“I think I should have something to say about my ending. It’s my decision to make, and it’s a great comfort to me, and other patients like me, to know that we can ask our doctor to honor our choice.”

Steve Johnson,
Brain Cancer Patient
Helena, Montana
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Web: CompassionAndChoices.org
Facebook: http://bit.ly/CandCFacebook
Twitter: twitter.com/CompAndChoices
Dear Members, Supporters & Friends,

This year Compassion & Choices marks 30 years of promoting end-of-life autonomy. Looking back to the time of that beginning, 1980 seems like a very different time.


Today, most doctors accept that patients are their partners in determining appropriate treatment. Compassion & Choices has been a powerful voice in establishing that principle. We have grown to become the largest, oldest and most influential organization working to improve care and expand choice at the end of life. And we have never lost our patient-centered focus, always striving to achieve what people really want from health care.

We are proud of what we and our dedicated members have accomplished together:

- Passed laws that expand and protect compassionate choices for the dying;
- Established legal aid in dying in Oregon, Washington and Montana;
- Defended end-of-life choices from legal challenge, government intrusion and legislative attack;
- Advocated in legislatures and courtrooms for improved pain care and hospice services;
- Increased public awareness of the threats to individual decision-making from extreme “conscience” protections for providers and enforcement of religious moral teaching, especially the Ethical and Religious Directives for Catholic Health Care;
- Directly served tens of thousands of terminally ill individuals and their families through our national office and local chapters across the country.

Through 30 years of leadership, Compassion & Choices has played an important role in every significant victory to secure and protect choice at the end of life. In this anniversary issue, we take a look at thirty years of patient struggle and deliver insights into today’s battles. We highlight some faces that helped forge our movement over 30 years and continue to shape its future.

You have much to be proud of. The ideals of compassion, dignity and choice you champion have entered the mainstream and the principle of end-of-life autonomy is well established. Now on the defensive, opponents of these principles and ideals have hardened their positions. In the last year we have seen harsh attacks characterize patient-doctor consultation as “death panels” and a Catholic hierarchy impose tighter doctrinal restraints on health care providers.

The landscape today is different from 1980, but our challenges remain. Anti-choice forces in government, medicine and religion are working aggressively to undermine patient autonomy. They would have the health care system ignore our most private wishes and liberties. With your help, we are fighting to ensure that doctors know, respect and protect the will of individual patients in their most vulnerable time.

Thank you for your continued support.

Barbara Coombs Lee,     Debbi Gibbs,
President       Chair
Aid In Dying in Montana

On December 31, 2009, the Montana Supreme Court ruled that terminally ill Montanans like Steve Johnson have the right to choose aid in dying under state law.

Robert Baxter, a U.S. Marine veteran, outdoorsman and career long-haul truck driver suffered from lymphocytic leukemia. He joined four Montana doctors and Compassion & Choices in a lawsuit asserting that Montana’s constitutional guarantees of privacy and dignity protect the right to choose aid in dying. On December 5, 2008, Mr. Baxter died of his illness just hours after District Court Dorothy McCarter ruled “The Montana constitutional rights of individual privacy and human dignity, taken together, encompass the right of a competent terminally ill patient to die with dignity.”

“He feared when he filed this lawsuit that he would not live long enough to benefit from it,” said Baxter’s daughter, Roberta King.

The following September the Montana Supreme Court heard oral arguments in the appeal of Baxter v. Montana. Compassion & Choices’ Legal Director Kathryn Tucker led this groundbreaking case, with Montana co-counsel, Mark Connell.

On the last day of 2009, the Court ruled that

terminally ill Montanans have the right to choose aid in dying under state law. The 5 - 2 decision did not reach the constitutional question. Instead, the justices grounded their opinion in existing Montana law guaranteeing patient autonomy. “The Rights of the Terminally Ill Act very clearly provides that terminally ill patients are entitled to autonomous, end-of-life decisions, even if enforcement of those decisions involves direct acts by a physician,” the justices wrote.

“Furthermore, there is no indication in the Rights of the Terminally Ill Act that an additional means of giving effect to a patient’s decision—in which the patient, without any direct assistance, chooses the time of his own death—is against public policy.”

There is no further appeal from this decision, as the Montana Supreme Court is the highest court available to decide state issues.

Dr. Stephen Speckart, a Missoula cancer specialist and a plaintiff in the lawsuit, welcomed the court’s decision. “This decision affirms that a terminal patient’s fundamental right to self-determination will guide end-of-life health decisions,” Speckart said. “I regularly treat patients dying from cancer, and many of these deaths are slow and painful. Terminal patients will no longer be forced to choose between unrelenting pain and an alert mental state as they approach the end of their lives from terminal diseases. The comfort this brings to their last days

“I approach the end of my life with a clear mind. I would like to work with my doctor to minimize the pain and maximize the peacefulness in my dying,” says Steve Johnson.

