

**THE
BIAS AGAINST
LIFE-PRESERVING
TREATMENT
IN ADVANCE CARE PLANNING**

MARCH 2015

The Bias Against Life-Preserving Treatment in Advance Care Planning

is a report issued by the Robert Powell Center for Medical Ethics at the National Right to Life Committee (NRLC). Founded in 1968, National Right to Life, the federation of 50 state right-to-life affiliates and more than 3,000 local chapters, is the nation's oldest and largest national grassroots pro-life organization. Recognized as the flagship of the pro-life movement, NRLC works through legislation and education to protect innocent human life from abortion, infanticide, assisted suicide and euthanasia.

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ADVANCE CARE PLANNING:

There is currently a major nation-wide push, both in the private and public spheres, to promote Advance Care Planning. As this report documents, there is strong reason for concern that, motivated by cost concerns, promotion of advance directives and advance care planning frequently deviates from a neutral effort to elicit and implement patients' genuine wishes in the direction of influencing them, subtly or not too subtly, to reject life-preserving treatment.

The Desire to Reduce Health Care Spending Drives Implementation of Advance Care Planning Programs

Are advance care planning programs in practice predominately even-handed attempts to find out and apply patients' own wishes, or are they instead primarily directed to convincing them to agree to forego life-preserving treatment as a means of saving money?

Both governmental policy-makers concerned about the budgets of programs subsidizing health care and private health insurers see themselves as having strong incentives to limit health care spending.

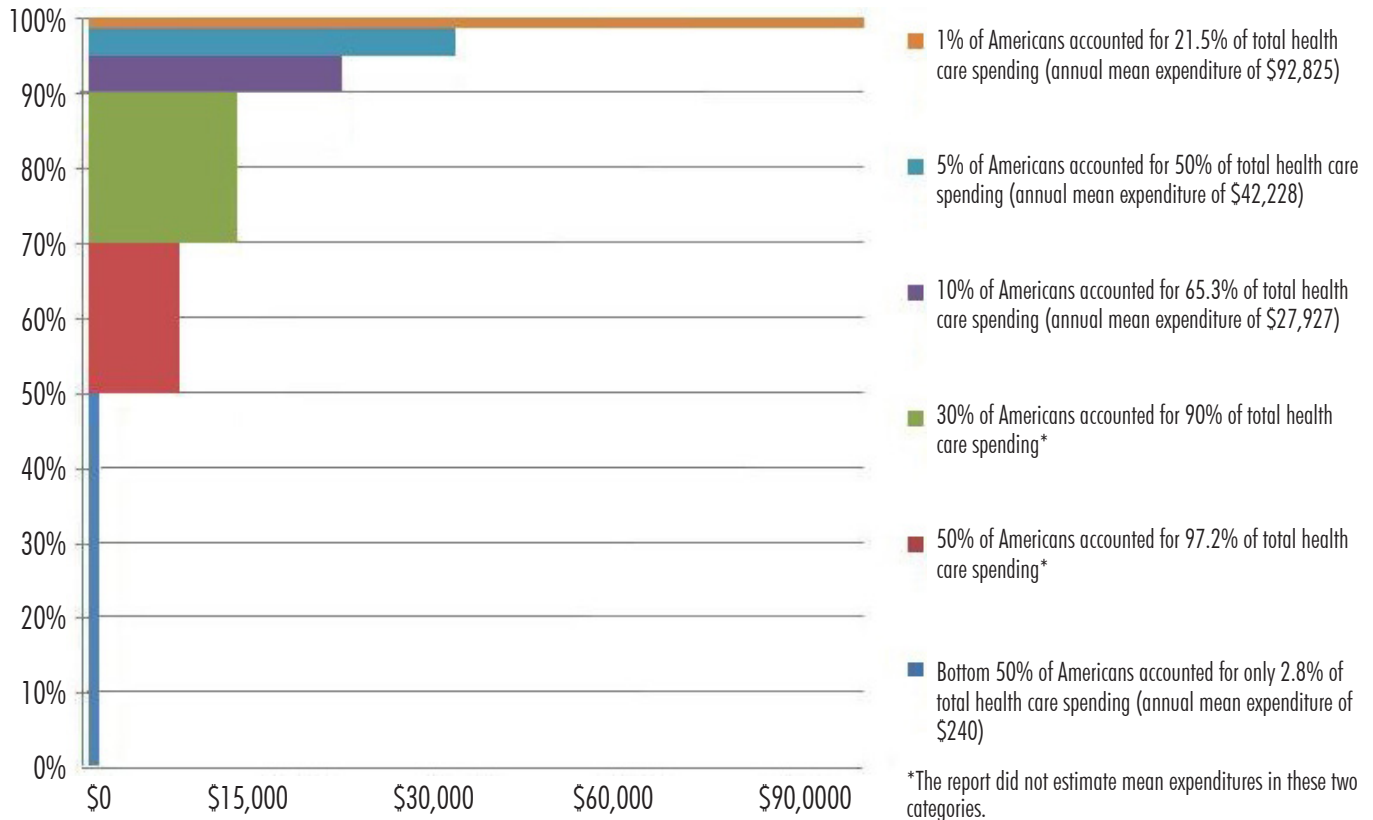
According to a 2014 government analysis, over one hundred million Americans were enrolled in government plans (primarily through a combination of Medicare for seniors, Medicaid for the poor, and Veterans' Health Care) even before the implementation of Obamacare. "These 107,581,000 pre-Obamacare government-health insurance enrollees equaled 34.3 percent of the nation's population, according to the Census Bureau."¹ And a fundamental premise of Obamacare is that Americans spend too much money on health care and the rate of growth in such spending must be significantly limited. In September 9, 2009, remarks to a Joint Session of Congress on Health Care, President Obama warned of "skyrocketing costs," and said, "Put simply, our health care problem is our deficit problem.... The plan I'm announcing tonight ... will slow the growth of health care costs for our families, our businesses, and our government."²

