

# Compassion & Choices

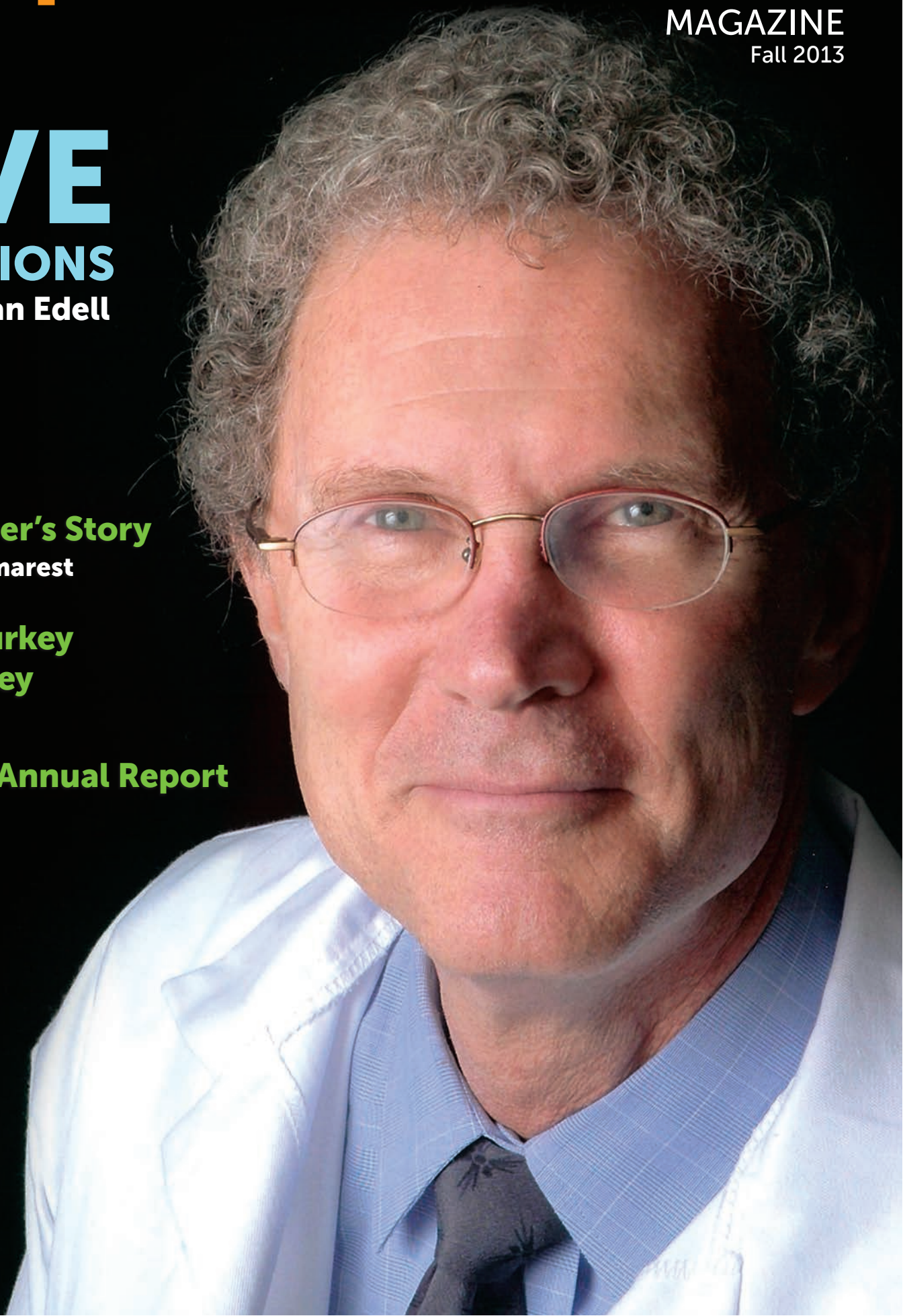
MAGAZINE  
Fall 2013

## **FIVE** **QUESTIONS** for Dr. Dean Edell

**DNR:**  
**A Supporter's Story**  
by Harry Demarest

**Talking Turkey**  
**Over Turkey**

**PLUS**  
**Our 2013 Annual Report**





# Create a Legacy

**Compassion & Choices  
can assist you in meeting  
your financial goals  
while advancing and  
defending end-of-life  
choice into the future.**

**“Creating a Charitable Gift  
Annuity helps Compassion & Choices and  
provides some lifetime income for me, too.  
It’s a great deal for both of us. I wish I  
had done this sooner!”**

*– Marcia Strean, Teaneck, NJ*

## Compassion & Choices Magazine

Fall 2013

Volume 12, Number 3

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**Compassion & Choices** is the nation's oldest and largest nonprofit organization working to improve care and expand choice at the end of life. We:

**Support** patients and families

**Educate** the public and professionals

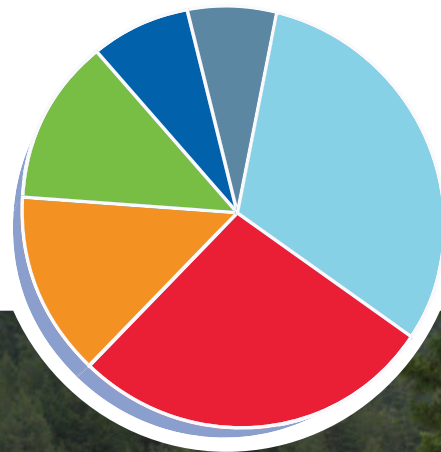
**Advocate** across the nation

*Advancing death with dignity since 1980.  
Learn more at [CompassionAndChoices.org](http://CompassionAndChoices.org).*



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21 Five Questions for Dean Edell



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

## Let No One Walk Alone

I look forward to time with family and friends around the holidays. As the light shifts and the leaves change, we reflect on what has passed and begin to imagine what is yet to come for ourselves, our children and our grandchildren.