“I would like my physician to be able to respect and honor my choice to die with dignity.”

Johnson, of Helena, Montana, has brain cancer.
can have an immeasurable benefit.”

The court’s decision brought a successful end to the legal battle in Montana and set the stage for the next phase in that state and similar cases in other states.

**Montana Case a Precedent?**

Compassion & Choices’ Legal Director Kathryn Tucker predicts the decision in Baxter could have persuasive influence in other cases, particularly *Blick v. Connecticut*, the case she is currently litigating (see related story on page 8).

“In Connecticut, the plaintiffs can point out that the Rights of the Terminally Ill Act (RTIA) is similar to the Connecticut Removal of Life-Support Systems Statute (RLSS),” Tucker said. “Both statutes empower patients with the right to refuse or direct the withdrawal of life-prolonging medical treatments. Both provide advance directive forms, provide for the appointment of a health care representative and immunize medical professionals from criminal and civil liability for withholding or withdrawing life-sustaining treatment.”

“The plaintiffs in Blick can argue that the RLSS reflects public policy vesting terminally ill patients with autonomy over end-of-life decisions, even where exercise of that autonomy involves a direct act of a physician”, explains Tucker. The RLSS, she says, is clearer vis-à-vis the rights of terminally ill patients than policy expressed in the vague, antiquated criminal statute, which does not speak specifically to terminally ill patients and their ability to make autonomous decisions governing end-of-life care.”

**A Legacy**

As with so much of the progress over the last thirty years, the Baxter decision was made possible because of dedicated people who believed in end-of-life choice. Their sacrifice made this achievement possible, and opened the doors to future successes. “My father died without the peace and dignity he so dearly wanted for himself and others,” says Bob Baxter’s daughter, Roberta King. “I’m sure he would be deeply gratified that other terminally ill Montanans will have the choice and comfort that aid in dying affords them.”

**Montana Advocacy Campaign**

How would we translate the court’s decision into a practical medical alternative? The morning after the Montana Supreme Court’s decision, Compassion & Choices’ advocacy, consultation and communications teams began working to make sure Montanans know this choice is available, and physicians know they can legally and safely provide aid in dying.

Since research showed that awareness of the court’s decision was low, Compassion & Choices began an education campaign in the state. Montanans watching the Winter Olympics in February saw three television ads explaining the court’s decision and what it meant for them.

Dr. Stephen Speckart appears in one commercial saying, “The Baxter decision is enormous because a physician is free to assist the patient in dying should the patient request that.” Dr. George Risi of Missoula says, “Peace of mind is there because you are the one who has the control over the final hours.”

Compassion & Choices is encouraging Montanans to talk with their doctors and their families about their end-of-life choices. We are working to protect aid in dying from politicians who would try to overturn the court ruling. Compassion & Choices will work with its partners in Montana to ensure fair and equal access to that choice across the state.

Learn more about our work in Montana and watch the Montana videos of Steve Johnson, Dr. Stephen Speckart and Dr. George Risi at CompassionAndChoices.org/montana.

Send a message of support to Steve Johnson at CompassionAndChoices.org/Steve.

Tell a friend or family member about our work in Montana: we’ve made it easy at CompassionAndChoices.org/JoinSteve.
Washington’s Death With Dignity Act A Year Later

Washington State marked the one-year anniversary of its Death with Dignity law on March 1, 2010. The Washington State Department of Health reported that in 2009, 63 terminal patients received prescriptions, although just 36 of them took the medication.

Advocates continue to work on the ground to facilitate the implementation of the law, educating physicians, hospice professionals and the public. Compassion & Choices of Washington, which provides assistance to those who wish to access the law’s options, notes as many as half of the qualified patients who inquire about the law approach their doctors too late. We encourage people to talk with their doctors as soon as they know they might derive peace of mind from having a way to end unbearable suffering during a prolonged dying process.

These are the voices of doctors, patients and family members whose lives were touched in the last year by the law.

“It is never too early to begin a discussion with your doctor about the options you would want to consider if you were diagnosed with a terminal illness.

“More and more physicians are realizing that “death with dignity” is a humane part of medical practice. By helping patients gain release from new forms of extended dying, physicians are staying with their patients in giving good end-of-life care.

“Physicians, a cautious group, don’t want to take chances. They are extremely careful in assessing and qualifying these patients because anything outside the letter of the law remains a felony. Physicians have used psychological screening when they suspect patients may not be competent to make important medical decisions. If the screening confirms a lack of decision-making capacity, the doctors do not qualify the patients.

