

Compassion and Choices

MAGAZINE

Fall 2005

ad•vo•ca•cy*

n.

*Public support for or a recommendation
of a particular cause or policy



AT THE SUPREME COURT MAKING IT LEGAL PROFILES OF COURAGE ACTIVIST IN ACTION

Compassion and Choices

MAGAZINE

Fall 2005 Volume 4 Number 3

Advocacy Issue

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Please don't forget to mail in your **Member Services Survey**.

Thank you for your help!

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www.compassionandchoices.org

From Your CEOs



Compassion and Choices

MAGAZINE

Barbara Coombs Lee *Marsha A. Temple*

ad•vo•cate

Advocate. If the mission of Compassion & Choices were summarized in one word, this might be the one. In courtrooms and in legislatures across the country, on First Street and on Capitol Hill, we are the advocates who speak for the pain and suffering of the dying. Our charge—to make our voice resonate permanently in the hearts, minds, and principles of America—is a heavy one.

Yet we have gladly accepted it. Compassion & Choices has a lengthy history of campaigning for choice in dying. From the radicalism of the early 80s, our issue has become a topic of serious legal, legislative and scholarly debate. Choice in dying is now an earnest subject, not a revolutionary one.

That makes today the time to take action. While people are thinking and talking about choice in dying, they need a trusted voice, a reliable resource to balance the discussion. Compassion & Choices understands the needs of dying patients and their families and how they may need us to support their advocacy efforts.

We're making progress. California and Vermont are giving serious consideration to a choice-in-dying bill like the one in Oregon, and our Vermont chapter spearheaded a new statewide advance directive registry. In New York and California, we were instrumental in enact-

ing legislation addressing pain management, with more on the horizon. And it seems that Oregon's trials may nearly be at an end, as the U.S. Supreme Court will consider the case by the U.S. Attorney General this fall.

But we can't let up the pressure. Our opponents are alert to our successes, and they are becoming increasingly vocal—and amassing significant resources. We must redouble our efforts to educate courts and lawmakers about why choice-in-dying laws are needed, what degree of comfort and control they can offer to the dying, and why they must be vigorously protected.

As we do this, we owe a deep debt of gratitude to our members and supporters. You are the bedrock of this organization and the foundation of all our work and accomplishments. While this year has seen a lot of organizational change, you kept our vision at the forefront and our purpose constant: to advocate and to serve people who are dying.

With this support and with such a calling in front of us, we will not falter. This issue of *Compassion and Choices Magazine* is devoted to advocacy and our legal and legislative efforts. With our combined effort, perhaps this issue, supported by the majority of Americans, will soon acquire appropriate precedence in our courts and capitols.

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The Supreme Court by the NUMBERS

| | |
|------|--|
| 215 | Years since the Supreme Court was established |
| 36 | Most years served by a Supreme Court justice |
| 15 | Average length of years of a justice's term |
| 16 | Number of chief justices the court has had |
| 108 | Total number of justices the court has had |
| 30 | Minutes allowed to each side to argue their case |
| 22 | Average number of months before a new justice is appointed |
| 8 | Number of justices who have served terms of more than 30 years |
| 9 | Number of justices on the court, including 1 chief justice |
| 1 | Number of presidents serving a full term without an appointment (Carter) |
| 10 | Record number of justices appointed by one president (George Washington) |
| 8 | Next greatest number of justices appointed by one president (FDR) |
| 7000 | Approximate number of petitions the court reviews each term |
| 2000 | Number of petitions the court reviewed each term 50 years ago |
| 100 | Number of petitions that are granted full review |
| 24 | Number of cases that might be heard in one sitting |
| 2 | Number of women who have served as justices |
| 2 | Number of African Americans who have served as justices |
| 79 | Average age of a justice upon leaving the court |
| 68 | Average age of a justice upon leaving the court 3 decades ago |
| 50 | Age of John Roberts, the nominee for Justice O'Connor's replacement |
| 32 | Age of the youngest justice ever appointed (Joseph Story, 1811) |
| 90 | Age of the oldest justice to ever retire (Oliver Wendell Holmes, 1932) |



Compassion & Choices at the Supreme Court

by Carissa Snyder, staff writer

“Equal justice under law.” Described in a few words, the charge of the U.S. Supreme Court is straightforward and sincere. Yet in reality, political quagmires can plague this court, making the motive of the cases before it even murkier than the questions of law it must decide.

This term, the court is faced with rendering a final decision regarding *Gonzales v. Oregon*, with arguments scheduled to begin in October. Formerly called *Oregon v. Ashcroft*, this case was brought by the state of Oregon, an Oregon physician and a group of terminally ill Oregonians challenging the U.S. Attorney General’s attempt to use the federal Controlled Substances Act to sanction doctors who issue prescriptions under Oregon’s assisted-dying law.

The Case

The case began in 2001, when former attorney general John Ashcroft directed agents of the Drug Enforcement Administration to take action against doctors who wrote such prescriptions. In the lawsuit challenging the attorney general’s action, a U.S. District Court and the Ninth Circuit Court of Appeals sided with Oregon, concluding that the Controlled

Continued on Page 6



Compassion & Choices at the Supreme Court

Continued from Page 5

Substances Act did not give the attorney general such authority. John Ashcroft had overstepped his bounds.

Mr. Ashcroft resigned his position in late 2004, but his successor, Alberto Gonzales, has chosen to continue the crusade against Oregon doctors and their terminally ill patients. He appealed to the U.S. Supreme Court, which is scheduled to hear the case on October 5, 2005.

Our Role

The patients who are plaintiffs in the case are clients of Compassion In Dying of Oregon, an affiliate of Compassion & Choices. Kathryn Tucker, legal director of Compassion & Choices, represents patients in this suit, serving as co-counsel with Nico van Aelstyn of Heller Ehrman White & McAuliffe. Ms. Tucker was also counsel in the *Glucksberg v. Washington* and *Quill v. New York* cases; it was the 1997 *Glucksberg* decision that invited the states to grapple with the question whether to legalize assisted dying. Compassion & Choices assists financially with the case.

