

# FINAL OPTIONS ILLINOIS

Advancing the Right to Aid in Dying

June/July 2017

## Aid in dying has its first anniversary in California, Canada

**Aid in dying is now legal in six states (California, Oregon, Washington, Colorado, Montana and Vermont), in Washington DC, all across Canada, and in several European countries**

This June marks a major milestone for our movement—the one-year anniversary of aid in dying laws being fully live in both California (on June 10) and Canada (on June 17.)

In the past year, the dedicated staff and volunteers of Compassion & Choices have worked tirelessly to make the California law a success. More than 12,000 people have obtained information, nearly 500 healthcare facilities and over 100 hospice locations have adopted supportive policies, more than 400 doctors have sought information, and approximately 80% of private insurance companies are covering the cost. C&C alone has done over 400 presentations.

And most important. The numbers are still preliminary, but so far **more than 500 terminally ill Californians have received prescriptions for medical aid in dying.**

**In Canada, more than 800 people took advantage of the law in its first six months.**

**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 laws must be changed to allow it. So that if our suffering becomes intolerable, we can choose to end it, peacefully and painlessly.

**Why 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.

## New York Times and Chicago Tribune carry overwhelmingly positive stories about aid in dying

**Chicago Tribune piece features Ray Perman and New York Times article features John Shields**

In a further sign of rapidly growing support, the New York Times and Chicago Tribune recently ran stories presenting aid in dying in an overwhelmingly positive light.

The Trib article, on the web on April 4 and in the print edition on April 12, profiled Ray Perman, a 64-year-old Californian suffering with advanced metastatic prostate cancer, who took advantage of the law and died peacefully last February.

"As soon as my oncologist told me that there was nothing more that medicine could do for me, my very next words were to say that I would like to go with the End of Life Options Act," said Mr. Perman. **"I want everyone to know that it's a beautiful law, a helpful law, a psychologically comforting law, not just for you as a patient, but for all the people around you. It's a monumental, favorable step towards quality of life.** And no one's pushing you down any pipeline, you can get off any time."

On Sunday, May 25, the Times carried a lengthy (more than six full newspaper pages), front-page story profiling John Shields, a 78-year old Canadian terminally ill with a rare, incurable disease called amyloidosis, a truly horrible way to go. Mr. Shields died peacefully on March 24, taking advantage of the wonderful new Canadian aid in dying law, in his hospice in Victoria, British Columbia.

**Visit our website at [www.finaloptionsillinois.org](http://www.finaloptionsillinois.org) for links to these fascinating stories, including a tremendously moving video of Mr. Perman done by Compassion & Choices.**

**(continued on page 3)**

## Truth In Treatment: A new movement to improve end of life care

**First program sponsored by the Illinois End of Life Options Coalition featured Compassion & Choice's Kim Callinan and state rep Robyn Gabel**

A sizable crowd was on hand at IIT Chicago-Kent Law School in downtown Chicago on March 20<sup>th</sup> for an event sponsored by the Illinois End of Life Options Coalition.

**Kim Callinan**, chief program officer for Compassion & Choices, and **Robyn Gabel**, Illinois state representative for the 18<sup>th</sup> district, were the featured speakers. The program was introduced by **Ed Gogol**, president of Final Options Illinois, and the discussion moderated by former state representative **Julie Hamos**.

Representative Gabel outlined key components of dying well: clear and effective communication with doctors and loved ones about treatment goals; advance directives; medical powers of attorney. She talked of the importance of taking advantage of all possible offerings of palliative care, of shifting focus from cure to care at the appropriate time, and of legalizing medical aid in dying in Illinois.

Most importantly, she emphasized that health care must become a human right, that no insurance company should be able to deny coverage for pre-existing conditions, that there should be no lifetime caps on benefits, and that funding for Medicaid needs to be increased, not cut. Amen. Thank you, Ms. Gabel!

Ms. Callinan walked us through the history and status of Compassion & Choices, a large and effective organization, and described how remarkable it is that we've passed laws in three jurisdictions – California, Colorado and Washington DC – in the past two years. Bottom line, said Callinan: **“Passing medical aid in dying laws is essential. It is something that we want to see. We believe it's a right. It should take place in every single state.”**

### Truth In Treatment

Truth in Treatment is aimed at a transformation in health care that will allow people to hold onto their key values. “People want control around how they live the final days of their life,” said

Callinan. “They want autonomy, they want self-control, they want to be in charge of things.”

