5 Questions for Montel Williams

Do No Harm? When Healthcare Goes Too Far

Patient Inspiration, Doctor Leadership
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Volume 12, Number 1

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Moral Leadership

More than 40 years ago, when I was a lowly student nurse laboring on the wards of the New York Hospital, I caught my first glimpse of true medical leadership. Dr. Fred Plum was head of the department of neurology, and he was known far and wide for his encyclopedic knowledge, his razor-sharp reasoning and his unparalleled diagnostic skill. What made him great, however, was his extraordinary moral direction in tethering his clinical brilliance to the service of humanity.

Students of all the medical sciences, doctors in training and even other faculty members packed the auditorium for neurology grand rounds each week, mesmerized by the display of his skills. The neurology resident would present the case; Dr. Plum might ask for detail and then would call the audience's attention to the most meaningful elements of the case.

Then he called for the patient to be escorted into the auditorium, and everything in Dr. Plum's affect changed. The focus changed from "a case" to "this person." He greeted the patient warmly, welcomed him by name and thanked him. He was encouraging and appreciative, and patients were eager to help, apparently grateful to be truly seen and heard, and for the opportunity to help humankind by sharing the details of their frailty.

Our spring magazine focuses on doctors. We look at the leadership they exert, their crucial role in determining whether a death honors the wishes of the dying, and how they deliver their scientific knowledge. All these characteristics make up a great physician and remind me of Fred Plum.

When he died a few years ago, a line in his obituary showed he was as compassionate and understanding of mortality as he was of his patients. His wife told The Washington Post, "He felt very strongly that people should die with dignity and control at the end of their lives as much as possible, and that lives should not be extended beyond the point where a person could feel his own humanity."

Dr. Plum did not shrink or cower before death. He met his patients straight on, person to person, mortal to mortal. And they loved him for it. That's moral leadership.
CompassionAndChoices.org

Newspaper
Associated Press
A February 8 Associated Press story alerted the nation that end-of-life choice is advancing in at least a half-dozen states, boosted by Compassion & Choices’ leadership. Chief Program Officer Mickey MacIntyre commented, “The Massachusetts initiative lifted the consciousness of the nation and in particular the Northeast region to this issue that there are other alternatives patients and their families should have an opportunity to access.” The story, which ran in over 300 news outlets, pointed to each of our active campaign states, and it confirmed the growing impact of our organization and the citizens’ demand for the freedom to make their own health care decisions.

Dear Margo: Whose Life Is It, Anyway?
“How do you feel about allowing patient choice at the end of life? Have you had any personal experiences with a dying relative or friend? Help me sort through this stuff,” concluded a letter to Margo Howard in her syndicated advice column “Dear Margo.” Margo, daughter of long-time advice columnist Ann Landers, stated that aid in dying would be a “wonderful gift to suffering patients.” And she volunteered that she and her husband voted for Massachusetts’ Death with Dignity initiative last November. She also referred readers to Compassion & Choices for guidance on end-of-life issues. You can read her full response, which ran in numerous papers and online sources on January 18, at http://tinyurl.com/DearMargo.

Radio
The Diane Rehm Show
President Barbara Coombs Lee offered her reasoned, compassionate perspective during the March 5 episode of NPR’s The Diane Rehm Show, “Legal Debate Over Doctor-Assisted Suicide.” “Control is exactly the element that patients desire most,” was Barbara’s response when another guest minimized the crucial difference between aid in dying and other palliative measures. The Diane Rehm Show is one of public broadcasting’s most-listened-to programs, reaching more than 2.4 million listeners on nearly 200 affiliates across the country weekly. To hear this thoughtful episode, visit http://tinyurl.com/RehmShow.

Web
HuffPost Live
Compassion & Choices President Barbara Coombs Lee appeared on a segment of HuffPost Live January 30. The episode, “Catholic Hypocrisy?” addressed a recent lawsuit against a Catholic-run hospital. As the only woman and only non-Catholic on the panel, Barbara stood firm amid a barrage of theological justifications. She made a compelling connection to our movement in this comment: “This case shows how imposing religious doctrine on legal representation can inhibit effectiveness in court. The same with medicine – religious doctrine can compromise best practice.” You can still watch the segment online as well as read and submit comments at http://tinyurl.com/HuffPostLive.
WHAT WOULD DOCTORS DO?

65% of physicians have completed an advance directive.

20% of the general public have completed an advance directive.

90% of physicians said they would not want CPR if they were in a chronic coma.

25% of the general public said they would not want CPR if they were in a chronic coma.

In a 2010 study, out of 61 patients who received CPR, only 8 regained a pulse, and all died within 48 hours.

Sources: *Journal of the American Geriatric Society*, *Johns Hopkins Precursors Study*, 1998, and *Supportive Care in Cancer Journal*. 
words to live (and die) by

**Advanced progressive illness**
An illness with no cure that has worsened over time, will continue to do so and cause death in the foreseeable future. Someone with an advanced progressive illness may decline treatment if she decides its burdens are too great and the benefit will only postpone death.

**CPR (cardiopulmonary resuscitation)**
Procedures — pushing on the chest, electric shocks, drug injections, inserting a breathing tube in the throat — aimed to restart heartbeat and breathing. This process can save the life of an otherwise healthy person, but someone with a progressive illness likely will not survive CPR. He may, at best, live only a short time and require continued life support.