“I have worked as a volunteer advisor with some of the terminal patients who have died under the DWD law. The patient’s family and loved ones express overwhelming gratitude for the help their loved one is receiving.”

Dr. Tom Preston, Medical Director for Compassion & Choices -Washington.
“I have witnessed many deaths working in hospice: some peaceful, some painful. Now, with my own terminal illness, I’m very grateful for our Death With Dignity Act. I don’t want to die; I’m trying very hard to live.

“I’ve undergone chemotherapy several times. I’m going through experimental treatment now to gain some time. The spiritual part of me is hopeful for the very best in my final days. The nurse part wants to be prepared for the worst. I’m very grateful that my own doctor will respect my end-of-life decisions. I intend to acquire a prescription to provide me with peace of mind and some measure of control for a peaceful death. I don’t know if I’ll even take the prescription. But having it and the choice to use it to aid in achieving a peaceful death is of great benefit to me.”

Kathy Sparks, a former hospice nurse with stage 4 melanoma, Issaquah, WA

“Since the Death With Dignity Act took effect last year, three of my patients have asked me to help them use the Death With Dignity Act.

“All three were in complete terminal stages of their cancers; they were dying. They had severe symptoms, including being weak, thin, almost starved to death. Each of these individuals benefited from the Death With Dignity Act in different ways.

“One is still alive today. One died in her sleep, but was greatly reassured by having her prescribed medications in case she needed them for a peaceful death.

“The third was himself a physician, with metastatic cancer in his bones. He took the medication and died peacefully according to his own values and choices.

“These three patients show how the Death With Dignity Act serves patients. First and foremost, it provides peace of mind to patients concerned about unbearable pain or prolonged suffering at the end of life. It is not necessary to take the medication to benefit from the peace of mind the law provides.

“All three of these patients received that benefit – one still is doing so.”

Robert Thompson, M.D., Seattle Doctor of Internal Medicine

“On May 21, 2009, my mother died. In the morning, I journeyed around the peninsula to share in the gift of her last day. That evening, we told each other goodbye and shared one last hug.

“She passed away, simply, quietly and at peace. Her passing was played out in the same way that the rest of her life had been: on her terms, in her way and through her own choices. The final days we spent together are some of the most important of my life and I will always be grateful that we could share her last hours.

“My mother was a fighter. From supporting migrant workers, to being a single mother, to returning to college, and all the different ways she fought for those causes that mattered most to her. She always believed that one made choices with both eyes open, knowing full well the consequences and having done your homework beforehand. She didn’t make decisions without sincere, purposeful deliberation. She was an individual to the end. She was also the first person in Washington State to take advantage of the Death with Dignity Act.

“She chose to die in her own time, in her own home, and in the manner of her choosing. We rekindled our intimacy and connection in those last days, and I gave her peace and security by ensuring that her dog Seri would be loved and treasured. In the end I am left with some very sweet memories: a final hug, a little Chihuahua, and knowing that my mother died peacefully.”

Lisa Osborne, daughter of Linda Fleming

Learn more about Washington’s Death With Dignity Act on our web site at CompassionAndChoices.org.
Does a state’s criminal statute governing “assisting a suicide” reach the conduct of a physician in providing aid in dying to a terminally ill, mentally competent adult?

This is the question posed in Blick et al v. Connecticut.

**Blick et al v. Connecticut**

Courts have addressed the constitutional question of whether aid in dying is protected as a matter of privacy, liberty or dignity. However, none has ever directly considered whether a mentally competent, terminally ill patient’s desire to bring about a peaceful death constitutes “suicide” under the law, such that a physician’s act of prescribing medication which the patient could ingest to bring about such a death could be subject to prosecution for assisting a “suicide”. A case recently filed in Connecticut does just this.

On October 7, 2009, two prominent Connecticut physicians, Dr. Gary Blick of Norwalk, and Dr. Ron Levine of Cos Cob, asked the court to clarify that physicians who provide a prescription for medication to a mentally competent, terminally ill patient, which the patient could consume to bring about a peaceful death, would not be subject to criminal prosecution under the Connecticut law, because the dying patient is not “committing suicide”. The physician plaintiffs are represented by Compassion & Choices’ Legal Director Kathryn Tucker, Connecticut appellate specialist Dan Krisch and noted Connecticut civil-rights attorney Jamie L. Mills.

Dr. Blick is the Medical and Research Director of CIRCLE Medical. “I have seen many patients in agony while dying from their terminal illnesses, and heard them cry for help in their dying,” Dr. Blick said. “They’ve begged me to help them ease their suffering, and aid in their dying. But I have refused these patients’ requests, as it is unclear whether providing such treatment could subject me to criminal prosecution for manslaughter.”

