

Expanding Access to Medical Aid in Dying

By Chris Palmer*

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What if the laws intended to give people more control over dying actually fail many of those who need them most?

For people with dementia and other progressive neurodegenerative diseases, this isn't a theoretical problem. It's a harsh reality. Despite the promise of autonomy and choice embedded in medical aid in dying (MAID) laws, the way these laws are written in the U.S. excludes many who suffer unbearably, precisely because of how they suffer.

A Narrow Window That Shuts Too Soon

In every U.S. jurisdiction where MAID is legal, patients must meet several criteria to be eligible, including the following:

- Have a terminal diagnosis with a prognosis of six months or less to live
- Possess the mental and physical capacity to request and self-administer the lethal medication

This framework may work for people with certain cancers or other conditions where cognitive function and physical ability remain intact. But it will likely exclude large numbers of people with illnesses like ALS, advanced Parkinson's, and especially dementia.

People with these illnesses may remain mentally competent for years while experiencing increasing suffering. But once they approach the six-month-to-live threshold, they may no longer be able to communicate clearly, swallow medication, or legally authorize the use of MAID, even if they've long expressed a wish to avoid prolonged decline.

When the Law Fails the Very People Who Need It Most

When I speak with people about end-of-life planning, I often hear some version of a line they never want to cross:

- "If I don't know who I am or who you are, I don't want to keep living."
- "If someone has to feed me because I don't even know I'm hungry, that's not life."
- "If I'm just sitting in a diaper, staring into space, unable to connect—please let me go."

People know what kind of life they find meaningful. The tragedy is that our current legal frameworks don't respect these deeply held boundaries.

MAID laws were designed with certain diseases in mind, typically late-stage cancers where suffering is clear, decline is predictable, and patients retain capacity. But progressive neurological illnesses don't follow that script.

For example, people with ALS often remain mentally alert while their bodies fail them. If they lose the ability to lift a cup or push a plunger, they may be disqualified from using MAID, even if they meet every other requirement. While family members or caregivers can assist with steps like picking up the prescription, preparing the medication, or placing it within reach, they are not allowed to administer it. If the patient cannot complete the final act, the option disappears.

Dementia patients face an even more rigid wall. You can only request MAID if you are mentally competent, but the law requires that you also be terminal. By the time dementia qualifies as terminal, patients no longer have the capacity to make the request.

Alternatives to MAID

There are legal, compassionate alternatives to MAID. They include withholding or withdrawing life-sustaining treatments, and going to Switzerland to take advantage of their more progressive MAID laws (which the Swiss call VAD, or Voluntary Assisted Dying).

Another option is voluntarily stopping eating and drinking (VSED). Excellent books such as *Herself to the End* and *Winter's End*, and the 2021 clinical guide *Voluntarily Stopping Eating and Drinking: A Compassionate, Widely Available Option for Hastening Death*, edited by Paul Menzel, Thaddeus Pope, and others, show that VSED, while requiring fortitude, is often manageable with the proper support and preparation. VSED is fully legal and should be guided by medical professionals, hospice teams, and loving caregivers.

Organizations like Final Exit Network (FEN) provide non-medical guidance and compassionate support for people who want to explore lawful ways to end their suffering when they are excluded from MAID. Despite misunderstandings, FEN operates squarely within the boundaries of the First Amendment, offering information and emotional support, not physical assistance in dying. FEN's noble mission is to educate and support those who want choice in dying.

A More Humane, Inclusive System

While all the above alternatives to MAID are welcome, the US needs to rethink its narrow, restrictive approach to MAID. A better system would account for the slow, often invisible suffering of progressive diseases. It would allow people to express their values and wishes in advance, while they are fully competent, and to trust that those choices will be honored. It would

expand eligibility to include conditions that are grievous and irremediable, not just terminal within six months.

This is not a radical idea. Canada has already adopted a more flexible model, where patients suffering intolerably from incurable conditions, whether or not they are imminently dying, may qualify for MAID. California considered a similar expansion but has yet to enact it.

Groups like A Better Exit and the Hemlock Society of San Diego, both California-based nonprofits, are working to broaden California's End of Life Option Act to include individuals suffering from progressive, incurable diseases, such as early to mid-stage dementia, ALS, Parkinson's, and multiple sclerosis. Some patients with those types of neurodegenerative diseases may not be currently covered under the law, thereby denying them the right to choose a legal and peaceful death with MAID.

Janet Hager, cofounder and board member of A Better Exit, says, "One of our goals is to allow those with progressive neurodegenerative diseases access to MAID before they lose their mental or physical capacity to make that choice." A Better Exit also wants to allow all patients using MAID an IV option in addition to the ingested option, which is currently the only method allowed in the US, with both methods remaining self-administered.

If This Matters to You, Speak Up Now

If you have strong feelings about what makes life worth living, don't wait. Talk to your loved ones. Put your values in writing. Choose a healthcare agent who will honor your wishes. And support advocacy efforts to expand end-of-life options for everyone, regardless of diagnosis, disease progression, or physical ability.

The fight for MAID is about more than laws. It's about justice. It's about ensuring that people who suffer unbearably can access compassion, not bureaucracy. It's about recognizing that dignity means different things to different people, and honoring that diversity of need with a broader, wiser, more humane system.

Dying is hard enough. Let's not make it harder by denying people the right to face it on their own terms and with a rich array of choices. We should all have choice in dying.

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FEN blog post on expanding access to MAID