

## What About Margo?

Bill Colby

Americans hear a lot these days about health care from our politicians. Importing Canadian drugs. Cuts in Medicaid. Fifty million uninsured. Universal health care. Complex problems without obvious answers. Here's an idea: Why not start with a health care problem that we can fix – better care for all Americans at the end of their lives? What about Margo?

Margo was an elderly, cheerful Alzheimer's patient. Each day she listened to the same music, painted the same simple pastel shapes, randomly read from the same book. She had no memories of her earlier life or even what had happened hours before on any given day, and she could make no new memories. When Margo first learned of her diagnosis many years ago, she filled out a living will making clear that if an infection came as her dementia advanced, she did not want antibiotic treatment. She now has pneumonia. What should her family do? What should a compassionate, respectful, life-affirming society do?

The President's Council on Bioethics its recent report, *Taking Care: Ethical Caregiving in Our Aging Society*, concluded that doctors had a "moral obligation" to administer antibiotics to Margo regardless of her earlier living will. Dr. Leon Kass, chair of the council at the time, has written elsewhere that such a decision by a family would demonstrate "what it signifies to love another in [her] gravest need." I respect Dr. Kass's work and writings, but for me, the actions he describes do not signify love.

Dementia runs in my genes. If years from now my wife and four adult children have watched me slide down the abyss of Alzheimer's to the point that I do not know them, and an infection comes to me, I hope they say "no" to penicillin. That, to me, would signify love, respecting beliefs I'd shared with them when I was most fully myself. The whole purpose of medical treatment for me is to act as a bridge to recovery. When it cannot, then medical treatment beyond that which eases suffering is not appropriate. I find it wrong for my value system, and contrary to my religious beliefs, to say that medically treating the infection in my demented body is something I "need" or somehow such medical intervention is "loving me."

It's not. Medicine's value to me will have ended.

These are not abstract questions. Of the 2.5 million deaths this year in the U.S., by far the largest group, about one million, will be the frail elderly. An estimated 500,000 of those frail elderly will suffer from dementia. (The corresponding numbers for **[insert state/city]** are **[insert]** total deaths each year, **[insert]** of those the frail elderly). And the numbers are poised to skyrocket – the Census Bureau says that in 23 short years, in 2030, 44 of the 50 states, including **[insert state]**, will have the elderly demographic that only

Florida has now. The hard questions about end of life issues are rising before us like a great wave.

Why would a savvy politician wade into such a seemingly sensitive debate? Simple. Better end-of-life care is a problem we can fix. The solution will cost taxpayers nothing. And, remarkably, that solution is relatively simple. There are communities sprinkled around the country where citizens have started a community dialogue about better health care at the end of life. The result in those communities – higher hospice usage, lower in-hospital death rates, fewer unwanted ICU and ER visits, better treatment of pain.

In other words, talking about dying improves how we die. I traveled across the U.S. for many years, talking about how we can care for one another better at the end of our lives. Of particular concern at every stop was how we navigate the brave new world of medical technology so pervasive at life's end, and which most of us when surveyed say that we do not want.

I'm convinced that this navigation will best take place through sharing stories with one another – talking about Terri Schiavo, and the father across the street who fell and broke his hip, and Aunt Ruby's stroke. And Margo.

War, global warming, the economy – our country, and our political leaders, face many challenges. As we begin the remarkable democratic process of electing a new president, I want to know about all of these issues. But wouldn't it also be fascinating to hear each candidate answer this question: "What about Margo?"

**[Alternate ending, non-election time.]** War, global warming, the economy – our country, and our political leaders, face many challenges, and I want to know what those leaders think about all of these issues. But wouldn't it also be fascinating to hear answers this question: "What about Margo?"

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