In the same way, I like to recall the year's successes you, as part of Compassion & Choices' family, have made possible. Our movement has accomplished much: Vermont secured explicit protection for aid in dying, Montana protected its right, and other states moved closer (page 10). We fought for patient autonomy and sparked a national conversation on unwanted medical treatment (page 14). Each day our consultation service walked patients and their families through the decisions associated with the end of life.

I am proud of bringing national attention to the case of Barbara Mancini (page 13). Compassion & Choices will continue to urge the state to abandon this misguided prosecution of a compassionate, loving daughter.

If only we could undo the anguish and fear Barbara and her father, Joe Yourshaw, suffered. All Joe wanted was a peaceful death at home with his loved ones. But he and Barbara didn't have comprehensive information on all the options for end-of-life care. To prevent future tragedies, we must expand awareness that options exist and help is available.

This challenge, among many others, will burn brightly in our hearts this season.

## Compassion & Choices MAGAZINE

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Cover photo courtesy of Dean Edell  
Page 31 photo by Steven St. John



## Newspapers

### Los Angeles Times

Does the growing demand for death-with-dignity laws across the nation increase California's chances of passing one? Steve Lopez, whose past columns passionately argued for end-of-life choice, discussed this prospect with Director of Legal Affairs & Advocacy Kathryn Tucker. "We're taking a look at what the best strategy might be," Tucker said. View the entire article at [tinyurl.com/DWDinCA](http://tinyurl.com/DWDinCA).



### The Times of Trenton

In support of the death-with-dignity bill advancing through the New Jersey legislature, Rabbi Richard Address of Cherry Hill wrote a thoughtful piece in *The Times of Trenton* stressing the significance of informing people of their options and urging them to discuss their preferences. "Medical technology has raised the importance of educating for choice," he said. Read the full story at [tinyurl.com/RabbiAddress](http://tinyurl.com/RabbiAddress).



The Diane Rehm Show



## Web

### ReasonTV

"Rather than shirk and hide from it, I want to be honest with people and society, and tell them what I've done. I'm proud of what I've done," said Montana physician Eric Kress about deciding to publicly declare his support of, and participation in, the practice of aid in dying. ReasonTV, a libertarian documentary website, featured Dr. Kress in its film "Who Decides How You Die? Inside Montana's Assisted Suicide Fight" about the so-called "Doctor Imprisonment Act" that failed in February. Watch the video at [tinyurl.com/EricKres](http://tinyurl.com/EricKres)

## Radio

### The Diane Rehm Show

Acclaimed National Public Radio personality Diane Rehm hosted Compassion & Choices representatives on her show twice this year. President Barbara Coombs Lee gave her informed perspective on the March 5 episode, "Legal Debate Over Doctor-Assisted Suicide." Then in August, Rehm invited Chief Program Officer Mickey MacIntyre on her program to discuss assisted dying and the tragic story of Joe Yourshaw. The case became a national flashpoint when prosecutors charged Yourshaw's daughter, Barbara Mancini, with "assisted suicide." Hear this episode or read the transcript at [tinyurl.com/RehmNPR](http://tinyurl.com/RehmNPR).

## The Nation Slams Pennsylvania v. Mancini

Dozens of journalists called out the absurdity of Pennsylvania Attorney General Kathleen Kane's prosecution of Philadelphia nurse Barbara Mancini for her father's death, including columnist Frank Bruni in a powerful *New York Times* piece. Compassion & Choices is assisting in Mancini's defense and generated some buzz of our own with a *USA Today* op-ed by Director of Communications & Marketing Gwen Fitzgerald. To browse these stories and learn the latest on this baffling tragedy, visit our Mancini case web page at [tinyurl.com/ManciniCase](http://tinyurl.com/ManciniCase).

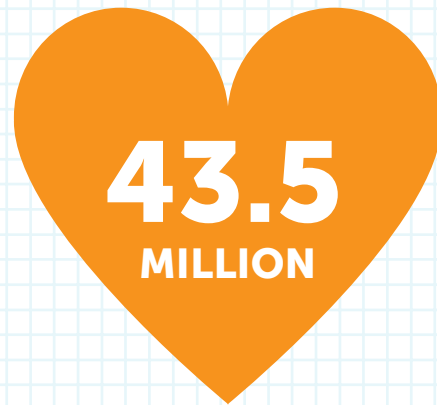


Barbara Mancini with her father

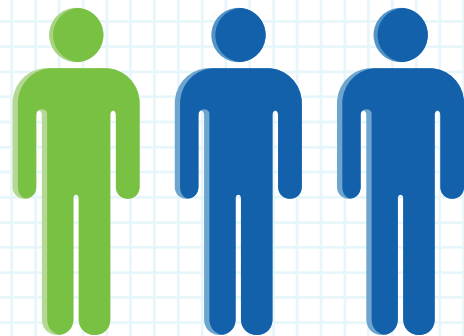
keeping count

# Lean On Me

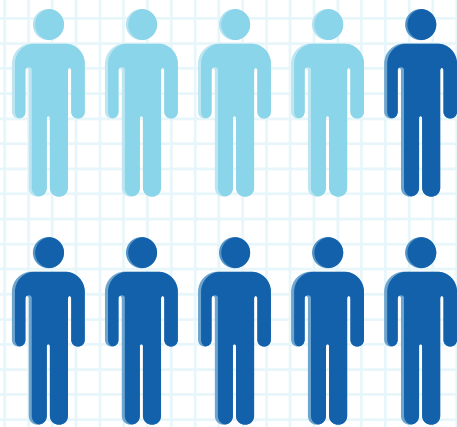
**43.5 million adults**  
over 50 care for aging  
loved ones.



