

# FINAL OPTIONS ILLINOIS

Advancing the Right to Aid in Dying

September 2018

## The Sick Among Us Are Not Burdens To Be Tossed Aside

### Health Care Must Become A Human Right

#### Disabled people must have the resources they need to lead dignified, productive lives

*Opinion – by Ed Gogol, FOI president*

In 2008, Washington became the second state to pass an aid in dying law – the first one after Oregon. It was a hard-fought battle, documented in the 2011 film, “How To Die In Oregon”. In one of the most affecting scenes, earnest opponents of the law carry signs, “The Sick Among Us Are Not Burdens To Be Tossed Aside.”

The implication is that poor sick people will be pressured to end their lives in droves. Of course, the facts show that nothing of the sort is happening. In Oregon, where we have more than twenty years of data, people taking advantage of the aid in dying law tend to be better-educated than average. They tend to have excellent health care, and to be enrolled in hospice. And they’re choosing aid in dying to skip the final stages of their suffering, at a time when death is fast approaching anyway. They tend to be people who are decisive, who have thought a lot about their dying. Often they’ve had relatives who’ve had bad deaths, and they’ve seen firsthand just how bad it can be. While the cost of care may be a factor in their decision, it’s rarely a primary one.

Now, it is a sad reality that in our society, the amount of money we have sorely influences the

quality of the medical care we get – or even whether we get care at all. This fact, while extremely important, is not an argument against aid in dying. The case for aid in dying rests on the simple and unavoidable biological fact that the diseases that kill us often cause immense, intolerable pain and suffering – and that is true even with the best palliative care. Palliative care can reduce our suffering – but it cannot eliminate it.

Nevertheless, there is more than a kernel of truth in the argument, “The Sick Among Us Are Not Burdens To Be Tossed Aside.” In fact, I couldn’t agree more with this saying.

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Life is precious, so there’s no reason to rush dying. But when our time comes, we don’t want to suffer.

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Let’s go back to first principles. Why are we so concerned about establishing a right to aid in dying? Because we are concerned about having a good death. An easy death. Life is precious, so there’s no reason to rush dying. But when our time comes, we don’t want to suffer. Aid in dying is an insurance policy. We don’t want to die. But sometimes, it’s what we choose when despite everything else, our suffering has become intolerable.

A wise person knows that, despite everything we do, dying is inevitable. So the challenge, in the period leading up to death, is to make the right choices, the right decisions. Should you have that surgery? That chemo? When is the right time to say, enough is enough, and forgo further aggressive medical treatments and focus on comfort care? How much pain medication to take? These are the most personal, the most intimate of decisions – and every person’s path is different.

*(continued on next page)*

**Our motto: Our doctors can help us die – if we let them.** No one must ever be encouraged or coerced to hasten their death. But if our suffering becomes intolerable, we must have the choice to end it, peacefully and painlessly.

**Why do we call it death with dignity? Because there’s no dignity in suffering.** Every one of us should have the right to choose -- whether to say, and when to say:  
**“I’ve suffered enough, it’s time to go.”**  
It should be our choice, and no one else’s.

## The Sick Among Us Are Not Burdens To Be Tossed Aside

So when we're on our path to dying, first we should choose palliative care. Stay comfy. Relieve our suffering. Cutting our suffering short should be seen as a last resort – if our suffering has become intolerable to us, and never before our suffering has become intolerable to us.

So first, we choose care. And the essential fact about the end of life – the months and years leading up to our death – is that typically we become helpless. People need a lot of care at the end of life (exactly as at the beginning.)

So in a sane and sensible world, every person would have the full spectrum of care available to them at end of life – appropriate medical care, palliative care, and just plain caregiving. Someone to rub your back, bring you a drink, help you to the commode. I have helped my share of loved ones through their final illnesses, I know what it's all about.

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I feel strongly about this – that health care must become a human right. In a just and compassionate society, everybody would be able to go to the doctor. Everybody would be able to get the care they need. And it's not just out of empathy and compassion that I feel this way. Each of us is healthier when everybody is healthier. There are fewer infectious diseases, and the medical system gets better.

