

# HEMLOCK OF ILLINOIS

Advancing the Right to Death With Dignity

November 2014

## “Highlights from the World Federation Conference” Saturday, December 6

### Hemlock of Illinois to hold annual meeting at Skokie Weber Center

Mark your calendars and please come on out for the annual meeting of Hemlock of Illinois, titled **Highlights from the World Federation Conference**. It's at 1:00 pm on **Saturday, December 6<sup>th</sup>**.

The event will feature video highlights from the recent international conference of the **World Federation of Right-To-Die Societies**, which was held in Chicago in September. We'll have a panel discussion about what we learned, about progress from around the world, and where we go from here. And we'll talk about prospects for legal change to establish the right to aid-in-dying here in Illinois.

It's all happening at the **Weber Center** of the **Skokie Park District**, on the northwest corner of Church Street and Gross Point Road in Skokie. Admission is free and there's plenty of free parking. See you there!

## Thank you, Brittany Maynard

Our heartfelt condolences go out to the family of Brittany Maynard. Ms. Maynard was the courageous young woman with aggressive brain cancer who moved from California to Oregon to take advantage of Oregon's wonderful death-with-dignity law. She advanced our cause tremendously by going public with her story and showing how right and important it is.

**More than fifteen million people watched the videos that Brittany made.** Millions more watched her interview on CBS Morning News, read her front-page story in People Magazine, and followed her story in many other media outlets including Time Magazine, the New Yorker magazine, and the New York Times.

Our website at [www.hemlockofillinois.org](http://www.hemlockofillinois.org) has links to all of the major coverage. The best

## Barbara Coombs Lee to speak in Chicago on Saturday, December 13

### Compassion and Choices to sponsor major event at Chicago Cultural Center

We're happy to report that the national group **Compassion and Choices** is sponsoring a major event in Chicago at 1:00 pm on **Saturday, December 13<sup>th</sup>**.

The event starts with a showing of the powerful documentary **“How To Die in Oregon”**. The film describes the Oregon death-with-dignity law, follows the poignant stories of several Oregon residents taking advantage of the law, and shows the successful campaign to get a similar law passed in Washington state. It's a very important film. If you've never seen it, you won't want to miss it.

The event continues with a panel discussion featuring **Barbara Coombs Lee**, president of Compassion and Choices; **Gene Robinson**, retired Episcopal bishop; **Holly Nelson Becker**, professor of social work at Loyola University; **Stan Curtis**, husband of Cody Curtis, featured in the film; and moderated by **Alison Cuddy** of the Chicago Humanities Festival and WBEZ.

The event will be at the **Chicago Cultural Center, 78 E. Washington**, in the Claudia Cassidy Theater on the second floor. Admission is free, but it will be crowded and seating is limited. So reserve your ticket(s) today at <http://chicago-how-to-die-in-oregon.eventbrite.com>

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place to start is with Brittany's own videos at [www.thebrittanyfund.org](http://www.thebrittanyfund.org).

Ms. Maynard defended her right to decide on the manner and timing of her own death, writing: **“I would not tell anyone else that he or she should choose death with dignity...My question is: Who has the right to tell me I don't deserve this choice?”**

## New book: “Being Mortal,” by Dr. Atul Gawande

Best-selling author Dr. Atul Gawande has a new book just published, titled **Being Mortal: Medicine and What Matters in the End**. Here are two perspectives from Hemlock of Illinois board members on this important new work.

### From Joan Sophie:

Atul Gawande’s new book is a must-read for anyone interested in the final stage of life. Gawande is a surgeon and regular contributor to *The New Yorker* magazine. In this very personal book, Gawande combines stories from his medical experience and his father’s death with research on what may be needed to improve life as people age and approach death.

Gawande calls for major changes in how the medical profession handles aging, illness and death. He wants every doctor to be trained in geriatrics, and to be able to help patients achieve a meaningful life right up to the end. His call for change is very timely, given the recent report from the Institute of Medicine. The report, titled “Dying in America: Improving Quality and Honoring Individual Preferences Near The End of Life,” found our current system seriously flawed.

