

HOW TO ADVOCATE FOR AID IN DYING

by Ed Gogol

“What can I do to help the cause of Aid In Dying?”

People often ask me this question. I tell them that every one of us needs to be an advocate for our cause. So here is a guide to what you can say to your friends, family, and acquaintances – and to opponents - that will help us move forward.

WHAT TO SAY

- **We are part of a broad movement that recognizes that there is way too much suffering at end of life, and aims to reduce and minimize that suffering.**

This broader movement includes features such as preparing advance directives, encouraging open communication, recognizing that there often comes a time when goals must shift from cure to care, and taking full advantage of palliative care.

- **Dying can be hell. Sometimes, even the best palliative and pain-relief care are not enough. Sometimes, the pain, suffering, and indignity are still intolerable despite all medical efforts to relieve you. It can be a very rational choice to hasten one’s death to avoid suffering through the final, oh-so-horrific stages of bodily disintegration.**
- **Mentally competent adults should have the choice to control their end of life as a fundamental human right.**

This includes the right

- to obtain the means to a peaceful, dignified, humane, and pain-free death, and
- to have the assistance of one’s physicians and loved ones, without fear of prosecution.

- **Ours is a worldwide movement that has succeeded in establishing this right, fully or partially, in the following places:**
 - Oregon (1994 and 1997), Washington (2008) and Colorado (2016) through the passage of ballot initiatives.
 - California (2015) and Vermont (2012) by action of the state legislatures.
 - Montana (2009) by ruling of the state supreme court.
 - All across Canada, by action of the Canadian legislature (in 2016) following a unanimous 2015 ruling of the Canadian Supreme Court.
 - In Europe in Germany, Netherlands, Belgium, Luxembourg and Switzerland.
 - In the Latin American country of Colombia.

- **Oregon’s law, first passed more than 20 years ago in 1994, was the first in the U.S. The Washington, California, Colorado and Vermont laws, and most legislative initiatives in other states, are patterned on the Oregon law. These laws all contain the following provisions:**
 - **Two separate doctors:** Your doctor and a second consulting doctor must agree in their reasonable medical judgment that you are “terminal” and can be expected to die within six months.

 - **A mental capability test: Both doctors must agree that you are “mentally capable”** – that you understand what you are asking for and are capable of making an informed decision. If either doctor suspects this is not the case, they must refer you to a licensed mental health professional for evaluation. The process can move forward only if that professional decides that you are capable of making an informed decision.

 - **Multiple requests required:** It can’t be an impulsive decision. You must make **three separate formal requests**, including one in writing that must be witnessed by at least one person without expectation of gain from your estate.

 - **Two separate waiting periods:** a fourteen day one, and a second 48 hour one.

 - **All criteria must be met:** All these criteria must be met before your physician may write you a prescription.

- **You can always change your mind:** You do not have to take the prescribed medicine, and you can change your mind at any time.
 - **You must take the medications yourself:** The ultimate protection is that you must “self-administer” the medication. It’s something **you** do, not something that is done to you.
- **Death-with-dignity laws work very well.**
 - **In the more than twenty years of experience with the Oregon law, there’s not a single shred of evidence of any abuse.** Indeed, by making aid-in-dying legal, by bringing it out into the open, we’re providing protections against abuse.
 - Oregon statistics show that **many people who get the prescription, never take the medicines.** Often, just knowing that you have the means to cut your intolerable suffering short gives people the courage to go on another day, and another day, until they die.
 - **The law is a godsend for the people who need it.** The people who most commonly use the law to end their lives are suffering from metastatic cancer and neurological diseases, such as ALS, Parkinson’s, and Multiple Sclerosis – diseases that typically bring a horrific end of life.
 - **No one is ever coerced or encouraged to hasten their death.** The legal change we want includes stringent protections against such abuse or coercion.
 - **We’re working to establish the right to a CHOICE.**

I HOPE I have a long life, healthy to the end, and go to sleep one day and not wake up. But I know that I may not be so lucky. I know that dying can be absolute hell, even with the best of palliative care. That’s why I want to establish this **choice**.

- **Never use the word “suicide.” Call it “aid-in-dying”, “death with dignity”, “physician-assisted dying”, “physician aid-in-dying”, or “medical aid in dying”.**

We never call it “suicide” or “physician-assisted suicide,” because in our society, suicide has very negative associations. It is often understood to mean the irrational act of a mentally ill person or a teenager with everything to live for. That’s the exact opposite of the act of a rational person who chooses to hasten his or her death to avoid suffering through the horrible final stages of a disease at end of life.

In fact, the Oregon and other state laws all explicitly define the act as not committing suicide. The Oregon law specifically says that actions taken “... **shall not, for any purpose, constitute suicide, assisted suicide,** mercy killing or homicide, under the law.” If you take advantage of these laws, your death certificate will list your underlying illnesses as the cause of death - not suicide, and no life insurance contract will be affected.

A Gallup poll in May 2013 found that 70% of Americans favor allowing doctors to hasten a terminally ill patient's death when it is described as allowing doctors to "end the patient's life by some painless means." However only 51% support it when the process is described as doctors helping a patient "commit suicide."

Our opponents commonly use the word “suicide” because of its negative implications – so we must make an effort to avoid that term. Instead, say “aid-in-dying” or “death with dignity” or “physician-assisted dying” or “physician aid-in-dying” or “medical aid in dying.”