That's one of the reasons why the unanimous 2015 decision of the Canadian Supreme Court, which led to the 2016 law legalizing aid in dying all across Canada, is so inspiring. In striking down all of Canada's laws against aid in dying, the court positioned aid in dying as a human right, part of a broader right to compassionate care at end of life, which in turn is part of a broader right to health care.

### Disability and aid in dying

It's no secret that some of the strongest

opposition to legalization of aid in dying comes from segments of the disabled community. People who live with severe disabilities often struggle to obtain the care they need. It's natural that many people in that boat, and those who care for them and work with them, should be skeptical of aid in dying, should be concerned. Those in power often cut resources for disabled people to the bone and beyond. Many disabled people fear that the message of legalized aid in dying is, "We won't give you what you need to live in dignity, and to be a contributing member of society. But here, go kill yourself!"

Of course there are plenty of disabled people who feel otherwise, who strongly support a right to aid in dying. Nevertheless, the disabled people opposed to it are highly vocal and organized.

Our movement's typical response is, there's no reason to fear, the legal change we seek only applies to dying people. And that's true, as far as it goes, because all of the laws we have passed and are trying to pass in the United States, require you to be terminal, reasonably likely to die within six months, and are explicit that nobody qualifies solely because of age or disability.

But this argument is also, partially, a cop-out. Because the legal change that we ultimately need, must make aid in dying available to competent individuals who are physically suffering intolerably and irremediably, even though they are not "terminal." Such people are a small minority. In a large majority of cases, aid in dying will be used by those who are on a clear trajectory towards death, in the relatively near term. But not always, and ultimately the decision as to how much suffering is enough, should only be made by the person doing the suffering.

Of course we applaud the efforts of people who struggle to live lives of dignity despite disabilities large and small. Aid in dying is absolutely not opposed to the struggles of disabled people to obtain the resources they need. In fact, there are many disabled people in our ranks, and those who think *they* will never be disabled are fools indeed.

## Disabled people must have the resources they need to lead dignified, productive lives

So just as we fight for the right of all people to have health care, we must fight for the rights of disabled people to have the resources they need to live lives of dignity. This is the only way to overcome the objections of so many people in the organized disability community to aid in dying. And it's the only sane, sensible, just and compassionate thing. Our society must care for all its members.

Stephen Fletcher is one of the Canadian legislators must responsible for the passage of Canada's groundbreaking 2016 aid in dying law.

### If a person is diagnosed with a terrible terminal illness, or is in intolerable pain, why force that person to suffer?

And he himself is severely disabled, having become quadriplegic in 1996, at age 23. It has been hell. "In my case, it is complete paralysis from the neck down. I cannot feel my body below the neck. No pain. No pleasure. No heat. No cold. No diaphragm to breathe. Nothing. All that remains is a continuous burning from nerve endings meeting a disconnected spinal cord. The practical result is 24-hour care, no privacy for any bodily functions ... And then there's pain, physical pain. The kind of pain where you think your head is going to explode and would give anything for such an explosion if the pain would just stop. The emotional pain never dies."

And he carries on, having a most distinguished career. He perfectly illustrates (a) that no one should ever end their suffering before it has become intolerable to them, (b) that life is precious and that we can and should tolerate a lot of suffering before giving up, but that (c) it can only be the suffering person's choice as to whether and when to say, this is it, I can't go on any longer, help me to have a peaceful and easy passing. As Mr. Fletcher writes, "If a person is diagnosed with a terrible terminal illness, or is in intolerable pain, why force that person to suffer?"

Last but not least, Mr. Fletcher writes, "Society should not view end-of-life measures as a budgetary way to reduce costs. Those who wish to live should be given the opportunity to do so

Statement by Final Options Illinois on its website

## About Health Care

Aid in dying must become a fundamental human right. We need legal change, so that terminally ill people, suffering intolerably at end of life, have the right to choose a peaceful, dignified, humane and pain-free death.

But aid in dying is just one part of having a good death. Aid in dying must become part of a broader human right, a right to compassionate care at end of life. Every dying person must be able to access the full spectrum of appropriate medical and palliative care.

