

# Compassion & Choices

MAGAZINE  
Fall 2012



***in this issue:***

Voice of Choice: Florence Henderson | Going Gently Into That Good Night | Annual Report



# DO TELL

Be a powerful advocate for end-of-life liberty by telling others about Compassion & Choices. Talk to your friends and family, pass this magazine on, or join the conversation on Facebook and share our Web site at [CompassionAndChoices.org](http://CompassionAndChoices.org).

More people than ever understand their options for a gentle death. **Together let's keep the number growing!**

## Compassion & Choices Magazine

Fall 2012

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## A Sanctuary

Together we have achieved great things. Over the past fiscal year we nurtured an open aid-in-dying practice in Hawaii, blocked choice-limiting hospital mergers in Kentucky, Connecticut and Oregon, and began a national campaign to stop the epidemic of unwanted medical treatment. Our years of engagement with the media resulted in an avalanche of stories on the end of life. Compassion & Choices has grown by leaps and bounds.

But our greatest rewards come from opportunities to overcome America's deep denial and phobia around mortality. Acknowledging death—not as an adversary but as a companion—strengthens our resolve to live each moment in fullness and love. In the wisdom of Seneca, "The art of living well and dying well are one."

The founders of Compassion & Choices understood that a relationship with death evokes wholeness. We adapt to busy lives by adopting roles, suppressing pain, ignoring love and wearing masks. But those who carry out the programs of Compassion & Choices—and you who make that work possible—tap on the door of something quite different. The home of a consciously dying person is a refuge from everything not loving or authentic in our culture. It can become a place of sanctuary. Working with people who are dying brings us to fuller, more conscious living.

As the year draws to a close, I am proud of what we have accomplished and look forward to the challenges the new year will bring. But most importantly, I embrace the opportunity to foster social changes that will enable us all to cherish and celebrate the lives we live.



Barbara Coombs Lee, President



**Barbara Coombs Lee,**  
*PA, FNP, JD, President*

Barbara is president of Compassion & Choices, and as a chief petitioner for the Oregon Death with Dignity Act, she championed an initiative that empowers individuals with a complete range of options in their healthcare decisions.



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**PASS IT ON. Spread the word about end-of-life choice just by sharing this issue with a friend.**

## Radio

### Fresh Air

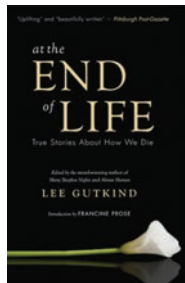
*Fresh Air*, the award-winning weekday program of contemporary arts and issues hosted by Terry Gross, is one of National Public Radio's (NPR) most popular programs, with nearly 4.5 million listeners weekly. Terry recently interviewed Compassion & Choices' Judith Schwarz, our East Coast clinical coordinator. Judith offered informed, empathetic insights on the freedom to choose one's own end-of-life options including aid in dying: "Nobody makes this choice unless the burdens of living have so consistently, day after day, outweighed all benefit." This compelling episode, titled "When Prolonging Death Seems Worse Than Death," aired October 9th on more than 450 stations across the country as well as in Europe. You can listen to and share the broadcast here at [npr.org/programs/fresh-air](http://npr.org/programs/fresh-air).



## Book

### At the End of Life: True Stories About How We Die

This collaborative book project, edited by Lee Gutkind, features 22 moving personal narratives about death, dying and the healthcare system. Hospice workers, grandchildren, medical interns and mothers share grippingly honest insight into the many ways we die—as well as the pain, wonder and ambivalent emotions around what one of the book's authors calls "our own breakable humanity."



## Multimedia

### The Conversation

In August of this year, ABC News partnered with The Conversation Project, a grassroots public campaign spanning both traditional and new media to facilitate conversations about dying. Their collaboration, *The Conversation*, is a national discussion with Americans about what each of us want toward the end of our lives. ABC hopes to prepare family members for the emotional journey beyond advance directives, estate planning and insurance policies. So they've started a series of thought-provoking articles, physician interviews and viewer-submitted stories on their Web site and television network. Viewers can share their experiences with—and wishes for—dying. For air times, archived stories or to share your own personal story, visit [abcnews.go.com/health/conversation](http://abcnews.go.com/health/conversation).

## Magazine

### YES!

Claudia Rowe's contemplative piece "A Graceful Exit: Taking Charge at the End of Life" appeared in the Fall 2012 issue of *YES! Magazine*. In addition to firsthand experience with her grandmother's nightmarish death, she drew on the professional insight of Compassion & Choices President Barbara Coombs Lee to explore our society's need to open up about dying. "We have a death taboo in our country," Coombs Lee stated. "Americans act as if death is optional. It's all tied into a romance with technology, resisting acceptance of ourselves as mortal." Read the full story online at [yesmagazine.org/issues/its-your-body/graceful-exit](http://yesmagazine.org/issues/its-your-body/graceful-exit).

## The Big Story

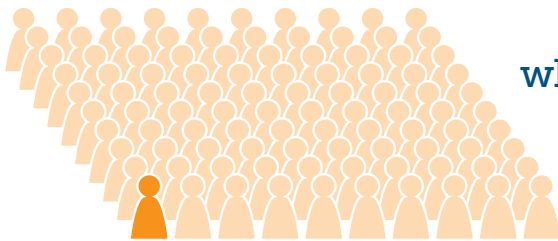
After a decade of urging journalists to highlight our issues, the effort finally paid off this year. From extensive international coverage of Peter Goodwin, to "How We Die" on the cover of *Time*, to thoughtful series in both *The New York Times* and *The Los Angeles Times*, the deeply personal perspective of Compassion & Choices enjoyed unprecedented visibility. We have finally persuaded the media to talk honestly about death.

## THE TERMINALLY ILL AND AID IN DYING



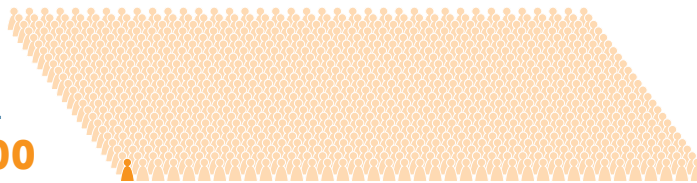
Those who want the option of aid in dying available for future use: **1 in 2**

who seriously consider aid in dying: **1 in 10**



who specifically request aid in dying: **1 in 100**

who request and receive a prescription for medication: **1 in 1000**



Those who ultimately take medication most often express concern about losing three things: autonomy, the ability to engage in activities that make life enjoyable and dignity.

Sources: National data from *The Journal of the American Medical Association*

# words to live (and die) by

**Compassion & Choices** *advocates autonomy for the terminally ill in options for peaceful dying. We put the person experiencing the dying process in the driver's seat.*

## aid in dying

An end-of-life option in which mentally competent, terminally ill adults request a prescription for medication that they can, if they choose, self-administer to bring about a peaceful death.