**DNR (do-not-resuscitate order)**
A doctor’s order placed in a patient’s medical chart to indicate there should be no attempt to restart a failed heartbeat or apply CPR to restore normal breathing. A DNR can be changed, and it should be reviewed regularly. In a DNR situation, a patient is still provided comfort care. Without such an order, emergency medical technicians are legally required to perform CPR. Increasingly, these orders are called “AND” for allow natural death.

**Informed consent**
A requirement to tell a patient of risks and benefits before she consents to any medical treatment. Beyond the legal requirement, a patient — or patient with her advocate — achieves true informed consent through shared decision-making with the doctor based on a full understanding of the facts: how close the patient is to death, the wishes she has expressed, alternatives including nontreatment, and the risks and benefits of each.

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**Where is there dignity unless there is honesty?**
—Cicero

**Advance directives** are important for everyone 18 and over, but they’re not complicated, and they’re not expensive. In fact, we offer free advance directives — easy-to-complete forms and corresponding instructions — specific to every state. Find them at CompassionAndChoices.org

Document what you want — and what you don’t — just in case.
Dr. Katherine Morris initially was reluctant to appear in *How to Die in Oregon*, the 2012 Sundance-award winning documentary on terminally ill people who use Oregon’s Death with Dignity law. At the request of her oncology patient Cody Curtis, she had agreed to prescribe medication for aid in dying should Curtis’ suffering overtake her pleasure in living. But opening up on camera to discuss that difficult and poignant decision? That was a different question.
Two things changed her mind. First, the documentary was really important to Cody, and given the relationship she had developed with Cody in treating her for two years, Morris wanted to support her. She also realized that people need to understand aid in dying from a doctor's perspective as well as from a patient’s. Only a doctor could tell that story. She knew she had to do it.

“We have more practice at this type of discussion than most – it doesn't make it easier, but it is part of our responsibility as physicians.”

Medicine is a self-governing science, shaped by best-practice standards established by doctors. If healthcare consumer advocates hope to incorporate aid in dying into standard medical practice, then legislators, voters, attorneys, lobbyists and journalists can do only so much. Doctors themselves must lead by example and encourage other doctors to include aid in dying as part of the spectrum of end-of-life options.

Morris is no longer hesitant. She speaks powerfully in the documentary. Along with Dr. Aroop Mangalik she is a plaintiff in a Compassion & Choices case seeking legal protection for aid in dying in New Mexico. “I did this to honor my patients past, present and future,” she says. “Their courage in facing devastating illnesses and the end of life inspired me to try and help all of us have the choices about our deaths that make us feel most comfortable – whatever those choices may be. I didn’t want death to silence people like Cody Curtis.”

With 15 years of data about Oregon’s experience with aid in dying, it is clear the practice is successful. But translating ballot-box victory into medical practice was no small feat. That’s where Dr. Nancy Crumpacker stepped forward.

An oncologist with a thriving practice, she had vast experience with patients at the end of life. But Crumpacker had more than experience and expertise; she had a role model. “My father was a general surgeon. I saw the adoration of the community for him,” Crumpacker says. “He was a leader; he was adored; he was worshipped. In the ‘50s and ‘60s, doctors practiced a more paternalistic model. I thought patients needed to play a more important role; they needed to be more active.”

She threw her heart and soul into implementing Oregon’s Death with Dignity law and educating her colleagues about it. Crumpacker was able to show doctors as a peer how to explore and respond to a patient’s request under the new law and meet its exacting requirements.

“I grew up in an empathetic family. If my patients really want this, then who am I to say I know better?”

Just two years later, in 1999, she retired from her private practice to serve as full-time medical director for Compassion & Choices Oregon. When a market shortage of a drug commonly prescribed for aid in dying threatened the availability of the practice, Crumpacker leapt in to help lead a task force to come up with alternatives.

“I grew up in an empathetic family,” Crumpacker says; listening to her patients was all it took to convince her to act. “If my patients really want this, then who am I to say I know better? I’m not in their shoes. They’re sitting before me telling me that this is what they want. How can I discount that decision?”
Charlie was a 91-year-old patient of Dr. David Muller through the Mt. Sinai Visiting Doctors program in New York City. Declining, but still sharp and fiercely independent, Charlie made clear in a series of careful conversations with Muller that he wanted to stay in his home until he died and avoid aggressive care.

In one discussion, Charlie asked how long dying would take if he were hit with various life-ending events or illnesses. Muller understood only later that Charlie may have been probing for information about aid in dying. In Muller’s view it’s a doctor’s responsibility to help broach this topic, assure patients that such thoughts are common and encourage them to discuss them openly.

“In providing care, educating patients and influencing policymakers, physicians are in a unique position to advocate for social change.”

After a fall that broke his hip, Charlie asked explicitly for medication to control the circumstances of his death. Since that was not possible under New York state law, Charlie chose to stop eating and drinking, and Muller supported him with comfort care through that process. A little more than a week later, Charlie passed peacefully at home.

“My own experience has grown out of lessons learned from patients,” says Muller, “who had the courage and foresight to take control of their care and teach me what role I needed to play in supporting them.” Muller has written encouraging doctors to have these frank conversations with patients and has advocated incorporating the option for aid in dying into end-of-life care practice. He is one of three physicians on the board of Compassion & Choices, along with Drs. Robert Brody and Charles Hamlin.