This is a battle that we must win. If the attorney general prevails, Oregon's assisted-dying law will not be nullified, but it will be mercilessly gutted. Terminally ill patients would still have the legal right to ask their doctor for a prescription to end their lives, and the right to take that medication if necessary—but any doctor who wrote a prescription would risk being branded a drug trafficker, and even going to prison.

We have high hopes that the Supreme Court will see this case in the same light as the other federal courts have. The Controlled Substances Act is meant to prevent interstate drug trafficking. It was not written to police legitimate medical practice, even less to put family doctors behind bars. In the words of the Ninth Circuit Court, the Ashcroft-Gonzales attempt “contra-

dicts the plain language of the Controlled Substances Act, and contravenes the express intent of Congress.”

Our Issue at the Supreme Court

This isn't the first time the Supreme Court has decided cases that are central to the choice-in-dying movement. Two 1997 decisions brought the issue to the public forefront and established a standard of letting states decide this issue for themselves—a precedent the court should recall when considering *Gonzales v. Oregon*.

In *Glucksberg v. Washington* and *Quill v. New York*, both sponsored by Compassion In Dying, terminally ill patients and their doctors argued that the right of terminally ill, mentally competent adults to hasten death was protected by our Constitutional rights to privacy and equal protection. The court concluded that was not the case, instead leaving the question of assisted dying to individual states to decide.

In a mixed decision issued in 1990, the court determined that Nancy Cruzan, who had been in a persistent vegetative state for seven years, had the right to have life support discontinued if clear and convincing evidence showed that was her wish. However, the court did not think sufficient evidence had been presented. New evidence presented in a lower court eventually allowed Ms. Cruzan's life support to be withdrawn.

Recently, the court refused to hear an appeal in the case of Terri Schiavo in Florida, finding insufficient grounds for further review.

What's Happening Now

While we anticipate that the Supreme Court will agree with the lower courts' analysis, nothing is guaranteed. Advocates of choice in dying must put our full efforts behind its defense, and that advocacy comes with a price tag.

Ask the Expert

Q. I just don't understand how the Oregon case affects me. My Bible-belt state doesn't have an assisted-dying law, and we probably never will. I feel bad for the Oregon patients and for the doctors who are being threatened, but what does it have to do with me?

A. Great question! There are definitely states where an assisted-dying law like Oregon's isn't on the horizon yet.

The issue in *Gonzales v. Oregon* is larger than assisted dying. It concerns a state's right to enact its own laws. In this case, the federal government interfered with rights that belong to states.

The rights of our state governments help enforce our individual right to privacy, protecting our personal freedoms. We don't want the government coming into our kitchens, living rooms and bedrooms and telling us how to live our lives—and we don't want them at our deathbeds, either.

The Oregon plaintiffs went to court to prevent bureaucrats from stepping into our homes and telling us how we can die. If states' rights are shelved regarding choice in dying, the precedent could allow interference in other aspects of our lives. Your state may not be considering assisted dying, but is probably interested in advance directives and improved pain and palliative care.

Decisions on these topics should be made by people in your state, not by far-off edicts in Washington. By supporting Oregon and the terminally ill patients at the Supreme Court, you're also supporting your own individual liberties—and that's what the United States is about.

— Barbara Coombs Lee, PA,
FNP, JD, co-CEO, President

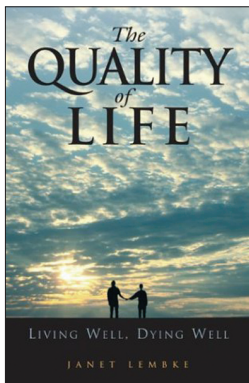
Do you have questions for us? Our staff and volunteer experts are on hand to respond to your questions and concerns about choice in dying! Send your questions to us at expert@compassionandchoices.org



Since early 2005, Compassion & Choices has spearheaded a fundraising drive among members, supporters and others to raise funds for the Supreme Court fight. Through our publications, mailings and membership efforts, we are striving to increase public awareness of this important battle.

Our members and local groups are also joining the fight. Our Indiana chapter held a specific fundraiser for the Supreme Court case, and has thrown down the gauntlet to other chapters to do the same. Member contributions earmarked for *Gonzales v. Oregon* help lay the groundwork for this fight—each one puts us one step closer to victory.

If you're interested in helping, please contact us by email at info@compassionandchoices.org or by calling 800.247.7421. We, and the terminally ill patients in Oregon, are grateful that we can count on your support at this defining moment for choice in dying. ©



Off the Press

The Quality of Life
Janet Lembke

Retail price: \$22.95
Members' price: \$16.00

When author Janet Lembke's mother was a sprightly 78 years old, she made her daughter promise to help her die when the time came.

Pills with a stiff bloody Mary and a hug. But when the time came, it was not so simple. The book examines assisted dying, advance medical directives, the bioethics of withdrawal of life support, dementia and how to cope with it, hospice, and the quality of life.

Call 800.247.7421 or visit our bookstore online at www.compassionandchoices.org to order.



Making It Legal

Michelle Holbrook, director of legislative affairs

Since the passage of the Oregon law in 1994, and the 1997 Supreme Court invitation to states to consider whether to legalize assisted dying, many states have shown interest in enshrining this basic right in law.

This year is no exception. Compassion & Choices was instrumental in getting assisted-dying bills introduced in California, Hawai'i and Vermont. Yet, introducing a bill or even writing a ballot initiative for choice in dying is nothing new. Each of these states has had similar bills introduced in the past, and the 1990s saw ballot initiatives in California, Maine and Washington.

So what has changed? What's different about this year's attempts?

California is a great case study to show why now is the time for assisted-dying legislation. Early ballot initiatives in California were attempted in 1987 and 1992—underfunded and unprepared for the highly virulent and heavily bankrolled right-to-life opposition. A 1999 bill drew more support due to its similarity to the Oregon law, but the campaign fell short on its public education strategy.