## death with dignity

Many people use this term generally to mean offering a broad range of choices for the terminally ill. Specifically, it is the name of the laws passed with Compassion & Choices' support in 1994 in Oregon and in 2008 in Washington that affirmatively permit aid in dying.

## refusing treatment

To refuse or stop additional treatment. That could mean declining another round of chemotherapy with difficult side effects and little chance of success. It can also mean saying no—or no more—to treatments like ventilators, feeding tubes, kidney dialysis or medication that extends the dying process. Everyone has the right to refuse or cease treatment directly or through an advance directive.

## VSED

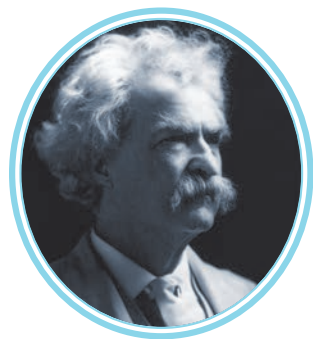
This acronym stands for voluntarily stopping eating and drinking, which involves consciously refusing all food and fluids to bring about a natural death. VSED is an end-of-life option legal everywhere.

## assisted suicide

Intentionally advising, encouraging or helping someone commit suicide. Assisting a suicide is a crime in many states, including Oregon and Washington. These laws protect people with poor mental health and disordered thinking from anyone who would encourage and facilitate their attempts to harm themselves.

## euthanasia

Euthanasia is a direct act to deliberately, painlessly cause the death of another because they are perceived to suffer from an intolerable disease or condition. In euthanasia, someone else—not the dying person—chooses and acts to cause death. Euthanasia is commonly thought of as lethal injection, is often referred to as mercy killing and is illegal throughout the United States.



***The difference between the right word  
and the almost right word is the difference  
between lightning and a lightning bug.***

—Mark Twain



***“Assisted suicide” is a biased, inaccurate term. When you talk about the importance of end-of-life choice, use the neutral term “aid in dying.” If you hear or read a story that inappropriately uses “assisted suicide,” call or write the media outlet and ask them not to use that term to describe the choice of a terminally ill patient to achieve a peaceful death.***



***Compassion & Choices recognizes the power of grassroots action. This year we've redoubled our efforts to support activists who are on the ground effecting change at the federal, state and local level. Engaged supporters, acting where they live, are the heart and soul of our power to guarantee all Americans can live and die as free people.***

## **New in the Field**

Our expanded field department has a new director, Ashley Carson Cottingham. Ashley dedicates resources to fostering and helping advocates channel their energy into effective action. Jessica Grennan leads the charge on state campaigns with state directors and field organizers in seven states. Roland Halpern supports over thirty local groups, and their outreach and education activities. The field department enhances the work of every Compassion & Choices community, from volunteer action teams to full-fledged campaigns in the states our strategists have identified as being on the cusp of major change.



## Campaign States

### Connecticut

Our full-time organizer is raising awareness about aid in dying and assisting with neighboring Massachusetts' Dignity 2012 ballot initiative. Our newly formed volunteer team, the Connecticut Executive Council, is working toward passage of explicit legal permission for aid in dying within the next several legislative sessions. To succeed—and prevent the advancement of any opposition bill—we must build a strong grassroots organization. To join the Connecticut efforts contact Tim Appleton at [tappleton@compassionandchoices.org](mailto:tappleton@compassionandchoices.org) or 860.922.1988.

### Hawaii

Last year a group of physicians expert in end-of-life care formed the Physician Advisory Council for Aid in Dying (PACAID) to consult with and advise doctors and patients about aid in dying. In October, PACAID issued its first report on aid in dying, showing the practice in Hawaii is happening openly and with appropriate safeguards: 31 people called for information, seven qualified, four received aid-in-dying prescriptions and none

ingested the medication. Acting to protect the full range of end-of-life choice, the Hawaii state director for Compassion & Choices alerted the Hawaii Long-Term Care Ombudsman to a situation where a brother refused to honor his sister's advance directive. To get involved in the Hawaii efforts please contact Mary Steiner at [msteiner@compassionandchoices.org](mailto:msteiner@compassionandchoices.org) or 808.225.4563.

### Massachusetts

Through our Massachusetts Compassion & Choices Dignity 2012 Support Committee, field organizers and supporters have worked tirelessly to host house parties, place letters and opinion pieces on local editorial pages, and recruit new volunteers all in support of the Dignity 2012 campaign. Volunteers in nearby Connecticut and Vermont pitched in to help the Massachusetts campaign, joining supporters from across the country to call voters and secure their pledge to vote on Election Day. As we go to press, Massachusetts voters are making their decision. To learn the results visit [compassionandchoices.org/massachusetts](http://compassionandchoices.org/massachusetts) or call 800.247.7421 ext. 2293.

### Montana

Early this year, the Board of Medical Examiners (BOME) reaffirmed that it views aid in dying as it would any other medical procedure if physician conduct becomes an issue. Opponents of end-of-life choice have repeatedly asked the board to change its policy and condemn aid in dying, but our activists and supportive legislators have carried the day. Our strength on the ground will help defeat any threat arising in coming legislative sessions. To get involved with the Montana campaign please contact Jessica Grennan at [jgrennan@compassionandchoices.org](mailto:jgrennan@compassionandchoices.org) or 800.247.7421.

### New Mexico

The Las Cruces group, which formed less than a year ago, has been holding monthly meetings and helping raise awareness of *Morris v. New Mexico*, a case filed by Compassion & Choices to clarify the legal status of aid in dying in the state. In October, supporters packed a legislative briefing where our president, Barbara Coombs Lee, testified alongside plaintiffs in the case, Dr. Katherine Morris and Aja Riggs, and our partners from the ACLU of New Mexico.



We've ramped up efforts to engage people through social media. Visit us on Facebook and Twitter for daily updates.

# states spotlight 2012

## Local Group Activities

### Arizona

A network of Compassion & Choices groups stretches across the state, ensuring there is always some type of coordinated activity taking place.

### California

Two new groups formed in Palm Desert and San Diego, and nineteen people took part in advocacy and consultation volunteer training in September. Additionally, supporters across the state contacted legislators in favor of AB 369, a bill to protect access to prescription pain medication. With their support, the bill passed the Assembly

and Senate with wide margins. Disappointed that Governor Brown vetoed the bill in October, California activists will press this issue in the next legislature.

### Colorado

If a mother hasn't shared her treatment wishes, what happens when children disagree on her end-of-life care? The Colorado group has created an interactive play entitled *Letting Go*, which presents this dilemma and invites the audience to share ideas. Audience response is strong, and Colorado hopes to build a template for other organizations.

### Georgia

After a short hiatus, the Georgia group is back in action and has held several meetings to develop ideas for new growth and vigor.

### Illinois

Chicago-area activists have started a new group. After only one meeting they've formed teams to focus on advocacy and policy, outreach and education, media monitoring and response, and the importance of judicial nominations. A key project is recruiting volunteers for the end-of-life consultation program.

