

Traveling to die: The latest form of medical tourism

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In the 18 months after Francine Milano was diagnosed with a recurrence of the ovarian cancer she thought she'd beaten 20 years ago, she traveled twice from her home in Pennsylvania to Vermont. She went not to ski, hike, or leaf-peep, but to arrange to die.

"I really wanted to take control over how I left this world," said the



61-year-old who lives in Lancaster. "I decided that this was an option for me."

Dying with <u>medical assistance</u> wasn't an option when Milano learned in early 2023 that her disease was incurable. At that point, she would have had to travel to Switzerland—or live in the District of Columbia or one of the 10 states where medical aid for dying was legal.

But Vermont lifted its residency requirement in May 2023, followed by Oregon two months later. (Montana effectively allows aid in dying through a 2009 court decision, but that ruling doesn't spell out rules around residency. And though New York and California recently considered legislation that would allow out-of-staters to secure aid for dying, neither provision passed.)

Despite the limited options and the challenges—such as finding doctors in a new state, figuring out where to die, and traveling when too sick to walk to the next room, let alone climb into a car—dozens have made the trek to the two states that have opened their doors to terminally ill nonresidents seeking aid in dying.

At least 26 people have traveled to Vermont to die, representing nearly 25% of the reported assisted deaths in the state from May 2023 through this June, according to the Vermont Department of Health. In Oregon, 23 out-of-state residents died using medical assistance in 2023, just over 6% of the state total, according to the Oregon Health Authority.

Oncologist Charles Blanke, whose clinic in Portland is devoted to <u>end-of-life care</u>, said he thinks that Oregon's total is likely an undercount and he expects the numbers to grow. Over the past year, he said, he's seen two to four out-of-state patients a week—about one-quarter of his practice—and fielded calls from across the U.S., including New York, the Carolinas, Florida, and "tons from Texas." But just because patients



are willing to travel doesn't mean it's easy or that they get their desired outcome.

"The law is pretty strict about what has to be done," Blanke said.

As in other states that allow what some call physician-assisted death or assisted suicide, Oregon and Vermont require patients to be assessed by two doctors. Patients must have less than six months to live, be mentally and cognitively sound, and be physically able to ingest the drugs to end their lives.

Charts and records must be reviewed in the state; neglecting to do so constitutes practicing medicine out of state, which violates medical licensing requirements. For the same reason, the patients must be in the state for the initial exam, when they request the drugs, and when they ingest them.

State legislatures impose those restrictions as safeguards—to balance the rights of patients seeking aid in dying with a legislative imperative not to pass laws that are harmful to anyone, said Peg Sandeen, CEO of the group Death With Dignity. Like many aid-in-dying advocates, however, she said such rules create undue burdens for people who are already suffering.

Diana Barnard, a Vermont palliative care physician, said some patients cannot even come for their appointments. "They end up being sick or not feeling like traveling, so there's rescheduling involved," she said.

"It's asking people to use a significant part of their energy to come here when they really deserve to have the option closer to home."

Those opposed to aid in dying include religious groups that say taking a life is immoral, and medical practitioners who argue their job is to make



people more comfortable at the end of life, not to end the life itself.

Anthropologist Anita Hannig, who interviewed dozens of terminally ill patients while researching her 2022 book, "The Day I Die: The Untold Story of Assisted Dying in America," said she doesn't expect federal legislation to settle the issue anytime soon. As the Supreme Court did with abortion in 2022, it ruled assisted dying to be a states' rights issue in 1997.

During the 2023-24 legislative sessions, 19 states (including Milano's home state of Pennsylvania) considered aid-in-dying legislation, according to the advocacy group Compassion & Choices. Delaware was the sole state to pass it, but the governor has yet to act on it.

Sandeen said that many states initially pass restrictive laws—requiring 21-day wait times and psychiatric evaluations, for instance—only to eventually repeal provisions that prove unduly onerous. That makes her optimistic that more states will eventually follow Vermont and Oregon, she said.

Milano would have preferred to travel to neighboring New Jersey, where aid in dying has been legal since 2019, but its residency requirement made that a nonstarter. And though Oregon has more providers than the largely rural state of Vermont, Milano opted for the nine-hour car ride to Burlington because it was less physically and financially draining than a cross-country trip.

The logistics were key because Milano knew she'd have to return. When she traveled to Vermont in May 2023 with her husband and her brother, she wasn't near death. She figured that the next time she was in Vermont, it would be to request the medication. Then she'd have to wait 15 days to receive it.



The waiting period is standard to ensure that a person has what Barnard calls "thoughtful time to contemplate the decision," although she said most have done that long before. Some states have shortened the period or, like Oregon, have a waiver option.

That waiting period can be hard on patients, on top of being away from their health care team, home, and family. Blanke said he has seen as many as 25 relatives attend the death of an Oregon resident, but out-ofstaters usually bring only one person. And while finding a place to die can be a problem for Oregonians who are in care homes or hospitals that prohibit aid in dying, it's especially challenging for nonresidents.

When Oregon lifted its residency requirement, Blanke advertised on Craigslist and used the results to compile a list of short-term accommodations, including Airbnbs, willing to allow patients to die there. Nonprofits in states with aid-in-dying laws also maintain such lists, Sandeen said.

Milano hasn't gotten to the point where she needs to find a place to take the meds and end her life. In fact, because she had a relatively healthy year after her first trip to Vermont, she let her six-month approval period lapse.

In June, though, she headed back to open another six-month window. This time, she went with a girlfriend who has a camper van. They drove six hours to cross the state border, stopping at a playground and gift shop before sitting in a parking lot where Milano had a Zoom appointment with her doctors rather than driving three more hours to Burlington to meet in person.

"I don't know if they do GPS tracking or IP address kind of stuff, but I would have been afraid not to be honest," she said.



That's not all that scares her. She worries she'll be too sick to return to Vermont when she is ready to die. And, even if she can get there, she wonders whether she'll have the courage to take the medication. About one-third of people approved for assisted death don't follow through, Blanke said. For them, it's often enough to know they have the meds—the control—to end their lives when they want.

Milano said she is grateful she has that power now while she's still healthy enough to travel and enjoy life. "I just wish more people had the option," she said.

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