“Expanding choice at the end of life is fast becoming this generation’s most important patient rights issue. Society has weighed in, and our patients have told us what they want: access, excellence and choice. Now it’s our turn. Physicians cannot afford to squander this opportunity to be on the right side of history. In providing care, educating patients and influencing policymakers, physicians are in a unique position to advocate for social change.”

In 2011, Compassion & Choices completed a careful review of Hawaii law covering end-of-life choice. We convened a panel of experts on law, medicine, elder care, legislative and end-of-life issues; their review concluded Hawaii physicians could already provide aid in dying subject to professional best-practice standards. But as in Oregon, a supportive public policy does not by itself create an accessible medical practice. That would require the leadership of empathetic physicians.

“Serving as an oncologist for over 35 years, I have cared for thousands of dying patients,” says Dr. Charles Miller of Honolulu. “In my experience these patients, more so than almost any others, depend on their physicians to assist and guide them through what is their ultimate journey.”

“To those critics who charge that physicians should never provide support for a patient who desires to end their life, I would ask ‘who else but their physician should do this?’”

Miller served for 30 years in the U.S. Army Medical Department, was chief consultant to the U.S. Surgeon General and spent nine years as chief of hematology-oncology at Kaiser Medical Center, Honolulu. Why did he put his professional reputation on the line by helping to lead a coalition of physicians ready to
enable terminally ill patients to control how much suffering they will endure before death arrives?

“I firmly believe that it is my responsibility as a doctor to act as my patients’ surrogate and help in their end-of-life choices, regardless of their final decision. And I believe this includes assisting patients in obtaining medication to end their life in a manner of their choosing.

“To those critics who charge that physicians should never provide support for a patient who desires to end their life, I would ask ‘who else but their physician should do this?’ A physician who has followed and cared for a patient – sometimes for many years – should be the one to care, advise – and yes – assist that patient in their choice of how to end their life. Writing a prescription at a patient’s request is simply supporting that patient’s autonomy – that patient’s choice – of how they choose to end their life. Supporting our patients has been physicians’ duty for millennia. We should not fail to honor our obligations to those who need our help the most.”

A Connecticut physician who specializes in treating patients with HIV and AIDS, Dr. Gary Blick has long believed patients’ end-of-life choices should be expanded to include aid in dying. “My patients’ plea for this option has brought me to this place in my life where I believe we must have one more legal end-of-life choice.”

In February, Blick joined Connecticut legislators at a news conference in Hartford to announce their resolve to do just that. Blick says it’s natural for a doctor to lead the call for change on behalf of patients.

“My patients’ plea for this option has brought me to this place in my life where I believe we must have one more legal end-of-life choice.”

“The aid-in-dying legislation heard by the Senate Public Health Committee this year is a critical piece of legislation,” Blick says, “giving patients another important choice in expanding their end-of-life decisions. I have had this discussion with hundreds of terminally ill, mentally competent patients over the past 26 years, and many of my patients, had this legislation been in place, would have chosen to receive medications from me to plan the end of their suffering in a dignified manner, with loved ones present and without prolonged agony.”

Without the leadership of these doctors and others like them, spurred on by their conversations with patients, our movement cannot continue to change social policy affecting end-of-life choice.

“Because it is challenging to discuss end-of-life issues for all of us,” says Dr. Morris, “it is critical for doctors to take a leadership role because we have more practice at this type of discussion than most – it doesn’t make it easier, but it is part of our responsibility as physicians.”

The Oath of Maimonides reads, in part, “I have been appointed to watch over the life and death of my fellow human beings.” Dr. Blick believes these words light the path doctors must follow. “The unique physician-patient relationship regularly allows for such discussions regarding end-of-life choices, and, as uncomfortable as the subject may be, it is our role to discuss all options with our terminally ill patients.”

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Photo Credits:
Katherine Morris, page 8: Kira Jarmer, Eli Photography
Nancy Crumpacker, page 9: Carla Axtman
David Muller, page 10: Matthew Septimus

CompassionAndChoices.org 11
My mother, Sara Mitchell Parsons, was 99 when she fell in her retirement complex in July 2011. She fractured her hip, had a mild heart attack and was unconscious. EMTs revived her and took her to Emory University Hospital in Atlanta. The surgeon in charge said she needed a hip operation to relieve the pain. I knew Mom, at 99, would not want the operation. For the last several years she had told me and her husband that she “was ready to go” and that she didn’t care a thing about living to 100. Her quality of life was clearly deteriorating.

When I finally saw Mom in the ICU – surrounded by beeping monitors, tubes, nurses constantly in and out – she looked so stressed: thrashing her head from side to side, not able to recognize anyone or respond. She kept repeating two things: “I already died once, why am I still here?” and “Let me go, let me go.” It was heartbreaking. … (continued)

We need doctors. We trust them and look to them for expert guidance. We accept their recommendations because we assume they’re “right.” But too many people, like Sara Mitchell Parsons, receive aggressive, excessive treatment at the end of life. Is there a disconnect between patients’ wishes and some doctors’ advice on what is “right”?

