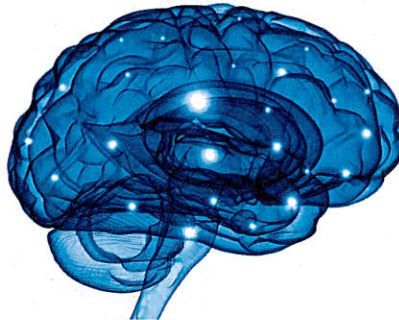


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## Guest column: Make care available to all who have dementia



(Sergey Khakimullin/Dreamstime/TNS)

One of the most common misconceptions about Alzheimer's disease is that it's a "normal" part of aging. But that is not the case.

At age 32, my beautiful daughter Rhonda was diagnosed with Alzheimer's. In fact, the Alzheimer's Association estimates that of the more than 5 million Americans living with the disease, 200,000 are under the age of 65. And while her journey with the disease was short — she died two years after diagnosis — her ability to access quality care and support services was limited. As anyone who is living with Alzheimer's or providing care to an individual with the disease knows, these resources are critical to navigating the challenges ahead.

Palliative and hospice care are vital services for people with Alzheimer's and other dementias. For people with advanced dementia, team-based care — which focuses on managing and easing symptoms, reducing pain and stress, and increasing comfort — improves quality of life, controls costs, and enhances patient and family satisfaction. Here in Oregon, 19 percent of people in hospice have a primary diagnosis of dementia. Yet, the availability and quality of palliative and hospice care is a concern. With Rhonda, I was in the process of arranging for hospice care for her when she passed.

Rhonda was not alone in her need. Nearly half of all people with Alzheimer's and other dementias are in hospice care at the time of their death, but today, less than half of surveyed nursing homes report having some sort of palliative care program. Of those with a program, only 42 percent include consultation by a physician certified in hospice/palliative care, and only 28 percent have a designated director of palliative care.

While the availability of palliative and hospice care is growing, the need is growing faster. In 2000, less than one-quarter of U.S. hospitals had a palliative care program; however, by 2013 that had increased to three-quarters. This number contrasts with the fact that only 265 physicians were trained in hospice and palliative medicine in the 2014-15 academic year, and according to an expert task force, more than 6,000 full-time health care professionals are needed to serve current palliative and hospice care needs alone. We are making progress, but more has to be done.

Thankfully, there is growing bipartisan support for transformational legislation — the Palliative Care and Hospice Education and Training Act (PCHETA) (Senate Res. 693/House Res. 1676) — to ensure an adequate, well-trained palliative care workforce through workforce training, education and awareness, and enhanced research. PCHETA would make this critical service available to millions of Americans by establishing workforce training programs, creating a national education and awareness campaign to inform the public about services and supports, and enhancing research on improving delivery of palliative care.

This legislation is pending before the House Energy & Commerce Committee chaired by Oregon's own Greg Walden, R-Hood River. For 11 years I have been an advocate in the fight not only to end Alzheimer's but also to support those living with this cruel disease and their caregivers. As an advocate with the Alzheimer's Association I have had the opportunity to get to know Representative Walden, and have shared the impact of this disease on my family as well as the estimated 63,000 Oregonians living with Alzheimer's.

Please join me in asking Representative Walden to support this worthy legislation and, in his role as chairman, to bring PCHETA up for consideration among the committee.

— *Dawn Frazier lives in Prineville.*