### Indiana

The Indiana group just held a meeting to educate the public on the POST (Physicians Order for Scope of Treatment) form that may be part of legislation introduced in the next session.

### Iowa

The second annual Senior Expo saw Iowa group members engaging and educating seniors. The theme, "Live it Up for Life," was a natural starting point for our volunteers, who distributed information and connected with Iowans interested in Compassion & Choices.

### New York

Advocates acted in support of or opposition to no less than ten bills in the New York legislature. Their action resulted in a major victory with the passage of S. 6256, establishing a Prescription Pain Medication Awareness Program and a work group of experts in palliative and chronic pain management. Grassroots supporters will see an infusion of additional energy over the next year, as Compassion & Choices plans to place new outreach, media and advocacy staff into a New York office.

### Washington, D.C.

The National Capital region group, which represents areas of Maryland and Virginia as well as the District of Columbia, has been holding meetings throughout the area featuring authors, legislators and medical professionals. The group has been so successful that in one of the retirement communities where it regularly holds meetings, opponents of end-of-life choice formed a counter-group!

**Compassion & Choices' work can't happen without your contributions. You can support end-of-life choice right now:**

- ★ **Connect** – Join or start a local group in your state.
- ★ **Donate** – Help fund our programs and services.
- ★ **Join** – Become a Compassion & Choices member.
- ★ **Volunteer** – Contribute your time, energy, passion and skills.
- ★ **Advocate** – Spread awareness and help achieve our goals.

**Visit [CompassionAndChoices.org](http://CompassionAndChoices.org) or call 1.800.247.7421.**



# *A Case for* **Clear Instructions**

Too few Americans have advance directives: clear instructions that state their wishes and designate healthcare agents or proxies to make decisions if they can't.

They're important for all adults. But they're not complicated, and they're not expensive. In fact, we offer free advance directives—and corresponding instructions—specific to every state. You'll find them on our Web site in fillable PDF form to either complete right there or print and write out.

**People can face life-limiting accidents or illness at any age. So if you're over 18 and haven't created your advance directive yet, visit [CompassionAndChoices.org](https://www.compassionandchoices.org) today.**

## The End of Unwanted Medical Treatment

**Our client Margaret Furlong went to the hospital armed with her advance directive, which clearly stated she did not want invasive, life-extending procedures.**

Unfortunately, that's exactly what she got and spent ten horrific days in the ICU tethered to machines and tubes. When she was finally allowed to die, the hospital billed Medicare for all her unwanted treatment. Medicare paid without objection, with taxpayer dollars.

Cases like this are appallingly common. Sadly, Medicare, Medicaid and private insurers incentivize healthcare providers by paying for useless and unwanted treatments. Compassion & Choices believes

### **Help us expose instances of unwanted treatment by sharing your story.**

With compelling ammunition like that, we can more effectively alert federal officials to needless suffering in the lives of so many and the misuse of taxpayer dollars to pay for it. Describe your experience on our Web site in *Voices of Compassion* or by phone at 1.800.247.7421. Or, enter the 2012 story contest announced in this issue!

no one should endure tubes and machines they do not want—and if they do, the provider should bear the burden of unreimbursed treatment. We are leading the effort in Washington, D.C., and elsewhere to stop this epidemic by:

- consulting with consumers, advocates, health professionals, members of Congress and the Administration to prompt change within the Medicare and Medicaid systems.
- working in existing coalitions and partnering with diverse allies to bring our unique perspective to the broad discussion of unnecessary treatment.
- building a body of evidence, compiling reports and testimonials for policy forums and Washington opinion leaders.
- developing real solutions like excluding unwanted treatment from Medicare benefits, disclosing that policy on release forms prior to treatment, and creating a mechanism within the payment system to withhold reimbursement.
- engaging federal officials at the Department of Health and Human Services and Department of Justice to assert that when healthcare institutions repeatedly fail to honor patient wishes and seek reimbursement for unwanted treatment, they are participating in fraudulent behavior.

Once providers realize the costly and unnecessary procedures, excessive tests and painful treatments imposed on dying patients may be at their own expense, advance directives will acquire unprecedented power and authority. We are making great strides to achieve that goal.

## “Disregarded”

### Compassion & Choices’ 2012 Storytelling Contest

Since 1914 American courts have consistently held that individuals have the right to decline any medical intervention or life-prolonging measure.

Yet people continue to suffer excessively – and pointlessly—because they are forced to endure what they don’t want. For last year’s contest, we asked readers to write about bad deaths. Our winning entry and dozens of others recounted the frustration of medical procedures that violated a loved one’s directive. So this time we’d specifically like to call for stories of unwanted treatment, for example when providers ignored explicit healthcare instructions or persuaded family members to disregard patient wishes. Our hope is that these stories not only provide some comfort in solidarity for the writers and readers, but that their combined voice helps us reduce the infuriating epidemic of unwanted treatment in America.

You’ll receive a set of notecards hand-crafted by our chief operating officer, Marcia Campbell, just for entering. Authors of the top five stories will also get a complimentary one-year Compassion & Choices membership.

In addition to appearing in the Summer 2013 issue of *Compassion & Choices Magazine*, the first-prize winner will receive a \$100 gift certificate to Powell’s City of Books as well as the cards, the one-year membership, a *Living to the End* journal plus a copy of *Compassion in Dying: Stories of Dignity & Choice* autographed by author and Compassion & Choices president, Barbara Coombs Lee.

Thank you for sharing your experiences, and good luck!



**Submit your story by March 1, 2013.**

We prefer electronic submissions of 750 words or fewer to [president@compassionandchoices.org](mailto:president@compassionandchoices.org) or mail to: Compassion & Choices, PO Box 101810, Denver, CO, 80250, Attn: Story Contest.



## Five Questions for Florence Henderson

*Florence Henderson's multi-faceted career encompasses over three decades of extraordinary work on stage, screen and television.*

Although she is known around the world for her role as Carol Brady on *The Brady Bunch*, Florence began singing at the age of two, landed her first Broadway role at 18 and became the first woman ever to guest host *The Tonight Show*.

Here's what Florence had to say about the past, present and future, about living, and about dying:

**Your television and stage career included some very long runs. What did you discover in playing a character for years and years?**

I loved playing Carol Brady for five years and doing *Fanny* on Broadway for nearly 900 performances. Playing a character for so long and being able to keep it fresh and new is a wonderful challenge. You also learn a lot about yourself.

**You acted as a television host on *The Today Show*, *Country Kitchen* and *The Rosie O'Donnell Show* to name just a few. What are the delights and challenges of hosting celebrities on television shows?**

I love interviewing celebrities and people in general. I love to know how people have achieved their success and what makes them tick. You have to know how to ask questions so they just can't answer yes or no.