Intensive care unit (ICU) use, multiple hospital admissions and transitions between care sites in adults’ final days have all increased, according to a study in the February 6 Journal of the American Medical Association (JAMA). The study’s author, Dr. Joan Teno of Brown University, commented on her conclusions, “The findings reveal that the goals of many Americans – to avoid end-of-life heroics and die at home, in relative comfort – still remain out of reach.” And, in their accompanying editorial, geriatricians Dr. Grace Jenq and Dr. Mary E. Tinetti of the Yale School of Medicine noted, “The increased availability of palliative and hospice care services does not appear to have changed the focus on aggressive, curative care.”
Compassion & Choices works to ensure families receive patient-centered care, and that patients and families understand and agree to the care provided. The JAMA study and the real stories we hear every day confirm the tragedy that too many are enduring the unbearable for too long and that there should be more of an effort to elicit patients' preferences.

Hindsight is always 20/20, but I feel utterly duped by the medical establishment in my father’s case: I had never before gone through anything like I did and didn’t recognize the hidden messages couched in the information I was given.

My father went in for a routine surgical procedure at his local community hospital and though he came out of the surgery doing well as expected, six hours later he left in an ambulance bound for Boston due to a stroke. In Boston, we were given nothing but optimistic predictions to surgical treatment response. We felt hopeful as my father was subsequently discharged to rehab to learn to walk, talk and swallow again. Unfortunately, things did not go well, and he had another stroke. This one was even more debilitating, but again we were shuffled through the system as though treatment were the only course. At every turn doctors were told of my father’s DNR, given a copy and reminded he wished for no extraordinary measures of any kind. The next thing we knew he had a feeding tube. He would never walk, talk or eat by mouth again, and he was moved to the first of three nursing homes, where he died over a year later.

I wish most of all that my father’s doctors and nurses had been honest from the start: about what happened medically and about a realistic prognosis taking quality-of-life issues into consideration. Not to mention open acknowledgement of my father’s wishes per the official documents he had prepared a few years earlier with his attorney. I felt so isolated at the time, and looked desperately for families of stroke support and guidance to no avail. Maybe Compassion & Choices could’ve helped me in some way bad I known about your organization.

– Pippa Hamman Comfort

Why are these sad scenarios on the rise, when more people than ever are armed with advance directives and family advocates? Dr. Teno identified “a complex set of reasons” behind the problem. A sudden change in health status sometimes doesn’t leave people time to prepare. Or patients may not fully understand their prognosis, and they may have never discussed care preferences with their doctor. The reimbursement system is another factor. ICU clinicians and hospitals are paid for each service they provide, and there are financial incentives for nursing homes to transfer patients back to emergency rooms.

One obvious impediment to patient-centered care is that Medicare does not pay for doctors to discuss end-of-life preferences with their patients. Requirements for such discussions were initially included in the Affordable Care Act but removed as the bill advanced through a politically charged Congress. Without these frank talks and a clear understanding of likely outcomes, many patients and their families do not receive the information they really need to give true informed consent for the procedures clinicians prescribe. So they agree to exhaust multiple treatment options while remaining unaware of all available options, including hospice and palliative care.
My old girlfriend Marsha had a brain tumor. She was 31. Flat brain waves made it certain that she was brain dead and that she would not recover. She was on life support, and then her kidneys failed. The family was distraught to the point of being dysfunctional and were unable to make wise choices. They would have agreed to anything. A decision was made, probably with the acquiescence of the family, to put her on dialysis, which extended her life an additional week, greatly increased the cost of care and prolonged the family’s sorrow. Even offering dialysis to a brain-dead patient is morally questionable and should not be in the realm of hospital choices.

– Sid Adelman

The old belief that more care is always better has proven untrue. Advanced technology to treat illness does not necessarily improve the patients’ lives, but doctors aren’t inclined to see things that way. If you do, thoughtful navigation and knowledge of all the facts can save you from giving uninformed consent for futile suffering at the end of life.

Sara Mitchell Parsons’ son Perry Mitchell saved her from an even more miserable death. He knew what she wanted, and he advocated loudly enough to end the doctor-recommended but unwanted torment his mother was enduring. Sara’s story goes on:

... At the hospital, my stepfather “couldn’t bear to let his beloved Sara go,” so he agreed to the operation. And it turned out that he had health care power of attorney, so I had no legal power to stop it. The operation was scheduled to begin in three hours. I had a hard talk with my stepfather, reminding him that Mom repeatedly said she was “ready to go.”

Less than an hour before the operation, I got my stepfather to agree to at least talk to a hospice representative. Within 90 minutes the hospice evaluation nurse arrived and immediately said Mom was eligible for hospice at their nearby facility. Three hours later she was in a calm, simple, machine-free hospice room. With the stepped-up pain medication hospice gave her, she looked so much more peaceful — no more head-thrashing, no more asking why she was still here; just calm, relaxed breathing.

Mom died 10 hours later, still in that completely calm state. I know I did what she would have wanted. But I’m still incredulous and angry at a system that would seriously consider a major operation on a frail 99-year-old, especially one that would so negatively affect her quality of life.

Going through this is a major reason I’m so supportive of Compassion & Choices. In fact, I’ve agreed to serve as president of the Georgia chapter, in great part to make sure others avoid what I went through and to posthumously honor what I know would have been my mother’s last wishes.

– Perry Mitchell


Doctor, would you be surprised if I died this year?