The physicians’ lawsuit, Blick et al v. Connecticut, asserts that the choice of a dying patient for a peaceful death is no kind of “suicide,” and the physician does not assist such a patient in “committing suicide.”

“No court has been asked the specific question of whether a statute of this sort reaches the practice known as aid in dying,” said Tucker, a Connecticut native.

Hunt Williams supports Compassion & Choices’ effort to clarify the legality of physician aid in dying. Otherwise terminal patients, friends and families could find themselves in the dilemma that he did. In 2004, Hunt’s friend John Welles was dying of cancer and ready to end his suffering. Struggling to make it outside with his walker, he asked his friend to carry his loaded .38. Hunt did what his friend asked, walked down the road and called out “God bless,” before he heard the blast that ended John’s life. A year later, Hunt was convicted of “assisting a suicide.”

“It’s time for the courts to make it clear that John Welles deserved better, that I deserved better, and that terminal patients and their families in our great state deserve better,” Hunt told a news conference in October, 2009.

The executive director of the Connecticut Catholic Conference immediately announced the church’s opposition. “This lawsuit and any legislative
efforts that would be forthcoming as a result of the lawsuit is something we would oppose.” Attorneys for the State of Connecticut moved to dismiss the case on the grounds that the doctors have no pending request for aid in dying.

On March 8th in Hartford, Judge Julia Aurigemma heard arguments on the state’s motion to dismiss and the motion to intervene from the Catholic Conference. A ruling on these matters is expected within 120 days.

Sheldon Smith, an 86-year old, terminally ill Bethany man with fourth-stage abdominal cancer, was at the courthouse March 8th. “I’ve had three years now to consider the effects of my cancer, and to prepare for the end of my life due to this terminal disease,” Sheldon said. “I know the type of pain that abdominal cancer can cause. I want to leave this world with the same dignity with which I’ve lived my life.”

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**LIVING TO THE END: MY THOUGHTS AND WISHES**

Compassion & Choices is excited to announce a new tool for individuals who wish to leave a written legacy for their loved ones.

Living to the End: My Thoughts and Wishes is a 5”x 7” journal with inspiring photos and quotations about living and dying. With 50 lined pages, this journal can be used to start a difficult conversation or simply share your thoughts with those closest to you.

In these pages you can capture your most personal feelings about living and dying, love or anything else that you wish to have remembered.

Retail price: $18.50. Members’ price: $15.00

Find this, other suggested books and DVDs by visiting our online bookstore at CompassionAndChoices.org/bookstore.

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To learn more about this level of membership, call us at 800.247.7421.

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**Did You Know?**

Your membership card from Compassion & Choices has space on the back for the name and phone number of your agent(s) for health care.

As a benefit of membership at the Benefactor level and above, Compassion & Choices can put your advance directive on a wallet-size CD or jump drive that you can carry with you.

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Ruth Proskauer Smith

Ruth Proskauer Smith’s Death Honors the Life She Led
By Barbara Coombs Lee

Ruth Proskauer Smith, a friend and an activist for individual autonomy, died late last year, closing her life in the manner she had wished for, planned for and devoted her life to securing as her right.

When I met Ruth in 1996, she was already an icon in the movement for freedom of choice at the end of life. She had a long list of accomplishments behind her. But she was not happy. At that time, only Oregon had succeeded in affirmatively legalizing aid in dying, and its Death With Dignity law languished in legal limbo. Ruth was determined to make a difference and joined the work of Compassion & Choices, serving as a dedicated ambassador of end-of-life choice.

Among the things I treasure from my 15-year friendship with Ruth is having had the opportunity to see her growing pleasure with advances we’ve achieved in end-of-life choice. Together Ruth and I witnessed the triumph of justice over repeated legal challenges to Oregon’s law, the passage and implementation of Death With Dignity in Washington, the passage in California of the Terminally Ill Patients’ Right to Know End-of-Life Options Act and a ruling by the Montana Supreme Court to recognize and affirm physician aid in dying.

Ruth was a generous, fierce and dedicated supporter of our movement, as she was for reproductive choice. Her passion for human liberty was not limited to one issue, but spanned from the cradle to the grave. Gloria Steinem summed that up beautifully in a letter she wrote when Compassion & Choices honored Ruth on her 100th birthday.

Ruth manifested deeply held personal beliefs throughout her life, and she wanted her death to be the same. She gave her family a detailed, written plan of her wishes should she become incapacitated, including guidance on whether and when to call an ambulance and the disposition of her body after death. She discussed her plan with her family and doctors, obtaining their assurance that her wishes were known, and that they would be honored. Her proactive approach gave her children the security of knowing, without question, what was right for Ruth when the time came.