**More than one-third**  
of those family  
caregivers look after  
someone who has  
Alzheimer's disease or  
other dementia.



**Nearly 40 percent**  
of caregivers die from  
stress-related disorders  
before those they care  
for.



## **Geriatric:**

Relating to elderly people, or dealing with the challenges of old age.

## **Healthcare Proxy:**

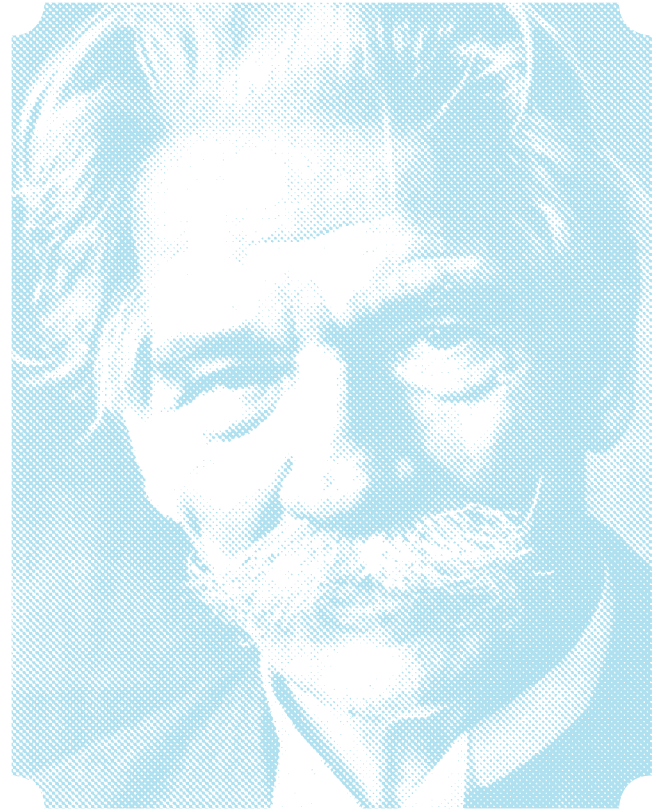
A person designated to make healthcare decisions for you if you can't make them yourself.

## **Informed Consent:**

Signed permission for a medical procedure. In principal, it's shared decision-making based on a full understanding of all options and their risks.

## **Caregiver Syndrome:**

A debilitating condition brought on by unrelieved, constant caring for a person with a chronic illness or dementia.



“ *No law or ordinance is mightier than understanding.* ”

