Testimony of Victor Thuronyi
Support for HB0403 and SB0443
The End-of-Life Option Act
Feb. 8, 2024

My body – My Choice

My name is Victor Thuronyi. I have an incurable and fatal blood cancer (myeloma), and I strongly support passage of the End-of-Life Option Act.

In the not-too-distant future my treatment options will likely run out. At a point when I might just have a few days to live, I would like to have as many options as possible.

Myeloma used to have a life expectancy of three years. I have now lived over ten years, and I hope to continue living as long as possible. I am not atypical. Most cancer patients want to live longer, not die.

While I would likely ask for aid-in-dying once I qualify, I would wait to decide whether to use the prescription until my doctor advises that (1) further therapy for the cancer is futile, and (2) I am likely to die soon. Who knows whether I get there. Many myeloma patients die of an infection like pneumonia, or from another side effect of therapy.

The debate about this bill often involves the motivation of patients: to avoid pain, to achieve control over the manner of death, or what? Relatedly, some ask why patients need this if pain relief can be obtained through hospice care. These questions seem to me misguided. Medical care often does not go as planned. My motivation for wanting the end-of-life option is simple: if things don't go well with Plan A, I want a Plan B.

It may be an issue of pain. I experienced level 9 pain when first diagnosed (pain just below what causes you to black out), as well as during bone marrow biopsies. I'd want to avoid that.

Specifically why I might want to end my life using this legislation is something I can't predict at the moment, and might not know until shortly before. I do know that I do not wish to die while comatose or drugged.

Supplement to Testimony of Victor Thuronyi

I do not wish to die while comatose or drugged

I know someone who died from myeloma while comatose on a respirator, after his family pulled the plug. (He was blogging until near the end; his last post was about 3 days before he died.) Another patient I know was in a similar situation. Dying while comatose does not seem ideal. Neither would I want to die having been administered high levels of pain killing drugs (which would also imply being comatose or nearly so). Both these methods of dying are legal and not uncommon. Patients (or their designated agent) can refuse treatment (including requests to disconnect their respirators) and high levels of pain relieving drugs can be administered as long as the intention is to relieve suffering.

This is a matter of planning the time and manner of death, not suicide

Opponents sometimes label the process authorized by the end-of-life option act "physician-assisted suicide." In this context, the term "suicide" is inappropriate. Patients using this legislation will in any event die shortly from the underlying illness. "End-of-life option" better reflects the reality. Dying in this manner might be called planning or speeding along the death process. It is a death that will occur shortly anyway. For a patient, the legislation offers a way to best arrange the manner and timing of death so as to be able to say good-bye to loved ones and die while still alert and mentally functioning. I would rather be remembered as someone with the courage to end my own life at a time of mental clarity, rather than being delirious, unable to communicate, or the like.

Under this law, the patient takes the action to end life, not the physician or family members

Family members or designated health care agents often face what can be an agonizing choice about discontinuing life support or authorizing the injection of high-dose pain-killing drugs. This places a burden on family members. Often, family conflicts linger for years about whether the decision was right or if other family members should have been involved or consulted. By contrast, when a patient takes responsibility to plan their own death under the end-of-life option act, the patient can take responsibility and lift the burden of making this decision off others. This is a gift that I would like to give my family members – I would rather take responsibility myself rather than having them make a decision to end my life when I am comatose or delirious.

When a physician prescribes life-ending medication under this legislation, death is not a necessary consequence of the physician's action. This is because many patients (roughly one-third) never use the medication. If the physician intends to provide an option to the patient, rather than to cause the patient's death, then the physician is even less involved in causing death than in the case where the physician terminates life support or administers pain relieving drugs at a dosage that will likely lead to death. Providing this option benefits the patient by providing peace of mind. The patient knows that if the dying process becomes undesirable for whatever reason, the patient has this option for the manner of death. If the doctor's intention is to provide peace of mind to the patient and to comply with the patient's wishes to have life-ending medication available to use should the patient decide to do so, then the physician is not causing the patient's death. The physician is empowering the patient, and providing the patient with a tool that the patient can decide whether or not to use.

Legislators should base decision on facts, not hypothetical abuse

Opponents of this bill tend to emphasize hypothetical abuses that could occur. The proper approach is to ask whether there is any evidence of actual, as opposed to hypothetical, abuse. In the several states that have had an end-of-life option act for years, there is no evidence of any abuse of this law. On the contrary, the law is being used by a patient population that is clearly qualified and informed. Roughly one-third of patients end up not using the prescribed drugs. This suggests that patients are by and large not rushing into it. The prescription provides peace of mind to the patients, who know this is an option that they can use when they need to and when the time comes.