On January 22, 2010, Ruth died peacefully, as and when she had hoped. Family members at her side remained in touch with a Compassion & Choices counselor throughout Ruth’s dying process. Ruth spent the last chapter of life in her home, in the company of her children, her grandchildren and her great-grandchildren.

Ruth’s careful plans and clear communication made it possible to experience a death that honored the life she led. Her courage, advocacy and unfailing support for human liberty will enable millions who follow her to achieve the life, and the death, they choose.

The New York Times’ obituary of Ruth is available online at tinyurl.com/RuthPSmith. On that web page, you can also listen to recordings of Ruth discussing Al Smith, Lillian Gish, the street traffic in New York when she was a girl and the secret of her longevity.

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When I was in South Africa, I watched the Queen of the Lovedu, a tribal group of about 300,000 that had settled in a remote rural area after a long migratory past.

She was one of a long line of wise leaders who had been chosen communally as a young woman, and then trained for many years by her predecessor until she, too, was ready to become a source of guidance and continuity.

When I came to the remote area and her village, I noticed that all the earthen, thatched-roof structures were as round and smooth as sculptures. So were the central large armchair languages.

I entered into a smaller round structure at a little distance from the rest, and was welcomed by a devoted ambassador.

I finally realized the obvious: those who take away the power to decide birth also take away the power to decide death. The first one is unique to women; the second is unique to people.

Among other rights of the past had been the right to decide when to die. For example, among some rural African women had understood how to control their own fertility with herbs and abortifacients—how to have children well spaced and no more than they wished—but this knowledge was called sinful by some Europeans and by the church.

In response to my questions, she said she had heard there was violence against women in other places, but she had understood to have children well spaced and no more than they wished—but this knowledge was called sinful by some Europeans and by the church.

In response to my questions, she said she had heard there was violence against women in other places, and that they would be honored. Her proactive approach gave her children the security of knowing, without question, what was right for Ruth when the time came.

At least it had been—until scandalized missionaries punished and put an end to the practice. Only a male god could decide life and death.

I finally realized the obvious: those who take away the power to decide birth also take away the right of us all. In our country, is it not odd that those who support capital punishment also tend to oppose abortion and birth control. The question is not life or death but who has power over life and death.

Ruth, you knew this long ago—and you set out to empower us all. Your work also restores balance between women and men, between people and nature.

— Gloria Steinem

I thank you for being the wise woman of Manhattan.
South Africa a few years ago, I went to see a wise woman known as the Queen of the Lovedu, a tribal group of about 300,000 that had settled in a remote area after a long migratory past.

She was one of the most respected tribal leaders in the country, partly because she, unlike many, had not been put in place by the apartheid government or even by heredity. She was one of a long line of wise leaders who had been chosen communally, and then trained for many years by her predecessor until she, too, became a source of guidance and continuity.

When I came to the remote area and her village, I noticed that all the earthen, thatched-roof structures were as round and smooth as sculptures. So were the central places where livestock were kept.

A smaller round structure at a little distance from the rest, and was calm woman who seemed to be in her late fifties. She was seated in a large armchair facing me and the two translators who brought us together across three languages.

She had two paramount duties: keeping the peace and making rain. She was about to begin instructing the young woman who would eventually succeed her—a long course of learning stories that contained their history and customs, ways of healing.

To my questions, she said she had heard there was violence against women, but she had not personally witnessed it here. Traditionally, women knew how to control their own fertility with herbs and abortifacients—how to have children well spaced and no more than they wished—but this knowledge was called sinful by some Europeans and by the church.

Rights of the past had been the right to decide when to die. For example, after her duty of transferring her knowledge to the next wise woman was complete, it was up to her to decide when she was ready to leave this life.

Had been—until scandalized missionaries punished and put an end to the right a male god could decide life and death.

I realized the obvious: those who take away the power to decide birth also take away the power to decide death. The first one is unique to women; the second is the right of us all. In our country, is it not odd that those who support capital punishment also tend to oppose abortion and birth control. The question is not life or death but who has power over life and death.

You knew this long ago—and you set out to empower us all. Your work also restores balance between women and men, between people and nature.

For being the wise woman of Manhattan.

Gloria Steinem
Opponents turned back ballot measure I-119, so Tucker pivoted, looking for a different path to help Compassion & Choices establish legal aid in dying. She served as lead counsel representing patients and physicians in two landmark federal cases asserting that mentally competent, terminally ill patients have a constitutional right to choose aid in dying. Both cases reached the United States Supreme Court and were considered together. At 35, Tucker argued the first case, Glucksberg v. Washington; Laurence Tribe of Harvard Law School argued Quill v. NY.

While the court did not affirm a constitutional right, the cases established a federal constitutional right to choose aid in dying. Both cases reached the United States Supreme Court and were considered together. At 35, Tucker argued the first case, Glucksberg v. Washington; Laurence Tribe of Harvard Law School argued Quill v. NY.