**What is coming up for you that you're excited about?**

One big difference between Carol Brady and myself: Carol never had a job, and I've been working most of my life! And I am excited every day about my life. I always feel the best thing is just around the corner. I'll be performing my one-woman show called *All the Lives of Me*, appearing with Robert Wagner on Fran Drescher's *Happily Divorced*, and I'm in the process of writing a children's book.

**In your book, *Life Is Not a Stage*, you say it takes courage to be happy. Why does happiness take courage?**

I think it takes courage to be happy because often that entails making changes in your life, which can be extremely difficult but necessary to get to a place of peace.

**People are inspired to support better care and greater choice at the end of life for different reasons. Why is this issue important to you?**

When my husband, John Kappas, was facing the end of his life at City of Hope, the doctors and nurses gave me permission to help him with the transition through hypnosis. John was a renowned hypnotherapist and founder of the Hypnosis Motivational Institute in Van Nuys, California. John taught hypnosis to me, and I became a certified hypnotherapist myself.

I would often ask the nurses how they dealt with dying patients day in and day out. They said it was such a privilege to be of help. I feel the same way.

I think being able to die with dignity is as important as living with dignity.

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**JOIN US for a limited-seating lunch with Florence Henderson!**

This lively event will also feature Compassion & Choices board member Dr. Robert Brody.

It's happening Thursday May 9<sup>th</sup> at Alexandra's in the Westin St. Francis Hotel on Union Square in San Francisco. To order tickets, please visit [CompassionAndChoicesnca.org](http://CompassionAndChoicesnca.org) in spring 2013.







# GOING GENTLY INTO THAT GOOD NIGHT

A year after his mother's uncomfortable decline, a son asks: Should the terminally ill have control over when and how they die?

*By Daniel Krieger*

This article was originally published by Narratively, a digital publication devoted to original, true and in-depth stories about New York, with plans to expand to other cities. Narratively explores one theme a week and publishes just one story a day—in longform writing, short documentary films, photography and other media. This story ran in the week titled “How We Die.”

Visit [www.Narrative.ly](http://www.Narrative.ly) for more.

 narratively | nyc

*If you're dying and don't care to wait around for death, you can always book your own appointment. One simple way to do this would be to stop eating and drinking; another would be to stop life-sustaining medicine or devices. Assuming you can decide on your own, both of these methods are good and kosher as far as the law goes. A third approach, however, ventures into a grayer area of legal and ethical terrain—quaffing a lethal cocktail. In the business of ending your life, the means matter a lot more than the final result.*

These were three things my mother, Ann Krieger, was pondering when she reached the final leg of her terminal illness last year, a month before Mother's Day. After several years of fighting colon cancer, her doctor broke the news that the cancer had spread and the treatment was no longer working. There was no more they could do.

"You've got months, not weeks," he said.

"What should I do?" she asked. "Should I end it now?"

"No," he said. "You don't want to do that."

Actually, my mother kind of did, but the doctor referred her to hospice and gave her information about palliative care, a mode of treatment that relieves the pain of patients with serious illnesses. But in my mother's case, the physical distress was less acute than the existential. Coming to terms with the fact that you're going to die is elusive. For some people, like her, an attempt to manage the logistics could make it seem more doable. She and my father had given this some thought and had very specific ideas about how they wanted their end-of-life matters handled.

Six years earlier, horrified by what was taking place with Terri Schiavo in Florida, they sat my sister and me down to give us instructions. Should it ever come down to it, my parents told us, they wanted no artificial resuscitation, experimental procedures, machines or IV—none of that stuff. They just wanted us to make sure they would be allowed to die naturally. "The idea," my father explained to me recently, "is to be pain-free, comfortable and not go through a lot of unnecessary, costly and painful treatments which won't help anyway."

My mother had first-hand experience with this 21 years ago when her mom, my grandma Trixie, who was in perfect health at 85, was struck by a hit-and-run driver near her home in Queens. The doctors at New York Hospital said she had severe trauma in her brainstem and wouldn't wake up. She was hooked up to a ventilator.

Since there was no hope of her getting any better, my mother wanted to have the ventilator removed. She believed Trixie

wouldn't have wanted to be left like that. But the doctors told her they couldn't do that. There had been a brain surgeon, my mother once mentioned, who had wanted to try out a procedure on her.

"Is it going to help her?" she asked him.

"No," he said, "it's not, but I'd like to do it for research."

She didn't give her approval, and the doctors wouldn't remove the ventilator. So my mother found someone high up in the hierarchy, a neurologist, who she was told might be sympathetic. She went to him and explained the situation. He was willing to give the order. Two days after the ventilator was disconnected, grandma Trixie died.

Meanwhile, out in Forest Hills, my grandpa George Kaminsky, her husband, was on his own deathbed. Trixie had been out getting his medicine when she got hit crossing Queens Boulevard, grimly known as the "Boulevard of Death." A few weeks earlier she had been a sure bet to outlive him.

For months afterwards, George lay in bed, helpless and wasting away, with 24-hour nurses who washed and fed him and changed his diapers. He was lucid, and asked my mother and her sister to poison him. They told him they couldn't do that, but my Aunt Nina pointed out that his medicine was probably keeping him alive. Ending his life merely by omission hadn't occurred to him.

"It was humane to put him out of his suffering but done through his choice," Aunt Nina told me recently. "He certainly acted on that information pretty quickly."

He died a few days later.



The author with his mother; as a child. (Photos courtesy Daniel Krieger)



Judith Schwarz of Compassion & Choices at home in Manhattan (Photo: Elizabeth Ladzinski)

I believe that having the right to make choices about how and when we die, when terminally ill, should be a basic human right. But there are various arguments against it. My favorite one says that it's not for mortals to make such decisions because we are in God's hands, however fumbling they may be. If God wants you to die in a certain manner, the logic seems to go, that's because it's part of His plan. But what if God really doesn't care one way or the other? It would be quite an administrative headache, after all. Consider that across the globe, roughly 150,000 people die every day, at a rate of about 107 per minute. A little human intervention could go a long way during that last bumpy stretch.

***I believe that having the right to make choices about how and when we die, when terminally ill, should be a basic human right.***

Many doctors, however, tend to think differently. Knowing this all too well, my mother had filed away the name of an organization she thought might offer some guidance when the time came.

The week she started hospice care, at the beginning of April 2011, my father, Melvin, contacted them. A few days later, they got a call from Judith Schwarz, the clinical coordinator of Compassion & Choices, who lived nearby on the Upper West Side of Manhattan. She came over and spent a few hours talking with my parents, explaining her organization's mission and discussing my mother's illness and the options available. "She was warm, and it was personal," my father said. "She was a professional who is very skilled at dealing with situations like this."

Judith Schwarz, who is 68 years old, wears brown oval glasses and her hair short. She speaks with great precision, intensity and an uncanny command of the issues that comes from decades of being in the thick of it.