In the absence of evidence of substantial abuse, legislators should heavily discount complaints about the bill that are made on the basis of imaginary situations Under current law there are hundreds of people dying in Maryland every year who might like to use the end-of-life option act but cannot, and some of the deaths are not good ones. This is a fact, and a consequence of legislative inaction. These actual bad deaths should be balanced by legislators against the hypothetical abuses that the opponents describe.

The legend of the greedy relative

The legend of the greedy relative is an example of hypothetical abuse adduced by opponents. This story features a greedy relative of the dying patient. The relative stands to inherit money on the patient's death, and can't wait for the patient to die. The relative browbeats the patient into asking for end-of-life medication and then either coerces the patient to take the drug or administers it to the patient by stealth. The first thing about this story is that it is entirely hypothetical; such a thing has never been observed in the history of thousands of patients who have benefited from the end of life option act in different states. If this sort of thing were at all common, we would expect to see patients dying soon after getting the prescribed drug, but the opposite is the case: unless they are late in asking for aid in dying, patients tend to wait for quite some time before taking the drug and many never take it. Second, it is entirely implausible. It would be quite rare for someone's spouse or child to be so malignant. Aid in dying does not advance the time of death by much, so in most cases the financial benefit to the relative from a slightly earlier death would be minimal. Moreover, the relative would have to fool the doctor as well as hospice care providers. Remember that virtually all patients taking advantage of aid in dying are getting hospice or palliative care.

Finally, compare the regulated situation under the aid in dying legislation to the virtually unregulated alternatives. Under Maryland law, there is no interview with a doctor when a patient signs an advance directive designating a relative as a health care agent. Isn't the greedy relative scenario much more likely in a context where the relative is the designated agent and either authorizes the administration of high-dose pain killers (leading to the patient's death), the cessation of life support, or the cessation of treatment such as antibiotics? On the order of half a million patients die in the U.S. each year in an intensive care unit,[1] a high portion of which die after life support is withdrawn. There are no safeguards in the system against abuses by "greedy relatives" who authorize withdrawal of life support in the ICU context. Part of the reason is that in most cases the problem is not family members who want the patient to die earlier; typically,

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[1] Angus DC, Barnato AE, Linde-Zwirble WT, Weissfeld LA, Watson RS, Rickert T, Rubenfeld GD; Robert Wood Johnson Foundation ICU End-Of-Life Peer Group. Use of intensive care at the end of life in the United States: an epidemiologic study. Crit Care Med. 2004 Mar;32(3):638-43. doi: 10.1097/01.ccm.0000114816.62331.08. PMID: 15090940.

family members are arguing with physicians to prolong care, even if the physician considers this futile.

Under Maryland law, there is no rule that a designated health care agent cannot be one who will receive a benefit from the estate. In fact, probably most designated agents are spouses or others who will inherit from the patient. The only restriction is that one of the two witnesses to the signature on the advance directive is someone who will not receive money from the estate.

Gun suicides

Suicide by gun in the United States is unfortunately not hypothetical. There were over 24,000 suicides by gun in the U.S. in 2020 and 26,328 in 2021.[2] Motivation for suicide varies, but certainly some suicides are committed by people who are diagnosed with a serious illness. Guns are a pretty effective way to commit suicide, but the consequences for the family are usually grim and often devastating. A patient with a terminal illness who has a gun and who might be tempted to commit suicide, could be deterred from doing so if there is a system in place for achieving a death that is much less fraught than suicide by gun. Offering patients this alternative, which is bolstered by safeguards, empowers patients to act in a way that is more considerate of family members and is likely to be preferred by the patient.

Cessation of eating and drinking

Opponents of aid in dying legislation sometimes point out that patients are free to end their life by stopping eating and drinking. That is certainly an option I would consider when the time comes, but it has the disadvantage of being a prolonged process and involving delirium or a long period of unconsciousness towards the end. Whether this is a better method as compared with taking a prescription under the end-of-life options act is a decision that should be made by patients and their doctors, not by legislators. Experience with legislation in other areas of medical care (banning abortions where the health of the mother is in danger; banning certain forms of care for transgender persons) shows us that difficult medical decisions are better made by the patients concerned and their doctors than by legislators.

Encouraging honest patient conversations and use of hospice care

Many patients with terminal conditions are reluctant to face reality. Medicare criteria allow admission to hospice if the patient has a prognosis of living six months or less. But the average stay in hospice is much shorter. According to a study published in the Journal of Palliative Medicine, roughly half of patients who enrolled in hospice died within three weeks, while roughly one-third died within one week. Even physicians might have a tendency to continue prescribing drugs where the chances of success are close to zero. As a patient, I have heard pushback in discussion groups where a patient reports that their doctor said there was nothing more they could do. Typical reactions are: “Get another doctor!” “Keep on fighting!” The current tendency is for both patients and physicians to be unrealistically optimistic. By contrast, the end-of-life option act encourages patients to have honest conversations with their doctors about end of life. The existence of the law can encourage patients to have a conversation with their doctor that includes all available options. Use of the end-of-life option act goes hand in hand with hospice. In California, about 92% of patients who ingested the prescribed aid-in-

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[2] https://www.pewresearch.org/fact-tank/2022/02/03/what-the-data-says-about-gun-deaths-in-the-u-s/.

dying drugs, were receiving hospice or palliative care (see California Department of Public Health report on 2021).