Having garnered the missing pieces from these past experiences, we are at last able to put it all together. Compassion & Choices supports the California Compassionate Choices Act, working aggressively to combat the misinformation often conveyed by opponents. The bill's committed sponsors, Assemblymembers Patty Berg and Lloyd Levine held two public informational hearings

before even introducing the bill, allowing public commentary and providing a forum for open and accurate debate.

As always, timing can mean everything. The legislative process is often a slow one, particularly with issues that generate as much controversy as assisted dying. After two initiatives and one legislative attempt, assisted dying is beginning to be a familiar concept to Californians. Citizens and legislators have had an opportunity to study and

think about the issue. Education about assisted dying has been accomplished by persistence and consistent repetition of the facts.

Repetition and persistence are also paying off in another state that has been hard at work on assisted-dying legislation. Vermont's assisted-dying bill is now in its third year, waiting out the legislative recess for a committee hearing. Vermont advocates have advanced this

bill by deliberate patience, allowing the legislature time to conduct studies and analyze its own reports on how well assisted dying works in Oregon.

The climate in Vermont is ripe for a successful bill. Like Oregon, Vermont has a homogeneous voter demographic, a geographically small campaign area and very strong poll numbers in support of the bill—nearly 80 percent statewide. Best of all, Vermont citizens are known for their fierce independence, and tend to lean sympathetically toward expansion of personal liberties.

In other states, we continue to lay groundwork.

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In the News

Supreme Court Nominee Comments On Assisted Dying

In a 1997 TV interview, Supreme Court nominee John Roberts gave a revealing quote on assisted dying. "I think it's important not to have too narrow a view of protecting personal rights. The right that was protected in the assisted-suicide case was the right of the people through their legislatures to articulate their own views on the policies that should apply in those cases of terminating life, and not to have the court interfering in those policy decisions. That's an important right."

Roberts has not heard any end-of-life policy cases per se, making it difficult to predict his stance with any certainty. However, this quote is a good reflection of his record of strong respect for states' rights and an approach to statutory construction which involves careful and close reading of laws. These indicators suggest he would not favor the federal government in *Gonzales v. Oregon*, the U.S. Attorney General's attack on Oregon's assisted-dying law. Arguments in the case are scheduled to be heard October 5.

California Democrats Show Support

In a move most welcome as we work to pass the California Compassionate Choices Act, the California Democratic Party has adopted a resolution to support assisted dying. Adopted in July, the resolution states that party members "stand in strong support of efforts to ensure death with dignity for all Californians."

Increased Interest in Living Wills

Across the country, agencies that provide information and forms for living wills and advance directives for health care have been deluged with requests. The Terri Schiavo case, which garnered national attention this year, captured the interest of many younger people, since Terri was only 26 when she suffered her initial collapse. As a result, Compassion & Choices has filled more than 27,000 requests for advance directive kits, and other agencies report similar spikes.

The increased interest of younger people in our movement and work is a welcome trend. With living wills and end-of-life decisions now a common topic at universities, high schools and youth-oriented companies, Compassion & Choices is reaching out. Our recently introduced interactive blog, *Final Say*, encourages Internet users to speak out on these important topics. Visit online at www.finalsay.org.

Mobile Phones Can Help Protect Your End-of-Life Choice

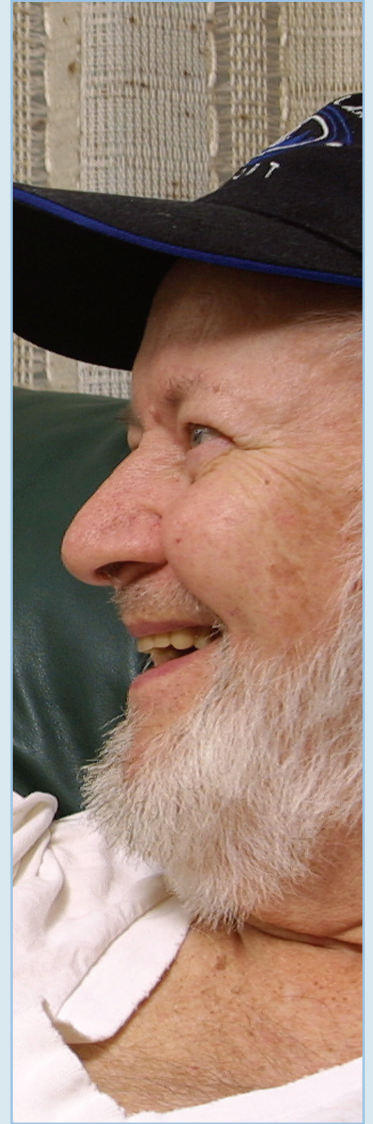
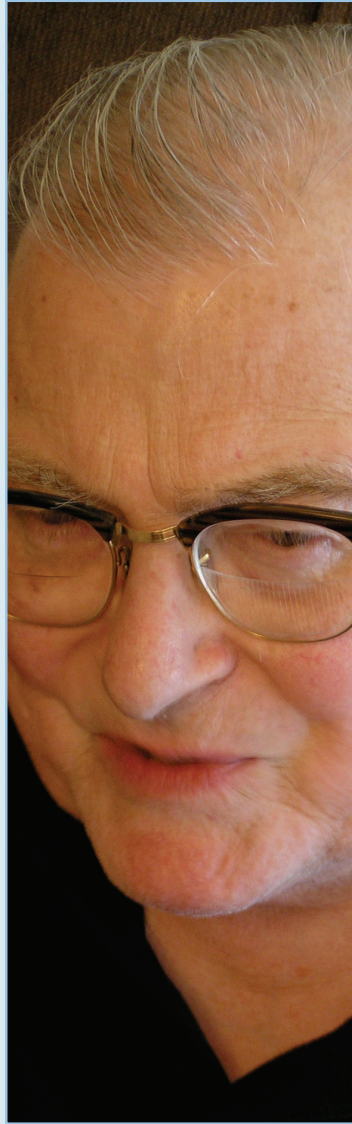
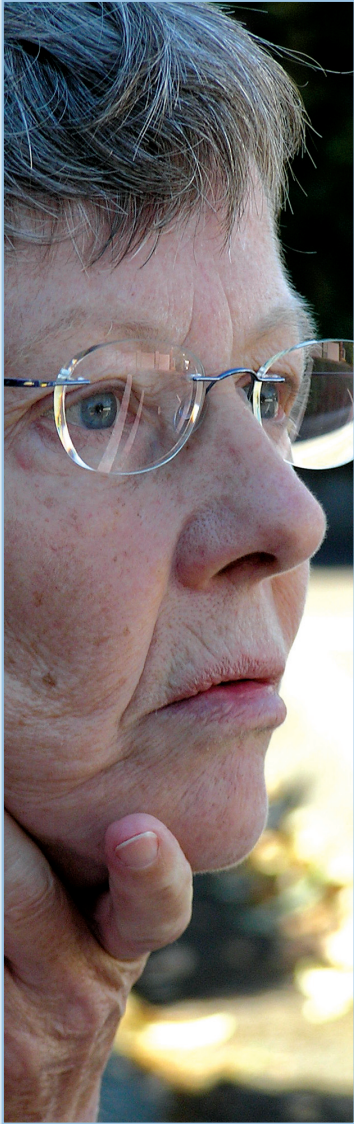
An idea that began last spring in the United Kingdom has also taken hold in America. Mobile phone users are encouraged to list an emergency contact in their cell phone address book under the acronym ICE—In Case of Emergency. Paramedics and hospitals can use this information to reach your next of kin or designated decision-maker if you are unable to communicate.