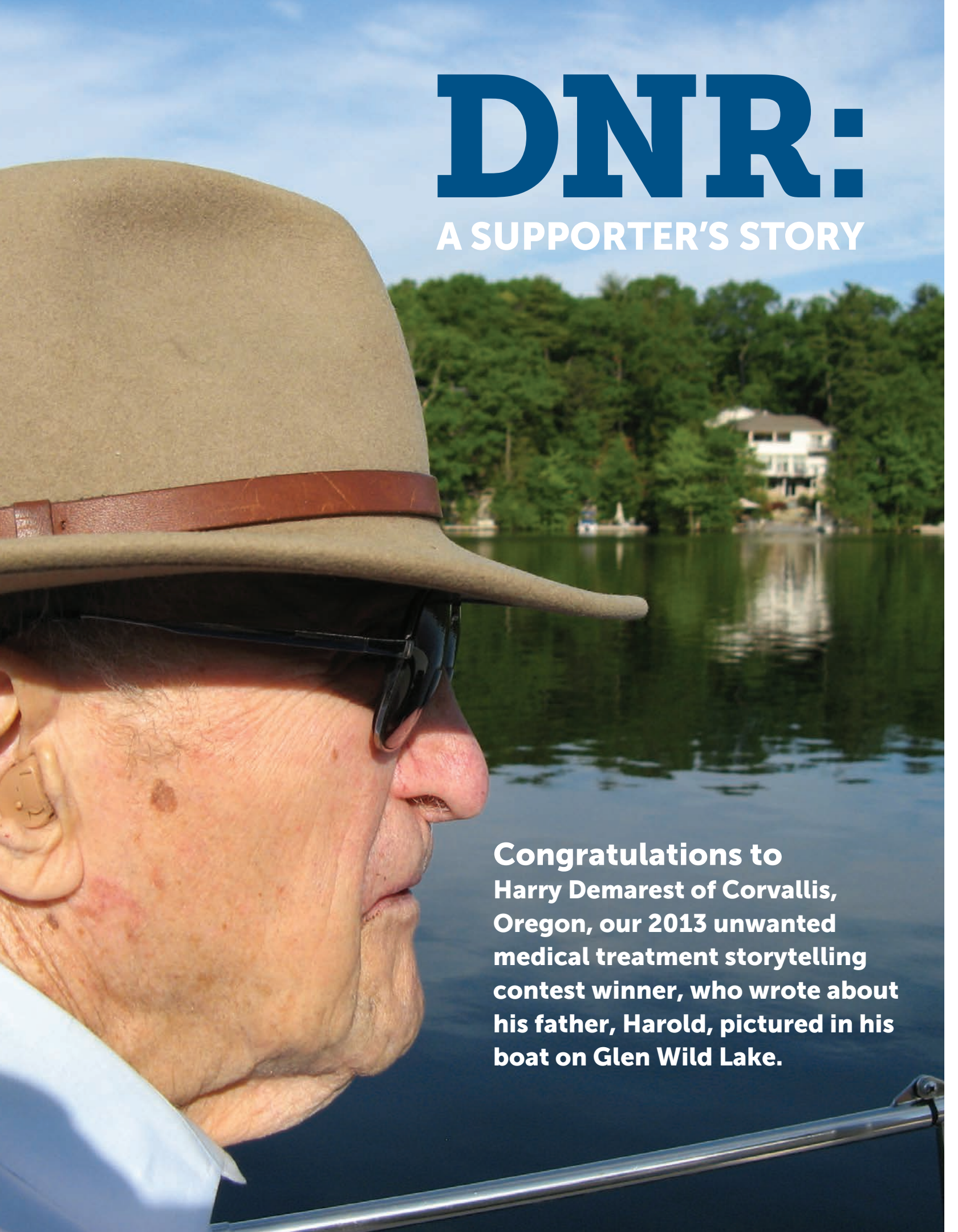
— Albert Schweitzer

## **Four Top Tips** for Caregivers of Aging Parents

- 1**
  - Make sure they update their advance directive every two to three years — tops — so everyone knows their current thinking.
- 2**
  - When you get professional help — medical, legal, financial, mental health, etc. — find someone who specializes in geriatric clients.
- 3**
  - Ask questions and advocate with providers. Make sure your parent knows enough to consent only to options that really align with their values.
- 4**
  - Supportive adult children need breaks, and their own support. Seek an outlet to discuss what you're going through.

# **DNR:**

## **A SUPPORTER'S STORY**



**Congratulations to Harry Demarest of Corvallis, Oregon, our 2013 unwanted medical treatment storytelling contest winner, who wrote about his father, Harold, pictured in his boat on Glen Wild Lake.**



## Mr. Demarest powerfully exposes how the medical system disregards the most thorough end-of-life plans with its default mode to provide treatment – no matter the patient’s circumstances and wishes.

The stories Mr. Demarest and others shared complement our national campaign to stop this tragedy and raise awareness to ensure that someday we’ll all be allowed to die with peace and dignity.

**M**y father prided himself on doing everything right, by planning everything in advance. By the time he was in his 70s and I was in my 30s, he had shown me where he kept the key to his filing cabinet and where I could find his stash of silver coins. He told me about his will. And his living will.

I watched as Pop declined from a spry 85-year-old who won sailing races on Glen Wild Lake, and traveled to China and all over the United States to run his business, to a 95-year old who hobbled around – first with a couple of canes, then a walker and finally in a wheelchair – while his wife, Eileen, ran the business.

During this decline, we discussed his living will more than once. When the time came, there were to be no heroic measures. There were to be no feeding tubes or respirators, no CPR and no defibrillation. We neglected to discuss the most important part of his living will: Under just what circumstances were there to be no heroic measures?. Did he believe, at the age of 95, that he had reached that point? I didn’t ask, nor did I look at a copy of the living will. Everything seemed to be far off in the future, and I lived 3,000 miles away. His end-of-life plans were the responsibility of his wife, Eileen.

A few days before Pop’s 96th birthday, he and Eileen planned to go out to dinner with friends. Two of the friends, Jane and Angie, wheeled Pop out of the house and transferred him into the car. Almost immediately he said, “I want to go home,” started to get out of the car, and slumped back into the seat, not moving.

Angie interpreted his statement to mean *I want to go to heaven*, and said to Pop, “It’s all right, you can go.”

Jane called 911. Pop’s house was on a long, hilly, twisty one-lane road, and there was no expectation



Harold Demarest (left) with his sister Grace and brother Charles

that emergency personnel would arrive quickly. A few neighbors came over until there were a half dozen people standing in the driveway while the minutes ticked by with Pop, or rather his dead body, sitting in the front seat of the car.

During these ten minutes waiting for help, any possibility that Pop, not breathing, could survive slipped away

When the policeman arrived, he moved the body from the car to the driveway and began administering CPR. The ambulance arrived with the EMT, who continued the CPR and then used the defibrillator, applying the paddles and the electric shock to Pop's chest. They loaded Pop's body into the ambulance, still doing CPR, and everybody followed to the hospital where he was officially pronounced dead.

I can't blame Eileen or Pop's friends and neighbors for not attempting CPR, because I don't know the wording of Pop's living will. I'm sure that the police and the EMT followed the rules by attempting CPR and defibrillation.

I'm also sure that my father never would have wanted people pounding on his dead body for more than a half hour, and that's what happened.

At the hospital, Jane asked the EMT about the CPR and defibrillation. "Why did you do this?"

"It's for the widow."



# Get What **YOU** WANT

- Complete your advance directive**  
in as much detail as possible. Helpful instructions and state-specific forms are available at [CompassionAndChoices.org](http://CompassionAndChoices.org).
- Talk with your family**  
as well as doctors and others close to you about the specifics of your directive.
- Designate a healthcare proxy**  
who will speak for you if you can't.
- Don't just file it away**  
—make sure to share what's in it and where to find it.
- Share your stories about planning**  
and the good or bad deaths you've witnessed at [CompassionAndChoices.org](http://CompassionAndChoices.org). Help alert others to the importance of making their preferences known.
- Take action to stop unwanted medical treatment**  
with our petition at [tinyurl.com/stopUMT](http://tinyurl.com/stopUMT).

## New Jersey

**Compassion & Choices New Jersey is advancing a death-with-dignity bill even in a rough-and-tumble election year.**

Our seasoned field organizer, Evan Nison, leads volunteers in making hundreds of phone calls each week, activating our supporter base to persuade legislators. Over 150 people are circulating petitions. Supporters will soon be hosting house parties across the state, expanding the network of activists to their friends and neighbors.

Sal Anderton, legislative director for the state’s best lobbying firm, Porzio Government Affairs, has taken Compassion & Choices’ arguments to members in both the Assembly and the Senate. Even over the Legislature’s summer recess, with members busy on election campaigns, Sal helped us get additional legislative co-sponsors. President Barbara Coombs Lee testified at the successful assembly committee hearing.

