
HEALTH

The Doctors Who Invented a New Way to Help People Die

The two lethal medications used by terminal patients who wish to end their own life recently became unavailable or prohibitively expensive.

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Youssef Cohen, a right-to-die advocate with an incurable cancer, rides to a doctor's appointment in New York with his wife in 2016. (JOHN MOORE / GETTY)

In 2016, a small group of doctors gathered in a Seattle conference room to find a better way to help people die. They included physicians at the forefront of medical aid in dying—the practice of providing terminal patients with a way to end their own life. And they were there because

the aid-in-dying movement had recently run into a problem. The two lethal medications used by most patients for decades had suddenly become either unavailable or prohibitively expensive. When doctors briefly tried a substitute, some patients had rare but troubling experiences.

The Seattle group hoped to discover a different drug. But the practicalities of aid in dying, a controversial policy still illegal in most of the United States, are not like those in other medical fields. “There’s lots of data on stuff that helps people live longer, but there’s very little data on how to kill people,” says Terry Law, a participant at the meeting and one of the most frequently used aid-in-dying doctors in the U.S.

Seven states—including Hawaii, where a law took effect on January 1—and the District of Columbia now allow doctors to write lethal prescriptions for qualifying, mentally capable adults who have a terminal illness. And support for the practice has gained new national momentum after the widely publicized death of Brittany Maynard, a young cancer patient who moved to Oregon in 2014 to take advantage of that state’s aid-in-dying law.

[[Read: Brittany Maynard and the challenge of dying with dignity](#)]

But the public remains deeply conflicted about the laws—as does the medical community itself. No medical association oversees aid in dying, and no government committee helps fund the research. In states where the practice is legal, state governments provide guidance about which patients qualify, but say nothing about which drugs to prescribe.

“Nowhere in the laws is there any sort of guidance for *how* to do it. There is no oversight to make sure that it’s happening in a safe way, apart from annual reports and kind of a face-value annual hearing,” says Laura

Petrillo, a palliative-care physician who opposes legalized aid in dying.

The meeting of the 2016 group set in motion research that would lead the recipe for one of the most widely used aid-in-dying drugs in the United States. But the doctors' work has taken place on the margins of traditional science. Despite their principled intentions, it's a part of medicine that's still practiced in the shadows.

On the surface, figuring out protocols for hastening death doesn't seem complicated. Lonny Shavelson, a California physician who specializes in aid in dying, says that when he explains to patients it might take an hour or more for them to die, they're often shocked. They tell him, "When I put down my dog, it took 10 minutes," he says.

But veterinarians can use lethal injections on pets. In the U.S., aid-in-dying drugs must be ingested by the patient. The first proposed aid-in-dying law in Washington State would have allowed physicians to inject medications, but that legislation failed to pass. In 2008, a modified law was voted in, with an added requirement that patients self-ingest to help protect them from the possibility of family coercion.

For years, the two barbiturates widely considered the best drugs for hastening death in terminally ill patients were pentobarbital and secobarbital. These medications were painless, fast-acting, and relatively affordable. But since 2015, they've been largely unavailable. U.S. pharmacies stopped carrying pentobarbital approved for human use, and the price of secobarbital, under the brand name Seconal, doubled from an already historic high after Valeant Pharmaceuticals (today known as Bausch Health) bought the manufacturing rights. A few years ago, a lethal dose cost about \$200 or \$300; now it can cost \$3,500

or more.

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To help patients who could no longer afford the drug, aid-in-dying groups sought a fix. In Washington, an advocacy organization called End of Life Washington briefly advised prescribing a drug mixture with the sedative chloral hydrate to about 70 patients. “We know this is going to put you to sleep, and we’re pretty sure it’s going to kill you,” Robert Wood, a medical director at the organization, says they told the patients. It worked, but with a tragic catch: In a few cases, the chloral hydrate burned people’s throats, causing severe pain just at the time they expected relief.

The End of Life gathering was born out of the need for a better solution. Wood enlisted three others affiliated with End of Life Washington: Law, its president; Tom Preston, a former medical director; and Carol Parrot, a retired anesthesiologist who, like Law, is one of the most experienced aid-in-dying doctors in the U.S. Others joined that meeting or later ones by telephone: a toxicologist in Iowa, a veterinarian, a pharmacologist, another anesthesiologist. The group had three main criteria, Parrot says: They wanted “a drug that would: number one, put a patient to sleep and keep them asleep; and, number two, make sure there was no pain involved; and number three, ensure that they would die, and, hopefully, die relatively quickly.” Plus, it had to be cheap. They aimed for \$500 a dose.

The doctors considered a malaria medicine known to be lethal in large doses, but read that it caused severe muscle spasms in some patients. They discussed the synthetic opioid fentanyl, but were deterred by the drug’s newness and dangerous reputation. So the group decided to use a

combination of medications, and eventually settled on high doses of three: morphine, diazepam—also known by its early brand name, Valium—and propranolol, a beta-blocker that slows the heart. They called the mixture DMP.

Next, the group had to test the drug. But they still didn't have a way to follow standard procedure: There would be no government-approved clinical drug trial, and no Institutional Review Board oversight when they prescribed the concoction to patients. The doctors took what precautions they could. Patients could opt in or out, and for the first 10 deaths, either Parrot or Law would stay by the bedside and record patients' and families' responses.