There are multiple mechanisms in Obamacare to prevent "too much" private money being spent on health care—even money people might want to choose to spend on preserving their lives or the lives of their family members.³ The original House bill controversially funded "advance care planning" in Medicare, precisely because of the belief that it would help reduce what otherwise would be spent on health care. In fact, the President himself called for "a very difficult democratic conversation" about "those toward the end of their lives [who] are accounting for potentially 80 percent of the total health care bill out here."⁴

With health care spending disproportionately concentrated on treating those who need it most, a small segment of the population, the incentive for insurers to encourage sicker patients to reject costly treatment is obvious and enticing:*

* Contrary to conventional wisdom, over the long term increases in productivity have consistently decreased the proportion of expenditures needed for such essentials as food, clothing and shelter, freeing up more and more resources Americans have been able to devote to preserving their lives and health so as to be able to enjoy that food, clothing and shelter as well as other goods and services. See www.nrlc.org/uploads/medethics/AmericaCanAfford.pdf ; Sherry Glied, *Chronic Condition: Why Health Reform Fails* (Cambridge, MA.: Harvard Univ. Press, 1997), 86-121. Moreover, it is feasible to subsidize those who cannot afford health insurance without requiring rationing or deficits; see www.nrlc.org/uploads/medethics/ObamacareAlternativeNRLC252015.pdf

Concentration of Health Expenditures 2012



Source: Agency for Healthcare Quality and Research. *Statistical Brief #449: The Concentration and Persistence in the Level of Health Expenditures over Time: Estimates for the U.S. Population, 2011–2012*. September 2014. http://meps.ahrq.gov/mepsweb/data_files/publications/st449/stat449.pdf

Myra Christopher, former head and current project chair at the Center for Practical Bioethics, a major “bioethics” think tank that has long pushed for advance directives, has left no doubt of the economic motive for promoting advance care consultations. In the context of advocating them, she said:

The reality is that 9% to 11% of the entire health care budget is spent on end of life care—nearly 27 to 30% depending on whose data you want to believe of the Medicare budget is spent on end of life care. Conservatively, conservatively, \$6.1 billion every year of Medicare is **wasted** on what we refer to as futile care....⁵

Holly Prigerson of Boston’s Dana Farber Cancer Institute has been quoted as saying, “We refer to the end-of-life discussion as the multimillion-dollar conversation because it is associated with shifting costs away from expensive...care like being on a ventilator in an ICU, to less costly comfort care....”⁶

According to an April 2014 study published in *Health Affairs*, “Advance Directives and Nursing Home Stays Associated With Less Aggressive End-Of-Life Care For Patients With Severe Dementia,” patients with advance directives were 9.2% less likely to receive in-hospital life-sustaining treatment. Moreover, the study stated,

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Community-dwelling patients with severe dementia and written advance directives incurred \$11,461 less in Medicare spending in the last six months of life, compared to patients with severe dementia who remained in the community and did not have written advance directives.⁷

A 2009 *Archives of Internal Medicine* study concluded, “Patient-physician discussions about [treatment] wishes are associated with lower rates of intensive interventions.”⁸ The mean cost of care was 35.7% less in the final week of life for patients who reported having such discussions compared with patients who did not.