In many poignant stories, Gawande describes how poorly our doctors often do at helping patients at end of life. Describing one particularly bad case, he writes:

**“What strikes me most...is how much we all avoided talking honestly about the choice before him. We had no difficulty explaining the specific dangers of various treatment options, but we never really touched on the reality of his disease. His oncologists, radiation therapists, surgeons, and other**

**doctors had all seen him through months of treatments for a problem that they knew could not be cured. We could never bring ourselves to discuss the larger truth about his condition or the ultimate limits of our capabilities, let alone what might matter most to him as he neared the end of his life. If he was pursuing a delusion, so were we. Here he was in the hospital, partially paralyzed from a cancer that had spread throughout his body. The chances that he could return to anything like the life he had even a few weeks earlier were zero. But admitting this and helping him cope with it seemed beyond us. We offered no acknowledgement or comfort or guidance. We just had another treatment he could undergo...We did little better than...primitive nineteenth-century doctors – worse, actually, given the new forms of physical torture we’d inflicted on our patient. It is enough to make you wonder, who are the primitive ones.”**

What will happen to us when we can no longer manage to live independently? Who will make that decision? How can we prepare for that eventuality? Where will we go? How do we decide what treatments we will accept?

These are the kinds of questions that Gawande helps us grapple with. This book will help those who want the option of choosing to hasten our own death, to understand our own aging and the dilemmas we will have to confront on the way to our chosen death. It is not enough to know that I intend to exit when life becomes unendurable to me. If I have not considered what may happen along the way, how will I be able to make and carry out that decision when the time comes? With his warm and very readable style, Gawande helps us face these emotionally difficult issues.

**From Ed Gogol:** Gawande has written an extremely important book. Like Katy Butler’s recent book *Knocking on Heaven’s Door: The Path to a Better Way of Death*, it is an urgent manifesto calling for change in the way so many of us die.

Our goal is legal, moral, and cultural change. We want to establish the right of mentally competent adults, suffering intolerably and

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### About Hemlock of Illinois

Founded in the 1980’s, **Hemlock of Illinois** is an independent affiliate of **Final Exit Network**, one of three major national groups advancing the right to death with dignity. Please join us.

Web: [www.hemlockofillinois.org](http://www.hemlockofillinois.org).

Email: [info@hemlockofillinois.org](mailto:info@hemlockofillinois.org)

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**Final Exit Network** is at [www.finalexitnetwork.org](http://www.finalexitnetwork.org)

or 866-654-9156.

**New book: “Being Mortal”, by Dr. Atul Gawande (continued)**

irremediably, to choose to hasten their deaths. And they should be able to have assistance from their physicians and loved ones, free of fear and legal risk.

In the end, Gawande comes out as a supporter of aid-in-dying, writing:

**“Certainly, suffering at the end of life is sometimes unavoidable and unbearable, and helping people end their misery may be necessary. Given the opportunity, I would support laws to provide these kinds of prescriptions to people. About half don’t even use their prescription. They are reassured just to know they have this control if they need it.”** And he adds: **“...for the terminally ill who face suffering that we know will increase, only the stonehearted can be unsympathetic.”**

But there’s a problem. He hedges this support by expressing a concern that providing the right to hasten one’s death will detract from the effort to improve care at end of life: **“All the same, I fear what happens when we expand the terrain of medical practice to include actively assisting people with speeding their death. I am less worried about abuse of these powers than I am about dependence on them.”** He portrays the fact that one in thirty-five Dutch people seek aid-in-dying at life’s end as evidence of failure, not success, writing that **“we damage entire societies if we let providing this capability divert us from improving the lives of the ill. Assisted living is far harder than assisted death, but its possibilities are far greater, as well.”**

Gawande misses the point here. **Of course** we must improve palliative care. But there’s no need to choose one or the other, palliative care or aid-in-dying. **Aid-in-dying should be seen as part of palliative care.** Indeed, in Oregon, the vast majority of people who take advantage of the death-with-dignity law are enrolled in hospice.

