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YOUR END-OF-LIFE OPTIONS ARE BROADER THAN EVER

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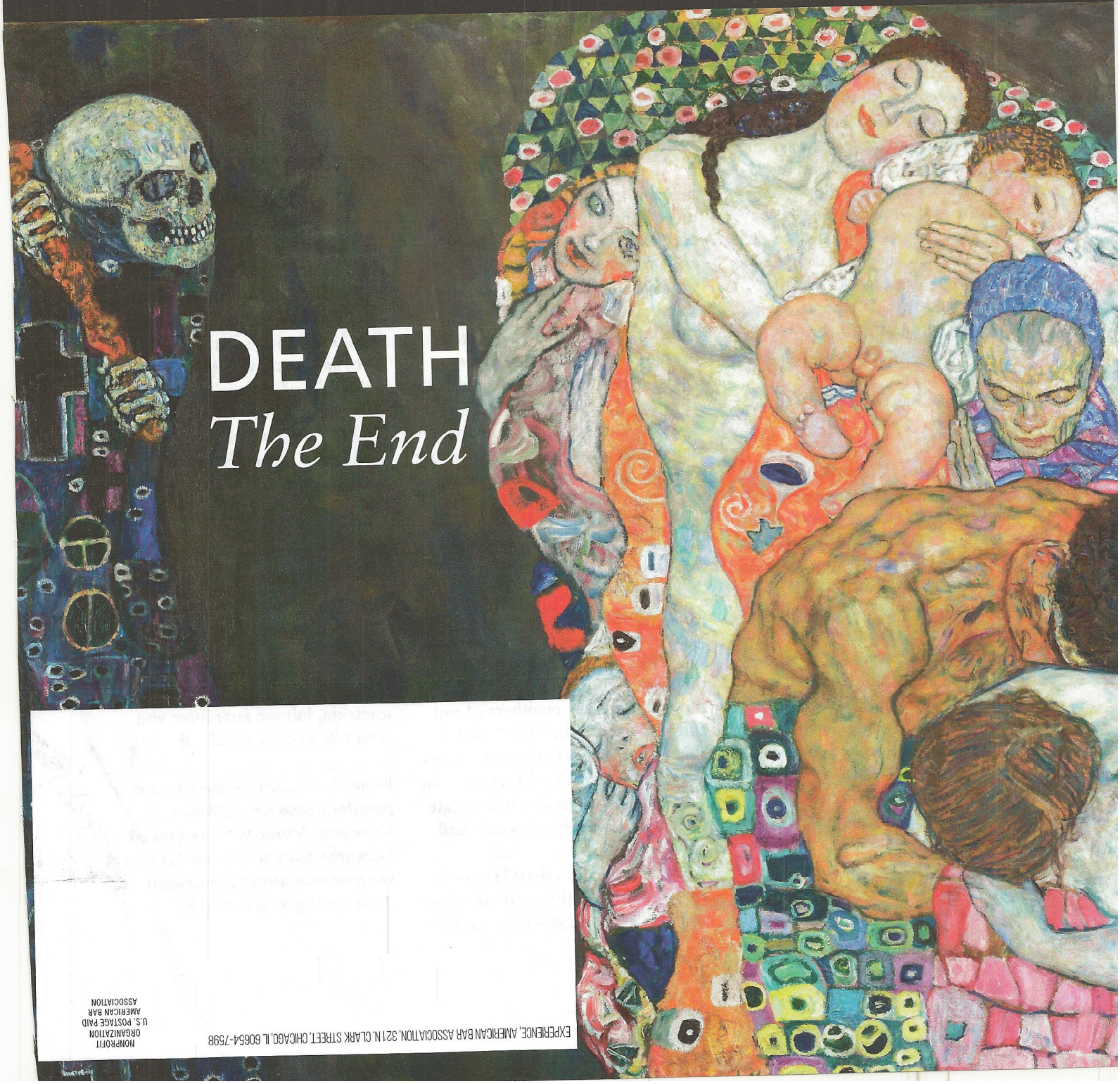

DEATH
The End

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cover image: Death and Life by Gustav Klimt

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DEPARTMENTS

Your End-of-Life Options

Medical aid in dying may allow you or your loved ones to take steps to avoid unnecessary end-of-life suffering.

