in dying," or "We take a neutral stance," proved to be less than useful in understanding what, if any, aid-in-dying services a patient might expect. Unless accompanied by specific details about the care provided, imprecise phrases do not provide adequate information to patients, families, referring clinicians, or even hospice frontline clinical staff.

Only recently have hospices in some aid-in-dying states been required to make their policies public. Compliance has

continued on page 12

been poor, so data is hard to come by. But extensive anecdotal information suggests that hospices have become increasingly knowledgeable about the processes and care involved. Most have found ways to compassionately work with patients considering this option, moving beyond the opt-in/opt-out binary into a variety of approaches to care.

Rare hospices, mostly religious based, still tell patients, “We don’t participate in any way and can’t talk about it.” The vast majority of these organizations have moved beyond that limitation and their staff now ask about and discuss the reasons behind the patients’ inquiries. They embrace compassionate conversations about goals of care and end-of-life needs — even when the patient continues on the path to medical aid in dying (typically by hiring an outside clinician). Some Catholic-based hospices now allow their nurses to be present with the patient on the aid-in-dying day (while an outside clinician organizes and monitors that care).

Hospice care variations form a continuum, from those which “support” patients considering aid in dying but provide no specific care (referring that to outside clinicians), to those which provide “integrated aid-in-dying care” within their agency. These hospices coordinate all care from contemplation to the final decision and, if the patient wishes to proceed, provide staff for medical and emotional support on the aid-in-dying day.

Other hospices have reached varied middle grounds. Some do not allow their doctors to be attending/prescribing physicians, while they permit the legally-mandated consulting/2nd-opinions role. Frontline clinical staff policies vary, as well. For example, in many hospices, nurses, social workers, and chaplains may provide the crucial interval monitoring of patients considering aid in dying, and can be present on the aid-in-dying day. But those same hospices might forbid their nurses from preparing the medications — leaving the daunting task of adding liquid to a bottle of lethal powders to already anxious family members. And some ban all clinical staff from being in the room during medication ingestion. These hospices commonly cite legal restrictions prohibiting those activities, but no such limitations exist in any aid-in-dying law.

Hospice policies are still frequently outdated, originating from risk-management recommendations early in aid-in-dying history. They’ve persisted in spite of 28 years of clinical practice, during which no hospice, medical organization, or clinician has been sued or investigated for preparing the medications, complications of aid in dying, or being present during ingestion of the final dose. Of course, proving a negative (no lawsuits) is always difficult, but the Academy and multiple lawyers have searched for such cases, finding none. Of note, ethics reviews have found that “nurse leave the room policies” not only increase stigma against patients who choose aid in dying, they border on patient abandonment.

Yet signs of progress abound. When California’s law went into effect in 2016, hospices which provided integrated aid-in-dying care were extremely rare. They’ve since been increasingly common. Several large multi-location agencies provide fully-integrated care, successfully managing and coordinating workflows within their teams.

Since day-to-day clinical care in hospices concentrates on nurses, and quality aid-in-dying care means following patients over time, improved hospice and nurse outreach and training has become a major focus of the Academy of Aid-in-Dying Medicine.

Follow *their* gut.

Aid-in-dying laws mandate (in varying language) that patients ingest the medications — injections of any type are prohibited. This creates a pharmacologic dilemma that, surprisingly, took years to realize: The intestinal tracts of seriously ill patients, especially as they get closer to death, are not healthy. At a minimum, gastric emptying and peristalsis decrease and absorptive surfaces atrophy — leading to impaired transport and absorption of medications. At the worst, dying patients develop bowel obstructions (mechanical or medical), inability to swallow, or what we now refer to as “global gut dysfunction” — as the body shuts down, so does the gastrointestinal tract. So the legally mandated “ingestion” of aid-in-dying medications is, from a clinical point of view, an extremely troublesome requirement.

Major advances in aid-in-dying medicine have, to a significant extent, mitigated (but not resolved) the gut dilemma. First, legal opinions clarified that “ingestion” — thought from 1997 to around 2017 to signify “swallow” — means the administration of medications into the gastrointestinal tract. That opened the possibility of working not only with swallowing, but feeding tube, ostomy, and rectal administrations. This means that aid-in-dying clinicians, tasked with deciding which route would be the safest and most efficacious for each patient, have become experts in the oropharyngeal-esophageal-gastrointestinal tracts of dying patients — a changing functional capacity as they get closer to death. Again, aid-in-dying care moved from the original concept of a prescription-writing moment in time, to continued clinical care.