Whether we are helping a family seek recourse when end-of-life care is inadequate or fighting to establish the constitutional right to choose aid in dying, Compassion & Choices is leading the legal charge of the choice-in-dying movement.”

Kathryn Tucker, JD, Director of Legal Affairs, Compassion & Choices

Kathryn Tucker, JD

“When you are paddling white water rapids, it’s very fast and tumultuous,” says Compassion & Choices’ Director of Legal Affairs Kathryn L. Tucker. “You never know what will happen next.”

Tucker is a world class whitewater kayaker and was on the US National team throughout her time at college and Georgetown University Law School. “In whitewater kayaking, you’re paddling down a river and navigating through gates, like in a ski slalom. All kinds of crazy things come at you – rocks, canyon walls – at tremendous speed. And that is very much like the challenges of litigation.”

Not long after law school, Tucker began her work with Compassion & Choices doing pro bono work for their efforts to put the first Death with Dignity initiative in Washington, I-119, on the ballot in 1990. She helped draft the initiative and quickly realized she wanted to dedicate all of her time to the issue. She left her practice at the large Seattle-based law firm Perkins Coie and came to work for Compassion & Choices.

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Compassion & Choices in several states in the years since, helping shape the strategy for each. When voters passed Death with Dignity measures in Oregon and later in Washington, Tucker defended the newly-established rights against legal challenges. In Montana, whose state constitution guarantees both privacy and dignity, she successfully directed a legal strategy resulting in the state’s Supreme Court ruling that physician aid in dying was not in violation of Montana public policy.

A case currently underway in Connecticut targets that state’s law against “assisting someone to commit a suicide.” Blick v. Connecticut argues that the law does not cover the conduct of a physician who, in response to the request of a mentally competent, terminally ill patient, provides a prescription for medication the patient may ingest to achieve a peaceful death.

Tucker helps Compassion & Choices protect and improve patient care in other channels. She served as co-counsel in the first case in the nation to assert that failure to treat pain adequately constitutes elder abuse, resulting in a jury verdict award of $1.5M to the family of the patient against the involved physician. Tucker has been principal author of various state legislative measures, which serve as models for other states, to ensure physician education in pain management, and provision of information to terminally ill patients about end-of-life care options. She defends physicians facing adverse consequences for treating pain attentively and aggressively.

Yoga is a passion for Kathryn Tucker, along with downhill skiing. The slopes are close to the home in Ketchum, Idaho, that she shares with her husband and two teenagers.

In every legal case, Tucker adapts her strokes to respond to the unique opportunities and challenges of the particular environs. “There are a lot of variables and you are always adjusting and adapting to changing circumstances. When you are successful, when you are able to adapt and quickly find a way to go forward toward your goal, then you win.”
Reaching Across Generations: Member Betsy Van Dorn

“It’s fun to be with old people and around young people. Having both in your life gives you a very nice feeling for the big picture,” says Betsy Van Dorn. As she answers a call to talk about her years supporting Compassion & Choices, she’s watching over a sleeping nine-month-old boy while his mother hunts for sharks’ teeth on the beach. She makes the juggling act part of her life because it’s possible to “come to terms with your own demise if you experience the whole multi-generation thing happening around you.”

She thrives on that connection across generations. Betsy is a writer and the founding editor of the Family Education Network, an online consumer network of learning and information resources. She was Board President for Goddard House, the oldest non-profit eldercare system in New England. Today she sits on the board of a public high school and you can hear the excitement and admiration in her voice as she describes the disadvantaged kids who attend. “They are determined to change their lives.”

In 2006 while visiting one of her children in Toronto, she attended an end-of-life conference. She had read about Compassion & Choices and wanted to hear more about what was going on. After a speech by Compassion & Choices’ President, Barbara Coombs Lee, Betsy approached her and asked, “What’s your most pressing need?”

“Get the word out!” was Barbara’s response.

“My husband administers several charitable foundations,” Betsy says, explaining how they’ve contributed to Compassion & Choices’ efforts to spread the word via those foundation grants. Betsy’s interest in end-of-life choice grew out of her experience with her parents’ planned death. “Not everybody is going to do that,” Betsy says, “but everyone should have the option to stop eating and drinking, or refuse treatment.”

Betsy’s parents had made it clear for over a decade that they would choose aid in dying if their condition became intolerable. Those later years were mostly full and active, but by the end of 2001, her 86-year-old father and 89-year-old mother had lost the dignity and autonomy they wanted in life.

