Social Engagement and Education for Living Well with Dementia

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My name is Paulan Gordon. I was diagnosed with Vascular Dementia eight years ago. Yes, there is no cure for the most common forms of dementia. However, this does not mean there is no treatment. I don’t mean prescriptions, even though they are widely prescribed (Namenda and Aricept primarily).

One of the first things that happens when individuals are diagnosed with dementia is that they lose their occupation with obvious and not so obvious repercussions. It is not just a career and income that people lose when they lose their jobs. Many people lose their identity and social interactions. They lose their sense of purpose and retreat to their beds, literally and figuratively. It is incredibly sad and a waste of opportunity for these individuals.

I strongly recommend social engagement with other individuals living with dementia. This engagement not only provides social stimulation. Engagement also provides support, and people learn coping skills from each other. Dementia Mentors (www.dementiamentors.org) provides an online, free platform for social engagement. People learn that dementia is not an automatic and immediate death sentence. We meet each day online and receive encouragement and tips from each other.

Another organization that I participate in is Dementia Action Alliance (www.daanow.org). This is an advocacy organization that provides individuals living with dementia with education, support, inspiration, opportunities as well as speaking engagements. This is an opportunity to find new purpose in life with dementia as well as educate others. Purpose is critical when you have a terminal illness. It is too easy to give up and wait for death.

Physicians, please take note of what I am saying. You are in a position (at the time of diagnosis) to change a person’s life. You can either tell them to “Go home and get your affairs in order and wait to die” or “Find support from others living with this disease, learn coping strategies and stay engaged with life as long as possible”. Which is a better approach? Provide coping strategies and resources just as you would with a cancer patient.