Last year, Arizona passed a law establishing an advance directive registry, something also established in Vermont this year and currently being considered in Pennsylvania. Advance directives, end-of-life planning and pain management are all topics that are worthy of legislation in their own right, and provide fertile ground for further discussion about choice at the end of life.

Unquestionably, the key to choice in dying is gaining legislative momentum. Our tasks now are to keep this issue at the forefront, and to provide appropriate education to lawmakers and constituents. Our legislative and legal efforts are the key to our final goal—when choice in dying is both enshrined in law and protected by the courts. ©

Action Network

Ready to take legislative action? Join our free action network! Network members receive email action alerts of pending legislation, as well as the *Advocacy Bulletin*, an electronic newsletter published monthly during the legislative session. Stay up-to-date with what's happening in your state and around the country—and take action! To join call 800.247.7421 or visit us online at www.compassionandchoices.org.



Pictured Left to Right: Lovelle Svart, Don James, Richard Holmes, Allison Willeford, MD and Roger Watanabe

Profiles of Courage

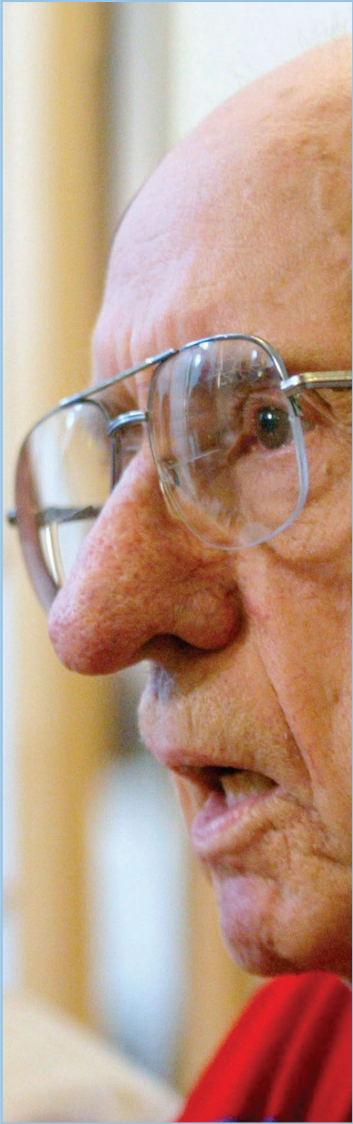
Declarations of support for Oregon's assisted-dying law

"I do not want my partner to have to watch me die a lingering protracted death marked by progressive loss of bodily function and integrity, increasing pain and other intensely distressing symptoms. It is important to my values and beliefs to be able to exercise this choice."

— Martin Weiss, suffered from esophageal cancer

"My decision to take the lethal dose of medication I presently possess is a very personal and important decision for me, it is based on my most deeply held values and beliefs. I believe everyone should have the right to make it when and if they become eligible to use Oregon's law."

— Richard Holmes, suffered from colon cancer



Charlene Andrews
 Melissa Bush*
 Jane Doe #1*
 Jane Doe #2*
 John Doe #1
 William Gilbertson*
 Cheryl Jeanne Gunning*
 Richard Holmes*
 Don James

Since the beginning of the Oregon court case in 2001, 16 patients have intervened on the side of Oregon. Five of these people have filed petitions with the court that will be heard this fall. Join us in thanking these individuals for their strength and their unwavering support of the Oregon law.

James Romney*
 Karl Stansell*
 Lovelle Svart
 Roger Watanabe*
 Martin Weiss*
 Allison Willeford, MD*
 Arthur Wilson

*deceased

“I will have no humane options if and when my dying process becomes unbearable to me. I will be subjected to extreme physical and emotional suffering that I would not have to endure if I am allowed to control the timing and manner of my death.”

— William Gilbertson, suffered from carcinoid and prostate cancer

“Emphysema is a disease that usually ends in death by suffocation. I do not wish to wait in fear for this type of terrifying death.”

— Melissa Bush, suffered from emphysema

“I am in a great deal of non-physical agony, due to my inability to eat, speak properly and to perform my normal bodily functions. I wish to have the option to end my life in a humane and dignified manner.”

— Karl Stansell, suffered from throat cancer

“I am a Christian and believe that my God understands my decision and would not want me to endure the pain and suffering that my illness will cause me in my final days.”

— Jane Doe #1, suffered from pancreatic cancer

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“I have notified my family of my decision and they support me in my wish for a dignified death.”