The campaign coalition includes the ACLU, the National Association of Social Workers New Jersey, The New Jersey Psychological Association, and a growing number of doctors and faith leaders.

Our social media organizers have grown our vibrant Facebook page from zero to more than 1,100 supporters and feature a new “Voice of Choice” each week.

Compassion & Choices Communities and Families Organizer Christy Davis Jackson leads the effort to engage New Jersey’s African American community. Her work has garnered the support of key legislators and faith leaders.

Tim White and Alex Habib of the Beckerman Group, a strategic communications agency, lead our media team.



Dr. Virginia Waters and President Barbara Coombs Lee in Trenton.

# 63%

**of NJ voters support death with dignity in Compassion & Choices’ independent polling.**

They’ve made sure our message has been in the media, with a steady stream of stories, editorials and supportive essays by independent voices. Ernestine Bradley — author, professor emerita at Montclair State University and a breast cancer survivor — wrote in support of the bill in *The Courier-Post*. She eloquently expressed what our polling shows the majority of New Jersey voters believe: “The highest form of liberty a government can bestow on its citizens is allowing them to have the ultimate right of self-determination.



Claudia Burzichelli, sister-in-law of a key state legislator, testifies in support of the bill just months before her death from cancer.

**Support on the ground is strong and growing. Now we need you to:**



**Sign our petition to help stop needless suffering in New Jersey:**  
[CompassionAndChoices.org/new-jersey](https://CompassionAndChoices.org/new-jersey)



**“Like” us on Facebook:**  
[tiny.cc/NJ-facebook](https://tiny.cc/NJ-facebook)

# Advocacy in Action



**The end-of-life-choice movement enjoyed a landmark year across the nation. Passing – and almost passing – new death-with-dignity laws, protecting existing ones, and expanding awareness of all available options, Compassion & Choices pushed the movement further than ever before. Advances this year position us well for a success-filled 2014 in states from coast to coast.**

## **ARIZONA**

Compassion & Choices' Arizona state chapter helped introduce a palliative care information bill similar to the one passed in New York. It failed in committee, so we are building strength to advance this bill in the next session.

## **CALIFORNIA**

Our California team is fighting a bill that threatens to leave dying patients in pain. SB 62 would require coroners to alert the state medical board of any death involving certain medications, a requirement that could curb physicians' willingness to manage pain and suffering adequately. In May, three of our state activists testified before the Institute of Medicine's Committee on Approaching Death: Addressing Key End-of-Life Issues during its second public forum, this time at Stanford University.

### COLORADO

Compassion & Choices' Colorado chapter premiered "Letting Go With Dignity," its short play about a patient at the end of life who never discussed her medical treatment wishes with her children or her doctor. The play's successful run led the group to produce it as a film to raise awareness of the importance of making and communicating end-of-life plans.

### CONNECTICUT



State Representative Betsy Ritter, bill sponsor.

Compassion & Choices Connecticut's campaign came close to moving a death-with-dignity bill out of legislative committee, only to be stopped in April by the threat of a filibuster. Advocates and supportive lawmakers from all over the state are preparing for another effort in the 2014 legislative session.

### FLORIDA

A new Compassion & Choices Florida group formed in Clearwater. These activists already have a dynamic agenda: They hosted attorney George Felos, who represented Michael Schiavo in the prominent case involving his wife, Terri Schiavo. As part of our campaign to stop unwanted medical treatment, Compassion & Choices filed a complaint, *Hallada v. Lakeland*, against a Florida hospital and nursing home that violated an elderly woman's DNR.

### HAWAII

The Compassion & Choices Hawaii team and the state's Physician Advisory Council for Aid in Dying continue their careful implementation of aid in dying as a medical practice governed by professional practice standards. The campaign's television and print ads, public appearances, and workshops have helped raise awareness that death with dignity is available in the state.

### ILLINOIS

Our Chicago team of activists hosted a Compassion & Choices booth at the national Aging in America Conference this year. They also held a National Healthcare Decisions Day event featuring Professor Lisa Anderson-Shaw, who served on the drafting committee for the new Illinois POLST (Physician Orders for Life Sustaining Treatment).

# California, Here We Come!

We're building strength as part of our goal to bring death with dignity to the Golden State within five years.

Here's how you can help:

- 1 Sign up for e-mail updates: [tiny.cc/action-alerts](http://tiny.cc/action-alerts)
- 2 Like our Facebook page:  
[Facebook.com/CompassionandChoicesNCA](https://www.facebook.com/CompassionandChoicesNCA)
- 3 Get your friends and neighbors to do the same.

# advocacy in action

## MARYLAND

Capitalizing on our strong momentum in the East, Compassion & Choices staff organized motivated area advocates and our two local groups to plan future legislative work advancing death with dignity. Six county action teams will focus on increasing support and awareness in key legislative districts and around the state.

## MASSACHUSETTS

A death-with-dignity initiative was narrowly defeated on the November 2012 ballot. But advocates of our Massachusetts campaign are unrelenting. New legislation has momentum, under the leadership of Compassion & Choices Massachusetts and staff, building alliances with key legislators, local advocacy groups and supportive physicians. A hearing may take place before year end.



Dr. Kress with supporters at our Montana victory party.

## MONTANA

Advocates triumphed in April as Compassion & Choices Montana defeated HB505, the “Doctor Imprisonment Act” that would have sentenced doctors to 10 years in prison for honoring their patients’ wishes for death with dignity. Our tremendous Montana team and an alliance of local physicians led by Dr. Eric Kress campaigned mightily to preserve access to aid in dying.

