



Peace of mind at end of life

For individuals and loved ones, Michigan's advance-directive registry makes medical wishes known everywhere in the county

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Good public policy takes time. The Michigan "Peace of Mind" Registry has taken more than six years, from the time the concept was created until the registry website went live earlier this year.

During that time, I ran two elections, moved from the state House to the state Senate, moved from the minority party to the majority party, negotiated numerous iterations of the bill with multiple state departments and stakeholders, and renegotiated the bill as key staff changed throughout the years.

In July 2012, Gov. Rick Snyder signed SB 723 into law. Almost three years later, Michigan's Peace of Mind Registry began accepting the first advance directives.

It began back in 2009. Michigan had been suffering years of budget deficits, and as the ranking Republican member of the House Health Policy Committee, I was given direction to find savings in Medicaid services. The statistic at the time, and probably still true today, was that roughly 80 percent of the health care expenses in your lifetime will come within the last two of years of your life. I thought that might be the best place to start.

An unexpectedly complex issue

This is when I first learned about the complexity around advance medical directives. When I thought about end-of-life decisions, the only thing that came to mind was a living will.

Michigan law had a definition of an advance directive as a document that would allow for residents to designate their durable power of attorney for medical issues and outline their end-of-life decisions. I did a little research and found out that only a small fraction of our population had an advance directive, and of those, only about one-third had that directive utilized during hospitalization.

This is when it turned from a policy and budget issue into something much more personal.

Everyone I talked to on the subject had a personal story about dealing with difficult decisions at the end of life. I have never had to directly deal with a situation in which I had to make a decision regarding a loved one's medical treatment, and I'm very fortunate to never have faced that process.

It was eye-opening to hear stories from friends and colleagues who shared details of families being torn apart over how someone wanted their life to play out. My mission then became to make this about the individual and what each person wanted his or her end-of-life wishes to be.

My first attempt at legislation would have created a statewide registry for advance directives that would be tied to one's driver's license. It seemed simple enough; the state had added heart icons to state IDs to designate organ donors. As it turns out, though, it is much more difficult and extremely expensive to add anything to a state document, let alone one that had no real support or any monetary return on investment.

Facts, figures on end-of-life care

- ✓ Almost a third of Americans see 10 or more physicians in the last six months of their life.
- ✓ 70 percent of Americans say they would prefer to die at home, but only 24 percent of those over 65 actually do. Nearly 70 percent die in a medical facility.
- ✓ 25 percent of all Medicare funds are spent on the 5 percent of patients who are in their final year of life.
- ✓ 40 percent of households find that the costs of end-of-life care exceed their assets.
- ✓ Six of 10 people say they don't want their family burdened by end-of-life decisions, but nearly as many (56 percent) have not communicated their preferences.
- ✓ 35 percent of Americans have actually written and stored some form of advance directive with instructions for treatment in the event that they are unable to communicate with their doctor.
- ✓ One large-scale study of cancer patients found that costs were about a third less for patients who had end-of-life discussions than for those who didn't.

Sources: National Public Radio, Money.com, AfterCares

Then, representatives of Michigan's chapter of Gift of Life sat down with me. (The organization was the driving force behind adding the organ-donation option to driver's licenses.) The group had a vested interest in advance directives, since there was no way for a person to refuse to have their organs donated once they were dead.

After a few years and countless discussions, they agreed to become a partner for the broader cause of advance directives. They offered free use of their extensive network with health care providers. We decided that a registry would need to be broad enough to accept any document for an end-of-life decision, whether it was about organ donation, durable medical power of attorney, or even disposition of remains.

I rewrote the legislation around this concept of a repository for these decision documents using the Gift of Life network. A federal rule states that when a hospitalized patient is checked for organ-donation status, they must be checked in their state of residence.

Registry has nationwide reach

By using Gift of Life's network, when a Michigan resident with an advance directive on the registry is checked for organ-donation status anywhere in the country, that health care provider will be notified that the patient has a document regarding his or her end-of-life wishes. This makes Peace of Mind the first registry accessible for residents anywhere in the country for any provider.

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However, there were still significant political hurdles to cross. We are now in a post-Affordable Care Act world where the media uses terms such as "rationing" and "death panels" when it comes to end-of-life care. Likewise, Michigan was once home to the infamous Jack Kevorkian, who brought the debate over physician-assisted suicide to national attention in the 1990s.

I spent countless hours with my legislative colleagues explaining the nature of the bill, and almost every time it ended in a personal story about one of their friends or family members. It had taken almost four years to get to this point, but the bill passed both legislative chambers nearly unanimously, with full bipartisan support and 34 of 38 senators co-sponsoring the bill.

It took more than two years for our Department of Community Health and Gift of Life to develop a website and to have the proper data-sharing agreements in place. I'm proud that you can log on today to www.mipeaceofmind.org as a Michigan resident and sign up to have your advance directive available anywhere in the country.

However, my work is not over yet. The next step is to get the word out, and I've worked with hospitals, physicians, financial planners, retiree groups, and many others to educate people on advance directives. I've included language in statute for our Medicaid contracts in Michigan as well.

We need to do everything we can to ensure that someone's end-of-life wishes are followed with respect and dignity. It was a good day for me when I could finally put up my advance directive so that my own family has that peace of mind. ★

Sen. Jim Marleau, a Republican from Lake Orion, was first elected to the Michigan Senate in 2010 and is a member of its Health Policy Committee. He previously served six years in the House.

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