

Aid in dying the right thing to do

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November is a milestone for me. This month will be 33 years that I've spent in a wheelchair after an automobile accident.

Believe it or not, being in the chair hasn't been the worst thing. It sucks, but dealing with things that come with it are the hardest: the pressure sores, the health issues, the reliance on others and the attitudes of some.

However, I've learned some valuable lessons.

I hope I never took them for granted when I was on my feet, but I have a great family! My friends and support system have kept me alive.

I've had a job I love for the last 23 years. I've had mentors that have pushed and challenged me. I have a woman in my life that I truly love, and a stepson who has made my life a whole lot happier.

The one thing I've tried to maintain is independence.

Independent living means something different to everyone, especially to someone with a disability.

The independent living philosophy emphasizes consumer control over their lives, and people with disabilities are the best experts on their own needs.

The premise that people with disabilities are deserving of equality, and equally deserve the right to decide how we live, work and interact with others.

We've all come a long way since the Americans with Disabilities Act (ADA) became law in 1990.

The ADA allows the disability community the opportunity to live as equals to anyone.

Self-determination and autonomy underlie the ADA; they are the rights people living with disabilities have sought our entire lives.

The Medical Aid in Dying Act (MAID) is legislation pending in Albany allowing a terminally ill, mentally capable adult the option to self-administer medication - when and if they choose - to bring about a peaceful and humane death, should their end-of-life suffering become too great to bear.

I was surprised to learn some in the disabled community expressing their sincere, but misguided opposition to MAID at a recent conference in Utica, held by the Resource Center for Independent Living.

Self-determination has always been the goal of people living with disabilities.

We have fought for equality, and this equality shouldn't end as our lives come to a close.

We cannot advocate for the rights of people living with disabilities to be able to make their own choices and health care decisions during life, only to deny those freedoms at the end of life.

I believe much of the objection to MAID is driven by fear and misunderstanding.

Dying is a part of living.

To advocate, to strive for equality only gets cheapened by the claim that we are now vulnerable, or our lives are somehow now diminished because of a law is an insult. Giving people with disabilities the choice at the end of life would empower us, and give our control in life legitimacy.

My life's value cannot be diminished by aid in dying.

To the contrary, my life would be empowered by MAID.

It would give me the autonomy I've worked so hard to maintain since my very first day in a wheelchair.

MAID is not a disability issue. It is a human issue.

The law is explicit - only a terminally ill, mentally capable adult can qualify to receive aid-in-dying medication.

Questions are fair and understandable, but let's look at the facts, rather than misinformation and fear.

A disability or chronic condition alone is clearly not a terminal illness, and therefore does not qualify under the legislation.

After 30 years of experience with aid in dying in the five states where it's available, aid in dying has been shown to work as intended.

There is absolutely no evidence of a disabled or otherwise "vulnerable" person being coerced into requesting or taking the medication.

After more than 18 years with aid in dying in Oregon, fewer than 1,000 people have utilized the medication, but untold more - including those facing a terminal illness, and the people who love them - have enjoyed an increased peace of mind knowing there was another option if their suffering became unbearable.

What may surprise some is that after aid in dying became available in Oregon, access to hospice actually increased and overall end-of-life health care improved because patients were able to have more open conversations with their families and doctors.

There are a number of currently available options for terminally ill New Yorkers.

We all have the right to refuse medical care and nutrition.

And for most, this is enough. For some, these options are not enough.

That's why New York must become the next state to make aid in dying an option.

Every New Yorker facing the end of life should have the right to decide when suffering becomes unbearable, this is equally true for those of us living with disabilities.

Gene Hughes has worked at the Resource Center for Independent Living for 23 years. The last 10 years working on Individual and systemic issues.