Kaiser Health News published a story on August 27, 2014, by Elana Gordon titled, “Operator? Business, Insurer Take on End-of-Life Issues by Phone.” In the piece, Gordon details how insurers are cold-calling lists of people the insurance company provides.

From her cubicle at Vital Decisions in Cherry Hill, N.J., Kate Schleicher counsels people with terminal illnesses. “My name is Kate. I’m a health care counselor,” the gentle voice says from her cubicle in Cherry Hill, N.J....

This is no telemarketing call,...it’s about the end of your life. Kate Schleicher, 27, is a licensed clinical social worker, who knows almost as little about you as you do about her. Except she knows your phone number, your insurance provider and that you are pretty sick.

Schleicher is one of 50 social workers at a company called Vital Decisions. After sending a letter (people rarely respond) counselors essentially cold-call to offer what they describe as “nondirected” end-of-life counseling.

While the stated goal of these conversations is to elicit patients’ views on treatment, another motivation often emerges. As *Kaiser* reported,

And when these conversations do happen, there can be another byproduct: reduced costs. Research is finding that when patients fully understand aggressive care, many choose less of it. By Daitz’ [Vital Decisions CEO Mitchell Daitz] own rough estimate, the company’s services have resulted in about \$10,000 less in health care spending per patient, “\$100 million to the health care system in 2014.”

The Center to Advance Palliative Care (CAPC), according to its mission statement, “provides health care professionals with the tools, training and technical assistance necessary to increase access to quality palliative care services in hospitals and other health care settings.”⁹ For the Aetna insurance company, CAPC developed the “Aetna Compassionate Care Program” (prepareforyourcare.org) to urge and assist insureds to think about and fill out an advance directive. CAPC proudly reported that, based on a representative sample of all Medicare Advantage members enrolled in the Compassionate Care program, there was an 82% hospice election rate, an 81% decrease in acute days, and an 86% decrease in ICU days, resulting in a total cost reduction of more than \$12,000 per member.¹⁰

Similarly, Gundersen Lutheran Health System, a physician-led, not-for-profit integrated delivery system serving more than 550,000 people in Wisconsin, Iowa, and Minnesota, implemented a program promoting advance care planning. According to an analysis done by the Commonwealth Fund, Medicare spends \$8,000 less on patients treated at Gundersen Lutheran than the national average—and roughly \$10,000

less at Gundersen Lutheran during the last six months of life than at other area hospitals. The analysis specifically attributed these lower costs to the completion of advance directives associated with the health system's promotion of advance care planning.¹¹

The Highmark Health Insurance Company promotes its Advanced Illness Services (AIS) to the company's Medicare Advantage (MA) members whose physicians "would not be surprised if the patient died within the year."

According to the stated goals of the program, an interdisciplinary network of physicians and other health care providers attempts to help members understand their medical conditions in order to make informed health care decisions through a variety of tactics—one of the principals ones being advance care planning. The program has been held up as a model for other insurers, and extolled in congressional testimony,¹² explicitly on the ground that it saves insurers a lot of money by dramatically reducing treatment. According to estimates there was a:

14% decrease in acute care admissions in the last six months [of life], 33% decrease in acute care admissions in the last month of life, 30% decrease in ICU admissions in the last six months of life, 48% decrease in ICU admissions in the last month of life, and a 39% decrease in ER visits in the last month of life.¹³

In an August 30, 2014, piece in *The New York Times*, "Coverage for End-of-Life Talks Gaining Ground," reporter Pam Belluck described the efforts of private insurers:

"We are seeing more insurers who are reimbursing for these important conversations," said Susan Pisano, a spokeswoman for America's Health Insurance Plans, a trade association. The industry, which usually uses Medicare billing codes, had created its own code under a system that allows that if Medicare does not have one, and more insurance companies are using it or covering the discussions in other ways.

This year, for example, Blue Cross Blue Shield of Michigan began paying an average of \$35 per conversation, face-to-face or by phone, conducted by doctors, nurses, social workers, and others. And Cambia Health Solutions, which covers 2.2 million patients in Idaho, Oregon, Utah, and Washington, started a program including end-of-life conversations and training in conducting them.