Patients should be free to act on their own religious views

Theologians differ on the morality of choices at the end of life. Most would not mandate taking extraordinary measures to continue life, leaving this to the decision of the patient. While some argue that the decision to give life or end life belongs to God, not to humans, others hold that "the all-merciful God, who has given men and women freedom and responsibility for their lives, has also left to dying people the responsibility for making a conscientious decision about the manner and time of their deaths….If God makes the whole of life a human responsibility, then this responsibility also applies to the last phase of our lives."[3] Religious views about end of life choices differ. Patients should be free to act on their own views of what morality calls for at the end of life. It is not legitimate for some to impose their religious views on others.

Relevance of six-month diagnosis

Some opponents of the legislation have fixated on the fact that a prognosis that a patient has six months to live can be wrong. The six-month rule included in the bill is the same as that used for hospice. It is true that some patients entering hospice end up living longer than six months (about 15 percent outlive the original six-month prediction). The question is what is the relevance of this? The purpose of the six-month rule is to limit participation in the aid-in-dying program to those patients who truly are terminally ill. The fact that a doctor has made a determination that a patient qualifies does not mean that the patient is certain to die within six months. Any careful doctor will tell their patient that the six-month prognosis is just an average, that there is a chance that the patient will live longer, and that it is impossible to predict so far in advance how long a patient will live. As a patient, if I were told that I qualified for aid in dying, I would not assume that it meant I had only six months to live, only that it seemed that I was getting into the terminal stage of my illness. The six-months rule gives the patient time to make the various requests needed, get the second opinion, and so forth in order to qualify for the prescription. Suppose this takes a few weeks. At that point, the six-month prognosis becomes irrelevant.

As a patient, I would normally want to live as long as possible. At the same time as getting a prescription for aid in dying, I might also be participating in a clinical trial, or taking other therapy for my cancer, as long as my doctor tells me that it might be effective. At some point after getting the prescription, I would expect my consultations with my doctor to give me a better idea of life expectancy. Normally, a patient would not want to take the life-ending medicine until a doctor advised that death was imminent, perhaps a few days away at most, assuming that the patient was still capable at that point and not in great pain. In other words, the patient does not rely on the six-month prognosis as an indication of when to take the medication. That decision comes much later when the doctor advises the patient that no further treatment is warranted and that death is imminent. So the fact that some patients live longer than six months after getting that opinion from a doctor simply is irrelevant. In fact, I would turn this around and say that the fact that some patients live much longer than six months after getting a prescription for life-ending medication is great. I would like to be in that group.

Possibility that drug will not work as hoped

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[3] Hans Kung, Dying with Dignity (1998).

Opponents of aid-in-dying have made much of the fact that there is a possibility of things going wrong and the drug not working as intended. As a cancer patient, I have gotten used to taking drugs with side effects, asking doctors about side effects, and dealing with side effects. No cancer patient is under the illusion that drugs always work perfectly without any side effects. This is not a good reason to disapprove aid-in-dying. A key point is that the legislation does not mandate any particular drug or drugs. That is up to the patient and doctor to decide. As with medicine generally, doctors are working to anticipate side effects and manage them where possible. The possibility that the drugs prescribed to end life will not work as planned is something that patients and doctors can be expected to take in stride and deal with, as they deal with other aspects of medical care. It is simply not a reason to disapprove aid in dying. The possibility of side effects may of course influence whether a particular patient decides to go through taking the drugs and how they do this. This is a decision that should be up to the patient, as the patient also makes other decisions about medical care in consultation with their doctor.

Insurers not paying for a drug but paying for aid in dying prescription

I am fortunate to have good health care coverage. If I told you how much the drug I am currently taking costs, you would blanch. I am concerned about the cost of drugs, and something should be done about it, but that is really a separate issue. Opponents of this legislation have raised the issue that insurers might pay for the end-of-life prescription but not for a treatment drug. But there has never been a credible case of an insurer denying treatment coverage because the patient qualifies for an aid-in-dying drug. It would be desirable for people to have insurance that covers all the necessary drugs for treatment, and to keep the costs of those drugs down, but this is not really relevant to aid in dying. The number of people who use aid in dying is quite small, so the availability of this option is not going to be significant for insurers in determining which drugs to cover.

Conclusion

The End-of-Life Option Act should be approved as a modest expansion of the existing legal framework allowing physicians to comply with a request of their patients about having an option as to how and when to die.