## NEW MEXICO

Compassion & Choices New Mexico made terrific progress in securing citizens’ right to aid in dying by raising support around *Morris v. New Mexico*, our case to clarify the legal status of the practice in the

state. Plaintiffs Dr. Katherine Morris and Aja Riggs embarked on a death-with-dignity speaking tour that took them all the way north to Michigan. Trial is set for December 2013. Scores of advocates also hit the Capitol and persuaded legislators to pass a joint memorial declaring March 1 “Healthcare Advance Directive Day.”

## VERMONT

In May Vermont became the fourth state to affirmatively permit aid in dying – and the first to do so through a legislature. Following that political breakthrough, Vermonters looked to Compassion & Choices for help implementing the new law. Our Vermont team is working alongside Patient Choices Vermont, the primary group behind the law’s passage, to educate doctors, organize volunteers and hire a state director to protect the law.

## OTHER LOCAL ACTIVITY

With our newly expanded advocacy department, regional outreach staff also made progress this year in Georgia, Iowa, Minnesota and Pennsylvania.

compassion & choices’  
work can’t happen without you:

### 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.

To learn what’s going on near you – or to start a group in your area – visit your state’s page at [CompassionAndChoices.org](http://CompassionAndChoices.org)

# Better Care. Greater Choice.

**Compassion & Choices helps people plan for and achieve a good death. We work to change attitudes, practices and policies so everyone can access the information and options needed for control and comfort at the end of life.**



Joe Yourshaw and his wife, Marge.

Barbara was at Joe's bedside when he lost consciousness after taking morphine, which hospice physicians had prescribed. When a hospice nurse found him unresponsive, her supervisor called 911 despite Joe's DNR. Police arrived and charged Barbara with "assisting suicide;" paramedics rushed Joe to the hospital and revived him. Joe awoke, angry to find himself in the hospital, and even more so to learn his daughter faced felony charges. Four days later Joe Yourshaw died in the hospital.

Compassion & Choices is assisting defense counsel in the case and mobilizing people nationwide. Since the Aug. 1 hearing, outraged citizens have delivered thousands of letters and calls to Attorney General Kathleen Kane demanding she drop the charges.

## Legal Advocacy:

### Why Is Barbara Mancini Charged With Assisted Suicide for Her Father's Death?

The unjust prosecution of 57-year-old Pennsylvania nurse Barbara Mancini could impact end-of-life care for millions and has sparked major national attention.

Barbara's father, 93-year-old Joe Yourshaw, suffered constant pain from various medical conditions. He had completed his advance directive and a do-not-resuscitate order (DNR), and he designated Barbara as his healthcare proxy to carry out his wishes.



**Give the Pennsylvania attorney general a piece of your mind for Barbara's peace of mind. Sign our petition to help stop the prosecution at [tinyurl.com/ManciniPetition](https://www.tinyurl.com/ManciniPetition), and visit our website for the latest developments in Barbara's case.**

## national program updates

This case rapidly received wide national press, including a *New York Times* column, a discussion on NPR's *The Diane Rehm Show* featuring Chief Program Officer Mickey MacIntyre, an opinion piece in *USA Today* by Director of Communications & Marketing Gwen Fitzgerald and CNN coverage.

"The fact that she's being charged is outrageous," said President Barbara Coombs Lee. "Dying patients have a federal constitutional right to as much medicine as they need to relieve pain, even if it advances the time of death."

Compassion & Choices will stick with this fight for Barbara Mancini, her family and her late father, who was denied his final wishes. We'll fight for physicians, who must not be fearful in providing suffering patients adequate pain medication, and for all Americans terrified by the prospect of government dictating their dying days.

## Ending Unwanted Medical Treatment



Marjorie Mangiaruca

Last year we launched the Campaign to Stop Unwanted Medical Treatment to ensure medical providers respect patients' healthcare preferences. Since then we have taken our concerns and recommendations to some of the most prestigious thought leaders in healthcare policy.

Chief Program Officer Mickey MacIntyre raised the issue with the Institute of Medicine's Committee on Approaching Death during its first meeting last February. He urged policymakers to "provide both the carrot and

the stick to ensure that patients' wishes are honored." We kept up the pressure all year:

In March MacIntyre discussed our recommendations at the American Society on Aging's "Aging in America" conference.

In June Director of Policy & Advocacy Ashley Carson Cottingham delivered testimony to the U.S. Senate Special Committee on Aging during their hearing, "Renewing The Conversation: Respecting Patients' Wishes and Advance Care Planning."

*The Hill*, a top Washington, D.C., political publication, featured our essay exposing the crisis.

Compassion & Choices is also fighting unwanted medical treatment by serving as co-counsel in *Hallada v. Lakeland*. This case seeks damages from a Florida hospital and nursing home that violated 91-year-old Marjorie Mangiaruca's do-not-resuscitate order, aggressively treating her in contradiction of her clear instructions.

**Help stop unwanted medical treatment. Sign our petition and learn more about this campaign at:**  
[tinyurl.com/CandCUMT](http://tinyurl.com/CandCUMT)





# End-of-Life Services to Expand

Because end-of-life issues affect everyone, we are expanding our direct service to families and health-care providers this year. Our new services will include more comprehensive support for terminally ill people, their family members, physicians and other healthcare workers. Our network of dedicated and experienced physicians will provide peer-to-peer support for doctors beginning to incorporate aid in dying in their medical practices, as they are doing now in Vermont and Montana. And we will provide more assistance for adults documenting their end-of-life preferences. Compassion & Choices' long-standing End-of-Life Consultation (EOLC) program will continue to provide confidential, personal counseling and support for those who call specifically about end-of-life choices, as we have for 20 years.

As Director Trish Bernstein explains, "It will be a very broad umbrella covering every end-of-life option, process and form, regardless of where clients live. The goal is that no matter who calls us, we have something to offer them."

