

Exit This Way

Denver lies dead center in the right-to-die debate.

By *Luke Turf*

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For several years, life was one long, lovely road trip for Sandy and Joann Bush, as the retired couple cruised from state to state in their RV. But while they were on the road in Iowa in the summer of 2004, Sandy's leg suddenly swelled to twice its normal size.

Sandy called his doctor back in Denver, who told him to get to the nearest emergency room -- immediately. But the ER doctors just told Sandy that the swelling had probably been caused by all his driving. They prescribed some painkillers and sent him back on the road.

The swelling didn't go down, though, and the pain continued. By that fall, Sandy was popping a dozen Vicodin a day.

Sandy started 2005 back in Denver, where he got a CAT scan. It showed a cancerous tumor in his abdomen that was squeezing a vein, cutting off circulation and causing a clot that had made his leg swell.

Sandy could be dead in six months. "Everything you've ever wanted to do, go do it now," his doctor said.

Traveling the country with the girl he'd loved since he was a boy was exactly what Sandy wanted to do. But the couple decided to sell their RV and remain in Denver, close to their sons and grandchildren. They moved into a luxury apartment with a view of the mountains and downtown that Sandy could see from his deathbed.

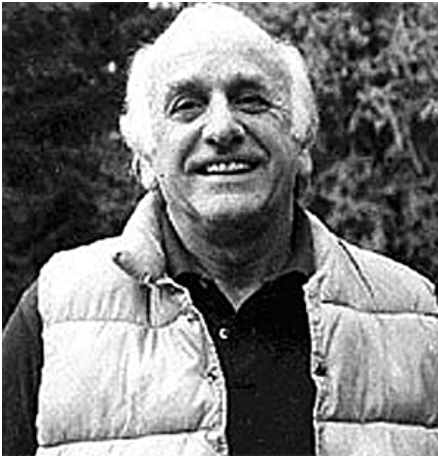
Dying didn't scare Sandy, but the idea of a torturous death did. He didn't want tubes crammed down his throat. He didn't want machines keeping him alive once the cancer took over. He wanted some choice in how his life would end.

He took the first step when he chose to stay in Denver. Although he didn't know it at the time, this city is dead center at the heart of the right-to-die debate.

The right-to-die movement in the United States was pioneered by an Englishman working out of a Santa Monica garage.



Having the pills that could end his life has helped Sandy Bush enjoy the time he has left.



The Hemlock Society USA was founded 26 years ago by Derek Humphry.

In the five years between 1975 and 1980, Derek Humphry found out that his wife had cancer, obtained drugs so that she could end her life, handed them to her when she asked, made newspaper headlines in London for doing so, and managed to avoid prosecution. He wrote *Jean's Way*, a book that chronicled that period, then moved to this country to work for the *Los Angeles Times*.

Jean's Way inspired a lot of discussion in both England and the United States, with Humphry making numerous appearances on television and in newspaper and magazine articles. The response was so strong that he soon founded a California-based nonprofit that he named after the poisonous weed Socrates had used to end his life. The Hemlock Society USA was dedicated to furthering the right-to-die movement that had already sprung up in other countries, and the people who wrote Humphry about his book formed the basis of Hemlock's initial membership drive.

"Hemlock had two strings to its bow," Humphry says. "One, to help people who were suffering and wanted to die because of their terminal illness in whatever way we could without getting into trouble. We weren't Kevorkians; he didn't come around for several years. And two, change the law to permit physician-assisted suicide for the terminally ill -- not for any old, depressed person."

In 1981, Humphry published another book, *Let Me Die Before I Wake*, which featured twelve true stories detailing how people had taken their own lives.

Soon Humphry was working with the Hemlock Society full-time, holding meetings and conferences. As the debate over the right-to-die movement grew more heated, the organization kept growing. In 1988, Humphry was visited by Jack Kevorkian, a Michigan doctor who wanted to set up a suicide clinic. If Humphry would send him clients, Kevorkian promised lots of publicity.

Humphry refused the deal. He told Kevorkian that the Hemlock Society believed you should be able to end your life quietly, in your own home. Kevorkian didn't like that, Humphry remembers, and he stormed out of Hemlock's office.