— Jane Doe #2, suffered from emphysema and chronic obstructive pulmonary disease

“I will get to the point in my life when my body will no longer function, but I will remain mentally alert. This will cause me great anguish and suffering because I will be able to maintain my mental faculties, but will not be able to perform normal bodily functions.”

— James Romney, suffered from Lou Gehrig’s Disease (ALS)

“Having the legal right to choose to hasten my death if my suffering becomes severe has given me great peace of mind. A dignified and peaceful death does not seem too much to ask. The alternative for someone with ALS is terrible.”

— John Doe #1, living with Lou Gehrig’s Disease (ALS)

“When I reach the point that my pain and symptoms are unbearable to me, I want to be able to hasten my impending death in a humane and dignified manner, in my home, in my bed, surrounded by my loved ones with whom I will be able to say a final goodbye.”

— Don James, living with prostate cancer

“I do not know if I will choose to use the law and take life-ending medication, but I do know I want the right to do so, as the law allows.”

— Charlene Andrews, living with breast cancer

“I have a lot of pain with this illness and take large amounts of a narcotic – morphine. The pain is likely to get worse and I will have to choose between a clear state of mind or taking increasing doses of the narcotic to control the pain. This choice is unacceptable to me.”

— Roger Watanabe, suffered from colon cancer

“If I am not able to access my right to die with dignity under Oregon law because physicians fear such prosecution, my rights under the Oregon law will be taken away from me permanently without any recourse. I will be forced to endure the ravages of end stage terminal ovarian cancer and experience pain and suffering that I wish to avoid.”

— Jeanne Gunning, suffered from ovarian cancer

“I can’t bear the thought of fighting for every breath, or waking in panic when I’m unable to get air to my lungs.”

— Lovelle Svart, living with lung cancer

“It is very important to me that I have the right to have this option when I believe it is necessary because I am fiercely independent and wish to control my destiny, including over how and when I cross the threshold to death. I am a devout Christian and believe God would agree with my decision. In fact I believe it is my God given right to make this decision.”

— Allison Willeford, MD, suffered from kidney cancer

“I want to tell my friends and loved ones that I love them and say “Goodbye” on my terms and in my time. I do not want to be in a drugged-dazed state or die gasping painfully for breath.”

— Arthur Wilson, living with chronic obstructive pulmonary disease

Family Members

Individual patients aren’t the only ones affected by Oregon’s assisted dying law, or by the threats against it. The

Profiles of Courage

statements below are published in the Survivors' Brief filed with the court. All the briefs are available online at www.compassionandchoices.org.

The Oregon Death with Dignity Act (ODWDA) relieves severe and prolonged suffering of some dying patients who would prefer death:

"It is possible to endure a great deal of pain and discomfort if one feels there is a purpose in doing so - that there may be a light at the end of the tunnel. But when Norma learned from her oncologist early in July 2001 that she had at most a few more weeks left to live, she decided she would prefer death on her own terms to a continuing, futile struggle ending in helplessness and misery."

— Alvin Davis, about his wife

The ODWDA promotes public safety and order by averting violent, ghastly, and often unsuccessful efforts to hasten impending death by patients who previously could not make use of the ODWDA:

"If physician-assisted dying had been available to my father, as it is to the people of Oregon, I have no doubt that he would have chosen a less violent and lonely death. My mother could have been brought around to accepting his decisions, death could have been peaceful, and his family could have been with him."

— Marcia Angell, MD

The ODWDA provides safeguards that ensure a decision to hasten death is made knowingly, voluntarily, and with proper medical advice and assistance after due consideration:

"She went through an extensive screening process over a two-week period which involved her having three sessions with her primary doctor, an interview with the chief of ethics of our HMO, and the review by a second doctor outside the HMO. There was no doubt from anyone that she was competent and not depressed. Her treatment options were discussed and reviewed with her over and

over again. She was given assistance with hospice care and pain management. We were encouraged to share her decision with our family members, which we did. We also took time to discuss her desires with her clergy person. After each meeting and discussion Colleen's resolve to hasten her death strengthened."

— Scott Rice, about his wife

The ODWDA advances the public interest in protecting families by relieving family members of the pressure to assist their loved ones to hasten death illegally:

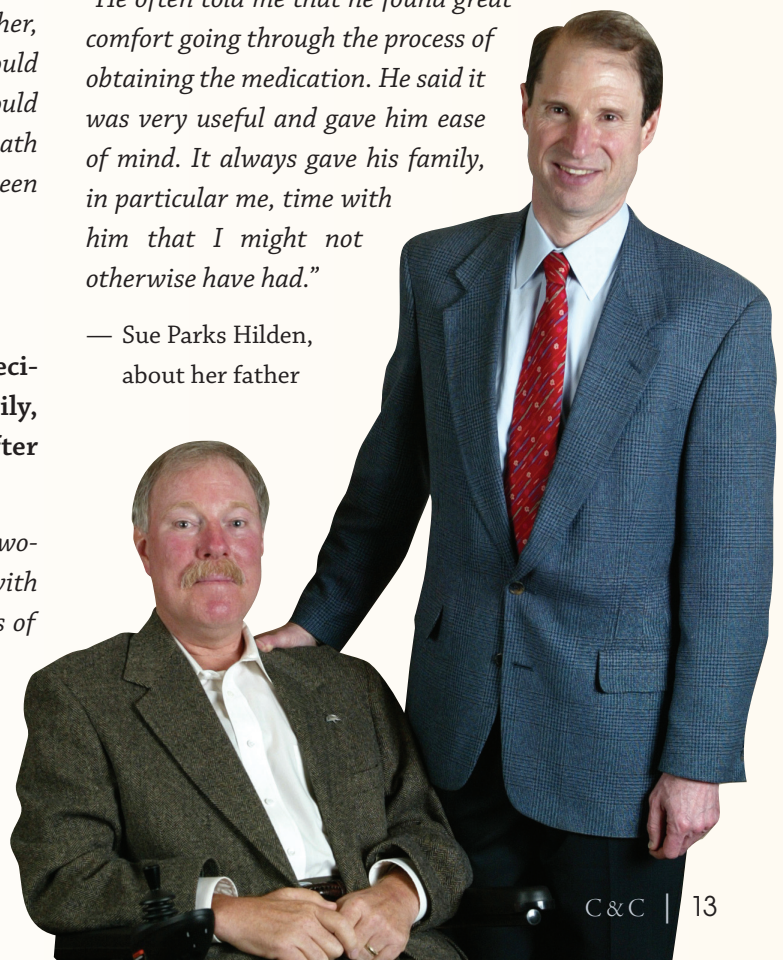
"I am proud to have supported my mother in the final deliberate act she had in her life...Oregon's law gave my family and me something special and it allowed my mother to die with dignity and grace."