THADDEUS MASON POPE

Medical aid in dying is an important end-of-life option for terminally ill Americans. First available in Oregon in 1997, MAID is now available in 11 U.S. jurisdictions. And the pace of legal developments is accelerating. New legislation and court judgments are further expanding access to MAID, with some bringing new and different twists.

THE LEGAL GROUNDWORK

What is medical aid in dying? It's a clinician-patient consultation that results in a prescription for lethal medications the patient might self-administer to hasten their death. This is permitted under four conditions. To be eligible for MAID, the patient must:

- Be an adult resident of the state (except in Oregon and Vermont)
- Be terminally ill, which means they have an illness that makes death probable in the next six months
- Have decision-making capacity, which means they must have the mental ability to request MAID on their own behalf; nobody (whether a guardian, healthcare agent, or surrogate) may request MAID for someone else
- Give informed consent; the clinician must ensure that the patient appreciates both what MAID entails and their alternative options

All U.S. MAID laws are modeled on the original law in Oregon, though there's increasing variability. The Oregon model includes significant patient safety protections. For example, two clinicians must assess the patient's eligibility.

Both an attending and a consulting physician must confirm that the patient is terminally ill and has decision-making capacity. If either medical professional is concerned the patient's judgment is impaired by a psychiatric or psychological condition, they must refer the patient to a mental health specialist who must confirm the patient's capacity.

If clinicians determine the patient is eligible for MAID, the patient can get a prescription. Today, that prescription is typically for a compound drug, DDMAPh, composed of digoxin, diazepam, morphine, amitriptyline, and phenobarbital.

Patients must self-administer these medications. They normally do this by mixing the powdered medications in two ounces of juice and drinking them. But

image: Bill Oxford/E+ via Getty Images

patients can also administer the medications by pressing a plunger on a rectal tube or feeding tube.

No clinician or third party can administer MAID medications through a syringe or otherwise. That would be euthanasia, which is prohibited in all U.S. jurisdictions. The patient must self-administer. Once the patient ingests the medications, they'll be asleep within eight minutes and dead in just over an hour.

WHO USES MAID—AND WHY?

Every state with a MAID statute has directed its department of health to collect and publish annual reports on usage (except Montana, which authorized MAID through a supreme court judgment and has no statute). That public data is remarkably consistent across all 10 states.

Nearly 75 percent of MAID patients are dying of cancer. Other terminal illnesses include amyotrophic lateral sclerosis, respiratory, and circulatory diseases. Most MAID patients are over age 70 and already enrolled in hospice. Most are white, college educated, and have health insurance.

The top three reasons patients ingest MAID medications are the loss of autonomy, the loss of dignity, and the loss of their ability to engage in activities that make life enjoyable.

MAID used to be called physician-assisted suicide. But policymakers determined that term was inappropriate because these patients don't want to die. They remain optimistic but recognize that they're already dying. They merely want to control the precise time and manner of their impending death.

Notably, one-third of patients who get a MAID prescription never fill or take it. They hope to manage their suffering so they won't need to take the medications. In other words, they treat MAID like fire insurance, as something to have just in case. Just as we hope never to make a fire insurance claim, patients hope never to need to take MAID medications.

It's also notable that fewer than 1 percent of terminally ill individuals who die in a state with MAID die from MAID. The others die from withholding or withdrawing life-sustaining or life-saving treatment, such as CPR, dialysis, or chemotherapy.

They die from voluntarily stopping eating and drinking or from palliative sedation. Or they die from their underlying disease, finding hospice and palliative care sufficient to address their physical or existential suffering.

WHERE MAID IS AVAILABLE

Eleven U.S. jurisdictions permit MAID: California, Colorado, the District of Columbia, Hawaii, Maine, Montana, New Jersey, New Mexico, Oregon, Vermont, and Washington. More than 22 percent of the U.S. population lives in these jurisdictions.

Plus, more than a dozen other states consider MAID legislation every year. Commentators expect that legislation authorizing MAID will soon be enacted in Maryland, Massachusetts, New York, and other states. After all, independent national and state surveys show that the American public consistently supports MAID by large majorities.