Pointedly ask your doctor not only what the prognosis is, but in fact whether an accurate diagnosis is “dying.” Talk with your family about what’s truly important to each of you. And don’t wait for doctors to suggest hospice. Ask the hospital for hospice information and referrals, and do your own research on end-of-life options as well. Protect your right to choose for yourself and your family: Be informed, be prepared and be outspoken.
“Disregarded”

Compassion & Choices’ 2013 Storytelling Contest

For this year’s contest Compassion & Choices seeks stories of unwanted treatment: instances when providers ignored, failed to determine or overruled explicit healthcare instructions, or persuaded family members to disregard patient wishes. These stories not only provide some comfort in solidarity for the writers and readers, but their combined lessons will help power our campaign to reverse the problem of unwanted treatment in America.

“… If they would have told me they were out of options and to take my husband home with hospice we would have done that. Instead I was led to believe there were treatment options, and ‘of course you do not want to lose your husband.’ We were never asked what our goals were, or for a code status, or how he wanted to die.”

– Marie Leven

Tell your story and we all win!

Deadline extended to July 1, 2013.

Electronic submissions of 750 words or fewer are preferable, sent to president@compassionandchoices.org or mailed to Compassion & Choices, P.O. Box 101810, Denver, CO, 80250 Attn: Story Contest.

You’ll receive a prize just for entering, and authors of the top five stories will get a one-year Compassion & Choices membership.

In addition to being published in Compassion & Choices Magazine, the first-place winner will also receive a $100 Powell’s City of Books gift card, a Living to the End journal and a copy of Compassion in Dying: Stories of Dignity & Choice autographed by author and Compassion & Choices President Barbara Coombs Lee.
Compassion & Choices Aims to Stop Unwanted Medical Treatment

Americans have vigorously debated the expansion of affordable healthcare coverage to the 47 million who lack it. While the nation struggles to increase care for so many, an irony surfaces: the scores of people who opt for less treatment — only to see others ignore their legally binding requests.

More than 45 million Americans have thoughtfully considered advance directives stating the care they want — and don’t want — in case of sudden accident or terminal illness. These legal documents are intended to prevent unwanted treatment, but often patients’ wishes are ignored or overridden. Too many dying Americans suffer needlessly in their last days and hours. Too many endure futile, invasive tests and treatments.

A study in the February 6 Journal of the American Medical Association found that 26% of Medicare beneficiaries spent part of their last month of life in an intensive care unit (ICU). The accompanying editorial asked, “Were these hospitalizations appropriate?” and its authors wasted no time drawing a conclusion. “To answer this question, it is necessary to consider whether these hospitalizations were congruent with this patient’s health goals. ... The focus appears to be on providing curative care in the acute hospital regardless of likelihood of benefit or preferences of patients.”

Compassion & Choices is driving home the imperative to end unwanted medical treatment with a national campaign to get every doctor, patient, family member and advocate to routinely ask that question in the setting of advanced disease: “Is this treatment appropriate?” This winter our staff and advocates stressed the importance of determining and honoring patient wishes before several of the most prestigious audiences in the health care field.

Compassion & Choices Chief Program Officer Mickey MacIntyre brought the issue to the influential Institute of Medicine’s Committee on Transforming End-of-Life Care during its first meeting February 20. As the committee makes its recommendations MacIntyre urged that policymakers “provide both the carrot and the stick to ensure that patients’ wishes are honored: financial incentives for honoring advance directives and financial disincentives for disregarding patients’ expressed wishes.” Among his other recommendations:

- Reimburse medical providers for participation in advance care planning with patients and their families, even without terminal illness;
- Create financial incentives and training to encourage medical providers to offer all the information and counseling necessary for informed patient decision-making;
- Ensure the full range of medical care and treatment decisions — curative care, palliative care and medical assistance in dying — are freely available to patients without institutional or reimbursement barriers;
- Deny reimbursement for any treatment that goes against a patient’s informed health care decision;
- Put in place procedures — for all providers who interact with the Center for Medicare and Medicaid Services — to bring attention to patient wishes;
- Create incentives to determine a patient’s wishes during an emergency — by asking the patient or his health care proxy, or by checking the patient’s advance directive.
I believe that I – in consultation with people I trust – have the autonomy to make my medical decisions, including how I die.

I believe that healthcare providers and institutions should respect terminally ill persons’ wishes.

Sign Our Petition: tinyurl.com/umt-petition

“If you’re looking for a model of what good end-of-life care could look like, look at the beginning of life.”

-Mickey MacIntyre
Unwanted Medical Treatment continued

How Patient Preferences Get Lost

A vast medical-industrial complex shapes the environment where most Americans spend their last weeks or days. This foreign atmosphere overwhelms patients and their families, who are not prepared for the pressure of making — as they come to believe — life-or-death treatment decisions. Patients or their advocates agree to procedures and interventions in a confusing, crisis atmosphere in which many people don’t understand the ramifications of the consent they provide. They often realize too late that the procedures delivered little real benefit, but extracted a very real cost: precious last days spent in a sterile ward and even agonizing discomfort.

How can real teeth be put into advance directives to ensure that patients’ wishes are honored?

Existing medical culture dictates that doctors diagnose and treat specific symptoms and illnesses, with less emphasis on collaboration with their patients on a comprehensive plan for care. Additionally, the current health care system has a big, built-in incentive for doctors, hospitals and nursing homes to provide treatment. Medicare, Medicaid and private insurers almost always reimburse providers based on the services and products they provide: the “fee for service” model. Unfortunately, even though “do nothing” may be the best medicine — and what the patient requested — there’s little financial incentive to do nothing more than comfort care.