— Julie McMurchie

The ODWDA protects the dignity, privacy, and autonomy of patients:

"He often told me that he found great comfort going through the process of obtaining the medication. He said it was very useful and gave him ease of mind. It always gave his family, in particular me, time with him that I might not otherwise have had."

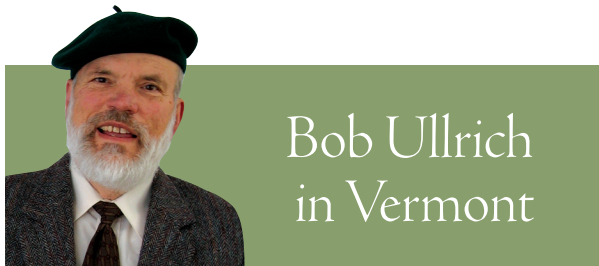
— Sue Parks Hilden,
about her father



Jim Romney (seated) with Oregon Senator Ron Wyden

Activist In Action

Carissa Snyder, staff writer



Bob Ullrich has known four people who took their own lives after receiving a diagnosis of incurable illness, shocking and saddening family members who weren't even allowed a final farewell. In addition, three family members have died of cancer, in less-than-ideal conditions. "When it happens in your family, you see it firsthand," he says. "We have to come to grips with these tragic circumstances."

A relative newcomer to the movement, Bob jumped in with both feet about a year and a half ago. Not yet a member of Compassion & Choices but a known supporter, he was approached by a delegation from the Vermont chapter and asked to become its next president. He was excited about helping to pass Vermont's assisted-dying bill—and having just retired for the second time from University of Vermont, where he is a professor emeritus in biological sciences, Bob figured he had the time.

He may have been mistaken! Since assuming the presidency of a chapter in the thick of a legislative campaign, Bob estimates that he has contributed between 2,000-3,000 hours to the cause, including some 120-hour weeks during the legislative session. "The problem I have is that I always conceive of additional things that can be done because I really want to see this legislation passed," he says.

He isn't alone. Vermont's assisted-dying bill is truly a grassroots effort. A group of volunteers who wanted to pass the bill approached End-of-Life Choices three years ago, became a chapter and began their work. The bill was first introduced in 2002, and though it did not proceed very far it did receive public testimony. Bob was one of the many who volunteered to testify.

This year, the bill earned a referral to the House Human Services Committee, where it now waits for a hearing. The Vermont legislature has a two-year session, so the session that resumes in

January 2006 is part of the same biennium. Bob and the Vermont chapter members are optimistic about the bill's chances in committee, even now working on a postcard campaign that has garnered about 4,000 signatures.

"The testimony the bill received in the Human Services Committee was incredibly good," Bob says. "We were able to answer the opposition's accusations—they really try to

obfuscate the message." He also says, "An overwhelmingly positive legislative council report on the Oregon law was a masterstroke making the bill much more likely to pass should it reach the House floor."

Passing an assisted-dying bill like Vermont's is a massive undertaking, but Bob and the Vermont chapter are up to the challenge. Bob, in particular, is passionate about making sure their efforts pay off. "Sometimes I feel this is too much for me to do," he admits. "But I think I have to see it to fruition." ©

"We were able to answer the opposition's accusations—they really try to obfuscate the message."

Voices

“I don’t know what was worse: watching my grandfather become incapacitated... or conversations with my mother about who would ask him what his final wishes were...”

Watching my grandfather’s body slowly shut down, I knew it was for the best. He had long since lost the battle for a quality life. But, it was still difficult to watch his breathing become slower and more labored. I finally gave up close scrutiny of the various machines attached to his body. The warning beeps of the machines were a dull echo no longer to be heeded, instead of calls for increased vigilance as they had been in previous months. I held my mother’s hand. We cried. And silently, we said our goodbyes.

Like in the movies, the steady monotone of the machines let us know when he died.

My grandfather didn’t have cancer, or heart disease, or any other illness that we knew would take him sometime soon. At 84, he was an active, alert retiree who ran his own errands, called us every day and kept track of what we were doing. Just a few weeks earlier, we had been heatedly arguing about sports and politics at a restaurant while he simultaneously did the old-man flirt with the waitress.

Then he was struck by a car while walking in the parking lot of his retirement home.

At first, the accident seemed so trivial. The car barely nudged him. How could it cause much damage to someone in good health? At first, we thought he would just recover. He hit his head hard, but the doctors thought he would be okay. They did reconstructive surgery on his nose so he would still look good for the ladies at the retirement home. But he never left a hospital bed again—from the time he was admitted to the ER until his death more than three months later.

Before the accident, our major concerns were about failing eyesight, diabetes and dentures. Living wills, organ failure and brain damage never entered the picture. When the doctor mentioned these things we were unprepared—which turned into agonizing suffering for my grandfather and for the rest of us.

I don’t know what was worse: watching my grandfather become incapacitated and dependent on machines for breathing and eating, or conversations with my mother about who would ask him what his final wishes were. Eventually, decisions were made by the slow elimination of choices. My mother and I were too emotional to make quality decisions with any sense of perspective.

Dignity and quality of life lost out to poor preparation and a legal-medical establishment ill-designed to uphold those values. My grandfather was always going to die. I regret that he did not die well—and that I was not in a position to help him do so.