I paid her a visit this past spring. We sat in her spacious, sunlit living room, and as her Portuguese water dog slept on the floor we talked about my mother and end-of-life issues. The first thing Schwarz did was set me straight on the terminology when I asked about "assisted suicide." The term "suicide" has a lot of baggage, she explained, whether religious, legal or moral, so to call it "assisted suicide" or "euthanasia" is to miss a crucial distinction.

"We use the term 'aid in dying,'" Schwarz told me, "because it more accurately reflects the information and support we provide to terminally ill and suffering clients"—information about how patients might control the circumstances or timing of their death. She went on to say that the motivation for suicide, which



The author and his mother (Photos courtesy Daniel Krieger)

often results from mental illness and depression, is another thing entirely. “We do not support suicide,” she said, noting the difference between it and the “thoughtful and considered decisions” made by some terminally ill patients as a means to avoid further suffering.

When a patient in the Northeast contacts Compassion & Choices, he is referred to Schwarz, whose first order of business is to find out who he is and what his current medical situation is. Then, Schwarz attempts to get a sense of what the patient is looking for. She tries to provide information to all callers, but to qualify for help, patients should be able to make their own decisions, and be suffering, whether in a terminal stage of illness or not.

“There’s a lot of misunderstanding about what we do,” Schwarz said. “What we do is provide information about end-of-life choices to help patients make informed decisions that reflect their values and wishes. We don’t provide the means. We don’t administer. We don’t encourage or coerce. We have no agenda other than to provide complete and accurate information about end-of-life options.”

And in doing this, Schwarz’s role is to help people navigate the end of their lives so they can maintain some control over it, instead of leaving it to doctors who are trained not only to lessen suffering but also to keep patients alive and death at bay.

One patient Schwarz consulted with last spring needed help arranging to have his ventilator removed without suffering. Schwarz told me about what the process involved, which includes requesting support from palliative care clinicians who would see to it that the man did not experience pain, hunger for air, or anxiety.

***“We don’t provide the means. We don’t administer. We don’t encourage or coerce. We have no agenda other than to provide complete and accurate information about end-of-life options.”***

Schwarz started out as a critical care nurse in intensive care units before studying bioethics at Fordham University in the mid-1980s. Around this time, she had a profound experience involving a terminally ill friend who tried to end her own life with medication, but was unsuccessful and woke up. It turned out to be a lot trickier than Schwarz had thought, and she started wondering how nurses—who are on the front lines in the battle against death—deal with this kind of situation. She got a PhD, exploring the questions surrounding nurse assistance in dying, which was an unexplored practice. This path eventually led Schwarz, twelve years ago, to Compassion in Dying, an earlier incarnation of what became Compassion & Choices. The organization now has sixty chapters across the country.

After so many years working with people at the end of their lives, Schwarz has a deep appreciation for their needs. “They

want to know they still have some choices, that they don't have to just take it," she said. A big part of what Schwarz does is debunk misinformation, like the idea that stopping eating and drinking could be painful. It's not, she said. Terminally ill people typically don't have healthy appetites to begin with, she explained, so hunger pangs are unlikely. Headaches are common at the beginning, but those pass quickly; thirst or dry mouth is the biggest challenge, but it's more discomfort than pain—and there are ways to ease it.

"I never tell patients I'm going to help them have a good death," she said. "What I say is, 'Let's work together to have the least bad death possible.'"

Compassion & Choice isn't the only aid-in-dying organization available to New Yorkers. Another, serving all 50 states with volunteers around the country, is Final Exit Network. But unlike Compassion & Choices, Final Exit instructs terminally ill people how to end their lives with helium and a plastic bag—self-acquired and -administered—and does not pursue legislative reform. The group has also run into legal trouble in recent years, notably in Phoenix, Atlanta and most recently Minnesota for breaking state laws that prohibit assisting in suicide, while Compassion & Choice has so far avoided such problems.

In New York City, Schwarz has as many as a dozen patients at a time, each at various stages of illness. I put in a request to meet one, but Compassion & Choices' communications director declined due to privacy issues. Schwarz did put me in touch with the husband of a patient who had passed away earlier this year.

He was eager to talk but thought it best not to give his name because of how things had played out at the end of his wife's life.

On a hot morning in early summer, we sat in his living room, which looks out on Central Park. The man, I'll call him Thomas, told me how his wife had successfully fought cancer for a decade. Then, in early 2010 the couple found out that it had spread further than could be contained. That's when she began talking about managing the timing of her death. After considering places like Dignitas in Switzerland, which takes you through every step of the process, they settled on Compassion & Choices.

They met Ms. Schwarz, and although Thomas' wife was concerned about how taking death into her own hands might affect her family members, it's what she wanted to do. They got the lethal dose of medicine ready for when she might decide she needed it. But not long after, the cancer spread to her brain and she lost her ability to make this decision on her own. "So that plan went out the window," Thomas said.

Even if his wife had been capable of deciding, Thomas wonders whether she would have actually chosen to take the lethal dose. "What point have you crossed where you truly don't want to live in the situation any longer?" he asked. "It sounds more clear-cut when you are talking about it in the abstract than when you're actually faced with it."

Nevertheless, in a state of dementia, with hallucinations of snakes, Thomas' wife was certainly not getting much in the way of dignity or quality of life. So after nearly 44 years of marriage, he decided to stop offering liquid when she stopped asking for it.

"She wasn't able to consciously express the desire to die," he said. "I acted on what I believed her wishes would have been."

It took over a week before she fell into a coma and died.

Thomas sat across from me on his sofa, holding his wife's living will and healthcare proxy in his hands, still wondering if he chose the right time. Could his wife have changed her mind? Sure, she could have lived weeks or months more, perhaps, but would she have really wanted if she had a say?

***"There aren't a lot of guides for this process," he said. "You would hope your own physician is, but they are there to treat you."***

Her living will did seem to cover such a scenario, though typically such a document applies to a patient who is in a vegetative state rather than one who is conscious and talking (but not making any sense). Hers read: "If I have an incurable, irreversible condition that will cause my death within a relatively short time ... I direct the withholding or withdrawal of all treatment, including nutrition and hydration, that only prolongs the process of dying."

"I was very fortunate to have met Judy," Thomas told me, explaining that she had "held my hand through this process and provided advice that wasn't coming from anyone else." Still, Thomas is angry that the American medical system isn't set up to deal with the complexities of the situation he faced.

"There aren't a lot of guides for this process," he said. "You would hope your own physician is, but they are there to treat you."

In recent years, Compassion & Choices has tried to do something about the shortcomings—or failure, in many opinions—of physicians to guide their patients through the dying process. David C. Leven, a lawyer and the executive director of the organization's New York chapter, has led the effort on the legal front in a number of ways.

On a bright spring morning earlier this year, I set out to attend a talk Leven was giving at the Coler-Goldwater Specialty Hospital and Nursing Facility on Roosevelt Island. About 25 doctors and nurses were there to learn about the importance of palliative care and how the related laws work in New York. When Leven finished, a slight bald man with a crisp British accent stood up and made an announcement to the room.