It’s against the law for Medicare or Medicaid to pay for unnecessary treatment, but the rewards are great enough that occasionally providers bill for services and procedures that are, at best, highly questionable. Recent media reports have exposed cases of abuse of this system.

Choosing Wisely

Compassion & Choices is not alone in its desire to limit unnecessary treatment. Consumer Reports together with the ABIM (American Board of Internal Medicine) Foundation and leading medical specialty societies have developed resources for consumers and physicians to engage in important conversations about the overuse of medical tests and procedures. For the Choosing Wisely® campaign, each specialty society created an evidence-based “List of Five Things Physicians and Patients Should Question.”

At the top of the list from two specialties:

*Don’t recommend percutaneous feeding tubes in patients with advanced dementia; instead, offer oral assisted feeding.*

The American Academy of Hospice and Palliative Medicine as well as The American Geriatrics Society led with this on their list of questionable procedures.

The academies recognize — and we agree — this is exactly the kind of procedure too often recommended with too little chance of benefit. If doctors, patients and family members have a frank discussion about the benefits and burdens of interventions, it is more likely the result will be truly informed consent.

To see the other recommendations and for more information about Choosing Wisely, visit: consumerhealthchoices.org/campaigns/choosing-wisely/
From *The Wall Street Journal*:

Therapists billed over two hours of physical, occupational and speech therapy for a 92-year-old patient with lung cancer on the same day he spat up blood at Life Care’s Orlando, Florida, facility, the suit alleges. He died two days later. Because Life Care billed for such lengthy sessions, it was able to charge Medicare at the top rate of more than $500 a day for the therapies, the Justice Department says in its lawsuit.

And in *Bloomberg News*:

A report by federal health care inspectors in November said the U.S. nursing home industry overbills Medicare $1.5 billion a year for treatments patients don’t need or never receive.

Not disclosed was how much worse it is when providers have a profit motive.

“Research shows for-profits are more likely to pursue money in all kinds of ways than nonprofits are, even by pushing the legal envelope,” says Jill Horwitz, a professor at the School of Law at the University of California, Los Angeles.

What about the more subtle area of unwanted interventions? If a course of chemotherapy, a feeding tube or a round of antibiotics has a reasonable medical objective, insurers consider reimbursement appropriate.

But what if that medical treatment is something the patient doesn’t want? If resuscitative efforts result in cracked ribs, intubation and dependence on a ventilator, the few patients who survive may do so only to endure the pain and distress of machines, wires and invasive procedures for their few remaining days. Many frail patients already have short life expectancy and have stated they want to avoid these interventions. The imposition of unwanted treatment rob them of the peaceful death they planned for.

If the treatment is not what the patient wants, it should not be considered medically necessary. How can real teeth be put into advance directives to ensure that patients’ wishes are honored?

Compassion & Choices is working to make the case that in a patient-centered model unwanted treatment cannot be categorized as medically necessary treatment. Therefore, it should not occur and should not be reimbursed. Our newest campaign aims to pivot the enormous medical-industrial complex toward a focus on patients, not procedures.

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### How can you help?

We need your help to raise awareness of this problem and make advance directives more effective.

**Go to tinyurl.com/CandC-Stories.**

Share the stories of those you know whose last days included treatment they didn’t want or where preferences changed in the hospital, or when the full effects, risks and alternatives to a particular treatment weren’t discussed prior to the treatment being administered. Monitor the media for stories of treatment that didn’t match a patient’s wishes. Compassion & Choices will share these stories with leaders and policy makers who can stop the excesses that mar the end-of-life experience for so many.
End-of-life liberty is generating unprecedented activity during the 2013 state legislative sessions, with aid-in-dying proponents driving the agenda in numerous states. Compassion & Choices has deployed organizers, legislative experts and media professionals to kindle the work of local activists like never before. Compassion & Choices staff, volunteer action teams, supporters and advocates are advancing six different legislative campaigns — activity that is visible beyond the states considering laws. National media outlets including the Associated Press and NPR’s syndicated The Diane Rehm Show reported on the tremendous progress, and noted Compassion & Choices’ leadership in the efforts. For the latest, visit the state pages at CompassionAndChoices.org.
**Campaign States**

**MONTANA**

Compassion & Choices battled a bill that aimed to strip Montana citizens of their autonomy over end-of-life medical choices guaranteed by the 2009 decision in Compassion & Choices' Baxter v. Montana case. The so-called "Physician Imprisonment Act of 2013," HB505, called for imprisoning doctors for 10 years on felony charges if they provide aid in dying to their patients who request it. As the bill moved through the House of Representatives, Compassion & Choices Montana mobilized its statewide network to call legislators, brought supporters to Helena for hearings and spoke out in the media against it. Despite bipartisan opposition, the bill narrowly passed the House and moved to the Senate. Seven Montana doctors denounced the bill with an opinion piece that ran in papers around the state. And Dr. Eric Kress, a Montana physician who has fulfilled a small number of patient requests for aid in dying, powered the effort in a Compassion & Choices Montana statewide radio ad. Calling the bill "just plain wrong," he furthered the effort to stop the legislation when he testified March 26 before the Senate Judiciary Committee. To learn how you can help stop this bill and get involved with the Montana campaign, please contact Emily Bentley at ebentley@compassionandchoices.org, 800.409.3137 ext. 4 or tinyurl.com/CompassionMT.