If Hemlock wanted to change the law, the organization couldn't break it, Humphry explains. But the law wasn't much of an issue for Kevorkian, who got the nickname "Dr. Death" after a woman suffering from Alzheimer's pushed a button on the "suicide machine" in his Volkswagen in 1990. After that, he facilitated more than 130 suicides.

Although Kevorkian's activities earned him numerous court appearances -- he showed up to one dressed like a Founding Father, in tights and a wig -- Dr. Death escaped conviction until 1999, when a Michigan court found him guilty of second-degree murder and the delivery of a controlled substance, acts documented in a videotape Kevorkian had made of the death and given to *60 Minutes*. (Kevorkian is still doing time in a Michigan prison, and will be there for at least another year.)

Soon after his first and only encounter with Kevorkian, Humphry moved the Hemlock Society to Eugene, Oregon, where the cost of living was lower. From this base, the organization continued to advise people on the best ways to end their lives. And in 1991, Humphry published *Final Exit*, essentially a manual on how to kill yourself.

The book advised against such risky suicide methods as running a car engine in a closed garage and breathing in the carbon monoxide, and instead suggested taking sleeping pills and then putting a plastic bag over your head, with a rubber band around your neck. You were to hold the rubber band out so that air could get into the bag until the sleeping medication took effect, at which point your arms would drop, the rubber band would snap and the air would stop flowing. Death would come quickly and painlessly.

By the book's third printing, Humphry had added a method that involved using helium with a plastic bag.

The Hemlock Society had financed *Final Exit's* initial publication. When the book became a bestseller, it provided a strong financial backing for the group.

Humphry left full-time involvement with Hemlock in 1992 to return to writing. By then, the right-to-die organization had about 46,000 members and eighty chapters. "It was getting so big," Humphry remembers. "I didn't want to be a CEO of a multi-million organization; it wasn't my thing. I'm a writer and a journalist." Still, Humphry has remained involved in the right-to-die movement in a variety of capacities since stepping down from Hemlock.

After Humphry's departure, some Hemlock chapters started talking about going their own way.

Following a discouraging attempt to change state law, in 1993 one Washington group broke off and formed an organization that would come to be known as Compassion in Dying. "We decided we would work with people and advise them and tell them what medications to ask their doctor for and stay with them through the whole process," says Susan Dunshee, a founding member of the group. "It was kind of a mutual agreement that we should separate."

Although Compassion in Dying wasn't able to get the medication, it worked with many people who were living with AIDS around Seattle, where there was a large population of sympathetic doctors. "We never actually did anything that broke a law," Dunshee adds. "The patient got ahold of the medications by him- or herself, and the patient took the medications by him- or herself."

The right-to-die movement had more luck in Oregon, where in 1994 voters approved the Hemlock-supported Death With Dignity Act. The law essentially allows terminally ill patients to obtain a prescription from a doctor for pills with which they can end their own life -- if they can prove they are mentally competent and physically able to take the drugs on their own. The law also protects the prescribing doctors from prosecution.

The law survived numerous court battles, as well as a ballot measure that called for its repeal. In 1998, the first Oregonian legally ended her life with a doctor's prescription. Another 245 people followed over the next seven years. _____

As the right-to-die movement took new forms, the Hemlock Society was shrinking, with members opting out to join smaller state groups, some of them spinoffs. The bank account was shrinking, too. John Pridonoff, the man who'd taken over for Humphry, was accused of overspending. (He is now deceased.)

In 1996, looking for a more central location, the Hemlock Society -- with a national membership down to just 16,000 -- moved to Denver. Faye Girsh became the CEO that year.

"All we could offer them at that time was to read *Final Exit* and call us in the morning," she remembers. She decided it was time to kick activity up a notch.

In 1998, under Girsh, the Hemlock Society organized a national group of volunteers who were trained to consult, advise and support people who were considering terminating their own existence. This is what Compassion in Dying was already doing in Washington -- but unlike Compassion in Dying, Hemlock also offered its services to people suffering from diseases that weren't necessarily terminal, such as multiple sclerosis and Alzheimer's. During Girsh's tenure, about half of the people who killed themselves with Hemlock's support used medication to do so, and the other half used a method outlined in Humphry's book.