"I would urge you to make the diagnosis of dying," he said. "'The patient is dying.' And then everything falls into place."

"This is not new," a doctor chimed in. "It's as old as medicine."

Though the commenter declined to give his name, he told me he was a former medical director at the hospital and was "through being on the front lines."



***“I felt alone until I called Compassion & Choices. They let me know I had choices and support. What a comfort that was.”***

— Compassion & Choices  
client Tom McDonald

# It's your decision.

## ***Compassion & Choices' End-of-Life Consultation Program***

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“Why do you feel the need to urge doctors to diagnose dying?” I asked.

“Nobody tells them to,” he said. “Nobody reimburses you for that diagnosis.”

Later, Leven and I walked along the East River toward the Tramway back to Manhattan. Along the river, there was a row of cherry trees bursting with pink blossoms. The petals were starting to fall off, carpeting the ground below. It was too warm and sunny to be discussing suffering and death, though we did just that as the tram glided over the river. We got off, walked for a few blocks in Midtown and found a café. After getting lunch and chatting about the Knicks, we returned to the subject at hand and Leven’s eyes became focused.

Leven, a spry 69-year-old with silver hair, began working with Compassion & Choices ten years ago (after providing legal representation for prisoners and the poor for decades). He didn’t know much about end-of-life issues, other than milestones like the 1997 Supreme Court ruling that individuals have no constitutional right to aid in dying (which left it to states to decide the issue for themselves). The issue, he told me, had only gained momentum in recent years, thanks to the Terri Schiavo case and more media play, such as an Atul Gawande article in *The New Yorker* two years ago.

“We are over-treating people at the end of their lives,” Leven said. “People who are dying often suffer unnecessarily because they’re receiving aggressive interventions they may not want and don’t benefit from.”

The solution, in his opinion, is to provide patients with more information so that they can make informed end-of-life decisions that suit their needs. To this end, Leven helped enact New York’s Palliative Care Information Act, which took effect in February 2011 and requires that doctors provide information and counseling to terminally ill patients who want it—which turns out to be most of them. But it seems that the vast majority of doctors don’t even know about the law. (In the group he spoke to at the hospital on Roosevelt Island, less than a quarter had heard of it). Another problem is that some doctors may reject a legal mandate that tells them what to do with their patients, which is why the New York State Medical Society opposed it. In Leven’s view, this shouldn’t be an issue because it is supposed to be part of a doctor’s job description.

“Doctors already have an ethical obligation to provide their patients with a diagnosis, prognosis, treatment options and the risks and benefits of those options,” he said, “so that patients can make informed decisions.”

Leven cited studies showing that a large percentage of doctors don’t have this conversation or don’t do it well. If they did, patients would be much better off, he said. For instance, when the big picture is explained to them and the options are reviewed, patients typically choose less aggressive treatment and opt more often for quality of life and palliative care than for extending it. (Gawande made the same point in his *New Yorker* piece.) Patients may get referred to hospice (New York ranks 49th in the country in hospice enrollment), set up a do-not-resuscitate order and put other measures in place to make sure that doctors don’t end up providing treatment against their

wishes. The result, Leven said, is reduced medical costs, better quality care, and ultimately, a better death, which is peaceful and dignified—all from a simple conversation between the patient and his doctor.

Dr. Alan B. Astrow, Chief of Hematology and Medical Oncology at Maimonides Medical Center in Brooklyn, said he agrees that it is a doctor’s responsibility to have this talk with patients. But he told me he can understand why they often don’t.

“Many doctors avoid having to tell the patient that things are not going well and that the patient is at risk of dying in the near future,” Astrow said. “It’s hard to tell people, and also patients don’t really want to hear that news.”

However, he does not believe that the solution is a statute ordering doctors to do this—a point he made in an article in *The New England Journal of Medicine* last year. Astrow instead favors “more training in how to discuss end-of-life care issues

***“People who are dying often suffer unnecessarily because they’re receiving aggressive interventions they may not want and don’t benefit from.”***

with patients.” (David Leven agrees that doctors need more training, and is currently working on a bill that would require all healthcare practitioners in New York to get training in pain management and end-of-life care every four years.) He acknowledged, however, that even with such training, such care will still be very different for doctors. Astrow stressed that he does agree with the goals of the legislation, which provide a path toward “good medical care,” but he doesn’t think a legal remedy is enough to bring about a change in the overarching medical culture.

Considering that most doctors still don’t know about the law—which isn’t enforced unless specific complaints are made to the New York State Department of Health—Astrow does have a point.

This is why Compassion & Choices, with a national staff of forty, has been trying to pick up the slack, making information available to anyone who needs it. After all, roughly a million and a half Americans die of terminal illness every year.

“Too many people are having bad deaths,” Leven said, “and it’s in some measure because they don’t have all the information they should have.”

Some religious groups, of course, have starkly different ideas. The Catholic Church has been vocal in its criticism of assistance in dying and, particularly, of Compassion & Choices. Last year, the United States Conference of Catholic Bishops laid out its

official position in a statement. The bishops make a range of well-worn arguments, including the sanctity of the Hippocratic Oath and how “suicidal” people need counseling, confusing the distinction between those who are truly suicidal—who do not want to live—and those who are terminally ill, who want to live but choose to hasten their death because they can’t prevent it. The bishops also argue that allowing people to have a say in how and when they die will inevitably lead to abuse of the practice.

“Taking life in the name of compassion also invites a slippery slope toward ending the lives of people with non-terminal conditions,” the statement said.

However, the many restrictions in place make such abuse virtually impossible. In the two states that have Death with Dignity Acts, Oregon and Washington, the number of terminally ill patients who choose to end their lives this way is quite small: about 600 in Oregon over the past 15 years and 150 in Washington from 2009 to the present. One-third of the people who get the prescription for the lethal drug, typically a barbiturate, never actually take it.

The Catholic Church’s battle appears futile, and the bishops are losing the fight. Little by little, the rights of terminally ill patients are getting recognized, and it’s conceivable that someday aid in dying will be mainstream in the U.S. (Massachusetts voters, for instance, will decide in November the fate of a proposed Death with Dignity Acts in their state.)

## ***“I’m ready,” my mom had said often during her final, miserable decline.***

### ***“I’m ready.”***

In the last month of my mother’s life, she was in at-home hospice care and housebound, but for the one time my father took her out in a wheelchair to see the cherry blossoms in Riverside Park on a gorgeous spring day. She passed the time sitting in her chair or lying in bed reading, watching TV or doing crossword puzzles. She wasn’t in great physical pain, but she was distressed by her inability to eat or drink more than a tiny amount and felt increasingly fed up with the whole situation.

Judith Schwarz had advised her to stay at home in order to maintain control of the situation. (Under hospice care, there is no police inquiry into the cause of death, since a doctor has already determined that the individual is dying; this protects anyone who could be held accountable for helping to hasten death.)