Excelsus Blue Cross Blue Shield of New York does something similar, and its medical director, Dr. Patricia Bomba, has spearheaded the development of New York's advance directive system. Doctors can be reimbursed \$150 for an hour-long conversation to complete the form, and \$350 for two hours.

By now, it should be clear that advance care planning is being promoted, and ever more widely implemented, with the objective of reducing the use of life-preserving medical treatments in order to reduce health care spending. But many of its advocates simply assert that it is what patients themselves prefer—that they would rather die quickly, with a minimum of "invasive" life-supportive measures, in order to be sooner quit of a life whose "quality," because of age, ailment, or disability, is poor. Providing advance care planning simply helps them implement their true wishes, it is argued, while saving a bundle for everyone else.

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But as we shall see, advance care planners in practice are often not content to give neutral, balanced information about treatment alternatives and the options provided by advance directives in the expectation that the majority of insureds and patients will voluntarily give informed consent to the withholding of costly life-preserving treatment. Rather, advance care planning programs routinely skew the information they provide so as to nudge their participants toward rejection of treatment they might otherwise choose.

Nudging Toward Death: How Advance Care Planning Often Shades and Distorts the Facts to Save Money for Its Sponsors

While a Medicare advance care planning provision in an early version of Obamacare was being debated in Summer 2009, author and blogger Lee Siegel, in general a strong advocate of President Obama's approach to health care restructuring, wrote:

[O]n one point the plan's critics are absolutely correct. One of the key ideas under end-of-life care is morally revolting.

. . . .

The section . . . offers to pay once every five years for a voluntary, not mandatory, consultation with a doctor, who will not blatantly tell the patient how to end his or her life sooner, but will explain to the patient the set of options available at the end of life, including living wills, palliative care and hospice, life sustaining treatment, and all aspects of advance care planning, including, presumably, the decision to end one's life.

The shading in of human particulars is what makes this so unsettling. A doctor guided by a panel of experts who have decided that some treatments are futile will, in subtle ways, advance that point of view. Cass Sunstein, Obama's regulatory czar, calls this "nudging," which he characterizes as using various types of reinforcement techniques to "nudge" people's behavior in one direction or another. An elderly or sick person would be especially vulnerable to the sophisticated nudging of an authority figure like a doctor. Bad enough for such people who are lucky enough to be supported by family and friends. But what about the dying person who is all alone in the world and who has only the "consultant" to turn to and rely on? The heartlessness of such a scene is chilling.¹⁴

Just such "nudging" was openly advocated in a 2013 article in the highly respected *Health Affairs* health care policy journal. Entitled "Decision Aids: When 'Nudging' Patients to Make A Particular Choice Is More Ethical Than Balanced, Nondirective Content,"¹⁵ the article argued for a fiduciary duty of health care professionals to nudge people away from potentially costly life-saving treatment – and gave tips on how to do so effectively.

Developers of these decision aids strive for balance, aiming to be as neutral, unbiased, and nondirective as possible. We argue that balance should not always be a goal [Instead,] decision aid developers could be considered to have a "cofiduciary responsibility" for patients since their aids influence the process of patient care—a responsibility that also requires them to be good stewards of resources.

The authors go on to recommend specific ways to nudge patients:

There are several ways in which decision aid developers could do this, all of them drawing on tools from decision psychology and the so-called nudge philosophy of Richard Thaler and Cass Sunstein. One example is normative messaging. In this case, that would involve presenting active surveillance [as opposed to cancer treatment] in decision aids as either socially acceptable (an “injunctive norm”) or popular (a “descriptive norm”), to help men consider that option more seriously. [Internal citations omitted]

The article points out that how information is presented can influence the likely patient response.

For example, if incontinence and impotence are presented as plainly stated—that is, with no detailed description of these risks—men with early-stage prostate cancer may be swayed toward the option of surgery. If instead those possible effects of surgery are presented vividly via personal stories, men may be swayed away from the surgery option.

Three examples of “nudging” will be addressed below: 1. Nudging Against CPR; 2. Nudging against IV fluids and medically delivered food; and 3. Nudging in a quality of life context.