Even if MAID isn't available in your state, you can still access it. Yes, all MAID statutes require that the patient be a resident of the state. But this is a low barrier because residency is easy to establish. For example, it's sufficient to show that you lease property in the state. Indeed, many patients have traveled from non-MAID states to MAID states to obtain medical aid in dying.

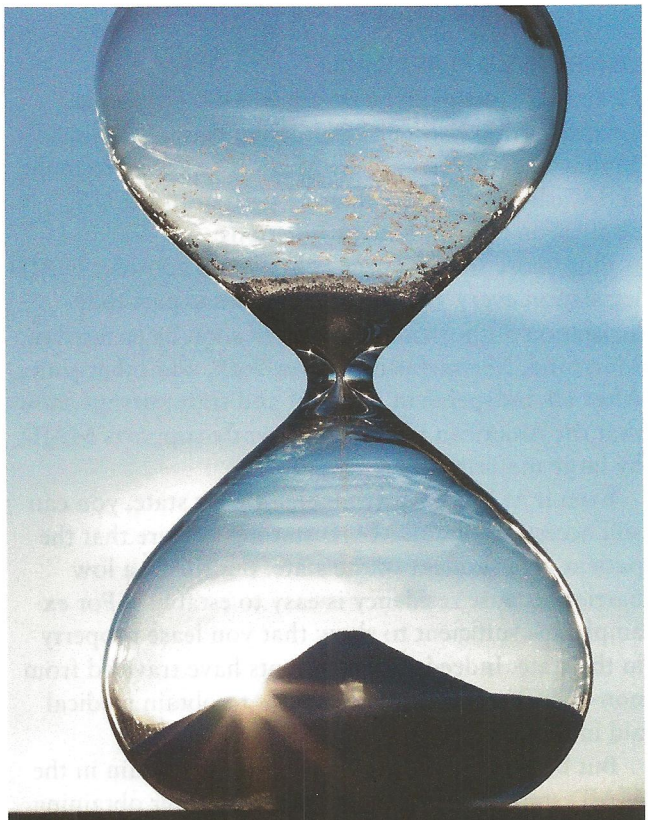
But be careful. It's probably safest to remain in the MAID state to ingest the medications after obtaining them. Bringing the medications back to a non-MAID state could pose legal risks for the patient's family. Without a MAID statute, helping a patient administer lethal medications likely falls within general criminal prohibitions of assisted suicide.

Prosecutors regularly enforce these laws in high-profile cases. Take, for example, 76-year-old Ellen Gilland, who fatally shot her terminally ill husband in a Florida hospital in 2023 [cnn.com/2023/02/23/us/ellen-gilland-daytona-murder-suicide-pact-charges/index.html]. She can't use his consent as a defense to criminal charges.

COULD ACCESS GROW?

Barriers to MAID medical tourism have been dropping even further. While the residency requirement has always been a surmountable obstacle, it's still an obstacle. Consequently, physicians and patients brought a federal lawsuit challenging Oregon's residency requirement as violating the privileges and immunities clause of the U.S. Constitution.

In March 2022, the state settled that lawsuit, agreeing not to enforce the residency requirement. That opened the door, over the past 18 months, to patients traveling to Oregon for MAID from as far away as North Carolina and Texas.



For decades, one of the standard safeguards in MAID statutes required that the patient make two separate oral requests, the second after a waiting period of at least 15 days. The rationale was to permit patients to calmly reflect and deliberate about their decision. But experience showed that many patients couldn't wait that long.

In March 2023, Vermont settled a similar lawsuit challenging the constitutionality of its residency requirement. The legislature then deleted that requirement from the MAID statute. Bills in other state legislatures similarly propose authorizing MAID without a residency requirement. States appear to recognize that they can't constitutionally limit healthcare services to their own residents.

Also, you may recall the several U.S. Supreme Court decisions interpreting the privileges and immunities clause to hold that, while states may generally regulate the practice of law, they may not exclude nonresidents from state bar admission. Just as an Idaho resident can get an Oregon law license, an Idaho resident can get Oregon MAID.