The far more appropriate lesson to draw from the Dutch experience with aid-in-dying is that suffering at end of life is often so extreme that given the opportunity, many of us will take advantage of it to avoid living through the final, oh-so-horrendous stages of our bodily

disintegration. The many stories Gawande tells highlight how extreme our suffering can be.

To sum up: Despite these imperfections, Gawande’s book will do much to relieve suffering and to help our cause. It’s fascinating reading, and recommended.

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## **New Jersey House Votes for Death with Dignity**

A tremendous victory to report: On November 13, the New Jersey State Assembly passed the **Aid-in-Dying for the Terminally Ill Act**. And not just passed it, but passed it with a large, 41 to 31 majority. Way to go, New Jersey!!

The bill now goes to the New Jersey State Senate for consideration. Whatever happens, this represents a tremendous victory for our cause.

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## **A Whirlwind of Publicity for Death With Dignity**

by Ed Gogol

At Hemlock of Illinois, we were determined to use the September conference of the World Federation of Right to Die Societies as an occasion to get lots of publicity for our cause right here in Illinois. And our work really paid off!

On Wednesday, September 17, we were on page nine of the Chicago Tribune, in a fascinating article titled “Advocating for ‘most graceful ending.’” The article quotes Hemlock of Illinois board member **Deborah Landis** saying, “We treat our suffering animals kinder than we treat our loved ones.” It has a lengthy section with Hemlock of Illinois member **Lynn Lawson**, and it quotes me saying, “I think one of the reasons we are ultimately going to be successful is because anyone who has ever nursed a loved one through a final illness knows just how bad it can get.” The web version of the story is even better, featuring a moving three-minute video with **Lynn and Court Lawson**.

Also on September 17, we arranged for **Veronique Hivon** to be interviewed at length on

## A Whirlwind of Publicity for Death With Dignity (continued)

the **Worldview** program on National Public Radio's WBEZ station in Chicago. Ms. Hivon is a Canadian legislator and the single person most responsible for the passage in early June of this year of a far-reaching, groundbreaking aid-in-dying law in the province of Quebec. I was also quoted several times during the conference on news reports on WBEZ.

On September 24, I had the opportunity to appear on the popular **Chicago Tonight** program, hosted by **Phil Ponce**, on Chicago's PBS station WTTW. It was a full eleven minutes of advocating for death with dignity on live broadcast TV. We were on Chicago Tonight's website again on October 7, commenting on an article by medical ethicist Ezekiel Emanuel.

Then the November issue of **Chicago Lawyer** had a very lengthy article about the conference and our cause. Titled "At The Movies With The Right-To-Die Society," it's a comprehensive overview of our cause and discusses prospects

for legal change in Illinois, with quotes from our movement's founder **Derek Humphry**, the ACLU of Illinois's **Khadine Bennett**, famed Chicago attorney **Fay Clayton**, disability rights lawyer **Kathryn Tucker**, and me. Here's my favorite quote: "**Choices will expand,' said Kathryn Tucker, executive director of the Disability Legal Rights Center in Los Angeles. 'Aid in dying will become increasingly available.'**"

On a national level, Compassion and Choices engineered a tremendous amount of publicity around the **Brittany Maynard** case and the story of **Barbara Mancini**. Ms. Mancini was featured in a lengthy segment on the famed "Sixty Minutes" program on the CBS network.

We have links to all of these on our website at **[www.hemlockofillinois.org](http://www.hemlockofillinois.org)**. Another article is expected soon in the upcoming January issue of **The Humanist**. And we're just getting started. Please join us!

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**ADDRESS CORRECTION REQUESTED**

Don't miss these two exciting events!

**"Notes from the World Federation Conference"**

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**Barbara Coombs Lee speaks in Chicago**

Saturday, December 13 – 1:00pm – Chicago Cultural Center