



words *matter*

By Caryn Sullivan

How Will Haste and Heavy-handedness Make Health Care Better?

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I am beginning to think that contracting breast cancer in 2003 was a blessing in disguise. For if proposed health care reforms are enacted, I question whether future breast cancer patients would have my positive experience. These thoughts persist as I attempt to follow the debate about health care rationing, cost containment, and governmental involvement.

It is impossible to track ever-changing proposals, floated by competing factions racing to meet or avert artificial deadlines. It is difficult to dismiss my churning anxiety over the speed with which elected officials are acting on such overarching change.

I've had a lot of experience with Minnesota's medical care. In the past decade, I have managed my family's complex medical crises, often resolving them satisfactorily because I acted as a consumer, persistently seeking answers and aggressively pursuing solutions. Before my breast cancer, my marathon-running husband had a heart attack. In 2005, our daughter had a bone marrow transplant. Our son has autism.

I never dreamed I would have so many "ologists" in my contact list – cardiologist, oncologist, hematologist, neurologist, to name a few – but they are great doctors – the best I could obtain for my family. As I contemplate the future of those relationships, I have huge angst. The president claims he does not want to stand between patients and their physicians. Yet, many who have evaluated his plan contend that would likely happen. Why would I forfeit the right to control some of my most important relationships to cost-cutting bureaucrats who know nothing about me?

We're told doctors order diagnostic tests unnecessarily, escalating health care costs. My experience has been quite different. The first doctor who read my mammogram did not see the lump we both felt so she ordered an ultrasound that confirmed it was there. Later, my surgeon ordered an MRI, which illuminated not one tumor, but five. If cost was the driving consideration, could the surgeon have ordered the MRI? It dictated my treatment. With one tumor, a lumpectomy was a viable option. With five, a mastectomy was the only choice, but it raised other issues, all of which I was empowered to decide under the terms of the health insurance contract we had secured.

How would proposed reforms affect a future cancer patient's ability to manage her care as I did in 2003? Could she obtain a second opinion from a surgeon? Choose either a single or a double mastectomy? Could she select one of several reconstruction options,

at no additional expense, or would reconstructive surgery be subject to the proposed surcharge on plastic surgery? As a Stage I patient, could she opt for the less potent chemotherapy regimen, regardless of cost, and receive the drugs in a timely fashion, or would she have to wait in line for an IV pole behind Stage II, III, or IV patients?

Our daughter's situation raises other concerns. At 10 years old, she acquired a blood disease, diagnosed after months of visits with doctors who, in retrospect, did not do enough testing. Her health declined for six months before we consulted a third hematologist, who ordered the test that produced the rare diagnosis.

Curing the disease was problematic. She could live with it, for a while, obtaining periodic blood transfusions, taking steroids and a blood thinner to fend off a deadly blood clot. Or she could undergo a bone marrow transplant – a costly, risky, but effective procedure. In 2005, we were able to select the transplant as her first recourse, rather than her last. We proceeded within three months of her diagnosis, still insured by a comprehensive policy. Today, she is disease-free, with no known residual effects of the transplant. I cannot imagine what would have happened if she could not have had the transplant when she did.

When another child is diagnosed with a rare disease, how would proposed reforms affect his right to both opt for a transplant and determine the timing of it? Would such an expensive procedure be rationed? Who would go first - the kids for whom transplant is their last hope or the kids who have more time before they reach that stage and may be better able to survive the rigorous transplant process? Would providers who work horrendous hours to rescue kids from potentially terminal illnesses be fairly compensated for the costly but life-saving therapy?

Overall, the quality of our medical care is probably somewhere between inadequate and ideal. The health care debate must be about more than saving costs and insuring those who either choose not to or are unable to secure insurance. It must also be about respecting relationships between providers and patients; fairly compensating those who take our blood pressure, deliver our babies, and replace defective heart valves; and preserving the medical advances that save millions of lives every year, to the envy of other nations.

Such critical issues warrant the protracted, considered debate typical of Washington. Absent that, I beseech President Obama and Congress to either keep their hands off my health care - or give me the same coverage they have.