—Marc-Paul Johnsen

About the author: Marc-Paul Johnsen is a freelance writer and a master’s candidate at a graduate theological school.

Send original *Voices* contributions to: Editor, Compassion & Choices, P.O. Box 101810, Denver, CO 80250 or email editor@compassionandchoices.org

Special Events

Rally at the Supreme Court

October 5, 2005

Location: Supreme Court Building

8:00 a.m.

Join the rally for choice at the end of life outside of the Supreme Court building on October 5! Compassion & Choices can help outfit you with signs, stickers and pins. If you plan to participate, meet us on the courthouse steps. Contact Summer Goodwin at 800.247.7421 or sgoodwin@compassionandchoices.org to let us know you will be there.

Supreme Court Briefing

Compassion & Choices will offer a live briefing following oral arguments at the U.S. Supreme Court at 1:00 p.m. EDT on October 5. Staff and attorneys will review the court proceedings. To join the conference call-style briefing by phone, dial in toll-free at 800.270.1433. For more information, contact Summer Goodwin at 800.247.7421 or sgoodwin@compassionandchoices.org. If you are in D.C., please join us!

Arizona State Conference

November 5, 2005

Location: Phoenix area, details TBA

10:00 a.m. to 3:30 p.m.

Keynote speakers include Marsha Temple, John Abraham, executive director of End-of-Life Choices Arizona, Linda Lopez, state Representative and Assistant House Minority Leader, and Chris Loker, national board member and client support volunteer.

Hammer Forum Change of Date

Because of the Supreme Court Hearing on the same date, the Hammer Museum Event has been rescheduled to October 11:

The Culture of Living and Dying in America

UCLA Hammer Museum, Los Angeles, CA

October 11

David Kessler, Barbara Coombs Lee, Alan Toy and Reverend Frank Wulf will discuss building a culture that acknowledges the primacy of conscience in defining the parameters of choice.

Speakout: Readers' Comments

The Depression Debate

To respond to James L. Werth's letter on depression and hastened death in the spring 2005 issue: One concern is that if there is such a medical deterioration that death is imminent; there may not be enough time to treat the depression.

There are also some individuals who have severe clinical depression that recurs repeatedly, chronically, and never fully remits. They live with it constantly...even when treated expertly, their depression is going to come back.

In some ways, the psychological pain is just as real and severe as the physical pain of end-stage cancer. After 20, 30 or even 40 years of exacerbations and recessions, some depressives simply can't continue. They have reached their end stage.

Do we really have the right to say, "Because you have a disease that is psychiatric in nature, you don't have the right to opt out?"

TALYAH FINEBERG, MS ED, LPN

New Jersey

Feeding Tubes

My mom had Alzheimer's disease for five years before she died at the age of 85. She couldn't walk or talk. When the question of a feeding tube came up, I was against it. She had told me in no uncertain terms not to prolong her life by artificial means. She was quite definite.

I agree. Don't ever give me a feeding tube! I wouldn't call this starvation. A feeding tube is an invention of medical doctors—they often do more harm with drugs and operations.

Is this a rant? Perhaps—but I feel deeply in these matters. Let common sense prevail!

ED GUSTAFSON

Indiana

Oregon Under Attack

I see that the Bush Administration is again trying to criminalize the Oregon Death with Dignity Act.

Twice the people of Oregon have exercised their Constitutional rights and passed this law. To criminalize such action would violate the right of people to vote.

During the height of the Kevorkian affair in Michigan, an official of the Detroit Diocese told a reporter, "Suffering is good for the soul."

I am an 86-year-old World War II veteran. I don't have much time left. When my time comes to go, I don't want the president to ring my doorbell and say, "Frederic, suffering is good for your soul and we want you to enjoy a lot of it before you go." I hope the Supreme Court will uphold the right of the people to pass laws affecting their lives.

FREDERIC ADAMS

Michigan

Teens Speak Out

"Healthy children will not fear life if their elders have integrity enough not to fear death." This insight by Erik H. Erickson reminds people that everyone will die and if a person keeps in mind that death is a promise, he or she will not be afraid to live.

People should be able to live enjoyably without the fears and burdens of death slowing the sunshine of their lives. Although winter may seem, cold and dreary, it holds a hint of hope with each falling snowflake. Winter dies so that spring may live—every beginning requires an ending. Thank you for your continuous efforts to help those who are suffering.

RACHEL

Westlake High School, California

Suicide is not an illegal act. But if a doctor, family member or close friends help ease or speed up the process of death, it then becomes criminal.

Keeping anybody alive against their will in a forceful or restrictive manner is not moral. Why shouldn't people be allowed to die with dignity and honor?

A person should be allowed the right to die with assistance—death should not be denied. I highly appreciate the efforts of Compassion & Choices. Please continue your work!

MICHAEL

Westlake High School, California

Editor's note: Many thanks to all the students from Westlake High School who wrote in to voice their opinions on choice in dying!

Did You Know?

Nearly 80 percent of adults nationwide would not want to exist in a persistent vegetative state,

Nearly 75 percent support assisted dying for people who are terminally ill,

Fully 65 percent support assisted dying when a disease or condition is incurable or causes severe pain,

But only 40 percent have a living will.

Do you have one?

Visit www.compassionandchoices.org or call 800-247-7421 for a state-specific kit today!

Source: The Gallup Organization, April 2005 and June 2005



The Armchair Advocate

Peter Freedman, director of development

Passion, commitment, dedication and time—four things needed in abundance for effective advocacy. The first three come easily to Compassion & Choices' members and supporters—but time is a commodity often in short supply.

There are ways you can assist our advocacy efforts that don't involve joining a local board, testifying at the capitol or even collecting signatures. Through our on-line action network, you can take action on state and federal bills that affect choice in dying. You can write letters to local papers and discuss the issues with your friends and family.

Your Generous Gifts

Compassion & Choices serves terminally ill adults and their families at the end of life, teaches people to have a compassionate view of the dying process, and through the legal and political systems, works to make law and medical practice respect the choices of individuals—all at no charge. We depend on the generosity of our loyal friends. Without you this would not be possible.