**CONNECTICUT**

The Connecticut legislature is considering The Compassionate Care for the Terminally Ill bill, HB 6645, which would allow terminally ill patients the choice to end their suffering with the support of their physician. Compassion & Choices organizers rallied supporters statewide, and advocates converged at a March 20 hearing of the Joint Public Health Committee. President Barbara Coombs Lee testified, "The bill before you is a responsible piece of legislation that responds to your many constituents who believe that aid in dying should be available as a medical treatment option and that this deeply personal decision should be left to the patient, his family and his doctor." An overflow crowd of supporters backed her, many of whom provided their own stirring testimony or joined in solidarity. In February, Compassion & Choices organized a powerful press conference in Hartford that grabbed statewide headlines and signaled the determination to expand options for a dignified death. To find out the current status of this legislation and get involved in the Connecticut effort, contact Tim Appleton at tapleton@compassionandchoices.org, 800.409.3137 ext. 1 or tinyurl.com/CompassionCT.

Compassion & Choices supporters at the Connecticut Capitol
NEW JERSEY

The New Jersey Assembly’s Health and Senior Services Committee overwhelmingly approved an aid-in-dying bill February 7 after a moving hearing that highlighted the imperative to permit end-of-life choice. Compassion & Choices President Barbara Coombs Lee explained that terminally ill people “should be free to decide whether to prolong life as long as possible, or to end their suffering,” with other experts and supporters also offering emotional testimonies. Assemblyman John Burzichelli, sponsor of the bill, emerged as a great champion for end-of-life liberty; he wrote a powerful op-ed in support of choice for The South Jersey Times. Compassion & Choices is now developing a comprehensive outreach strategy to move the legislation forward during New Jersey’s full-year session. For updates on this exciting initiative and to help ensure it progresses, contact Mark Dann at mdann@compassionandchoices.org, 800.409.3137 ext. 5 or tinyurl.com/CompassionNJ.

NEW MEXICO

Nearly 50 Compassion & Choices volunteers coursed through the halls of the Capitol in Santa Fe to urge passage of memorials declaring March 1, 2013, “Health Care Advance Directive Day” in both the House and Senate. They achieved their goal: New Mexico Senate Joint Memorial 8 and House Joint Memorial 41 passed unanimously in both chambers. Compassion & Choices New Mexico runs a creative campaign to identify, educate and mobilize new supporters enthused about advancing end-of-life choice. Local advocates continue their efforts to raise awareness of and support for Morris v. New Mexico, a case filed by Compassion & Choices to clarify the legal status of aid in dying in the state. For more information or to get involved, contact Erin Marshall at emarshall@compassionandchoices.org, 800.409.3137 ext. 6 or tinyurl.com/CompassionNM.

VERMONT

Vermont could be the first state to approve aid in dying through the legislature! The Vermont Senate approved a “Death with Dignity” bill that would protect doctors from criminal or civil liability when treating terminally ill patients who choose aid in dying. The bill passed the Senate on a solid 22 – 8 vote on February 14 and moved to the House Committee on Human Services. Compassion & Choices is providing ongoing support to our friends at Patient Choices Vermont for their wide-reaching publicity campaign to move this bill through the House. Governor Peter Shumlin has pledged to sign it. The great majority of Vermonters overwhelmingly support aid in dying and stand in a great position to make Vermont the fourth state to affirmatively protect end-of-life choice and autonomy. To join our effort or learn more, contact Jessica Grennan at jgrennan@compassionandchoices.org, 800.247.7421 or tinyurl.com/CompassionVT.

MASSACHUSETTS

Last November’s initiative on aid in dying created momentum that is being felt across the region — with bills also advancing in Vermont, New Jersey and Connecticut. Massachusetts has since introduced HB 1998, a bill that would allow terminally ill patients to access aid in dying, and HB 1888, to expand patients’ ability to make informed health care decisions. Our tireless organizers wasted no time building support for them; they convened two meetings for advocates the first weekend in February, where Compassion & Choices Chief Program Officer Mickey MacIntyre strategized with supporters on translating momentum from last year’s initiative battle into a winning legislative effort. To find out more or contribute to our Massachusetts efforts, contact Marie Manis at mmmanis@compassionandchoices.org, 800.409.3137 ext. 3 or tinyurl.com/CompassionMA.
Local Groups

ARIZONA
Compassion & Choices’ Arizona chapter worked with legislators to introduce a bill — similar to one passed in New York — to ensure doctors inform terminally ill patients about all their end-of-life choices. A committee chair killed this important bill by refusing to hold a hearing. Undaunted, chapter members are now gathering personal stories to help advance this bill in the next session. The Tucson group discussed resuming activity, two years after its leader died from cancer.

ILLINOIS
The Chicago group helped host a Compassion & Choices booth at the March Aging in America Conference, the premier event for advocates in the elder care field. The group also plans to hold an event for National Health Care Decision Day on Sunday April 28.

FLORIDA
A new Compassion & Choices chapter is forming in the Clearwater area. More than 30 people attended the inaugural meeting and planned regular meetings going forward. Compassion & Choices is co-counsel in a case against a hospital and nursing home for failing to honor a patient’s do-not-resuscitate order (DNR). Local advocates pledged to provide support as the lawsuit progresses.

PENNSYLVANIA
Several interested members in Pennsylvania are exploring a revived Delaware Valley chapter. And our legal team is assisting in the criminal defense of a woman charged under Pennsylvania’s assisted suicide statute for helping her dying father.