1) NUDGING AGAINST CPR

In the June 2, 2014 *Washington Post*, Lena H. Sun wrote a story titled, “Videos aim to inform patients about their medical options at the end of life”. The videos, developed by two Harvard doctors with a company called ACP decisions,¹⁶ have had a dramatic effect on those who view them. According to the article:

More than 50 health-care systems—including all hospitals in Hawaii, the Everett Clinic in Washington state and Kaiser Permanente—are using the videos.... Carilion Clinic, which operates 10 hospitals in western Virginia and southern West Virginia, began testing the videos May 1 with patients who have advanced dementia.

According to a study analyzing the video’s effect, when CPR was described verbally, 48% wanted CPR, 51% wanted no CPR, and 1% were uncertain. In contrast, in a group shown the video, only 20% wanted CPR while 79% wanted no CPR.¹⁷

The *Washington Post* piece describes the content of the video that produced so dramatic a contrast in CPR intentions:

The video was direct and dramatic. In a demonstration of cardiopulmonary resuscitation, or CPR, a technician pushed down hard on the chest of a dummy. A white-coated doctor narrating the video laid out grim odds: “Most of the time, in patients with advanced disease, CPR does not work,” she said. As a result, patients need a ventilator to help them continue breathing. Goff watched a technician maneuver a metal instrument down the dummy’s throat to prepare for insertion of a tube that pushes air into the lungs. Then the camera zoomed to a close-up of an elderly patient, eyes closed, in a hospital bed. He had a breathing tube in his mouth. Equipment surrounded his bed. “You cannot eat or talk while on this machine,” the doctor on the video said.

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Despite this very bleak video, in fact CPR can be effective. A major meta-analysis of 98 studies that looked at 19,955 patients over a 30-year period is cited in nearly every journal related to CPR. It sought to assess the disputed issue of in-hospital cardiopulmonary resuscitation (CPR) success rates among elderly patients.

The conclusions of the study were telling. Finding a 15% average success rate, the authors wrote, “The increasing pessimism about the value of CPR, specifically, its futility in the elderly patient, is not supported by this review. The results of this meta-analysis should assist both the physician and the patient in determining the probable outcome of CPR.”¹⁸

Looking at another kind of example, many new companies have emerged to be a “one-stop shop” for advance planning, from illness all the way through funeral arrangements. According to one of these plans’ website, “Everplans partners with institutions, employers and organizations who wish to offer our tools to their members, patients and customers.” In one particularly aggressive pitch to get people to reject CPR, Everplans has an article titled, “8 Movies Where CPR Performed Miracles (but would be fatal in real life)”. Everplans prefaces this fatalistic story with a fact and “statistic”. The article says:

While cardiopulmonary resuscitation is designed to keep you alive, it’s not necessarily designed to keep all the bones in your chest in one piece. The American Heart Association states “the chance of surviving an *out-of-hospital cardiac arrest* is near zero *for a victim who does not immediately receive high-quality chest compressions...followed by additional therapy within minutes.*” However, they also report that conventional CPR can cause fracturing of ribs and/or the breastbone (sternum) in at least one third of cases. [Emphasis added]

What is so absurd about this claim is that the website encourages advance directives that will only be relevant legally while IN a hospital. This “near zero” effectiveness statistic it cites relates only to OUT-of-hospital cardiac arrest *without effective CPR!* In fact, using Medicare Provider Analysis Review, a study in the prestigious *New England Journal of Medicine* found that of 433,985 Medicare patients (all over 65) who received CPR in a hospital, 18.3% survived to discharge.¹⁹ This massive sampling of a major age group, showing an almost 1 in 5 success rate, is, more optimistic than Everplans’ article would have a user believe.

The emphasis on the possibility that CPR might break bones is striking. Of course, broken bones can frequently heal, while the death that is presumably inevitable without CPR is irreversible—a point not stressed by “decision aids” designed to nudge against CPR rather than dispassionately provide balanced pros and cons for the patient to weigh.

2) NUDGING AGAINST IV FLUIDS AND MEDICALLY DELIVERED FOOD

Caring Connections, a program of the National Hospice and Palliative Care Organization (NHPCO), describes itself as a “national consumer and community engagement initiative to improve care at the end of life.” The company claims that since 2004, Caring Connections has provided more than 1.7 million advance directives to individuals. The negative view Caring Connections takes about simple IV fluids is startling.

