

The Illinois Patient Choices at End of Life Act

Briefing Paper

Life is not infinite. All of us will die, but the process of dying is rarely easy and often entails great suffering. While much can be done to relieve that suffering, sometimes pain medication and palliative care do not provide enough relief. Suffering at end of life can be so extreme that some people will choose to hasten their impending deaths – to avoid suffering through the final stages of their body’s disintegration.

Mentally competent adults have a basic human right to hasten their death when they are suffering from a fatal illness, from intractable pain, when their quality of life is personally unacceptable, and when the future holds only hopelessness and misery. **If we are suffering intolerably at the end of our life, we should have the right to choose a peaceful, dignified, and pain-free death.**

Closely modeled after death-with-dignity laws that exist in Oregon, Washington, and Vermont, the Illinois Patient Choices at End of Life Act will establish this right for Illinois residents who are mentally competent adults with a terminal illness. This Act will provide compassionate relief from suffering for many people in Illinois, as it has successfully done in other states.

How It Works

The process begins with the dying patient making a request to his or her physician. The language of the Law is quite specific: The request is for medication that will be self-administered to end the patient’s life in a humane and dignified manner.

This request sets in motion a process involving close collaboration and consultation between patient and physician. The goal is to ensure that the patient is terminal and is making a truly informed decision. Most critically, the physician must explain the alternatives to a hastened death, including but not limited to hospice and palliative care.

Numerous protections are built into the law to ensure that the patient is making a truly informed and considered decision:

- The patient's primary physician must enlist a second consulting physician who also must examine and meet with the patient. Both physicians must agree that
 - the patient is suffering from an irreversible illness which can be expected to produce death within six months, and
 - that the patient is mentally competent and is making an informed decision.
- If there is any doubt that the patient is mentally competent and able to make an informed decision, the physicians must refer the patient for evaluation by a psychiatrist or psychologist. Only if this mental health professional certifies that the patient is mentally competent and capable of making an informed decision may the process then move forward.
- The patient must make three separate requests, one of which is in writing. Two waiting periods are mandated – fifteen days from the initial request, and two days from the initial request..
- The patient may rescind the request at any time and in any manner.
- If all of these conditions are met, the patient is given a final opportunity to rescind the request. If he or she does not make such rescission, then the physician may write a prescription for medication to be self-administered by the patient, to end his or her life in a humane and dignified manner.
- The prescription is then filled.

What happens next?

Often, nothing happens next. In Oregon, where a death-with-dignity law has been on the books since the mid 1990's, statistics show that a significant percentage of people who go through the process to obtain the medication never take it. Knowing that you have the means to cut your suffering short if it becomes unbearable gives people the comfort and the courage to go on another day, and another day after that, until death comes.

Having the medication available never obligates you to take it. The legislation's goal is **never to encourage** anyone to hasten their death, but rather to provide a choice to dying people who are suffering intolerably at the end of their life.

Of course, a percentage of patients who go through the process and obtain the medication, will choose to hasten their death by taking it. Typically, they do this in a private place – at home, or in a hospice – and with their loved ones present. Once you take the medications, you go to sleep and fall into a coma very quickly. Death follows within an hour or two.

It's not suicide!

There is an immense difference between suicide – which is essentially the irrational act of a depressed or mentally ill individual – and the rational act of a terminally ill and mentally competent person to hasten his or her impending death. Hastening your impending death is explicitly defined as **not** being suicide under the existing laws in Oregon, Washington, Vermont, and in the proposed Illinois law.

Your physician signs the death certificate, stating that your underlying illness is the actual cause of death. The law prohibits the act of hastening your death from being considered as suicide, so contracts cannot be affected, including life insurance contracts.

It's not "euthanasia," and it's not "physician assisted suicide!"

The medication must be **self-administered** by a mentally competent adult who has gone through an extensive process to confirm that he or she is making an informed decision. You must take the medication yourself. It's something that you choose to do for yourself, not something that is done to you. The law explicitly states that it does not authorize euthanasia or mercy-killing.

The proposed law does not use the words "Physician-assisted suicide" because it is really the wrong term to apply to this process. While physicians are critical to the process, their involvement is limited to

- ensuring that you are mentally competent, that you are making an informed decision, that you can be expected to die within six months, and that you have every opportunity to change your mind, and
- prescribing the needed medication.

“Hastened death” or “compassionate death” are far more appropriate terms to apply to this process. You are choosing only to hasten your impending death, to avoid suffering through the final throes of your disease process.