In particular, no one should ever feel pressured to end their life because they cannot obtain the medical and palliative care they need. The appropriate ethical criterion for someone choosing to end their life, should be intolerable and irremediable suffering, even with the best palliative care — NOT an inability to obtain care.

There are many ways to ensure that every member of our society has access to health care. We take no position on the structure of health care delivery and payment systems, but insist that under any appropriate system, everybody should be able to get basic medical care, and all ill people should have access to the full scope of appropriate medical care including palliative care regardless of their financial state.

From the February 2015 unanimous opinion of the Canadian Supreme Court, striking down all laws prohibiting aid in dying:

*"An individual's response to a grievous and irremediable medical condition is a matter critical to their dignity and autonomy. The prohibition [on aid in dying] denies people in this situation the right of make decisions concerning their bodily integrity and medical care and thus trenches on their liberty. And by leaving them to endure intolerable suffering, it impinges on their security of the person."*

and to live meaningful, productive lives and reach their full potential as a human being. To do anything less is cruel and not consistent with the values of Western civilization."

## Fascinating new book by Sallie Tisdale:

### Advice for Future Corpses: A Practical Perspective on Death and Dying

Ms. Tisdale is the award-winning author of several books, and a nurse for many years, including a decade in palliative care. In her newest and most fascinating book, she offers invaluable advice for those of us who are planning to die someday, and for those of us who are caregivers and loved ones of dying people.

The book opens with a discussion of death itself, with a profound description of how things change when we have received a terminal diagnosis. “People with terminal illness talk about the knowledge as a kind of border. Life is divided into the time before and the time after one knows one is dying – *really* knows. The day will come when cross the border between theory and fact.”

The book’s most valuable sections talk about being a caregiver for a dying person. Starting with listening, which “isn’t that complicated. It’s hard but it’s not complicated.”

“If you are spending time with a dying person, you become a protector. You are the defender of modesty, privacy, silence, laughter, and many other things that can be lost in the daily tasks. You are the guardian of that person’s desires ... You will become a gatekeeper. Everyone needs a gatekeeper! Be the one who can say with a smile, *Goodbye, Aunt Lucille.*”

She gives many examples of what not to say, what not to do. “Don’t say: *why didn’t you call me first? Why did you tell her before me? ...* Don’t say: *Let’s just talk about something happy ...* Don’t say: *My mother had this and she was dead in three months.* Don’t say: *This is a blessing in disguise.* Don’t say: *If I were you ...* Your friend wishes it was you! ... Don’t predict how long a person will live. Don’t say: *Are you sure the doctors knows what he’s talking about?* Don’t say: *Why don’t you try harder?* Don’t say: *You meant so much to me,* forgetting to change the tense. Don’t say: *help me get through this.* Never complain that person’s death is difficult for you to bear ... The dying person has no obligation to sort things out for you, listen to your apologies, explain his past actions, or make you feel better about his death. It is not the dying person’s job to fix your loss of him.”

The discussion about pain management is particularly valuable. Of people screaming in pain, she writes, “I believe it happens, but I want you to believe it doesn’t have to happen.” Make sure the patients gets enough pain medication, including morphine, the most effective medicine. “I know there are a lot of people who believe that there is some kind of moral lesson in having pain or that treating pain is a sign of inner weakness or that you must stay awake in order to die well or that God will never give you more than you can handle. Rubbish. Treat the pain until the pain is controlled, and if your doctor refuses to work with you until your pain is controlled, get a new doctor.”

She writes about the realities of dying at home, and how dying in a hospital or other medical facility can be a better choice: “The amount of what is known as ‘bedside care’ required by a dying patient is more than a challenge to untrained caregivers. How will you handle confusion or agitation in the middle of the night? What will you do if the person falls? What happens if there is bleeding? Can you change the clothing or the bed linens if the person throw up or has diarrhea? Are you prepared to stay awake all night?”

By contrast, “Sometimes a dying person’s needs can only be met in a hospital... Many parts of hospitals are hushed and warm; the pace is deliberate rather than hurried; the staff is attentive and skilled... There are hospital units where the nurses know exactly how to take care of dying people and the hospitalists know the right medications to order and will lean against the window ledge and answer all your questions patiently.” There is a particularly valuable section on the limitations of hospice in the home – the limitations on amount of care provided, how you will still need a primary care doctor, and what is paid for. Be sure to read the fine print!

