No one can choose whether they die, but some Utahns want to choose how

Bill is based on similar laws in Oregon and California that have faced stiff opposition from critics who view life-ending prescriptions as medically unethical.

By BENJAMIN WOOD | The Salt Lake Tribune Published Feb 01 2016
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Between 2013 and 2014, Carrie Snyder went from a wedding, followed by a honeymoon in Spain, to being told she had two months to live.

The Salt Lake City resident first noticed she was having trouble breathing, which was followed by a pain in her chest.

After several trips to a doctor's office, tests and X-rays revealed stage 4 adenocarcinoma — lung cancer.

"I think they were pretty blown away," she said of her doctors. "It was horrible. My lungs were completely filled with tumors."

Snyder was told to get her affairs in order and has spent 18 months in drug trials and radiation treatments.

"If I said, 'I don't want to take this new drug, I'm tired,'" she said, "I'd probably be gone in two months."

She said she still bounces between acceptance, resentment and fear.

But her months of treatment have given her time to consider her final moments of life, including a desire to determine when and how those final moments occur.

"I don't think death has to be filled with fear," she said. "The more you are the writer of your death scene, the less fearful you become."

One Utah lawmaker is pushing to give patients like Snyder greater control over their deaths.

The End of Life Options Act, sponsored by Salt Lake City Democratic Rep. Rebecca Chavez-Houck, would create a legal pathway for terminally ill Utahns to obtain a prescription for life-ending drugs.
The bill is based on similar laws in Oregon and California, which have faced stiff opposition from critics who view life-ending prescriptions as medically unethical and morally tantamount to suicide.

But Chavez-Houck said her bill is empowering for patients, providing autonomy in the face of pain and suffering.

"They want to live, but that choice has been taken away from them by their terminal condition," she said. "This is their option of last resort to be able to take back when that happens and how that happens."

Snyder said she doesn't want to be confined to a bed for days or weeks, drowning in pain and unable to breathe while her family watches her suffer.

"In the same way that you have freedom to imagine all sorts of things about your life," she said, "it seems like such a shame that we can't imagine our death the way we want it to be."

Chavez-Houck said she was asked to run the bill by constituents in the wake of the death of Brittany Maynard, a California woman who moved to Oregon to take advantage of that state's Death With Dignity law.

Maynard, who died in November 2014 at age 29, became a national symbol for the Death With Dignity movement, as well as a lightning rod for critics of life-ending prescriptions.

"I think more and more people are looking at Brittany and saying 'I could be in that same situation,'" Chavez-Houck said. "She makes a good argument."

Under the Utah bill, a patient would need to have a terminal illness and a six-month prognosis verified by two physicians before receiving a prescription.

Two written requests, separated by 15 days, would be required, and any suspected depression or cognitive incapacity would need to be ruled out by a mental health professional.

Chavez-Houck said those protections are as much to ensure the will of the patient as they are to reassure the community at large.

"I think it really does give the community and families some comfort knowing that there is that pause button that is pressed," she said.

The prescription itself must be self-administered, Chavez-Houck said, and physicians who object to life-ending drugs would be free to recuse themselves from participating.

Cottonwood Heights Republican Sen. Brian Shiozawa, who works as an emergency room physician, said that right of refusal is critical, as life-ending drugs are a "tough sell" for many doctors.

He said the proposal merits discussion, and that there could be circumstances where both doctor and patient are comfortable discussing a life-ending prescription.

"The devil is in the details," he said. "We've got to do this absolutely right."

And Bountiful Republican Rep. Raymond Ward, a primary care doctor, said lawmakers need to be very careful about the life-ending drugs.

But he added that the proposal is reasonable if it protects patients from influence or exploitation.

"I would be willing to consider supporting it if those protections were in place," he said.

Logan Republican Rep. Edward Redd said laws like Death With Dignity and Chavez-Houck's bill go too far, opening up the potential for serious ethical issues.

A career physician with experience in hospice care, Redd said offering a fatal prescription to a terminal patient reinforces a negative view that the end of life is hopeless.
"I think that life, as painful and as miserable as it can sometimes be, still has value," he said.