I was living in Japan at the time, and my father was home with my mother as she veered closer and closer toward her end. Each day was getting harder for her.

“What am I doing?” she asked my father several times. “Life is not worth anything like this.”

Her hospice nurse, Nina Schneider, was part of a team sent by MJHS Hospice and Palliative Care, which also included a doctor, social worker and rabbi. Schneider told me when we met last spring that my mom’s quality of life had been deteriorating

as April dragged on. She said my mom had told her, “I’m ready.” But my mom knew better than to ask a hospice nurse for help with that task. The goal of hospice is to keep the dying patient as comfortable as possible until death naturally occurs.

The associate chief medical officer of MJHS, Dr. Bernard Lee, told me, however, that if a patient decides on her own to stop nourishment, medicine or machinery, no one will stand in her way.



The author and his mother (Photos courtesy Daniel Krieger)

About a week before Mother’s Day, in 2011, Mom told my dad again that she was ready and wanted to go ahead with it. But there was one hitch. Because of the havoc wreaked by her colon cancer, she could no longer drink enough liquid to get the eight-ounce cocktail down. She just couldn’t do it. It was not going to work. Her appointment with death would have to be postponed.

Then, after not eating or drinking anything for the next couple of days, she fainted. The doctor said she was severely dehydrated and suggested she go to the hospital for fluid, or that she at least hook up to an IV at home.

“I don’t want to go to the hospital,” Mom said. “I don’t want an IV. All I want to do is have morphine and sleep. I want to go to sleep.”

They gave her what she wanted and early the next morning, on May 6th, when my father went into her room, my mom’s body was shutting down. She was unresponsive.

“Mom is gone,” the e-mail from my dad said. “She was comfortable and without pain.”

The cause of death seemed to be dehydration, though my dad wonders if the morphine played a role. Either way, it’s what she wanted, though it came later than she would have liked. She was 79.

“It’s hard to wait to die,” Schneider, the hospice nurse, told me. “We try to give as much support as we can.”

But sometimes, a dying person doesn’t want support or empathy or morphine. They just want to get it over with.

“I’m ready,” my mom had said often during her final, miserable decline. “I’m ready.” ■■■



# Compassion & Choices 2012 Annual Report

Marked by individual bravery and collective impact, 2012 has been another year of exhilarating growth and progress for our movement. Look at this sample of all we have done together to expand freedom of choice across the nation:

- 1 Completed the first full year of our campaign for open access to aid in dying in Hawaii.
- 2 Launched "Critical Mass." to bring affirmative legal protection for aid in dying to Massachusetts and all of New England.
- 3 Moved toward trial in our case to clarify the legality of aid in dying in New Mexico.
- 4 Secured the continued practice of aid in dying, despite restrictive efforts by opponents, in Montana.
- 5 Gained membership in The Leadership Conference on Civil and Human Rights in D.C.
- 6 Played key roles stopping a choice-limiting hospital merger in Kentucky, and built opposition to similar mergers in Connecticut and Oregon.
- 7 Forged alliances with the three major national associations of assisted-living facilities to champion residents' rights and educate their members about honoring residents' end-of-life choices.
- 8 Launched our campaign to stop reimbursement for unwanted treatment and build on work started during Affordable Care Act deliberations.
- 9 Inspired an unprecedented avalanche of high-profile media coverage from *Time* magazine, to network news, to National Public Radio.

# Combined Statement of Financial Position

June 30, 2012

## ASSETS

### Current assets:

Cash and cash equivalents:	
Operating	1,092,236
Investments	102,585
Pledges receivable	327,500
Investments	11,208,236
Prepaid expenses	94,772
Beneficial interest in charitable remainder trusts	146,759
Other current assets	598
<b>Total current assets</b>	<b>12,972,686</b>

### Property, equipment and improvements, at cost:

Furniture, fixtures and equipment	541,692
Leasehold improvements	26,604
	<b>568,296</b>
<b>Less accumulated depreciation and amortization</b>	<b>346,955</b>
<b>Total property, equipment and improvements</b>	<b>221,341</b>

### Other assets:

Intangible assets	3,014
Deposits	15,431
<b>Total other assets</b>	<b>18,445</b>
<b>Total assets</b>	<b>13,212,472</b>

## LIABILITIES AND NET ASSETS

### Current Liabilities:

Current portion of obligations under capital leases	25,561
Accounts payable	200,959
Accrued payroll and vacation	310,062
Accrued expenses	43,186
Deferred revenue	500,000
<b>Total Current Liabilities</b>	<b>1,079,768</b>

### Long-term Liabilities:

Capital lease obligations, net of current portion	39,502
Gift annuity payments due	297,954
<b>Total long-term liabilities</b>	<b>337,456</b>
<b>Total liabilities</b>	<b>1,417,224</b>

### Net Assets:

Unrestricted:	
Operating	11,638,970
Net investments in Property, Equipment and Improvements	156,278
<b>Total net assets</b>	<b>11,795,248</b>
<b>Total liabilities and net assets</b>	<b>13,212,472</b>

# Combined Statement of Activities & Changes in Net Assets

For the Year Ended June 30, 2012

## TOTAL UNRESTRICTED

### Revenue and Other Support:

Conference and events	140,656
Contributions	5,376,632
Membership fees	207,882
Grants	8,472,293
Investment income, net of expenses	130,717
Realized and unrealized gain on investments	110,878
Loss on disposal of equipment	(664)
Other Income	221,472
<b>Total revenue and other support</b>	<b>14,659,865</b>

### Expenses:

Programs	6,333,076
General and administrative	866,345
Fundraising	543,387
<b>Total Expenses</b>	<b>7,742,807</b>
<b>Increase in Net Assets</b>	<b>6,917,058</b>

### Net Assets:

<b>Net assets, beginning</b>	<b>4,878,190</b>
<b>Net assets, ending</b>	<b>11,795,248</b>



## Program Costs

We manage our resources very carefully. More than 81% of your generous contributions are spent on program activities. Here is how those expenses are broken down:

### Program costs for the year ending June 30, 2012:

- Public Education: 47.50%
- Local Presences/Community: 37.73%
- End-of-Life Consultation: 14.59%
- Lobbying: 0.17%

# donors

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*As always, Compassion & Choices is profoundly grateful to the many thousands of donors who give so generously to the mission we serve. From gifts of five dollars to grants in the millions, each is vital to our success—and existence. Though we've only listed donors here who have given \$500 or more, Compassion & Choices appreciates everyone who is committed to our mission. You are our foundation!*

Totals are for gifts made in FY 2012, July 1, 2011 – June 30, 2012.