In journal articles, especially the Academy’s Journal of Aid-in-Dying Medicine, at conferences, in continuing education materials, and by word of mouth and mentoring, aid-in-dying clinicians increasingly understand dying patients’ gut function, and clinical best practices have evolved.

Megapharmacology

At aid-in-dying’s birth in Oregon in 1997, clinicians assumed that since sleeping medications like barbiturates bring on sleep by broadly suppressing brain neuron activity, a huge dose of a barbiturate would reliably also inhibit brain stem neurons that drive respiration. Megadoses of barbiturates, then, would first put the patient to sleep and then cause death by respiratory suppression. This, it turns out, is far from true. For example, if a patient can rapidly and completely absorb X milligrams of a barbiturate, the same does not apply to X-thousand milligrams, especially in the dysfunctional gut of a terminally ill patient. Although ER clinicians, toxicologists, and the media have reported about people dying from overdoses of various sedatives, including barbiturates, that doesn’t mean that everyone who takes such an overdose dies. But for aid-in-dying, reliability is crucial — and barbiturates, even in enormous doses, did not provide that.

Aid-in-clinicians have come to understand that megapharmacology differs from pharmacology — enormous overdoses don’t have the same absorption and pharmacokinetics of typical doses. As a result, a group of clinicians in Washington originated a system of three-system lethality — shutting down the brain, respiration, and heart — deeming such a protocol as necessary for the reliability of aid in dying. Over the 28-year history of these protocols, the pharmacology has advanced from admittedly ad-hoc word-of-mouth recommendations to sophisticated data-driven innovations and new medication combinations, as most recently described in the Journal of Palliative Medicine and extensively by the Academy.

Additionally, by using patient-report databases of the Academy, End of Life Washington, and End of Life Choices Oregon, predictive Clinical Factors Associated with Prolonged or Complicated Aid-In-Dying Deaths have been elucidated and widely distributed, mitigating complications and increasing the efficacy, reliability, and comfort of medical aid in dying.

The presently recommended medications are a combination of brain/respiratory/cardiac suppressants — DDMAPh, a mixture of diazepam, digitalis, morphine, amitriptyline, and phenobarbital in megapharmacologic doses that can be adjusted depending on the patient’s opiate/benzodiazepine resistance, extreme cardio-respiratory conditioning, and other risk factors. As well, the route of administration (oral, feeding tube, ostomy, rectal) can be changed depending on oropharyngeal-esophageal-gastrointestinal factors.

Autonomy

The moral imperative of aid-in-dying care rests in the clinician’s response to the autonomous decisions of patients considering aid in dying. And the very existence of autonomous decision making relies on information, readily provided, accurate, and detailed.

Autonomy thrives on information.

An interesting dilemma frequently comes up for clinicians, especially those in the attending/prescribing role, since those providers are the gatekeepers of aid-in-dying care. They determine if the patient qualifies, accepting or denying the possibility. But what if a patient legally qualifies, but the clinician disagrees with their motivations and reasoning?

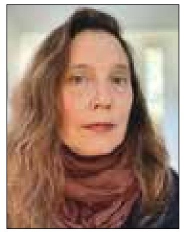
For example, one author of this article, Lonny Shavelson, cared for a patient who’d been a Vietnam war pilot, fire-bombing forests with napalm, resulting in thousands of civilians sustaining life-altering burns. Now dying of lung cancer with an estimated three to four months to live, this ex-pilot resided in a skilled nursing facility, the cost eating through his life savings. The patient qualified for aid in dying by all legal criteria. He decided to hasten his death to save money so he could finance a hospital in Vietnam for victims of napalm burns. (I’m switching to first person, given the personal nature of the dilemma.) I was deeply uncomfortable with and vociferously objected to his reasoning, even while understanding its foundation. I provided information and my own rationale for being distressed by his hastened death. As for any clinician, I, too had the right to autonomy. I considered denying or delaying his aid-in-dying request. But, I decided, his autonomy trumped mine.

I have since fielded questions from clinicians saying, “But this patient wants aid in dying so as not to be a burden to her family, even though they say she’s not a burden. I’m not comfortable with that.” Or, “This patient is having a pain-free hospice death and seems to me to have minimal suffering, with more than a month to live. Yet he wants me to help him die in a few days. That bothers me.”

