

First of all, I would like to thank the Alzheimer Association, for making it possible for me to be here today, and reach another milestone.

As many of you know, I started reaching out to this Advisory Council when it first formed.

Helen Lamont, was kind enough to read my emails and comments, and I was given the opportunity to speak out and have a voice.

I have made a lot of progress with all of your help, but I wish I could say that a cure has been found, or even that we are close to eradicating this disease once and for all, but I can't.

I know your challenges are not easy, but I believe, that if we make, some hard choices, we can get to our shared goal.

I truly believe, that if we redirect some of the funding, budget wisely, and fairly, we could be well on our way. While all medical causes are important, I feel that Alzheimer's and other related dementias are somewhat neglected, when it comes to funding compared to Cancer and HIV for example.

We have no cure; we have no way to slow its progress. There is a certain amount of discrimination, when funding is awarded, and I for one, would like to see this change.

Would the situation be different, if we had survivors who fought for the newly afflicted?

Would things be different, if we had the awareness campaigns attributed to other causes?

Would things be better, if more people, instead of suffering in silence, stepped up and said: 'we need help'?

I think the answer to those questions, is a resounding YES!!!

Why are people afraid to step forward? Because many of us are in denial, do you think I am looking forward to my life ending in such a devastating way?

Do you think I relish the fact, that my wife is going to have to take complete care of me?

Do you think I enjoy waking up everyday thinking: “is today the day I lose my voice or my ability to feed myself?”

Don't look me in the eye, and tell there is no funding, or that you can't get the support from your constituents! Please, fight for the more than 5 million Americans, living with Alzheimer', fight for me.

Someday, someone close to you, may be impacted by this disease. We are all paying the cost for not being proactive; we will all bear the cost if something is not done soon.

### **Talking Point #1**

Recently, the government has implemented a national plan, that addresses the growing needs of more than 5 million Americans living with Alzheimer's

As part of the National Plan, the government is looking at enhancing public awareness, through awareness campaigns, websites, etc. But this needs to be done on a large scale, for it to be effective.

The National Plan, includes a commitment to prevent, and effectively treat Alzheimer's disease by 2025. The time is now, for the government, to make a commitment to provide the funding necessary to make this goal a reality.

It is my hope, that this advisory council, recognizes the value voices, of people living with the disease, can bring to this process, and includes our perspective, in the development of the national plan.

### **Talking Point #2**

Let us talk about the stigma, of having Alzheimer's.

There are many misperceptions, surrounding Alzheimer's, to the extent, that even those of us who have the disease, often have misleading ideas about it.

Many caregivers, go through this journey alone, because they fear the reaction of others, to their loved ones diagnosis.

I have chosen to be an advocate, and share my story with others, on a national platform, as an Alzheimer's Association National Early-Stage Advisor. I do this because, I feel that the louder we shout about this problem, the more people will become aware of it. And as you know me, I do a lot of shouting.

This council has the opportunity, to make a significant impact, on the elimination of Alzheimer's stigma, and ensure, that individuals, and families living with dementia, do not have to experience this journey alone. Through public awareness campaigns, changing policies, implementing new policies, and prioritizing funding.

It is imperative, that you accept members on to the council, who are themselves are living with Alzheimer's disease. This will have a number of positive outcomes:

One, you will be publicly declaring, that individuals living in the early stage of Alzheimer's, are still capable of making meaningful contributions to society.

Two, when you are looking at changing policies on our behalf, it would be of great benefit, to consult with individuals, living in the early stage of the disease. While some may think they know what is best for us, take advantage of our ability, to provide you with a firsthand account of the physical, mental, and emotional toll, the disease is taking on our lives, and the best way to support us. I say this, because I can assure you, that from my side of the fence, the view is very different.

### **Talking Point #3**

After receiving my diagnosis, I felt a sense a relief, knowing that I had an answer, to the cause of my symptoms. I discovered, that Alzheimer's disease is the only disease, among the top ten, that has not had, the scientific input, in terms of funding, or the legislative interest, which has resulted, in the fact, that in 2013, this disease still cannot be slowed, cured or prevented.

- Currently, Alzheimer's disease receives only \$450 million for research, compared to \$5.8 billion for cancer, and \$3.1 billion for HIV/AIDS. I was astonished, at the lack of funding dedicated to addressing this health crisis
- With the additional \$50 million given to Alzheimer's research, and the **proposed** \$80 million, we are headed in the right direction, but more needs to be done.
- Historically, we know, that when the U.S. government makes a commitment to research, we have been successful, in finding disease modifying drugs. This has been the case, with HIV/AIDS, and for some cancers.
- I appeal to this council, to do everything necessary, to ensure, that Alzheimer's disease, gets the exposure, commitment, and funding necessary, to change the course of the disease, before it impacts the lives of many more millions of Americans.