Our services are always available free of charge at **800.247.7421**.

With so much happening, why wait for the news?



Stay **informed**. Stay **in touch**.

Receive the monthly Compassion & Choices News via e-mail.

Send your request to **info@CompassionAndChoices.org**

TALKING TURKEY  
**OVER**  
TURKEY



**The holiday season is coming, and with it dinners and get-togethers with family and loved ones. Yes, you guessed it: It's the perfect time to sit down and talk about your end-of-life wishes.**

Seriously. With siblings and multiple generations united, conditions are ideal to talk turkey about an important issue we all will face. Need to get Mom or Dad to discuss their end-of-life preferences? Trying to get your adult children to listen to your thoughts about dying? You'll find they're all surprisingly receptive at family gatherings. So how do you get the conversation started?

After many attempts to get family members engaged, one Compassion & Choices client set her Thanksgiving table with advance directive forms at every place setting and announced, "Nobody gets dinner until these are filled out." Now that's some tough turkey. Your best approach is the one that suits you and those around you. And while the paperwork is important, the essential thing is to get the conversation going!

## This **HOLIDAY** **SEASON**

**start the conversation.**

**Then tell us how it went. Sharing your story — at [tiny.cc/voicesofcompassion](http://tiny.cc/voicesofcompassion) — is a great way to share ideas on how to relish a meaty discussion.**

### **4 Key Questions** your conversation should cover-

- 1.** How do you feel about life support if:  
you have a terminal illness?  
you're in a permanent coma?  
you have an irreversible chronic illness like Alzheimer's disease?
- 2.** Do you always want to know the truth, the whole truth, and nothing but the truth? About your condition? About treatment options and their odds of success? And what success means for quality of life?
- 3.** What will be important to you when you are dying? No pain? Hold on as long as possible? Family members present? What are your priorities?
- 4.** Would you want to be placed in a nursing home if your condition warranted?

## talking turkey over turkey

# Are You Good to Go?

We have the tools you need to guide your conversation and document the results. They're all in our Good-to-Go Toolkit, and they're all free:

- ★ **A Values Worksheet to structure your decision-making.**
- ★ **Advance directive forms for every state.**
- ★ **An optional dementia provision — which only Compassion & Choices offers.**
- ★ **Contract rider for assisted-living facility contracts. Use this to ensure your new home intends to respect your choices.**
- ★ **Visit [tiny.cc/Advance-Directive](http://tiny.cc/Advance-Directive)**
- ★ **Call [800 247 7421](tel:8002477421) to get info by mail or speak to one of our counselors.**



## Conversation Starters

Here are some ways to get the conversation going. These “appetizers” will lead the way to a satisfying dialogue.

“ I want to be certain you guys know what I would want if I ever get seriously ill or can't speak for myself. What do you think I would want? What would you say to the doctors for me? What would you want me to say for you?”

“ My doctor/attorney/pastor says I need to go over my advance directive with you.”

“ If one of us ever had to make decisions about your treatment because you couldn't, it would be much easier if we knew what you really want.”



## Five Questions for **Dr. Dean Edell**

Dr. Dean Edell, one of the first physician broadcasters, hosted an enormously popular radio show for more than 30 years. He sometimes took controversial stands on hot-button topics, and was known for connecting to listeners and a remarkable ability to explain medical terms in everyday language.

*The Dr. Dean Edell Show* began in 1979 on KGO in San Francisco, eventually reaching 2 million listeners weekly on more than 400 stations before his retirement in 2010.

## 5 questions for Dr. Dean Edell

**What do you think is the most controversial health topic today? Where do you think America is on it?**

At the top of my list is the delivery of healthcare. We spend more and get less than other developed nations, and we are currently attempting a momentous change. Stay tuned.

**What was the strangest question you ever heard from a caller to your show?**

There are so many of those. Here's one at least you can print. A serious subject no doubt, but it took an effort to sound professional as I offered my assurances to a genuinely concerned mother about her son. At the height of public fear about AIDS, he was at a topless bar, and a lactating dancer squirted milk on him.

**Studies show that most people want to die peacefully at home with their families. How can patients and their families ensure they get the care they want at the end of life – nothing less, nothing more?**

At this time my best advice is for families to talk about this with each other and learn to navigate the ever-changing medical maze of today's healthcare. But the final answer, as with other similar issues we have faced as a nation, is a relentless awareness campaign leading

to an appropriate political and legal response.

**Millions of 50- to 70-year-old adults are now caring for their aging parents, spouses or both. This generation changed so much of society. What can they do to change how Americans live their final days, months and years, and die peacefully?**

I agree it was a generation that changed a variety of social values. There were pioneers in that generation who first introduced us to the subject of dying. Now that the years have rolled by, it's that same generation being hit by these issues. When I look at how quickly public attitudes have changed about other controversial subjects, I am optimistic that the same groundswell of activism will alter our attitudes surrounding death and dying.

**You taught medicine at U.C. San Diego. How can we, as patients, get our doctors to become more accepting of aid in dying as an end-of-life option for dying patients?**

That's an easy one. Bring it up. Talk to your doctors about it early in the game. Physicians change their attitudes as often from being challenged by patients as from the scientific literature.

“

**When I look at how quickly public attitudes have changed about other controversial subjects, I am optimistic that the same groundswell of activism will alter our attitudes surrounding death and dying. ”**



## 2013 Annual Report



### February

After testimony from Barbara Coombs Lee, the New Jersey Assembly's Health Committee cleared a death-with-dignity bill. Mickey MacIntyre testified during the Institute of Medicine's Committee on Approaching Death, sparking a national discussion of unwanted medical treatment.



### March

Our outreach resulted in a prominent and positive story in *USA Today* on the nationwide advancement of aid-in-dying legislation.