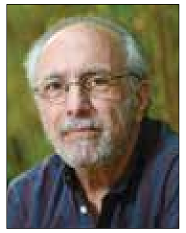
After lengthy discussions with many clinicians, we agreed that a provider can decline care to a patient if they are morally uncomfortable with that care (and all aid-in-dying laws support this “opt-out” right). Those clinicians might decide to transfer the patient to a different practitioner. We also agreed that, after we provide patients with detailed information and the reasons for our discomfort, we should not impose our moral imperatives on theirs. Or, as I put it to my own patients: “We may disagree on some aspects of your death, and I’ll make it clear when that’s happening. But in the end, if we disagree — you get to decide.”

Clinicians are not mere providers of information, we also offer the knowledge of our experiences — personal, clinical, and ethical — in as non-judgmental a fashion as we can. In the end, though, whether our patients consider stopping potentially life-extending chemotherapy, or are considering aid in dying, they get to decide.

So to further amend the UpToDate definition of aid in dying as where a clinician cares for a terminally ill patient who considers and potentially follows through with hastening their imminent death, we now add: The core of aid-in-dying medicine lies in respecting dying patients’ autonomy by providing evidence-based information and experienced knowledgeable opinions. And then, they decide if aid in dying is their chosen route to death, among many. The essence of our practice is to fulfill autonomy, not just provide medical aid in dying.



Thalia DeWolf, RN, is a certified hospice and palliative care nurse with extensive experience in end-of-life care. She is the Director of Nurse Education and Hospice Outreach Coordinator for the Academy of Aid-in-Dying Medicine.



Lonny Shavelson, MD, is the Director of Education for the Academy of Aid-in-Dying Medicine.

AID IN DYING MEDICINE UPDATE

Monique Schaulis, MD, MPH, FAAHPM

Here are a few recent musings on Aid in Dying Medicine. All in all, interesting times locally, nationally, and abroad.

I attended several presentations on MAID at the National Hospice and Palliative medicine (AAHPM) conference last year. I noted what seem like persistent generational and coastal divides. At the conference, a young physician from a well-regarded academic East Coast program presented on MAID. She felt so ostracized by her older colleagues that she felt unable to share her employer on her slides. Afterward, her boss stood up and publicly berated physicians who offered aid in dying. The discomfort in the room was palpable.

In contrast, physicians from Washington, Oregon, California, and Hawaii discussed ongoing refinement of practical and ethical processes around aid in dying. Their compassionate and unwavering professionalism served as a clear rebuttal to those opposed. Most physicians reported that improving collaboration with hospice agencies has been very helpful to patients and families. The change in the California waiting period from two weeks to 48 hours also had a positive impact as it has decreased the number who die or become incapacitated during the waiting period.

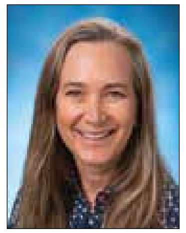
From our northern neighbors, a Canadian AID practitioner offered her perspective that US aid in dying is “barbaric” since there is no legal IV administration, creating significant barriers for some patients. There was a collective gasp in the room when she used this adjective but it provided some food for thought given the barriers that some patients (often with ALS) face in self-administration. The ongoing difficulties that patients with dementia face in the US as they cannot legally access aid in dying medication were also discussed.

Here in the Bay Area, the Academy of Aid in Dying Medicine continues to be a source of education, clinical standards, and support for clinicians and patients. The Academy has published several issues of the Journal of Aid in Dying Medicine which is offered free of charge and firewalls. https://www.aadm.org/journal

At the upcoming AMA House of Delegates, conversations between supporters of AID and those who oppose the practice will take place. The CMA and the medical student section have proposed using the term Medical Aid in Dying instead of the older and more pejorative Physician Assisted Suicide. Additionally, the Board of Trustees will recommend opposition to the civil or criminal legal action against physicians, health professionals, and patients who legally engage in physician assisted suicide. This is similar to the language that the AMA has supported for physicians who provide full spectrum reproductive care.

In California, there are concerns that the growing presence of faith-based hospitals and health systems restrict access to end of life medication (akin to reproductive services.) According to the Science Policy Group at UCLA, five California counties have exclusively faith-based acute, short-term care hospitals and faith-based hospitals have a majority market share in 25% of California counties. This is an exponential increase in the last decade. These organizations often explicitly prohibit their employees from participating in MAID. This increasing market share may represent an ominous shift in Californian’s access to aid in dying medication, particularly in counties where they are the only healthcare provider.