A special focus is on avoiding unnecessary care. “Many aspects of medical and nursing care become unnecessary or intrusive for a dying patient.”

This short review can’t possibly do justice to this profound, passionate, informative and deeply practical book. It’s highly recommended.

# A Tale of Four Organizations

Dear supporters of the right to aid in dying,

Please do something today for yourself, and for your loved ones. Support the movement here in Illinois, and across the country. Send a contribution to at least one organization – and as many as four.

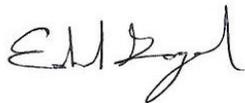
Start with **Final Options Illinois**. That's us. We are the direct descendant of the original group Hemlock of Illinois, founded in 1986. And we are working feverishly to make aid in dying a reality here in Illinois. The point is approaching at which it will be possible for an aid in dying bill to be introduced into the Illinois legislature. We've been picking up the pace of our operations and funds are needed, so please be generous if you can. I can assure you that we run a very tight ship. Nothing is wasted and everything goes to advance the cause.

If you can send a second contribution, please continue with **Compassion & Choices**. C&C, as it's called, is the nation's oldest and largest aid in dying group. C&C is the single biggest reason why our movement has made so many strides in the past few years. Here in Illinois, we are working in coalition with C&C. It's a tremendously effective group, well worth your support.

If you can keep going, continue with the **Death With Dignity National Center**, and with **Final Exit Network**. The National Center is similar to C&C; it fights to make medical aid in dying legal in states all across the U.S. And Final Exit Network (FEN) is uniquely valuable. FEN leaves the work to advance legal change to others, but focuses on helping suffering people in the here and now – all done by volunteers and at absolutely no charge.

You can find links to the websites for all three national groups on the left-hand side on the Final Options Illinois website at [www.finaloptionsillinois.org](http://www.finaloptionsillinois.org). In fact, we try with the "Groups" page on our website to provide links to the entire movement. Aid in dying is truly an international human-rights cause, and there are fascinating groups in Canada, the U.K., Australia, South Africa, Netherlands, Switzerland, Israel, and many others.

On behalf of the board of Final Options Illinois, thank you most sincerely and most fervently. Your contributions are what make our work possible.



Ed Gogol  
*President*

## FINAL OPTIONS ILLINOIS

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Free Showings of **Sundance Grand Jury Prize Winner**

## **HOW TO DIE IN OREGON**

**Saturday, Sep. 15, 2018, 10:00 am – Morris Public Library**

604 Liberty Street, Morris

**Sunday, Sep. 16, 2018, 1:00 pm–Winthrop Harbor Recreation Center**

Village Park, 2700 Ninth Street, Winthrop Harbor

**Sunday, Sep. 23, 2018, 11:45 am – First Unitarian Church of Chicago**

5650 South Woodlawn Avenue, Chicago

**Saturday, Oct. 13, 2018, 1:00 pm – Chillicothe Public Library**

430 North Bradley Avenue, Chillicothe

**Sunday, Oct. 14, 2018, 2:00 pm – Edwardsville Public Library**

112 South Kansas Street, Edwardsville

In 1994, Oregon made it a legal right for people who are dying to cut short their suffering with a doctor's aid. That legal right also exists now in the states of California, Washington, Colorado, Vermont, Hawaii, Montana, and the District of Columbia, throughout Canada, and in several European countries.

This fascinating film follows several terminally-ill Oregon residents who take advantage of Oregon's aid-in-dying law. Don't miss this opportunity to see this outstanding film, which won the Grand Jury Prize at Sundance in 2011.

The film's sponsor, FINAL OPTIONS ILLINOIS, is working to ensure that mentally competent adults who are suffering intolerably at end of life have the basic human right to choose a peaceful, dignified, humane, and pain-free death.

**FINAL OPTIONS ILLINOIS** • [www.FinalOptionsIllinois.org](http://www.FinalOptionsIllinois.org)  
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