Every year, Compassion & Choices receives contributions and memberships from more than 50,000 supporters. These donors and members are part of our **Friendship Circle**. Cash gifts comprise the backbone of our finances. We depend on them to meet our daily obligations. Friends who make a contribution of \$1,000 or more in a year become members of our **President's Circle**.

We can arrange for a recurring monthly or quarterly gift at your request, and will charge a credit card on the timetable you specify. Those who make recurring gifts are members of our **Champions Circle**.

Special Campaigns

As we see opportunities and challenges, Compassion &

Choices periodically seeks to raise additional funds for special projects.

The reason? Special campaigns often have special needs. Our costs for the Supreme Court fight are estimated at \$215,000 and a full-scale legislative campaign can easily cost half a million. On these occasions we challenge our donors to make a larger gift, something beyond their regular gift.

Looking Ahead – Friends for the Long Haul

Donors who make planned gifts or include us in their estate plans become members of our **Legacy Circle**. They are most often gifts of cash, but sometimes involve non-cash assets such as real estate, business holdings, or other estate assets. Such gifts help us by supporting the mission you cherish and may help you through tax advantages.

Please contact our director of planned giving, Jane Sanders, at jsanders@compassionandchoices.org or 800.247.7421, for more information. We advise you to contact your personal financial advisor or attorney when considering such a gift.

You Make A Difference

We value and appreciate every single one of our members, volunteers and donors. The health and effectiveness of Compassion & Choices depends on all of us helping according to our own abilities and hearts.

To learn more about giving to Compassion & Choices or how you can assist our advocacy efforts, please call our toll-free number, 800.247.7421. You can also find information online at www.compassionandchoices.org.

With this magazine we are sending you a survey. We hope that you will take a few minutes to fill it out so that we may learn how to make our efforts serve your interests.

Compassion & Choices Washington D.C. Supreme Court Briefing

1

Rally at the Supreme Court

Join the Compassion & Choices rally on the front steps at 8 am



2

Gonzales v. Oregon hearing

Scheduled for October 5, the hearing starts at 10 am



3

Briefing on the hearing

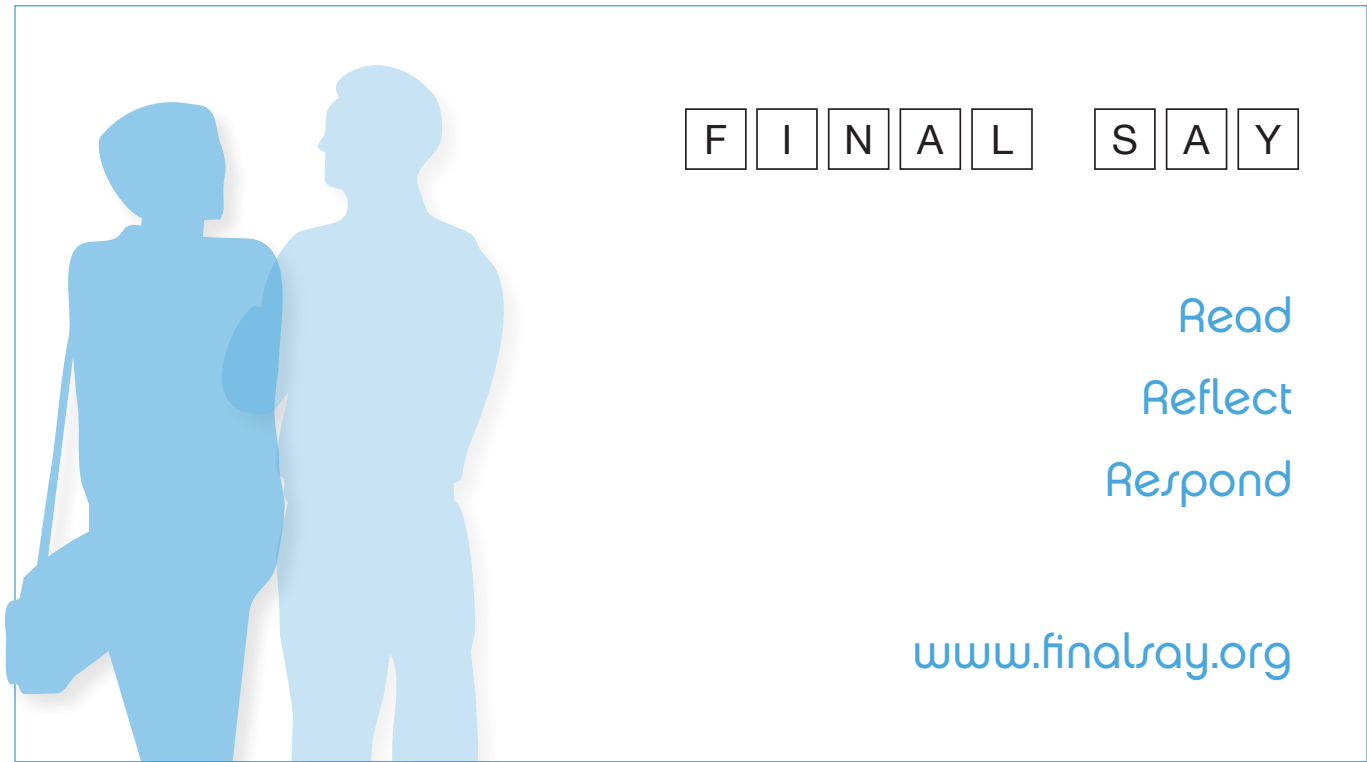
At 1 pm join us live in D.C. or call 1-800-270-1433 for the Compassion & Choices Supreme Court briefing



Listen in

Phone participants can listen to a discussion by Compassion & Choices staff and case attorneys about the hearing, as well as the impact of potential rulings

4



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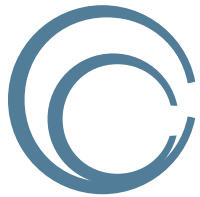
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Reflect

Respond

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