

Living Life to the Fullest, Even with Dementia

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I was diagnosed with Alzheimer's in 2008 after struggling for 10 years to get a diagnose. I was 49 years old. Last year I found out I did not have Alzheimer's but semantic dementia. I just turned 60 and I cannot believe I am still here. I never imagined I would live this long when they all gave me a death sentence all those years ago.

I have never spoken about what I think has prolonged my life, whether it is the steps I have taken or something else, I am of course grateful. Normally I would never make statements without the backing of scientific evidence, but since no one is like to study me at this point, I think it's important to at least share what I think I have learned, and let you decide. If there is something true in what I have learned I would not want it to die with me.

Over the course of the last decade I have become a world-renowned advocate. I have accomplished some amazing things during this time and it all because of my diagnosis. Most importantly, I have not focused on dying or what I can no longer do because I know this would have only brought me down quicker. Instead of focusing on the things I can't change, I have focused on the things that I can change, and this has been key to my survival. I also believe that becoming and advocate gave me a new purpose in life. This drive and determination has pushed me further than I thought possible, and now I focus on my future.

When I first started my advocacy, I had a very long list of issues to focus on. Normally, you get things done by concentrating on a few things at once, but there were so many issues that needed to be address in the dementia arena that I had to address them all. I find it hard to believe but I only have 4 outstanding issues today and I still continue to work on them.

I built a one-of-a-kind LinkedIn network that has over 11,000 connections, which has given me access to the most influential people in the world. Many of those folks helped me make the progress I have been able to reach today. These contacts also gave me lots of good information over the years.

Besides being in many clinical trials, I decide I was going to try my own experiments to see if I could help myself in any way since there was no cure in sight. I slowly started by adding all kinds of drugs and over-the-counter remedies that may have possibly help me. I will never know for sure. Below is a list of what I take.

Medications

Lansoprazole 30 mg daily AM

Sertraline 50 mg daily AM

Galantamine 4 mg AM, 8 mg PM daily

Memantine 10 mg AM, 10 mg PM daily

ASA 180 mg daily

Metoprolol ER 25 mg PM daily

Lisinopril 5 mg PM daily

Buspirone 15 mg PM daily

Rosuvastatin 40 mg PM daily

Cetirizine 10 mg PM daily

Multivitamin AM daily

Vitamin D3 1-2000 IU AM daily

Turmeric 1 capsule AM daily

Resveratrol 1 capsule AM, 1 capsule PM daily

Coconut Oil 2 gm AM, 2 gm PM daily

I also take 3 other drugs that I am experimenting with from a doctor from India. Very hard to get past customs unless someone hand carries it and shows it with an explanation. Not sure why it cannot just be mailed directly. While they are not proven to help, I am the only test subject. I am not able to share the name at this time. The items in bold above may be contributing to my delay of future decline. Many have been spoken about by other doctors as a possible recommendation to help with dementia.

Because of my dementia I had planned my bucket list and have been able to accomplish so many great things. By mid-2019, I will have traveled 6 continents and made some wonderful memories with my wife. I did not waste any time in my planning because I did not know how much time I had. While much of this has been very stressful I always keep pushing, which makes it a bit easier each time even though it is very tiring and sets me back each time I go. I believe the pushing has played a big role in being able to continue and delay it. Even when I knew it would be exhausting and too much for me, I always pushed on.

I even did things like skydiving that I never thought was possible. All of these things would not have happened if not for my dementia. While I am not a religious person by any means, I did get a chance to travel to Israel this year. I think I prayed more that day at the Wall more than I had prayed my whole life. I can assure you none of it was for my health.

For some reason my thinking has changed in the last few weeks. I am no longer thinking of how much time I have left but thinking that I will die from something other than my dementia. I don't know why but I seem to have made a full circle to want to live again. I am now trying to do the things I no longer could. I just will do it the best that I can. Life is too short to worry about what you can no longer do. I honestly think I may make it to 70 now. I will prove them all wrong and that is part of my passion.

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