But often that's not what happens. “One in three people at the end of life are receiving non-beneficial treatments,” said Callinan, “treatments that aren't helping them and often are actually hurting them, are taking away their quality of life.” People feel they are on a conveyor belt. “They're given a treatment option, but they're not told about *all* treatment options, and they're almost never told about what happens if they opt for no treatment.”

Callinan quoted Dr. Atul Gawande from his book *Being Mortal*: **“Doctors, uncomfortable discussing patients' anxieties about death, fall back on false hopes and treatments that are actually shortening lives instead of improving them.”**

She emphasized the power of asking questions of your doctors. “When you have a set of questions that allows you to ask the doctor really important things, that share your values and perspectives, then all of a sudden the doctor's treatment recommendations can change. Or the doctor would lay out, what we really want, *all* available treatment options. Which might include doing nothing.”

Ms. Callinan described two free online tools that are available. The first, **Trust Card**, allows you to create a customized card to provide information to your doctor about your values and priorities. The second, **Diagnosis Decoder**, allows you to create a customized set of questions to ask your doctors, given your specific diagnosis.

**The full 58-minute video of this fascinating program is available on the Final Options Illinois YouTube channel**, accessible from the FOI website at [www.finaloptionsillinois.org](http://www.finaloptionsillinois.org).

Visit [www.truthintreatment.org](http://www.truthintreatment.org) to learn more.

## The End – A Parting Gift – The Death and Life of John Shields

**Tormented by an incurable disease, John Shields knew that dying openly and without fear could be his legacy, if his doctor, friends and family helped him.**

“Two days before he was scheduled to die, John Shields roused in his hospice bed with an unusual idea. He wanted to organize an Irish wake for himself. It would be old-fashioned with music and booze, except for one notable detail – he would be present,” the article begins.

This remarkable man “intended to die swiftly and peacefully by lethal injection, administered by his doctor. Last June, the Canadian government legalized what it termed ‘medical assistance in dying’ for competent adult patients who are near death and suffering intolerably from irremediable illnesses. When his doctor, Stefanie Green, informed him that he qualified, Mr. Shields felt the first hope since a doctor told him more than a year before that he had a rare and incurable disease called amyloidosis, which caused proteins to build up in his heart and painfully damage the nerves in his arms and legs.”

**“Mr. Shields had seen a friend die from a painful and disabling disease. He was terrified of facing a similar fate. ‘One quality of life that’s important to me is my dignity – and sparing anxiety for my wife and daughter,’ he said. Becoming debilitated and being tube-fed was unacceptable to him. ‘All of those painful and demeaning things,’ he said, ‘I considered beyond the threshold of how I would like to live.’”**

“Having control over the terms of his death made him feel empowered over the disease rather than crippled by it. Mr. Shields believed that dying openly and without fear could be his most meaningful legacy, which was saying something. The man had packed five lifetimes of service into one.”

### **Aid in dying – the Canadian way**

The article profiles Canadian physician Dr. Stephanie Green, who exemplifies the difference between the Canadian law and the US laws. Similar to the US laws, the Canadian law requires that the patient be adult, mentally capable, able to provide informed consent, and terminally ill – in an advanced state of a

“grievous and irremediable medical condition.” Their suffering must be intolerable and their natural death “reasonably foreseeable.”

Like the US laws, the Canadian laws allow the doctor to prescribe medication which the patient will self-administer to cause death. But the Canadian law also allows the doctor to directly administer the medication – the classic definition of euthanasia. Nearly everyone chooses doctor administration, the article notes.