Redd said he was accused in 1989 of performing euthanasia, or the unlawful killing of a terminal patient.

The patient had undergone several treatments for a bone marrow malignancy, and without other options, Redd explained what was going to happen, then administered morphine to make the patient as comfortable as possible.

He struggled for 45 minutes to an hour before dying, Redd said.

"I did the best I could to relieve his suffering," he said. "My statement to the judge was if anything, I didn't give this guy enough morphine."

When a patient declines treatment, or when treatment options have been exhausted, Redd said it's common and ethical for doctors to take steps to provide a comfortable death.

But to go the next step and proactively offer a fatal treatment, Redd said, is a line that medicine should not cross.

"In the process of relieving pain and suffering, I'm comfortable with the concept that I might shorten someone's life by 15 or 20 minutes," he said.

He said the option of a life-ending prescription leaves patients vulnerable to emotional defeat, financial pressures or a desire to ease the caretaker burden on their family members.

"They start thinking they don't want to suffer," he said. "Then they think their life's not worth living."

But Chavez-Houck said those fears haven't manifested in the five states where life-ending prescriptions are legal.

Instead, she said, the laws have allowed patients and doctors to have robust conversations about end-of-life options.

"It opened the door for more ardent discussions about palliative care," she said.

Since Oregon's Death With Dignity law passed in 1997, 1,327 prescriptions have been issued and 859 patients died from ingesting the life-ending drugs, according to the Oregon Public Health Division.

Of the Oregon patients who ended their lives, 97 percent were white and 90 percent were also enrolled in hospice care. A survey of those patients also found that the most common end-of-life concern was a loss of autonomy.

Snyder said it's possible she wouldn't take the drugs if she received a prescription. But the ability to make that choice, she said, would be both comforting and empowering.

"If it sits in the cupboard and you don't use it, then that means somebody took care of your suffering," she said. "It's a success that we have it and a success if we never use it."

Chavez-Houck ran a similar bill last year, but it was set aside for study by the Senate Health and Human Services Committee.

She said she didn't expect it to pass last year, but wanted to give her colleagues a chance to begin considering the proposal.

"It is a very complex discussion," she said. "But I wanted them to hear from the families."

The bill was opposed by the Catholic Diocese of Salt Lake City.

And requests for comment from The Church of Jesus Christ of Latter-day Saints were directed to a statement opposing euthanasia and deliberate acts to end life.
"When dying from such an illness or an accident becomes inevitable, it should be seen as a blessing and a purposeful part of eternal existence," the LDS Church's statement reads.

LDS Church members should not feel obligated to extend their life by unreasonable means, it says, but "these judgments are best made by family members after receiving wise and competent medical advice and seeking divine guidance through fasting and prayer."

While the LDS Church is generally viewed as opposed to life-ending prescription laws, Chavez-Houck said she sees room for interpretation in the direction to seek out medical advice and spiritual guidance. She said spirituality is personal, and she's not comfortable with government or society imposing its views of death onto individuals.

"I can't say with surety that if I were in the same circumstance I would utilize [the prescription] because of the way I was raised," she said. "That should be between an individual, their family and God."

And Katheryn Lewis, a former hospice nurse, said end-of-life laws give doctors and patients the freedom to discuss every option available.

"What we're doing now is withholding that choice from everyone, regardless of their belief system," she said.

Snyder said it's inaccurate to look at life-ending drugs as a form of suicide.

"All of us want to live," she said. "All of us want the next memory with our children and our spouses."

After being diagnosed with cancer, she said her life was filled with a series of difficult choices. But now she's reaching a point with fewer options, and it's strange, she said, to have so little control over the end of her life.

"I think it's something that urgently needs to pass," Snyder said. "When you're dying, things are urgent. And to keep putting it off, you're forfeiting a lot of people's freedoms and happiness."

During her hospice work, Lewis said, she saw patients intentionally starve themselves, or suffer through incredible amounts of pain rather than extend their lives through additional rounds of treatment. Death, although an uncomfortable topic, doesn't have to be uncomfortable, Lewis said.

"Every single person dies and that's not a failure of the medical community," she said. "It's a failure of the medical community if a person does not die peacefully."

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