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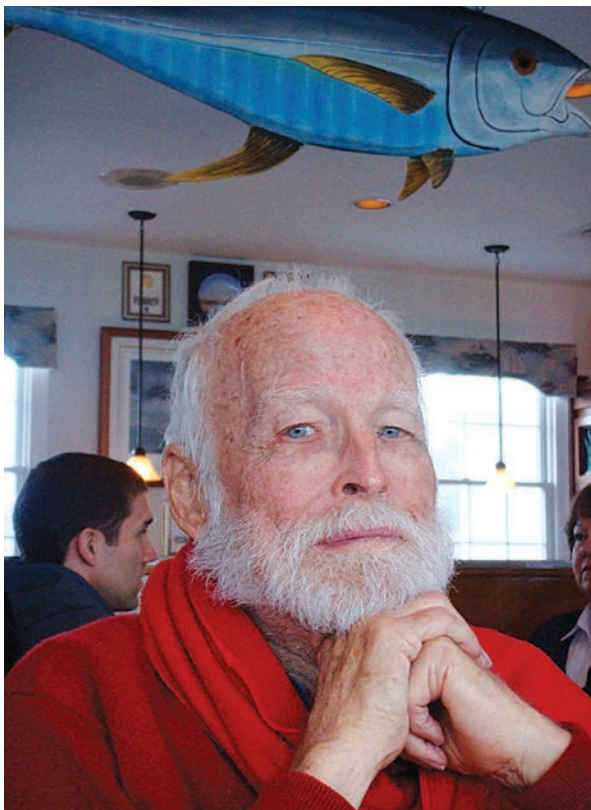
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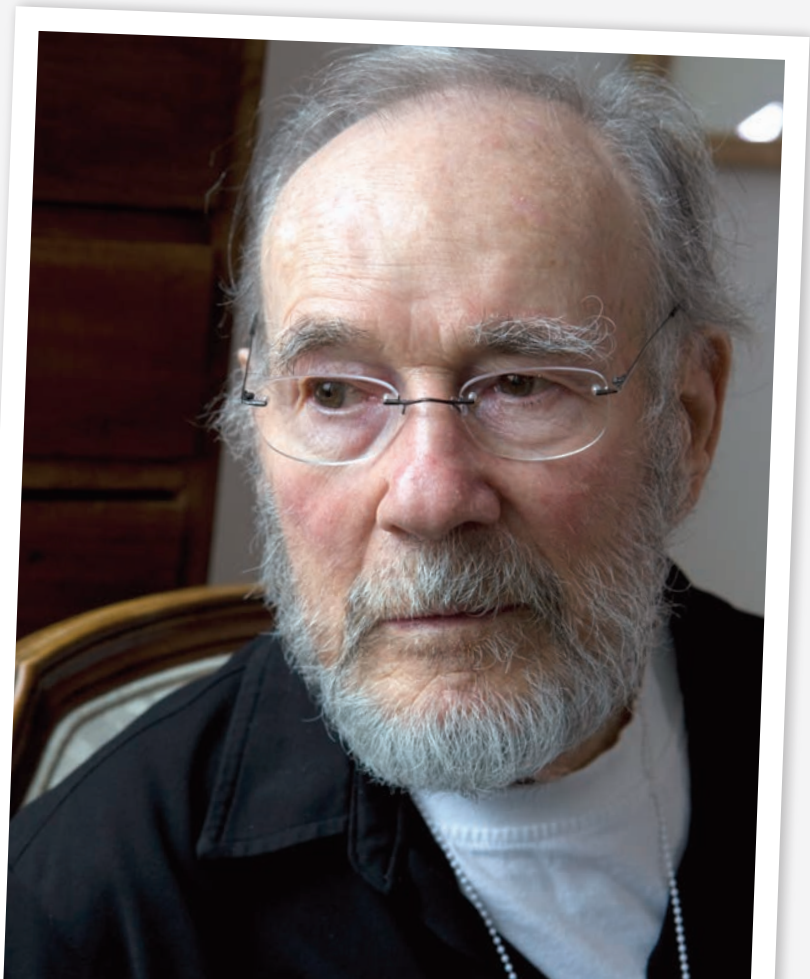
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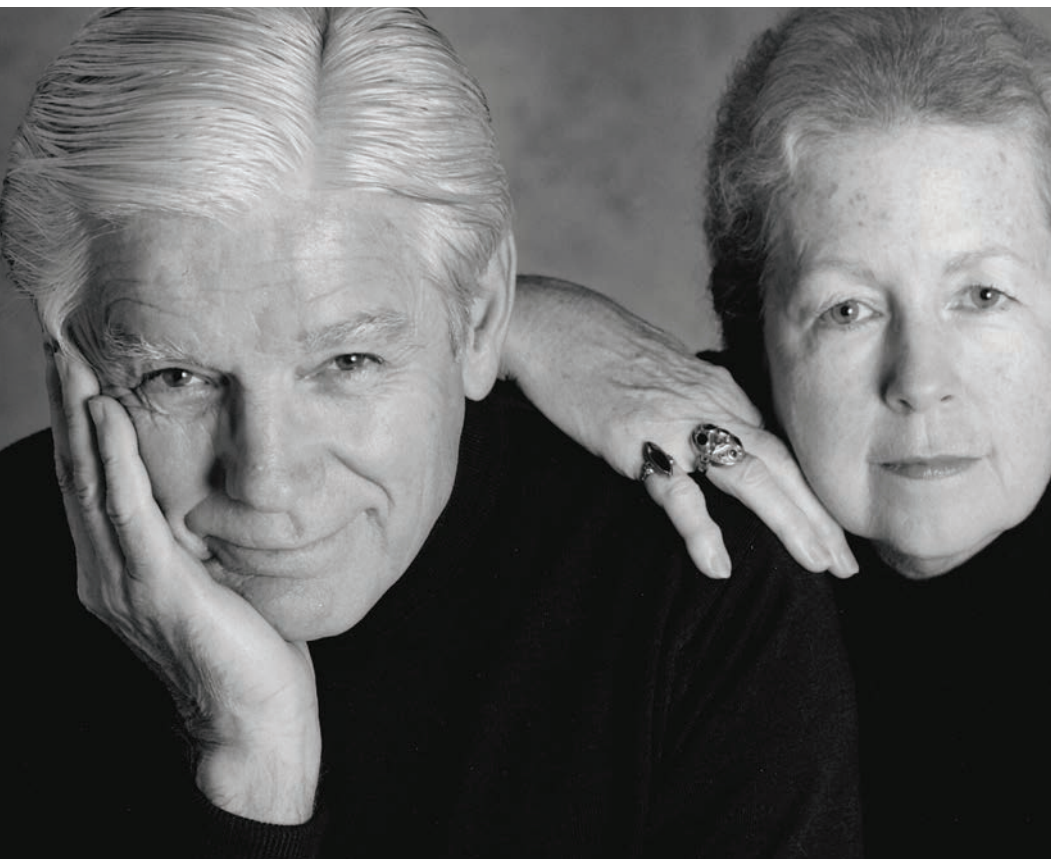
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