Removing the residency requirement isn't the only way access is expanding. For decades, only physicians could provide MAID. But it became increasingly obvious that this limited access. Especially in rural areas, physicians weren't always available.

So when New Mexico enacted its MAID statute in 2021, it also authorized advanced practice registered nurses and physician assistants to provide MAID. In 2023, Hawaii and Washington followed suit. Today, both current and prospective MAID states are considering legislation that would authorize not only physicians but also APRNs and PAs.

Another way states are expanding access to MAID is by reducing or waiving waiting periods. For decades, one of the standard safeguards in MAID statutes required that the patient make two separate oral requests, the second after a waiting period of at least 15 days.

The rationale was to permit patients to calmly reflect and deliberate about their decision. But experience showed that many patients couldn't wait that long. Since many patients don't seriously consider MAID until the late stages of their illness, they either died or lost decision-making capacity before the end of the 15-day period. In short, the waiting period frequently constituted an undue burden.

In response, several states have either shortened or waived the waiting period. Both California and New Mexico reduced their waiting periods from 15 days to 48 hours. Hawaii, Vermont and Washington also reduced their waiting periods. Today, bills in both current and prospective MAID states propose similar reductions.

In addition to, or instead of, shortening the waiting

period, some states exempt patients from having to satisfy the waiting period, however long it is, when the patient isn't expected to survive that period. New Mexico, Oregon, and Washington have already enacted such waiver laws. Bills in both current and prospective MAID states propose the same.

WHAT'S NEXT FOR MAID

States are already expanding access to MAID by expanding the types of authorized clinicians, shortening waiting periods, and eliminating residency requirements. Five more reforms could be coming next:

Six-month prognosis—All U.S. MAID jurisdictions require that the patient have a prognosis of six months or less to live. This strict temporal requirement is unusual compared to other countries, such as Canada, which require only that the patient have a "grievous and irremediable medical condition."

Indeed, many seriously and irreversibly ill individuals not within six months of dying may still suffer greatly every day from their disease. Some advocates want U.S. laws to be more like broader laws in Australia, Belgium, Canada, Luxembourg, Netherlands, New Zealand, Spain, and Switzerland.

Advance directives—Many older Americans fear living with late-stage dementia. But MAID isn't an option for these individuals. By the time they're terminally ill, they no longer have capacity. And when they still have capacity (for example, in early stages of Alzheimer's), they're not yet terminally ill.

In response, some advocates are pushing to permit individuals to arrange MAID through an advance directive. This is already permitted in some European countries and is being actively considered in Canada. (See p. 16, "New Legal Support Emerges for End-of-Life Decision Making" by Megan S. Wright for a deep dive into this challenge.)

Assisted self-administration—Some individuals otherwise eligible for MAID are unable to self-administer the medications because of neurological conditions like ALS. A case pending before the U.S. Court of Appeals for the 9th Circuit contends that the Americans with Disabilities Act permits, or even requires, clinicians to assist these patients in self-administering MAID medications when their physical disability prevents them from completing administration by themselves.

Intravenous administration—Under U.S. MAID laws, medications can be self-administered orally, rectally, or through a feeding tube. All three methods require ingestion (through the stomach and intestines). But evidence from other countries shows that intravenous infusion is more reliable and faster than ingestion.

Because U.S. MAID laws specifically prohibit ending a patient's life "by lethal injection," some advocates seek to delete that prohibition. They contend that IV administration would be safer and more effective.

Medicare coverage—While MAID is primarily a state matter, many terminally ill patients are on Medicare. That impedes access because the Assisted Suicide Funding Restriction Act of 1997 prohibits federal money from being spent on MAID. Patients must find another way to pay roughly $750 for the medications.

Furthermore, ASFRA deters many hospices and healthcare providers from offering MAID because they worry about inadvertently billing Medicare for it. For these reasons, while most advocacy has been at the state level, some advocates seek to repeal ASFRA.

MAY WE NEVER NEED IT

We're all going to die. While most of us won't use MAID, it's important to understand all our options so we can best ensure that our final chapter accords with our preferences and values.

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