The Hemlock Society also decided to get more active in pushing legislation. At a 2002 meeting, boardmembers discussed whether the group's name was too in-your-face, too radical for working with lawmakers. After Girsh voiced her opposition to a name change, she was demoted to senior vice president. The next year, the Hemlock Society became End-of-Life Choices. A year later, Girsh was fired.

"I was too radical, or maybe I wasn't a good administrator, I don't know," she says. "I increased the membership, and I more than quadrupled the annual income."

Girsh has stayed active in the right-to-die movement, often working with other Hemlock refugees.

"All movements eventually become fragmented," says Dennis Kuby, whose Berkeley chapter left the organization. "The natives are restless in the movement, and it's far from a unified thrust. We feel that the organization in Denver is just too centralized and building its own bureaucracy."

Ted Goodwin was a chapter leader of the Hemlock Society near his home in Atlanta. After the group changed its name to End-of-Life Choices, he joined the board.

Advising people on how they could best end their lives was what attracted him most to the right-to-die movement. "This is important stuff in our movement," he says. "This is where the rubber meets the road in helping others. Legislation will come very slowly."

Goodwin was on the board in 2005 when End-of-Life Choices decided to merge with Compassion in Dying, the early Hemlock spinoff, and officially became Compassion & Choices. The national headquarters is listed as Denver, although there's still an office in Oregon.

After the restructured group decreed that only the terminally ill could receive death instructions, Goodwin broke off to form his own organization. Three more boardmembers followed in the next two weeks, he says. About five of the organization's approximately fifty chapters also broke away.

"I felt that more people than just terminally ill people should be served in this way," Goodwin says. "They were only serving people who had been diagnosed with a terminal disease, given six months to live or less, and they were becoming more and more stringent about the cases that they'd take in."

Goodwin turned to both Girsh and Humphry for support. He got permission to name his group the Final Exit Network, after Humphry's groundbreaking book.

Goodwin has a business that does medical screenings for people affected by occupational hazards. Although he's not a doctor, he's had some training from doctors -- as have all of the volunteers in his group. The Final Exit Network now has fifty trained volunteers across the country, with a hundred people waiting to consult with them on how to end a life. The group's volunteers make sure that people have explored medical and psychological options, and then give information on how to end life peacefully, quickly and comfortably. They won't assist, but they'll do anything but. "Since our group was founded, we've supported several dozen people, and two-thirds of those have been non-terminally ill," Goodwin notes.

Over the past fourteen months, he's sat bedside with fourteen different people as they ended their lives -- the youngest was a 39-year-old with MS -- and he has a few more scheduled this summer. "You have no idea how lucky you are until you see some of the people we deal with," Goodwin says. "It's an eye-opener. This is their decision, and I will honor their decision."

Although Goodwin himself hasn't sat with anyone ending his life in Colorado, at least three people in this state have worked with the Final Exit Network.

Sandy and Joann first spotted each other at Jewish youth camps in the 1950s. Sandy's father raised chickens, and Joann's mother and grandmother would buy their chicken and eggs from the Bush family's Florida farm.

On their first date, Sandy was fifty cents short and had to borrow a couple of quarters from Joann. Later, he tried to pay her back, but she wouldn't take the money. So Sandy ripped a dollar bill in half and gave one piece to her.

"As long as we're together," he told her, "we'll always have a dollar between us."



Sandy Bush with his wife, Joann.

They were both attending college when they got married on March 16, 1963. Sandy went on to get a degree in electrical engineering, and the couple had two sons about two years apart.

In 1967, Sandy's mother was diagnosed with cancer. She was in her early forties, and the disease had already spread from her breast to her lungs, even though she was never a smoker. She was declared cured once, only to be told six months later that she had just a few days to live.

Her options: live a bit longer in greater pain, or increase the morphine and be less cognizant, but more comfortable. She opted to increase the morphine.

After she made that decision, Sandy and his father went out to lunch. By the time they returned, his mother was dead. To this day, Sandy isn't sure whether his mother wanted the additional morphine to ease her pain or help end her life.

Sandy and Joann and the boys lived in Dallas for four years, and then the family moved to Oklahoma, where Sandy worked for the state regent's office. While in Oklahoma, they first set their eyes on Colorado.