Protections for the vulnerable

The law has many safeguards built in to protect vulnerable populations and ensure that nobody is ever encouraged or forced to hasten their death. (Note: the material in this section repeats what was stated above, as so much of the basic structure of the law is dedicated at providing these protections)

- The patient’s primary care physician must make certain that the patient is making an informed decision and is fully knowledgeable about the alternatives including hospice and palliative care.
- Both the patient’s primary physician and a second physician must agree that the patient has an irreversible illness which can be expected to produce death within six months, and is mentally competent to make a decision to hasten their death. If there is any doubt on this score, a mental health professional must be called in, and only if this professional certifies that the patient is mentally competent and capable of making an informed decision can the process continue.
- The patient must make three separate requests, one of which must be in writing. There are two waiting periods mandated – fifteen days from the date of the first request, and two days from the date of the written request.
- The written request must be witnessed by at least two individuals, at least one of which is not related to the patient and has no financial interest in any part of the patient’s estate. (Forging or altering such a request is a serious felony!)
- The patient has every opportunity to rescind the request, and may do so at any time and in any manner.

- The medication prescribed must be self-administered. It's something you must do for yourself, if you choose to – not something which is done for you or to you!
- The law explicitly states that no one shall qualify solely by virtue of age or disability.
- The law explicitly states that no contract can be conditioned on or affected by your election or non-election to hasten your death in this manner.

Protections for the patient's physicians and loved ones

The law provides explicit protections for the patient's physicians and loved ones. If you elect to hasten your death in this manner, it's legally not a "suicide." Your physicians cannot be prosecuted or sanctioned for "assisting in a suicide." Your loved ones can be present with you, and they can counsel and support you without fearing prosecution.

No physician, pharmacist, or health care facility is forced to participate

If your physicians choose not to participate in the law, that's their choice. No one can be forced to participate. And that's fine. If your physician declines to participate, but you wish to move forward, you can find another doctor.

Similarly, no health care facility is required to participate. The law is explicit that if a health care facility so declines, it can prohibit physicians from participating on its premises, and it can sanction those physicians if they ignore such prohibition.

Protections against diversion of the medications

The law has several features to ensure that the medications are not diverted. Most critically, they may not be shipped by mail or courier, but instead must be delivered directly either to the patient or an expressly identified agent of the patient. And any unused medications must be properly disposed of.

The Law is only for Illinois residents

In a manner exactly analogous to the Oregon, Washington, and Vermont laws, the Illinois Death With Dignity Act is only for residents of Illinois.

Overwhelmingly positive experience in Oregon – no “slippery slope”

The Oregon death with dignity law was passed twice by binding referendum of the voters of Oregon – first in 1994 and again in 1997 (and by a larger majority the second time). Detailed records kept by the Oregon health department since then demonstrate an overwhelmingly positive experience:

- Only a small percentage of terminally ill patients actually take advantage of the law.
- Of these, only about half actually elect to take the medications and hasten their deaths.

Most critically, there is not the slightest hint in the Oregon experience of a “slippery slope.” Nobody is being pressured or encouraged to hasten their deaths.

Everything will be reported to and under the control of the Illinois Department of Public Health

The law mandates that detailed records must be kept by participating physicians and pharmacists, and all activities under the law must be reported to the Illinois Department of Public Health.

Although such records are private medical records, the Department is also mandated to prepare and publish an annual statistical report, detailing the number of patients going through the process, the percentage who take the prescribed medications, the diseases they are suffering from, etc. In fact, the Illinois Death With Dignity Act can be expected to bring new transparency to what often occurs today *sub rosa* – quietly and secretly.

The Illinois Patient Choices at End of Life Act gives people a choice – it is not mandatory

Some people may oppose the passage of the Illinois Patient Choices At End of Life Act.

Some will base their opposition on sincerely held religious or ethical beliefs. To them, we say: that's fine. No one is being encouraged or mandated to hasten their deaths. If you believe that suffering is good or that you would never wish to hasten your own death, that's your choice, and we respect it. We ask you, however, to respect our right to make a different choice.

Some members of the disabled community may oppose this legislation out of a mistaken belief that it will lead to pressure on them, subtle or otherwise, to hasten their deaths. We reply: Absolutely not! Again, nobody is being pressured or encouraged to hasten their death. And the law is absolutely explicit: **Nobody qualifies merely because of age or disability. Two doctors must agree that you have less than six months to live.**

Some will say that legislation is not necessary, that palliative care can keep the dying comfortable. While modern palliative care can work wonders, it's not perfect. Even with the best care, the dying process can bring horrible, intolerable pain and suffering.

It's a choice – a simple matter of fundamental human rights.

Finally and fundamentally, it comes down to a question of who gets to make decisions about what will happen to you? Whose life is it? Whose body? Death with dignity should be a fundamental human right.

Every person should have the basic human right to control their own life, their own body, and their own death. The Illinois Patient Choices at End of Life Act will establish the right for all mentally competent adults with a terminal illness to choose a peaceful, dignified, and pain-free death. We're all going to die, and it's a matter of simple human rights and compassion.