### April

Compassion & Choices attorneys filed a Florida lawsuit for failure to honor the DNR of 91-year-old Marjorie Mangiaruca. A successful campaign resulted in a bipartisan vote to defeat the "Physician Imprisonment Act," preserving Montanans' right to death with dignity.



### May

With Governor Peter Shumlin's signature, Vermont became the first state to pass a death-with-dignity law through the legislative process. Reporting on the law, the Associated Press, for the first time, used "aid in dying" in a news headline instead of "assisted suicide."



### August

Compassion & Choices' legal and public education work led a national groundswell of support for Barbara Mancini (see page 16). Thousands of supporters called for Congressional action on the "Personalize Your Care Act of 2013," which will reimburse doctors for advance-planning conversations.



### December

Arguments begin in *Morris v. New Mexico*, Compassion & Choices' groundbreaking case to establish that the medical practice of aid in dying is not assisted suicide.

## Combined Statement of Financial Position

June 30, 2013

### ASSETS

#### Current assets:

Cash and cash equivalents:	
Operating	405,913
Investments	180,382
Pledges receivable	1,008,974
Investments	13,154,400
Prepaid expenses	94,566
Beneficial interest in charitable remainder trusts	149,042
Other current assets	3,075
<b>Total current assets</b>	<b>14,996,352</b>

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

Furniture, fixtures and equipment	627,404
Leasehold improvements	32,481
	<b>659,885</b>

#### Less accumulated depreciation and amortization

**405,963**

**Total property, equipment and improvements** **253,922**

#### Other assets:

Intangible assets	3,014
Deposits	37,706
<b>Total other assets</b>	<b>40,720</b>

**Total assets** **15,290,994**

### LIABILITIES AND NET ASSETS

#### Current Liabilities:

Current portion of obligations under capital leases	13,118
Accounts payable	133,001
Accrued payroll and vacation	421,025
Accrued expenses	21,910
<b>Total Current Liabilities</b>	<b>589,054</b>

#### Long-term Liabilities:

Capital lease obligations, net of current portion	27,480
Gift annuity payments due	327,959
<b>Total long-term liabilities</b>	<b>355,439</b>
<b>Total liabilities</b>	<b>944,493</b>

#### Net Assets:

Unrestricted:	
Operating	14,133,177
Net investment in Property, Equipment and Improvements	213,324
<b>Total net assets</b>	<b>14,346,501</b>
<b>Total liabilities and net assets</b>	<b>15,290,994</b>



## Combined Statement of Activities & Changes in Net Assets

For the Year Ended June 30, 2013

### TOTAL UNRESTRICTED

#### Revenue and Other Support:

Conference and events	725
Contributions	7,494,951
Membership fees	191,559
Foundation Revenue	3,230,000
Restricted Gifts	10,000
Investment income, net of expenses	217,211
Realized and unrealized gain on investments	485,301
Loss on disposal of equipment	(293)
Other Income	197,727
<b>Total revenue and other support</b>	<b>11,827,181</b>

#### Expenses:

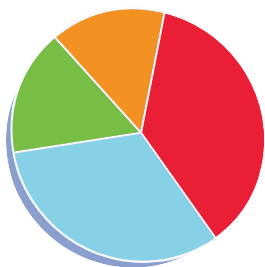
Programs	7,679,679
General and administrative	784,276
Fundraising	811,973
<b>Total Expenses</b>	<b>9,275,928</b>
<b>Increase in Net Assets</b>	<b>2,551,253</b>

#### Net Assets

<b>Total net assets, beginning</b>	<b>11,795,248</b>
<b>Net assets, ending</b>	<b>14,346,501</b>

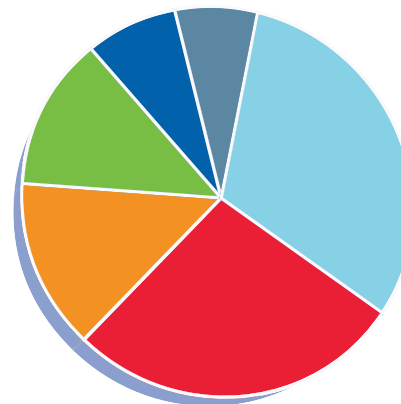
## Costs for the year ending June 30, 2013:

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

- Public Education: 37%
- Local Presences/Community: 32%
- End-of-Life Consultation: 16%
- Lobbying: 15%



All Costs

- Public Education: 31%
- Local Presences/Community: 26%
- End-of-Life Consultation: 13%
- Lobbying: 13%
- Fundraising: 9%
- Administration: 8%

## Thank You to All Our Donors

*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 of \$500 or more, Compassion & Choices appreciates everyone who is committed to our mission. You are our foundation!*

Totals are for gifts made in FY 2013, July 1, 2012 – June 30, 2013.

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(\$50,000.00 + )

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**"Opinion leaders in Washington, D.C., and across the country are talking about unwanted medical treatment. That wouldn't be happening if Compassion & Choices didn't have the resources to make it an issue."**

- Ashley Carson Cottingham,  
 Director of Policy & Advocacy



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 Iz Kopmar  
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# annual report

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 Marlene Lehrer  
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 Joan Levine & Alan  
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 Kurt Loebel  
 Mary Louise Loeser  
 Robert Loew  
 Bill Longton  
 Olinia Lovejoy  
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 Edward Lurie  
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 Alex Martin  
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 Robyn McLaughlin  
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 Meme  
 Mona Mender  
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 Doris Merring  
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 Ben Milgrom  
 Marie J. Miller  
 Ruth Miller  
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 Mary Jean Moody's  
 Aunt Genie  
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 Michael Patrick Moore  
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 Marlise Powell  
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