Sandy changed careers and started working as a broker, selling nursing homes. The couple had an airplane that they'd fly into Gunnison -- first for skiing, then for Colorado summers, too. By 1990, they were living in Colorado full-time. Sandy started cutting back on work, and the couple bought an RV. By 2003, he'd retired completely, and the couple spent all their time on the road. Eventually, they made it to every state in the continental U.S.

Then came the news that Sandy was dying. They packed up the RV for one last trip and headed to Texas for a second opinion. But the doctors at the M.D. Anderson Cancer Center at the University of Texas only confirmed the diagnosis that Sandy had already received.

Sandy started taking morphine, and Joann drove the RV to Florida so that he could say some goodbyes to his family. The realization that death was inevitable made it difficult for Sandy to leave his bed, where he was already spending most of his time because of the pain.

In March 2005, they returned to Denver, where Sandy planned to die.

But he wanted to die his own way, and he went online to find Compassion & Choices. From the first time he spoke with someone on the phone, he began asking about the pills he could take to end his own life.

Helen Beum is the clinical director of Compassion & Choices. When Sandy called, the newly merged group was just getting organized, and even though he was only a few miles from the office, his initial conversations with volunteer counselors were over the phone. At their suggestion, he began looking into hospice care. But once they were convinced he was terminally ill, the nurses also gave him tips about how he could end his own life.

"Hospice doesn't talk about hastening death, and families don't like to," Beum says. "Usually they call us because they want to know about options if the pain gets too bad or the suffering too unbearable. They call us about options to hasten their death. What we do is provide information, and that's not illegal in any state."

They don't provide that information on the Compassion & Choices website, though. Rather, it's given in the context of a volunteer/client relationship. Today, Compassion & Choices has 185 trained volunteers in 38 states.

Although they prefer to visit potential clients face to face, usually at their homes, some consultations are still done over the phone. Of primary importance, Beum says, is ascertaining that people aren't considering hastening death simply because of depression or untreated pain. Volunteers may request mental evaluations, if they deem them necessary. And before they even talk with potential clients, volunteers go through three-day training seminars during which they learn how to look for depression, as well as the various methods for hastening death.

Stopping medical treatment, therapy or medication are all options that clients can consider -- as is deciding to stop eating and drinking. All constitute essentially pulling the plug, a right that every U.S. citizen has.

Obtaining medications that could be used to end life is a final option.

"We don't provide the medications, and we don't administer them," Beum says. "The clients need to be able to obtain the medications and administer them themselves. We've never had an investigation. These are mentally capable, terminally ill people, and we believe what we do is legal. People don't want to die; they just don't want to suffer."

After talking several times with Compassion & Choices volunteer counselors, Sandy had an out-of-state friend with a medical background purchase the recommended pills. He won't say which state and won't say which pills, nor will he discuss where he keeps the pills. He's concerned that opposition to the right-to-die movement is mounting, and that someone might try to take them away.

And should he ever decide to pop those pills, Sandy adds, his wife and sons all have veto power.

Thus far, Sandy hasn't come close to considering it. He has a hard time even defining the line he'd have to cross before deciding to die at his own command. "If I'm bedridden, if I'm in major pain, that would be a primary area," he says. "If I can't do any of the normal things, I can't go to the bathroom, I can't go out to enjoy a show, if I am that way, then that's when I would start considering or thinking where I want to draw the line."

Right now, with whatever time he has left, Sandy wants to be with his family. After he and Joann sold their big RV, they bought a smaller version that will be easier for Joann to handle once Sandy's gone. And in the meantime, he's taking full advantage of it.

Thanks to morphine and that hidden stash of death pills -- which cost less than \$50 -- Sandy can think more of living than dying.

"It has cleared me up to a point that I no longer think about death at all," he says. "I'm not afraid about it, I'm not worried about it, because I'm thinking about life. Right now we're talking about taking a cruise. We want to keep doing things that I never would be willing to do before, because I was obsessed with the fear of what would happen to me if I got into intense pain, and then all of the things that happened to people weeks and months before death in the type of disease that I have. I couldn't accept it.