- **Three excellent national groups work on this issue: Compassion and Choices, the Death With Dignity National Center, and Final Exit Network.**
 - Compassion and Choices is the largest and best funded. C&C works in most states for legislative change and to transform cultural perceptions.
 - Death With Dignity National Center focuses especially on legislative change.
 - Final Exit Network offers members counsel and support at end of life. Alone among the three groups, the dedicated volunteer “exit guides” of

Final Exit Network may be able to help you even if you live in a state like Illinois, where there has been no legal change yet. Exit guides never physically assist, but they may counsel and support you, and help you learn about . Under certain circumstances, they can provide a compassionate presence if you choose to hasten your death.

In fact, FEN may be able to help you even if you live in a state like Oregon, but you are unable to ingest the medication, or you don't qualify for the law because you are not yet "terminal." FEN's criteria includes the requirement that you have intolerable and irremediable physical suffering. It may include people who are in the very early stages of Alzheimer's or other forms of dementia – but only in the early stages – you must still be mentally competent, you still have to know what you're doing.

- **Legal change in Illinois.**

A bill we have drafted for Illinois is closely modeled after the Oregon law. Working with our legislative sponsors, we are considering when the bill should be introduced, and we are working closely with other organizations who share our goals. We are also considering whether the bill should allow people to hasten their death who are not six-month "terminal," but who are experiencing intolerable and irremediable suffering, and have an illness where an inexorable decline to death is their only likely outcome.

- **Tell your own story. First person stories are perhaps the most persuasive method you have to persuade people of the righteousness of our cause.**

Whose bad death did you witness? Did you nurse someone through their final, heart-rending illness? What illness(es) are you suffering from that makes you want legal change for aid-in-dying? Please share your life experiences with others.

OUR OPPOSITION - WHAT THEY SAY – OUR RESPONSE

If you encounter opposition, respond calmly. Never get angry – never insult them. Your job and mine is to **educate people. We must help people to change their minds.**

Many who oppose our cause now will support it later --- as they learn more about it, or if they become ill, or if their loved one becomes ill or has had a bad death. Mention this to them --- “You may change your mind when....”

Some of the arguments you hear from the opposition may not make any sense to you, as you’ll see below. But this is what they firmly believe – at this time. And remember – people are educable.

Respect people’s rights to different opinions, but urge them to respect your right to your opinion. By remaining calm and informative, at least we have a chance of keeping them from actively opposing us from establishing the right to death with dignity.

- **Three forms of opposition you may encounter.**

1. **Some parts of the religious community.**

They may say “It’s against God’s will to commit suicide or hasten death,” or “God gave you life, and only God can take it away,” or “Suffering is noble and brings you closer to God.”

Our response: If that’s your belief, then more power to you. I hope you are prepared, because death can be excruciating. Please believe me, when you or a loved one is dying in agony, suffering great pain, unable to speak, and has lost bladder and bowel control, there is no dignity, no nobility.

You can also say: Certainly no one should ever be encouraged, coerced, or forced to hasten their death. We would never do that. But please don’t take away my right to make a different choice from yours.

2. **Some parts of the disabled community.**

They may say “This kind of legislation is aimed at us because society wants to get rid of us. It implies that our lives aren’t worth living. It will result in pressure on us to commit suicide. It will lead to fewer resources being committed to help disabled people live longer.”

Our response: These laws are not aimed at you. They are strictly for people who are at end-of-life and are suffering greatly. It is impossible under these laws to coerce anyone to hasten their death, because there are so many strict requirements to fulfill. The laws we want explicitly say that no one qualifies just because of their age or their disability. Your concerns are misplaced.

3. **People who fear a “slippery slope.”**

They may say: Old and ill people will be encouraged to die because they are a burden on the living – financially, physically, and mentally.

Our response: Twenty years of experience with the Oregon death-with-dignity law proves that there is no slippery slope. No one is being coerced - it’s not happening - it’s not a real concern. People do not WANT to die. But when death is inevitable and suffering is horrendous, sometimes people will choose to shorten their lives a bit.

We should stress that **bringing it all into the open, setting up strict requirements and procedures that must be followed is the best protection against covert coercion.**

OTHER ISSUES

- **What about children?**

In Belgium, laws have been extended to allow minors who are suffering intolerably to choose to hasten their death. There have only been a very small number of cases, typically minors with advanced metastatic cancer. However, **we are not arguing for that here in the U.S.**

- **What about euthanasia?**

In Belgium, the Netherlands, and Canada, the doctor can administer the medication for you – can give you a shot or put it into your IV. This is the definition of “euthanasia” – where the final act is something that the doctor does rather than something you do yourself.

From an ethical point of view, we don't have any problem with this. The key factors are that you are adult, mentally capable, suffering intolerably, and that your request to hasten your death is freely chosen and clear. As long as those circumstances are met, then we believe it's ethically fine either way – whether a doctor administers the medication or you do.

That being said, however, **we are not arguing for euthanasia in the bill we have drafted for Illinois, and it is not part of the laws that have been passed in other states.** Many doctors are uncomfortable with euthanasia. We believe that the requirement for self-administration is important in making this acceptable to the medical profession.

TELL PEOPLE TO JOIN US.

Tell people you talk with the following: - - - If you want the basic human right to control the end of your life for yourself and for your loved ones, then please join us. Our movement is making great progress around the world, but political and cultural change is never easy, and it requires us to get organized. Your joining and your involvement will make the difference.

PRACTICE, PRACTICE, PRACTICE!!!!

There's no one right way to advocate for death with dignity. And you can advocate for aid in dying in a few minutes, or you can take an hour. Be calm, but don't be afraid to show your emotion. The best way to get better and more comfortable doing it, is to do it. Use every chance you get to talk with individuals and with groups big and small.

Take comfort that this issue is not rocket science – that it's really very simple. Many people will already know about the issue and support it. They will welcome learning more about it and will be glad to learn that there are groups working to advance this right. Encourage them to join us.

Good luck, have fun, and be assured of the rightness of our cause.