

Thoughts by Michael Ellenbogen

The Injustice of Alzheimer's Disease

My name is Michael Ellenbogen and I am 57 years old. I knew something was wrong with me at age 39; however, it took 10 years to finally get a diagnosis of Alzheimer's disease. I have come to terms with the diagnosis, but I cannot accept how I am treated by society and the government. It seems that everyone is focused on curing cancer, which is admirable, but at what cost? Why can't the same dedication, funding and determination be directed equally toward curing dementia? Do I not deserve the same level of compassion and focus?

When someone says they have cancer those around them embrace that individual and feel sorry for them. They always ask them how they are doing. When I tell someone I have Alzheimer's, they first joke that they have it too. Then I tell them it is no joke and I do have it. Then they don't know what to say any more. In fact most of my family and friends tend to ignore it or never bring the subject up again, in fact many end up leaving.

Alzheimer's was first discovered in 1906. Breast cancer was discovered much earlier, but it was not until 1982 that people started talking about it. Then the Pink Ribbon was introduced in 1990, which seem to change things. A group was formed in 1981 for Alzheimer's and the history behind the Purple Ribbon is a bit unclear. Part of the problem was that other charities used that same symbol, which in my opinion created some confusion for what the Purple Ribbon stood for. While these key national organizations started around the same time, one failed to get national attention and the other blossomed.

When I ask people about it they tell me they tend to focus on breast cancer over Alzheimer's because there is hope with breast cancer, whereas there is no good outcome of Alzheimer's; however, they fail to realize that there could be that same hope for Alzheimer's if they were to focus their attention on it.

I speak to government officials about funding for dementia and cancer. They tell me the majority of people who come knocking on their doors for funding are those linked with cancer. If they were to get more people knocking and asking for funding for dementia they would get the same amount of funding consideration.

That statement just kills me inside. The reason you have so many people speaking up for cancer is because there are so many grateful folks who were saved by the miracles of today's treatments. That will never happen for those living with dementia. We lose our ability to talk, write, and die in the most horrific ways possible. **THERE ARE NO SURVIVORS.**

Many people with cancer have caregivers that help them through their struggles, and although cancer patients can take months or perhaps years to succumb to the disease, Alzheimer's caregivers often do it for decades. By the end, caregivers of Alzheimer's patients are so tired and overwhelmed that many fail to get their lives back to some semblance of order.

When it comes to funding, today Alzheimer's receives about \$936 **million** compared to over \$5.4 **billion** given to cancer. In fact we just received our first major increase this year of \$350 million. Cancer received around \$275 million around the same time. In actual fact cancer receives far more than the figure quoted. If you look at the NIH budget they have 3 categories for dementia and 12 categories for cancer. If you do the math it was probably in the region of \$2 billion more in 2015. What I find even sadder is I know there is a small pot of money that we all try to get money from. Unfortunately we cannot always get more money. But when we do get a little, the greedy cancer organizations come running, cry foul to the president and others, and apply all kinds of pressures for why dementia shouldn't receive money and cancer should. For that reason alone they are afraid to address Alzheimer's.

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Breast cancer is the most common type of cancer. There were around 235,000 new cases in the United States in 2015. If it is diagnosed early there is a 98% survival rate. Alzheimer's is the most common form of dementia with over 5 million people diagnosed. We have a **0%** survival rate. Alzheimer's is by far the most expensive disease to the caregiver, patient and government. In fact, it will bankrupt this country if we do nothing. And if that is not enough to change your mind, more than 500,000 people die from Alzheimer's each year. So you understand my frustrations?

It does not end there. A person who has cancer has the right to drive, make financial decisions and even the right to die with dignity. A person with Alzheimer's does not. When a person survives longer than expected with cancer we praise them and congratulate them for beating the odds. If a person with dementia lives a bit longer we never say a thing. A person with cancer can still work but not a person with Alzheimer's. Why are we treated so differently is what I keep asking myself and others?

Most know of these injustices but are afraid to call it for what it is and speak out. Just because we are not capable of asking for it does not mean we do not deserve your attention to it. Recently the president appointed the vice president to lead the fight for cancer. We had asked for years to create a czar to the president and we were told they did not want to make the same mistake as they made for other diseases in the past. We bought that but then why is it now okay for cancer? When you look at the numbers and suffering, we do the most and no one seems to care.

Don't get me wrong. I strongly believe we should be funding cancer. We should be funding both fairly. I lost my father, sister and father-in-law to cancer. The one thing they all had in common was hope. I only wish I could have some of that. Please help change that.