Caring Connections has a 2-page informational piece relating to artificial nutrition and hydration. In this material, under the heading, “What happens when artificial nutrition and hydration is given to patients who are at the end of life?” it writes, “Artificial nutrition and hydration will not bring the person back to a healthy state. Most doctors agree that artificial nutrition and hydration can increase suffering in patients who are dying and no longer have the ability or interest to eat food and drink liquids themselves. Artificial nutrition and hydration can add more discomfort to a dying person’s physical symptoms such as: bloating, swelling, cramps, diarrhea, and shortness of breath. It is important to remember that the person’s body is beginning to shut down because of the disease and dying process, not because of the absence of food and liquid.” [emphasis added]

This pessimistic view about hydration and nutrition not only is clearly designed to persuade readers to reject them, but it omits any description of the suffering associated with such rejection. According to the National Institute of Health, dehydration begins with feelings of thirst, headache and muscle cramps. It accelerates to include irritability or confusion, rapid heartbeat and breathing, and shock—ultimately ending in death.²⁰

A set of advance care planning materials from the Center for Practical Bioethics is called “Caring Conversations.” It characterizes food and fluids in a similarly negative way. The material states:

Artificial feeding is often assumed to relieve symptoms and prolong life, but the reality is that it causes more symptoms and can shorten life in advanced illness. Tube feedings can cause more symptoms such as pneumonia, bedsores, vomiting, lung congestion and diarrhea. It also shortens survival in most end state diseases. Therefore, it is not the same as eating normally. Providing IV fluids to someone who is dehydrated may alleviate symptoms in the short term, and fluids are often necessary for temporary support when someone has had surgery or is hospitalized and unable to take anything by mouth. However, IV fluids provided to patients who are dying usually cause more symptoms and do not prolong survival.

In fact, what people experience when faced with decisions regarding nutrition and hydration varies widely depending on the particular illness and many other factors, but this material seems designed to lead people to believe that giving food and fluids will worsen an underlying condition, when that is almost never medically the case.

What are the facts? A major global study concluded:

Malnutrition is commonly observed in cancer patients and adversely affects the quality of life (QoL) and survival of these patients. It is caused by a variety of factors, including decreased food intake, adverse effects from anticancer treatment and wasteful metabolic processes. Over the past two decades, there have been major advances in the methods and techniques used in the dietary therapy of patients with cancer and other diseases. Enteral nutrition is developing rapidly as endoscopic techniques have made it simpler to place feeding tubes, and a variety of enteral nutrition solutions are commercially available.²¹ [Internal citations omitted]

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What would a truly balanced informative piece say? An example is that on the website of the ALS Association, which advocates for people with Lou Gehrig's disease:²²

What are the advantages of getting a feeding tube?

To maintain hydration and a safe way to administer medications.

To have a decreased risk of aspiration pneumonia.

To decrease the risk of choking, chewing or swallowing problems when eating.

To help you maintain weight, reduce fatigue and improve your resistance to infection.

To conserve energy and time getting your food by mouth, simplify your meals, and reserve energy for other activities.

What are some reasons people don't want a feeding tube?

Insertion of a tube is a surgical procedure.

Fear of potential side effects:

A slight risk of infection at the tube site.

Pain or discomfort at site of insertion.

It does not prevent the progression of ALS.

Lack of control over the disease.

This balanced information is a far cry from the far more common advance care planning descriptions, like those quoted above, designed to give the impression that medically assisted provision of food and fluids will almost certainly worsen an underlying condition.

3) NUDGING IN A "QUALITY OF LIFE" CONTEXT

A 2014 report from the Institute of Medicine, "Dying in America,"²³ advocates expansion of advance care planning. The report's bias and motivation is on full display in the opening summary:

In the absence of adequate documented advance care planning, the default decision is to treat a disease or condition, no matter how hopeless or painful. A result of inadequate advance care planning, therefore, can be more intensive treatment, as well as more negative impacts on family members. Because most people who participate in effective advance care planning choose maximizing independence and quality of life over living longer, advance care planning can potentially save health care costs.

A major hospital system in Georgia, WellStar, serves more than 1.4 million area residents. WellStar created Advance Care Planning material that is used not only within its system but also by many major insurers. Its information booklet poses hypothetical questions, all extreme; each is meant to discourage treatment that might be very appropriate in less dire circumstances.²⁴

Imagine...You are in an intensive care unit of a hospital. Without warning, you have a life-threatening illness. Despite the best medical treatment, your physicians believe that it is unlikely you will leave the hospital alive. You are no longer able to interact with anyone. At this point, your heartbeat and respiration can be prolonged for some time through continued use of artificial life support. What would your goals be for medical treatment?