Overall, I see both steps forward and backward but a trend towards improved access to aid in dying.



Dr. Schaulis is an emergency and palliative physician at Kaiser San Francisco. She is a Past president of SFMMS and currently serves on the CALPAC board.

BEARING WITNESS AT THE END OF LIFE, SUPPORTING A CHOICE.

L. Nyberg, MD, MPH

“I don’t want you to get stuck in traffic,” she said to me. Then, turning to her sons, she said “You guys go get something to eat. It will probably take the mortuary way too long to get here to take my body away.” Ever pragmatic, Allison lived her own way and she died on her own terms.

Just after her terminal cancer diagnosis, she started planning her path. Allison was no stranger to tragedy and death. In childhood and adolescence, her sister died in a drowning accident and her brother died in the Vietnam War. She watched her father, then her mother, decline and die. She even came close to death, herself, after falling from a tree. She just had to get that mistletoe from the treetop.

Her brother’s death surely shaped her views about war and peace, sparking her activism against war, hate and cruelty. She was a humanist, believing that the majority of people are good and kind.

But the best companions in Allison’s view were animals. She always had at least one dog. For a time, she had the smallest dog and the tallest dog ever seen at San Diego’s Fiesta Island Dog Park. Seeing their silhouettes against the bay, one could swear that she had both a horse and a small rat in tow.

Allison loved Great Danes, her little dog, and the beach. But most of all, she loved her family — especially her two sons and her granddaughter. She was determined to plan a peaceful death sparing herself and sparing her loved ones the indignities that would likely occur as her advanced esophageal cancer progressed.

She started on Hospice and she learned of the end of life option. As a very private person, the Hospice visits felt intrusive to her. As she started the evaluation for the end of life option, the number of assessments, reassessments, repeated visits and repetitive information greatly annoyed her. She called me often to vent her frustration. Did she really need to see the chaplain – again? Yet another visit from the social worker? Another doctors visit for yet another signature? Really?

She did come to understand that the thorough evaluation was necessary and she finally received the bottle with the mixture of medications that she was to eventually add water, shake to mix, bring to her lips and hold in her own hands to drink.

The timing must be right. Her ability to swallow was rapidly worsening. She must be strong enough to hold the bottle and drink it. She felt empowered by the bottle on her shelf. It represented self-determination. It represented freedom from pain, control of her destiny, and an end to hersuffering. She knew that the time was rapidly approaching, but she was not quite ready.

When I saw Allison on Monday together with younger son, she said that she had called her elder son and had asked him to fly out from Utah . She had decided to take the medication the following day. She wanted her two sons and me to be with her at the end of her life.

On Tuesday morning, I awakened filled with anxiety and misgivings about being a part of a person actively ending their life. Initially, I feared that I would not be able to be present during the process. But I quickly got a grip on my feelings and understood that this was about Allison, not me. It was Allison’s decision to end her life under her own terms as her natural death was rapidly approaching. I knew that this was the kindest path rather than allowing the cruel disease to rob her of the self-determination and dignity that she had left. I also understood that the fact that she would take the medication herself not only ensures that the decision is her own, but it also serves to absolve those who are present of any guilt feelings they may harbor as they do not administer the medication.

I have witnessed many deaths in my field in health care. Some deaths have been peaceful and good. Other deaths have been extremely painful and difficult. I have also lost three beloved family members recently. Their deaths were not entirely peaceful. I believe that our loved ones who died were not in pain, but it was excruciating for my family and me to witness the sights and sounds of a loved one in the throes of dying. Allison’s was a beautiful death. To be present when Allison passed away was one of the greatest privileges of my life. It was a courageous and selfless act.

“I’m ready", she said. She hugged and kissed her sons and me. With quiet serenity and shining eyes, she drank the mixture, smiled and put her head down on her pillow. I stepped out to give Allison and her sons privacy in her last moments of lucidity. Shortly after, I was told that she was sleeping. Soon, she took her last breath. The peaceful calm that followed allowed us to grieve her passing while also celebrating her life and joys.

After I gave Allison a last goodbye kiss I hugged her sons and got on the freeway.

I didn’t get stuck in traffic

Allison would have liked that.

Dr. Nyberg is a semi-retired gastroenterologist in San Diego, CA.