"Now I can accept it, because I know that I will not have to suffer through that if I don't want to," he continues. "I'm convinced that the morphine and the positive attitude that came from this knowledge and this ability of having control at the end have given me an awful lot of life. I don't know how much more, but it's just absolutely relieved me of the fear and concern of 'what about if.'"

Though it's not easy for Joann to think about life without Sandy, she accepts what he is planning. She knows that Sandy always has to be in control, and if he wants to control his life right up to the end, she'll stand by him.

"He'd do the same for me," Joann says. "When he gets to the point that his life is not the life that he and I both know that he likes to live, being in control and not bedridden and not in pain, I think we'll just know when the time is right. I have no problem with it at all. I mean, I'm going to be upset, miserable, unhappy, I know I will be afterward. I'll be alone for the first time. I've spent my whole life with him."

Sandy Bush plans to make his mark before he goes.

Last fall, he even lobbied Governor Bill Owens's staff on behalf of a bill that would protect physicians who prescribe pain medication for the terminally ill from manslaughter charges, telling staffers that morphine made him comfortable and improved his quality of life.

Dick VandeBergh, president of the Denver chapter of Compassion & Choices, organized a group of physicians and citizens to get the legislation introduced. The move was a preemptive one, he says, since no manslaughter case has ever been filed against a Colorado doctor in such a situation. But it was also designed to remove pressure from physicians, who might err on the side of prescribing too little medication without it, VandeBergh adds. And it might even deter civil lawsuits.

"As we educated the legislators, there was a growing consensus that this was the right thing to do, and it ended up not being controversial, as we had anticipated it would be at the beginning," says state senator Suzanne Williams, who sponsored the measure. "It did not give permission for assisted suicide, and once people understood that it did not give permission for assisted suicide and that it's a right to relieve pain, they approved it."

The bill, which passed both houses and Governor Owens's desk, goes into effect July 1.

By enacting this type of palliative-care legislation, Williams suggests that there will be no need to pursue assisted-suicide legislation, such as the law in force in Oregon.



Marsha Temple is the executive director of Compassion & Choices, the group that grew out of the Hemlock Society USA.

But this state's right-to-die movement's leaders disagree. Compassion & Choices isn't lobbying Colorado legislators for a prescription death law now simply because the political climate isn't right, its leaders say. But the time will come.

"The United States doesn't want to talk about death," says Marsha Temple, executive director of Compassion & Choices. And she should know, because she's trying to get the national dialogue going from her Denver office.

The organization now has about 50,000 members and donors throughout the country. There are efforts under way for Oregon-style right-to-die laws in California and Vermont, and there's talk of it again in Washington.

"It is your right to choose at the end of your life," Temple says, "and the government or the religious right shouldn't interfere. We are a country of incredible freedoms; this should be one of the biggest

freedoms we're allowed, and that's not the case. People shouldn't have the government or the churches at their bedside unless they want it."

On that, the Final Exit Network and Compassion & Choices agree. But the two organizations still differ on whether anyone who is ill should have the choice to end his life. If someone who is not terminal contacts Compassion & Choices, for example, he will be referred to an organization that works with the specific disease he's suffering from.

The Final Exit Network remains willing to discuss the possibilities for making that final exit.

"We just don't know their protocols or criteria," says Temple. "When you refer people, that's a huge responsibility. If something happens to those people, you could be liable. I don't think it hurts our mission at all. Other organizations believe in the right to die, and that helps. But we have different programs and a different way of addressing the issue."

Compassion & Choices no longer recommends Humphry's book, which it considers outdated. Instead, it provide its own set of instructions.

But *Final Exit* still sells well. Almost fifteen years after its first publication, it continues to move at least 10,000 copies a year.

"The whole right-to-die movement, we're chugging along, but the political climate is not in our favor," Humphry says. "Currently, I would say that the movement in America is as strong as ever in terms of people and money and mailing lists and support, but it's biding its time until there's a swing of the pendulum toward more liberal attitudes toward the right to die."

In addition to the new RV, Sandy and Joann have bought a small dog so that Joann will have a companion once Sandy dies. However and whenever he dies.

They named the dog Sandy.

For decades, they each carried half of a ripped dollar in their wallets. Now those halves are in the same frame.

Together.