Imagine...You are living at a nursing home because your ability to make your own decisions is gone. You can feed yourself and interact, but the meaning of your interaction is minimal because you no longer know who you are, who your family members are or what happens from one moment to another. You will never regain your ability to interact and will likely get worse over time. (Such a condition is likely to occur because of a disease like Alzheimer's.) What would your goals be for medical treatment?

In another attempt to lead people to believe that life under certain conditions will be unbearable, the American Bar Association has a set of advance care planning materials that are circulated far and wide. The packet it created is linked to on nearly every government²⁵ and private website that refers to other guidance for advance care planning.

In the packet is a portion ominously titled, "Are Some Conditions Worse Than Death?"²⁶ On a scale from one to five, the patient is supposed to rank items (from "Definitely Want Treatment" down to "Definitely Do Not Want Treatment"). Then, the material goes on to frame condition after condition in the most negative light imaginable. Its authors write:

What if You....No longer can recognize or interact with family or friends; No longer can think or talk clearly; No longer can respond to commands or requests; No longer can walk but get around in a wheel chair; No longer can get outside and must spend all day at home; Are in severe untreatable pain most of the time; Are in severe discomfort most of the time (such as nausea, diarrhea); Are on a feeding tube to keep you alive; Are on a kidney dialysis machine to keep you alive; Are on a breathing machine to keep you alive; Need someone to take care of you 24 hours a day; No longer can control your bladder; No longer can control your bowels; Live in a nursing home permanently.

Who would choose any of these options when they are presented in such an unbelievably negative way? Where is the balance? What about people who might live amazingly full lives in wheelchairs, or might be receiving kidney dialysis pending a life-extending transplant? Many people spend much or nearly all of their time at home; are their lives less meaningful? The American Bar Association document certainly implies that.

Another example of "nudging" is a patient decision-making aid published by the Department of Veterans Affairs that was the subject of considerable discussion during the debate over the Patient Protection and Affordable Care Act, a 53-page production entitled "Your Life, Your Choices."²⁷

The booklet had worksheets to fill out for "Current Health," "Permanent Coma," "Severe Dementia," "Severe Stroke" and "A future situation of concern when I might not be able to express my wishes." For each of these there was a section on "quality of life." Only for current health was there a choice to affirm that life is worth living without reservation. For all of the others, the choices were "Life like this would be difficult, but acceptable," "Life like this would be worth living, but just barely," and "Life like this would not" – the "not" is underlined – "be worth living."

In each circumstance except current health, a negative picture was given. For example, “Terminal Illness” was described as a state in which you “have a lot of discomfort that requires medication [,] are in bed most of the time due to weakness [, and] need help with getting dressed, bathing, and bowel and bladder functions.”

Of course, what people experience when terminally ill varies widely depending on the particular illness and many other factors, but this booklet seemed designed to lead people to believe that life with terminal illness will be almost unremittingly bleak.⁺⁺

In the words of Paul Malley, president of the national non-profit organization Aging with Dignity, “Your Life, Your Choices’ encourages our nation’s service men and women to look at illness and disability as things that render life not worth living.”

Conclusion

Significant safeguards would need to be incorporated in any governmental program promoting advance directives or advance care planning in order for such a program to be truly protective of the values and intent of patients, and to ensure they are not pressured into rejecting treatment against their wishes. Further, materials being distributed by companies and organizations ought to be viewed with a skeptical eye to ensure that people are not pressured into rejecting treatment against their wishes – all in the name of cost-savings.

⁺⁺The lead author was Dr. Robert Pearlman, the chief of Ethics Evaluation for the VA’s National Center for Ethics in Healthcare. Given the excerpts, it should come as little surprise that Dr. Pearlman was one of a group who filed a brief before the Supreme Court in 1996 urging the Court to recognize “physician-assisted suicide . . . as a fundamental right.” Brief of *Amicus Curiae* Bioethicists Supporting Respondents, at 1 (Pearlman listed in Appendix A), *Washington v. Glucksberg*, 521 U.S. 702 (1997) & *Vacco v. Quill*, 521 U.S.793 (1997).

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ABOUT THE ROBERT POWELL CENTER FOR MEDICAL ETHICS

The Robert Powell Center for Medical Ethics at the National Right to Life Committee is dedicated to the memory of longtime National Right to Life Vice President Robert Powell, a Texan with a disability, who served as a leader in the struggle to protect the lives of people with disabilities and older people from euthanasia and assisting suicide.