COLORADO
The Colorado chapter wrote a play encouraging end-of-life planning with performances called “Letting Go.” The play, about a patient at the end of her life who never communicated her medical treatment wishes to her children or her doctor, ends without a conclusion; instead it pivots to an audience discussion about planning and its impact on outcomes.
Voice of Choice

Five Questions for Montel Williams

Montel Williams has had a long and varied career, though he’s best known as the host of one of TV’s most successful talk shows, winning a Daytime Emmy Award and running for a remarkable 17 years. In 1999, Montel went public with his diagnosis of multiple sclerosis (MS), determined to use his public position to raise awareness. “The world needs to mobilize against MS,” he has said, “and knock it out for good.”

Last year, he met Compassion & Choices President Barbara Coombs Lee when both were guests on an episode of “The Dr. Oz Show” devoted to the topic of aid in dying. Montel is an avid snowboarder — he finds the sport challenging and therapeutic, relieving some of the neuralgic pain in his legs — and we caught up with him near the end of a snowboarding trip.
You’ve always taken on challenging roles: Marine, Naval intelligence officer, counselor, motivational speaker, talk-show host. What do you like about taking on challenges?

I believe that we are all born with certain gifts. One gift I have is to be a problem solver. I have learned over the years that I have the ability to look at the big picture and examine issues differently than others, exploring them from all angles. This is what keeps me motivated.

I know that I have a choice: to focus on my personal issues and allow them to somewhat impact me in a negative way, or to reach outside of myself and take on what seem to be insurmountable tasks and accomplish them. This helps me keep perspective and ultimately helps me tackle things in my personal life, as well.

On “The Montel Williams Show,” you talked to a lot of “ordinary people dealing with extraordinary circumstances.” It must have been exhausting! Did you ever wish you could just talk to people in less extreme situations?

When I think back on the show and the history of talk shows, in general, one of the reasons I think my show resonated with viewers was because people got to live vicariously through those on screen.

Everyone has their struggles, whether they wear them on their sleeve or not; but many had no knowledge of how to get through various difficult situations or didn’t have the resources.

So what I liked about the show was that we approached it differently than any others. We helped people see what was going on in their lives and come up with solutions. This benefited people on screen and off. And this is still what I continue to do now in my everyday life, whether with my medical device company or my biofuel company. I look at what’s going on and why, and come up with solutions. So, no, I’m happy with how we approached it.

Is there an interview that really stands out in your memory — haunting or heart-warming?

This is actually one of the questions I get asked the most. I did nearly 600 shows, with probably an average of eight people on a show, so that is thousands of people that I sat with up on the stage.

And though I would love to be able to say there was one that was more important than another, it’s difficult to do so.

But, if I had to pick one guest who stands out in my mind, it would be a child, a young man named Travis who was about eight or nine years old at the time. His mother served in the military and had a brain tumor and knew she was dying. The only other family member in his life was his grandmother. So, for seven or eight months, she tried to teach her son everything about the world, everything he would need to know. She taught him how to pay bills, how to cook, clothe himself, all of these things.

This woman died in their home right on the kitchen floor. His grandmother was hospitalized at the time, and he was afraid he would be taken away and put into foster care. This little boy covered his mother’s face with a towel, sprayed her body down with perfume and lived in the house for 35 days alone, taking care of himself. He paid the electric bill, showered, got up and made it to school every day. He took care of himself. When someone came to the door and no one answered, there were some suspicions and, eventually, it was discovered that he was living alone.
This story had such a powerful impression on me because this was a young man who listened to everything his mother told him and, at eight or nine years old, was able to take care of himself. He even cut his own hair. He showcased the spirit that is born in every one of us. In even the most adverse situations, when I start to worry or question whether I can do something, I think of this young man and what he did. He showed his strong spirit, and it has remained with me ever since.

Our country needs to change how we handle planning, care and decisions at the end of people’s lives. What role should doctors play in that?

Doctors play an integral role in the discussion of a person’s health and their health goals in every facet of their life. However, when there is a finite amount of time left for the patient, their voice should not override others involved in the discussion. When they are sitting down with the family to determine how they will make the remainder of the patient’s life as comfortable as possible, their opinion or advice shouldn’t be given any more weight than that of others who need to be included in the discussion, including the patient’s sage counsel, psychiatrists, psychologists, their clergy or family members.

You’ve said people with a terminal illness should have the choice of aid in dying; that if you had a short time left to live and the prospect of terrible pain, you’d want that option. What would you say to someone who called that “assisting suicide”?

It is not assisting suicide. I have thought this out, including for myself, and I’ve had many discussions with members of my family. I have been through periods of time when the pain has been almost intolerable and to the point where I considered taking my own life. At the time, I wasn’t aware that there were other things I could possibly be doing to help myself.

But I’m also aware that my disease is going to progress. And there may be a day when I am told I have a finite amount of time left on this planet and when I may be in incredible pain. So when that time comes, I don’t care what anybody thinks or calls it. It’s my decision. And if I choose to go, then that’s my call.

They can call it whatever they want because at that point, I’m not going to be here to address that conversation. I don’t mean for that to sound callous or cold, but I do not believe people should be deciding what level of pain other people should endure, especially knowing they have no chance for recovery. It is a personal decision.
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Charitable gift annuities appeal to many donors for a variety of reasons:

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