Over the Christmas holidays they let their children know they were ready to carry out their plan, using medication they had obtained from a sympathetic friend. After a New Year’s Day spent with their children and grandchildren, the couple wrote the following before ending their lives together:

“Do not dial 911 in the event we are discovered unconscious but still alive. Our decision was made over a considerable period of time and was not carried out in acute desperation. Nor is it the expression of a mental illness. We have consciously, rationally, deliberately, and of our own free will taken measures to end our lives today because of the physical limitations on our quality of life placed upon us by age, failing vision, osteoporosis, back pain and painful
orthopedic problems.

“We wish our friends and relatives to know we are leaving their company in a peaceful frame of mind.”

Betsy has encouraged her children not to be reticent when people ask about their grandparents’ death. “It’s up to their generation to further the conversation about end-of-life choice so that eventually we can all talk about death in the same way we discuss every other life stage, like birth, child-rearing, or teenage angst. Why can’t we have the same chatty conversation about what we think would be the best way to die?”

Betsy understands that her parents’ determination, planning and communication of their wishes is unusual. She thinks the end-of-life support that Compassion & Choices’ counselors and volunteers provide is our most important work. “Having the comfort of someone sitting nearby to speak up for you is invaluable. Not everyone has a sidekick who can protect them from people who won’t respect their wishes.”

Betsy brushes off the question of what her legacy will be. “I hope I will be remembered for warmth, humor and my interest in other people,” she says. “I have done nothing profound or earth-shaking. Just a normal broad, I guess. Oh, I’m in the middle of trying to write a collection of poetry for kids. Maybe I’ll write a silly book of poems and that will be my legacy.”

Writing poetry for kids, creating an online educational network, guiding a high school, leading a nonprofit eldercare provider and supporting the organization that for thirty years has helped people at the end of life, Betsy keeps reaching across generations. With each connection she gains a greater understanding of her place in the whole.
Ethical & Religious Directives

This year, when the U.S. Conference of Catholic Bishops revised its “Ethical and Religious Directives for Catholic Healthcare”, Compassion & Choices sounded a nationwide alarm about the problems these new rules may create for patients — of all religions — in Catholic health care facilities.

The revision defines artificial feeding tubes as “basic,” not “medical” care and makes them “obligatory” unless a patient is actively dying or has one of several rare complications. This means families may face pressure to consent to artificial feeding if a loved one can’t swallow because of advanced dementia or permanent unconsciousness. Institutions following the Directives will honor only those advance directives that conform to Catholic teaching, so it may not matter what your advance directive or health care proxy says.

The stories here represent the kind of situation that could put a patient or family member in conflict with the new requirements placed on Catholic hospitals and nursing homes.

The recent change to the ERD sets out some narrow exceptions when artificial nutrition and hydration (ANH) is not obligatory: if a patient is actively dying; if the tube causes serious side effects like infection; if the patient’s body cannot assimilate the food and water.

But, “My loved one doesn’t want to eat and can’t swallow. I don’t want to force them to stay alive.” — Will that justify an exception?

My mom received an Alzheimer’s diagnosis when she was just 59, and we both had a pretty good idea what lay ahead. Not far from my home northwest of Chicago is a fine long-term care facility with a wing dedicated to patients with Alzheimer’s.

My mom has been there ten years. She has been well cared for, getting the day-to-day support I couldn’t give on my own. Even as I have watched and grieved her drifting away, I am grateful for the time we have had together over those ten years.

Then she lost her appetite and her ability to feed herself. It’s hard for her even to swallow. Two days ago her care coordinator asked me about a feeding tube. I knew what Mom would choose. My family was supportive. I told the care coordinator Mom wouldn’t want a feeding tube in this condition and I took another little step down that slow path of grief.

But the care coordinator wants me to meet with their chaplain before making a decision. She says my mom is not actively dying and there’s no indication that she wouldn’t tolerate a feeding tube. Will I have to find another facility and arrange a transfer to honor what I know would be my mother’s wishes?
Catholic bioethical thought has evolved over centuries. The ERDs that govern care in Catholic hospitals and nursing homes are extremely nuanced. Your directions about life support may or may not be honored in a Catholic institution. Your concern about the burdens of medical interventions might justify forgoing life-sustaining medical treatment. But a wish to be allowed to die under certain circumstances might not.

Compassion & Choices creates an atmosphere free from judgment where everyone can talk about, and come to terms with, the difficult issues surrounding death and dying. We honor all people as individuals, regardless of sexual orientation, gender identity, age, disability, race, or any other category. Call 1.800.247.7421 to find out more about planning for the future.

NEW: Sectarian Health Care Directive

In addition to an advance directive, you may choose to complete our Sectarian Health Care Directive. The language in this addendum clarifies that admission to a religiously-affiliated facility does not imply consent to particular care mandated by the institution’s religious policies, and directs a transfer if the facility declines to follow the wishes outlined in an advance directive.