Dr. Green, a 48-year-old mother of two, is happy to provide medical assistance in dying. It’s a matter of principle – about choice. **“You don’t judge a civilization by its riches, but by how it treats its vulnerable, I think this is a mark of our humanity.”**

**“She’s never understood doctors who say offering lethal medicine goes against their training. ‘I think people go into medicine because they want to help people,’ she said. ‘This is on the continuum of care of helping people.’”**

Vancouver Island, off the coast of mainland British Columbia, is one of the most beautiful places in the world, and is ground zero for the Canadian movement for aid in dying. “It was here that Sue Rodriguez, a 42-year-old suffering from amyotrophic lateral sclerosis, or A.L.S., began her battle to die with dignity in the 1990’s, going all the way to the Supreme Court. **‘If I cannot give consent to my own death, whose body is this? Who owns my life?’ she famously said.**”

The article notes that the new Canadian law has been quietly accepted. “Still, most doctors across Canada who have chosen to participate have done so quietly, even asking patients to withhold their names from their obituaries. The exception has been on Vancouver Island, where Dr. Green and many of her colleagues advertise the service and publish their email addresses and phone numbers online. They have formed a national organization on medically assisted dying, and are holding their first conference in June.”

Mr. Shields’ died as he lived, in a beautiful and moving way. Thank you, John, and thank you, Dr. Green!

**Final Options Illinois**

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Chicago IL 60660

**ADDRESS CORRECTION  
REQUESTED**

More showings coming up  
Of the award-winning film

**“How To Die in Oregon”**

**9:30am Saturday July 8**

**Urbana Free Library  
210 West Green, Urbana**

**1:00pm Saturday August 19:**

**Champaign Public Library  
200 West Green, Champaign**



**Free Showings of Sundance Grand Jury Prize Winning Film**

# **HOW TO DIE IN OREGON**

**Saturday, July 8, 2017, at 9:30 am**  
Urbana Free Library, 210 West Green Street, Urbana

**Saturday, August 19, 2017, at 1:00 pm**  
Champaign Public Library, 200 West Green Street, Champaign

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, and Montana, 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. It shows why death-with-dignity laws are so important. Even with the best palliative care, dying can be hell. We all must have the right to choose to hasten our death - to avoid needlessly suffering through the final, agonizing stages of dying. Physicians and loved ones should have the legal right to aid suffering people without fearing prosecution.

This outstanding film won the Grand Jury Prize at Sundance in 2011.  
A discussion will follow each screening. Admission free. Sponsored by the:

**Death With Dignity Group of the Unitarian Universalist Church of  
Urbana-Champaign** ([deathwithdignity@uucuc.org](mailto:deathwithdignity@uucuc.org))

**Funeral Consumers Alliance of Champaign County, and**

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# California and Canada – one year in

June 2017

Dear supporters of the right to aid in dying (death with dignity),

It's tremendously hopeful news that the new medical aid in dying laws in both California and Canada are now one year old. And I can personally testify how great the California law is. I recently visited a severely ill relative in Los Angeles, suffering with metastasized cancer.

While I was there, she signed herself up both for hospice and for the California End of Life Option Act. And it was clear what a wonderful law it is. Everything was done openly, fully legally, above board. A palliative care doctor and nurse spent several hours explaining everything to her, answering questions, talking about every possible aspect of the process. No need to keep anything secret. No winks, no nods.

California, Canada, Colorado, Washington DC – our movement is on a roll. And as more people learn that nobody is being coerced or pressured to hasten their death ... as more people learn about the realities of dying ... as more people realize that yes, the **choice** to hasten death is one that should be available to every mentally competent, terminally ill adult ... then support for medical aid in dying will only grow. But success is not inevitable, and our opposition will push back ferociously. It's going to take a lot of work, and a lot of money, to keep moving forward.

If you'd like to help make aid in dying legal in Illinois, please send your most generous contribution to Final Options Illinois today. Contribute online on our website at [www.finaloptionsillinois.org](http://www.finaloptionsillinois.org), or mail the form below. Contributions are tax-deductible as allowed by law. Thank you very much.

*Ed Gogol, President*

PS. The form below shows your most current information as we have it. Please update or correct as needed, and please let us know your most current email address, if you have one.

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**YES !!!! I support Final Options Illinois.**

**I want to make aid-in-dying legal everywhere, and especially in Illinois!**

«AddressBlock»

Email: «Email» «Email\_2»

Phone: «Home\_Phone» «Mobile\_Phone»

Contribution Amount: \$\_\_\_\_\_

Check Enclosed

Or  Please charge my credit card. (Visa or Mastercard)

Card Number: \_\_\_\_\_

Expiration date: \_\_\_\_\_

Security Code: \_\_\_\_\_

(the three-digit number on the back of the card – required for credit card donations)

Please save the paper – an email thank-you note is sufficient.

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