The first two deaths went smoothly. But the third patient, an 81-year-old with prostate cancer, took 18 hours to die, Parrot says. In Oregon, where aid in dying has been legal for 20 years, the median time from taking the medication until death is 25 minutes. Patients themselves typically become unconscious in five or 10 minutes, so they are not affected by protracted times, Parrot, Wood, and Law all emphasize. But longer waiting periods can be nerve-racking for families and other caregivers, especially in the exceptional cases where these have persisted for a day or more.

[Read: What people say before they die]

Parrot and Law halted the DMP trial. The informal research group met again, this time by teleconference, and Law dug through the literature and found an article about people who purposely overdosed on digoxin, a cardiac drug. The group added it to the prescription, and the drug became DDMP.

At first, Parrot gave patients latitude in how they took this new drug combination. “One guy chugged a half a cup of Bailey’s Irish Cream, his favorite thing, after he had his medicine,” she says. “He probably took five or six hours to die.” She suspects that the fat particles in the Bailey’s slowed his gastric emptying. So the researchers checked in with each other again, and decided to increase the doses to what Parrot calls “blue-whale-sized doses.” They dubbed the modified formula DDMP2.

The drug is not a perfect aid-in-dying solution. Secobarbital is faster-acting and remains the drug of choice when patients can afford it, Wood says. Just as in the case of the barbiturates, a few outlier patients on DDMP2 take hours longer to die. And the mixture tastes extremely bitter. “Imagine taking two bottles of aspirin, crushing it up, and mixing it in less than half a cup of water or juice,” Parrot says.

Still, DDMP2 has become the low-cost solution the Seattle group set out to discover. In 2017, secobarbital was still the most commonly prescribed drug in Washington and Oregon, but in Colorado, DDMP2 was more commonly prescribed. The drug consistently accomplishes its purpose in hastening death, Parrot says: “It always works. It always, always works.”

Parrot and Wood keep track of patient data, and they continue to make discoveries. By examining medical histories of the patients who took longer to die, they’ve learned about certain risk factors for longer deaths: being on extremely high doses of painkillers such as fentanyl or morphine; being very athletic; having a compromised digestive tract. For patients who are especially risky, Parrot or Wood will sometimes offer the choice of chloral hydrate, the drug that burned some patients’ throats, although they say they carefully discuss potential problems with

patients and families.

Together, Parrot and Law have written perhaps 300 lethal prescriptions over the years and observed the effects of medications on numerous patients. Neither set out to be an aid-in-dying advocate; they turned to End of Life Washington after witnessing the suffering of some dying patients. About eight years ago, Law says she was asked to prescribe lethal medications for a dying woman whose regular doctors had refused. She agreed to see the woman, and realized how difficult it was for some aid-in-dying patients to find doctors. Parrot says she was profoundly affected by the deaths of two close friends who asked her to help hasten their dying, but who lived in states where the practice was illegal. She was unable to help them, and began volunteering as an aid-in-dying doctor soon after she retired.

Most medical professionals don't participate in aid in dying. Some physicians are concerned that their Hippocratic oath prohibits intentionally helping someone die, or that aid-in-dying requests originate from treatable pain or depression. Some worry about the broader repercussions for a society that accepts medically aiding the deaths of the terminally ill. The American Medical Association remains officially opposed.

Without the support of the rest of the profession and much of society, aid-in-dying research methods don't fit the model of good medical research, says Matthew Wynia, the director of the Center for Bioethics and Humanities at the University of Colorado. There's no standard protocol, no standardized data collection or independent group that monitors data and safety—all of which are intended to protect patients and help ensure the quality of the research.

The Belmont Report, which guides federal recommendations for research on human subjects, recognizes that sometimes, no satisfactory options exist for some patients, Wynia points out. In those rare cases, a doctor may want to try an innovative treatment, something for which there's no approved research protocol. While that's legal, clinicians are supposed to avoid turning that innovation into established practice, or doing unapproved research on numerous patients, according to Wynia. Some of the same issues exist with medical marijuana, which is legal in several states but still illegal federally. "There's no way to fix this at the individual level," Wynia says. "There's no immediate answer."

That leaves researchers like Law and Parrot in a bind. They don't have good ways to do research and communicate what they learn. But they've witnessed the suffering some dying people experience, and contrast that with many peaceful deaths of patients who choose aid in dying. "These are not hard deaths," argues Shavelson, the California physician. "These are lovely deaths."

Shavelson says he tries to be at the bedside on the day of his aid-in-dying patients' death. "It's a lighter atmosphere than you think," he says. The patient takes the first drug, which Shavelson separates out from the rest of the mixture, and then Shavelson sits down at the bedside and reads aloud questions from the state's required report. After about 30 minutes, he asks: "Are you ready to take the medications?" He mixes the drug cocktail and the patient drinks it.

"Usually, they go silent after taking the medication," he says. "They've said what they're going to say by that time." For a few minutes, patients usually continue to sit silently, their eyes open. "And then, very, very

slowly, they'll close their eyes.”

Shavelson asks intermittently, “Are you still there?” At first, patients usually say yes, or nod. Within five or 10 minutes, they stop responding to the question. Then Shavelson will gently touch their eyelids. “When people aren't deeply unconscious, they'll sort of have a twitching response,” he explains. Within 10 or 15 minutes, the twitching response disappears, and patients enter a deep coma.

Using a heart monitor, Shavelson tells caregivers as a patient's pulse slows and oxygen levels drop. “We wait a little while, and then I say, ‘Ah, the patient's now dead.’”

This is the first generation of patients who have consciously hastened their death with medications in this way, Shavelson says. He tells them they're pioneers. “What a different thing, to be able to say, ‘This is the day I die,’” he says.

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