Download this and other planning tools at CompassionAndChoices.org/g2g.
Health Insurance Reform

In April, 2009, Compassion & Choices recognized an opportunity to increase the frequency of discussions between patients and their physicians regarding end-of-life treatment preferences. Oregon Congressman Earl Blumenauer introduced legislation allowing health care professionals to bill Medicare for time spent discussing end-of-life options and patient preferences. With supportive advocacy from Compassion & Choices members, the bill passed out of committee as part of the larger health insurance reform package.

Congressman Blumenauer’s provision was not included in the Patient Protection and Affordable Care Act that became law in March, 2010. Attacked, distorted and labeled “death panels” by anti-choice extremists, key legislators deemed the provision too controversial, even as a stream of news stories, commentary and personal stories debunked those claims and encouraged support. In October, Compassion & Choices delivered a petition in support of the provision to Congress, signed by thousands of people from across the nation.

However, the Affordable Care Act contains a number of provisions that will improve care and expand choice at the end of life:

- As a result of Compassion & Choices’ advocacy efforts, together with Senator Ron Wyden of Oregon, the new law includes a provision to require health insurers in the so-called Public Exchange to offer enrollees information on resources available for advanced care planning.

- Another provision authorizes an Institute of Medicine Conference on Pain Care to evaluate the adequacy of pain assessment, treatment, and management; identify and address barriers to appropriate pain care; increase awareness; and report to Congress on findings and recommendations.

- Under new law, the Department of Health and Human Services will make grants available to hospices and others to develop and implement pain care education and training programs for health care professionals.

In addition, Compassion & Choices, together with others, successfully prevented a measure that would have undermined aid-in-dying laws in Oregon and Washington from being included in the Act. Specifically, if passed, the measure would have effectively barred insurers and providers from covering aid-in-dying services if they received any federal or state funding, thus passing on the entire burden of paying for these services to patients.
Obama Tells Hospitals to Honor Your Wishes

On April 15th, in anticipation of National Health Care Decisions Day, President Barack Obama issued a memorandum directing the nation’s hospitals to assure advance directives are honored. Most news reports on the President’s memorandum to the Secretary of Health and Human Services (HHS) highlighted the protection it offers to same-sex couples in hospital visitation and decision-making rights.

Yet the memorandum bolsters the power of all patients and families by directing HHS to ensure that all hospitals participating in Medicare or Medicaid are in compliance with regulations to guarantee that all patients’ advance directives are respected.

National Public Radio’s Julie Rovner reported on the move to enforce these regulations. Her report included input from Compassion & Choices’ President, Barbara Coombs Lee.

The Ethical and Religious Directives in place at over 600 Catholic hospitals in America, along with the growing legal protection for provider refusal, shift medical decision making from patients to providers and institutions.

One section of law cited in the President’s memorandum requires providers to offer patients written information when the “provider cannot implement an advance directive on the basis of conscience.” HHS is not currently enforcing that provision, and patients and families are caught off guard when a hospital provides treatment contrary to an advance directive.

The President’s memorandum is a step in the right direction, but the cited regulations lack real teeth. Compassion & Choices believes it is time to shift choice in medical care back to patients, and federal Medicare enforcement can promote that shift. Compassion & Choices is working for changes that will assure Americans that providers will honor their advance directives.

Why should we allow hospitals to disregard the treatment wishes of a dying patient and then reward them with taxpayer dollars?

Listen to the full NPR story on our blog at CompassionAndChoices.org/blog/?p=964.

You are the voice of Compassion & Choices!
Are you part of our Online Action Network?

Compassion & Choices’ talented advocacy team is proud of the progress achieved this year and determined to continue strategizing a way forward. The positive coverage that we earned – and helped to generate – on patient-doctor consultations showed the broad popular understanding of the importance of communication and choice at the end of life. With great support from our members, legislators learned we are a passionate and active group who will be watching for progress in the future.
What’s So Special About Gift Annuities?

You have probably heard or read about charitable gift annuities and wondered, why all the excitement? What’s so special about gift annuities?

With a gift annuity, you give the cake and eat it too. By that, we mean you receive annuity payments after you give your gift to Compassion & Choices.

- With a gift annuity, you receive fixed payments for life.
- You not only help yourself, you help Compassion & Choices with your gift annuity. Part of what you give for a gift annuity is considered to be a charitable gift, a much-needed gift to help us carry our work into the future.
- There are tax advantages as well. These may include a charitable income tax deduction, an estate tax deduction, and even capital gains tax relief.

Would you like to learn more about gift annuities and how they can help you and Compassion & Choices? Simply call Jane Sanders, Director of Membership & Planned Gifts at 800.247.7421 or email at Jsanders@CompassionAndChoices.org.