Since its founding in 1968, the National Right to Life Committee has always opposed infanticide and euthanasia with the same determination and vigor with which it fights abortion. The November 1973 issue of *National Right to Life News* carried a lengthy examination of so-called “mercy-killing.” Proposals to legalize assisting suicide and euthanasia, and to ration health care, remain a constant threat. Even less well known is the widespread use of “futility protocols” at health care facilities. “Ethics committees” frequently use these protocols to deny treatment, nutrition, and hydration against the express will of patients and their families, due to a perceived inadequate quality of life.

The Powell Center for Medical Ethics has several major areas of concentration:

- Protecting against the legalization of direct killing and efforts that would legalize euthanasia, on the one hand, and proposing protective legislation, on the other.
- Protecting against involuntary euthanasia by providers by working against “quality of life” policies that allow providers to deny lifesaving medical treatment, food, and fluids against the will of patients and their families
- Fighting against rationing of life saving medical treatment - and often food and fluids - at the federal and state level. This includes working for repeal of Obamacare because its most dangerous provisions would result in the rationing denial of lifesaving medical treatment, and consequent premature and involuntary death of an immense number of Americans.
- Advocating for the “Will to Live” Project, a state-specific advance directive that differs from traditional “living wills,” by clearly expressing a preference for life, including presumptions for lifesaving medical treatment, food, and fluids.



Robert G.B. Powell (1950-1995)
National Right to Life Vice President
1991-1995



Founded in 1968, National Right to Life is the nation's oldest and largest national pro-life group. National Right to Life works to protect innocent human life threatened by abortion, infanticide, assisting suicide, euthanasia and embryo-killing research. National Right to Life is a non-partisan, non-sectarian federation of 50 state affiliates and more than 3,000 local chapters. National Right to Life is governed by a representative board of directors with a delegate from each state affiliate, as well as eight directors elected at-large.

National Right to Life's efforts center around the following policy areas:

Abortion: Abortion stops a beating heart more than 3,000 times a day. National Right to Life works to educate Americans on the facts of fetal development and the truth about abortion; works to enact legislation protecting unborn children and providing abortion alternatives in Congress and state legislatures; and supports activities which help women choose life-affirming alternatives to abortion.

Infanticide: National Right to Life works to protect newborn and young children whose lives are threatened and who are discriminated against simply because they have a disability.

Euthanasia: Through the work of the Robert Powell Center for Medical Ethics, National Right to Life fights rationing of health care on a national level, such as in the context of Medicare legislation or more general health care reform. National Right to Life speaks out against efforts by the pro-death movement to legalize assisting suicide and euthanasia based on an ethic which says that certain persons do not deserve to live because of a perceived "low quality of life." National Right to Life also makes available to individuals the Will to Live, a pro-life alternative to the living will.

BIAS AGAINST LIFE-PRESERVING TREATMENT

ABOUT NATIONAL RIGHT TO LIFE: THE NATION'S OLDEST & LARGEST PRO-LIFE GROUP

National Right to Life works to restore protection for human life through the work of:

- the **National Right to Life Committee (NRLC)**, which provides leadership, communications, organizational lobbying and legislative work on both the federal and state levels.
- the **National Right to Life Political Action Committee (NRL PAC)**, founded in 1979 and the nation's largest non-partisan, pro-life political action committee, which works to elect, on the state and federal level, officials who respect democracy's most precious right, the right to life.
- the **National Right to Life Victory Fund**, an independent expenditure political action committee founded in 2012 with the express purpose of electing a pro-life president and electing pro-life majorities in the U.S. House of Representatives and U.S. Senate.
- the **National Right to Life Educational Trust Fund** and the **National Right to Life Educational Foundation, Inc.**, which prepare and distribute a wide range of educational materials and advertisements.
- various **outreach efforts** to groups affected by society's lack of respect for human life: the disability rights community; the post-abortion community; the Hispanic and African-American communities; the community of faith; and the *Roe* generation – young people who are missing brothers, sisters, classmates and friends.
- **National Right to Life NEWS** – published daily Monday-Saturday and available at www.nationalrighttolifeneeds.org, is the pro-life news source of record providing a variety of news stories and commentaries about right-to-life issues in Washington and around the country.
- the **National Right to Life website**, www.nrlc.org, which provides visitors the latest, most up-to-date information affecting the pro-life movement, as well as the most extensive online library of resource materials on the life issues.

This report may be downloaded from the National Right to Life website at:
www.nrlc.org/uploads/communications/advanceplanningbias2015.pdf



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