

Chiplock's other battle: In-home nursing care

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If Deneane Chiplock could do one thing before she dies, it would be to drive major legislative change on the issue of custodial nursing care.

Chiplock proposes that the amount of money a patient's insurance plan is willing to pay toward nursing home care also be provided for in-home nursing care.

It would allow people to die with dignity at home, she says.

"Right now," she says, "we're asking families to put 30-, 40-, 50-year-olds in nursing homes" in order to receive coverage.

Few, if any, insurance plans, including Medicare, cover custodial care, defined as activities like bathing, dressing and using the bathroom. Yet custodial care is exactly what ALS patients require, and it's often provided by their families.

Steve Gibson, vice president for government relations and public affairs for the ALS Association, says it's an issue that needs reform.

Medicare will cover only a certain number of hours of custodial care if a patient also has a skilled nursing need, he says, such as being trained on a piece of therapy equipment. Worse, he says, nursing homes don't want patients with ALS.

"They don't want to assume those responsibilities if someone is immobile. They are so much more responsibility."

Chiplock's frustration spurred her to go to Washington, D.C., in May to participate in the ALS Association's National Advocacy Day and Public Policy Conference and to meet with her Michigan senators.

In an impromptu speech from the convention floor, she captured the attention of 400 conference attendees by chastising ALS Association officials for not making the reform of nursing care a top priority on their national agenda.

"I got a standing ovation because I said what everyone else wanted to say," she says.

Gibson was there: "Everyone looked and said, 'Who is this person?' She has the courage to address this as a fatal disease. That gets people to pay attention. I know that Senator (Carl) Levin was very, very touched by her."

After her speech, Levin, a Michigan Democrat, met with Chiplock and became a cosponsor of a Senate bill aimed at eliminating the five-month waiting period for the terminally ill to receive Social Security Disability Insurance.

He also told Chiplock in a follow-up letter that he has asked his staff to look into ways of addressing the issue of custodial care.

Sen. Debbie Stabenow, also a Michigan Democrat, says the young mother caught her off guard. "To have someone sitting in my office in a wheelchair saying, 'I'm here now because a year from now I may not be living or able to speak' -- she was very powerful," Stabenow says.

Although Stabenow, also a cosponsor on the bill aimed at eliminating the five-month waiting period for the terminally ill, is supporting legislation that would give some compensation to caregivers, she admits that custodial care has not been addressed.

"We've been talking about the best way to do it."

Meanwhile, her office contacted Chiplock in December to see how she was doing. Chiplock asked about the possibility of testifying before a committee. When told nothing would happen before late January because of the new Congress, she replied, "I might not be here."

Still, Chiplock will do what she can.

"Nothing is going to happen in time for us," she says. "But if it helps other families, if other people don't have to go through the nightmare we've gone through, that's all that matters."

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