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Moving Away From Death Panels: Health Reform for the Way We Die

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There is surprisingly little disagreement about what constitutes good care at the end of life, but we still can't seem to fix any of our problems.



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Later this month the United States Supreme Court will dedicate three days for hearings on the Accountable Care Act (ACA). As the Justices deliberate whether the federal government has the authority to require individuals to purchase health insurance, health care reform is certain to figure prominently in the presidential campaign. Core national values are at stake. With health care costs surpassing 16 percent of our gross domestic product, budget deficits soaring, and nearly 50 million Americans without health insurance, the question is not merely how to pay for health care, but what it means to live *in community with* one another, rather than merely *in proximity to* one another.

Debate over the ACA, commonly called ObamaCare, is likely to remain acrimonious. Tempers have flared over payment for abortion services and contraception. At the other end of life, tensions smolder. Social conservatives particularly distrust the motives of health reformers, suspecting that policy makers and bureaucrats give higher priority to cutting costs than respecting and preserving life.

Culture war politics has already derailed a valuable provision in the original version of health reform that would have reimbursed doctors for appointments to discuss patient's preferences for care at the end of life. In the summer of 2009, the bill's opponents tied the clause to everything from "death panels," to killing Granny, to euthanasia. So, despite having had broad bipartisan support when the bill was written, Democrats pulled the plug on that section.

The opponents' hyperbole was tactical, meant to engender fear and anger among the Republican base of social conservatives. Unfortunately, it became fuel for a theater of cultural conflagration that need not exist.

In fact, there is surprisingly little disagreement about what constitutes good care at the end of life. A year before the kerfuffle, Governor Sarah Palin signed a proclamation encouraging all Alaskans to have discussions with their families about their preferences for care and to complete advance directive documents. Prior to that summer Newt Gingrich spoke often about the exemplary care that his wife's father and their family had received at Gundersen Lutheran Hospital in La Crosse, Wisconsin, as he died in 2006, care which included thorough advance planning conversations.

A February 2011 member survey by the National Association of Evangelicals (NAE) confirmed that evangelicals "honor life from womb to tomb." It also revealed that a large majority accepted death as a part of life. Eighty-five percent of comments on the survey expressed concerns about extraordinary measures to prolong life. This sentiment is consistent with long-standing position statements of the NAE, which state, "We believe there is a profound moral distinction between allowing a person to die, on the one hand, and killing on the other," and "[M]edical treatment that serves only to prolong the dying process has little value."

It's time for conservatives and progressives to declare a truce on these issues before we lose valuable opportunities for health reform to substantially improve the way Americans are cared for and die.

Major improvements are urgently needed and the challenges we face cross cultural and political lines. For one thing, people are a lot sicker before they die than at any time in history. Up until the middle of the 20th century, life-threatening injuries, infections, or heart attacks would swiftly waft people away. The first episode of pulmonary edema commonly killed those with congestive heart failure. Cancer was typically an illness that lasted weeks. Nowadays, people commonly survive even severe trauma, are cured of infections, and live for many months and sometimes years -- often quite well -- with cancer, heart, lung, kidney, and liver disease. In effect, we invented chronic illness. That's a very good thing.

Regrettably, however, the dominant mindset of American medicine has become "more is better." Newer and more sophisticated treatments or medical devices are better still. If a treatment might work, why not try it?

It's worth pausing to recall that we have yet to make even one person immortal. Instead, we have made dying a lot harder than it has to be. In the course of a progressive illness, there almost always comes a point when more treatment is not better care.

Real reform can start from a base of good intentions and widely held values -- including reverence for life - - that are shared by people of all religions and by social conservatives and progressives alike.

When someone we love is seriously ill, we all want the best care possible. For most people, that includes effective treatments to enable them to live longer along with skillful attention to comfort to enable them to live well. When it comes their time to leave this life, most people want to die gently.

Naturally, one size does not fit all. Ethnicity, culture, religion, family, and personal history all influence an individual's choices. What is best for one person would be wrong for another. And the best care for someone at an early stage of illness might well not be the best care later on.

Working as a physician within a palliative care team at an academic medical center, much of my practice focuses on helping seriously ill people and their families clarify their values and preferences, and apply them to their particular medical condition and circumstances. Often, that entails helping people weigh the potential benefits of a treatment against the known and potential burdens.

This process of shared decision-making is an example of patient-centered practice that is advanced by the Affordable Care Act. Most importantly, key provisions of the law make local health systems -- comprised of doctors, hospitals, clinics, laboratories, and imaging facilities -- responsible for both quality and costs. The new approach, called accountable care, also makes health systems' performance data freely available to the public.

This new way of doing business amounts to a sea change that can move our health care system toward personalized, safer, and more effective care. Suddenly, things like care planning, thorough communication and coordination of care, ongoing monitoring, meticulous medication management, prevention and early response to problems, and shared decision-making -- all of which are currently reimbursed poorly, if at all - - acquire substantial economic value. Higher quality and lower costs are aligned.

It's time to dampen the culture war rhetoric and acknowledge broad agreement on the basics of what constitutes optimal care. Working together, across cultural and political spectrums, we can ensure that people reliably receive care that responds to their individual needs and honors their personal preferences. We must accept no less. But we need not be constrained to clinical and ethical fundamentals. Americans are a caring people. If we have the will, whatever the Supreme Court decides and whoever is elected president in 2012, we have the wherewithal to enable people to feel wanted, worthy, and dignified through their final days.