

HEALTH LEADERSHIP SUMMIT September 29, 2016

Life is an incurable disease. Every person that has life will die from it. Alzheimer's is currently an incurable disease. Given time, it will invade the mind and whole body, eventually shutting it down. With that reality, the foremost goal must be seeking out the most effective behaviors and treatments in improving the quality of life. In this context, Alzheimer's has the same paradigm for treatment as cancer and heart disease: Seek out the best and most effective treatments, and start them as soon as possible.

Early diagnosis and treatment is the best type of medicine we have, and it provides the best results for any disease. Can you name one disease where early diagnosis is NOT an important part of containing or stopping the disease?

The more difficult the disease is to treat, the more important is the early diagnosis.

Treating a disease in its early stage is much easier than in its mature stage. Think of a disease as a plant that is invading your flower garden. Do you pull it out when you see the first shoots, or do you wait until it totally covers the garden? Pulling out the invasive plants later may severely damage the flower garden.

I'm Marv Lofquist. In May of 2012, at age 68, I was diagnosed with Alzheimer's disease. This diagnosis came only two years after I had retired from Northwestern University, in Evanston Illinois. I had earned my Doctorate in Chemistry there and served for 18 years as an Associate Dean in the College of Arts and Sciences.

I spoke at the February 2015 Health Care Leadership Summit. Since that time my short-term memory has declined. I need to look at my calendar multiple times a day or need to be verbally reminded of what is next on my agenda. However, my cognition remains strong. I have just spoken to you about the importance of the early diagnosis of

Alzheimer's disease and now I would like to share some other thoughts about Alzheimer's.

First is the acceptance of the diagnosis. For me, the key to living well with a diagnosis of memory impairment began with the intellectual decision to accept the reality of my memory loss and to learn the new limits of my abilities for independent activities. The issue then became how to learn to restructure some tasks so I could do them independently and to work with others to partner to do tasks I cannot do myself. The result is that the world of what I do remains large, but the realm of what I do by myself becomes smaller.

The second thought is learning to live well and function within the new limits of my current abilities. Do I have the memory and reasoning skills I once had? Of course not. Can I run as fast as I once could? Of course not. There are lots of ways in which my 70 plus year old body does not perform as well as it could 50 years ago. But that does not mean it can't do anything. It merely means I operate more thoughtfully and take life at a slower pace. And it may mean that I look for, and need more assistance, to do some of the more difficult or challenging tasks.

If I can do 80% of a task and need assistance for 20%, that is still a passing grade. Please note that I did grade on the curve when I was a chemistry professor.

Again, this is all based on the necessity that I accept my diagnosis and understand that my new task is to learn my new limits and work collaboratively with others to maximize my abilities and not try to exceed my new ability level. Early detection and diagnosis are important in making the cognitive and emotional transition from wide ranging independent self-directed activities to collaborative shared activities. Early diagnosis of memory impairment and acceptance of its impact on activities provides a much more stable foundation for adjusting habits and practices to fit the new reality.

Early diagnosis also removes a huge emotional burden that can complicate communication and strain relationships, especially within a family and in a work or social environment. This intellectual and

emotional transition to acceptance can become harder as the disease progresses. Early diagnosis is also important to allow time for adoption of new ways of living while still able to make the transition.

Alzheimer's has reached into every part of my life and affects all of my thoughts and feelings. But Alzheimer's doesn't own me; it just monopolizes my mind and attention. I can't go anywhere or do anything without considering how my Alzheimer's will affect my ability to function and follow my plans. It is always there.

Again, one of the important transitions for the person with Alzheimer's is to understand that they can function so much better by acknowledging their disease. Recognizing the process of Alzheimer's allows the person to more smoothly adapt to new realities, find new ways to function, and integrate the necessary life style changes. Ignoring changing abilities slows the adaptation process that can help with future function. Early in the disease a person will be more adaptive than they will be later. Early in the disease is the time to find new strategies and new support tools.

As we work to better recognize and diagnose memory impairment, it becomes more important to develop a broad range of care options that address the great variety of individual needs. Everyone has their own pathway through the process of memory loss and cognitive decline, but to live well, we all need information, education, and support. Alzheimer's is a team sport, not an individual sport, and to win the game and achieve success, we must build a team of dedicated and talented players. Today, I ask you to join the team.

When I spoke to you at the Health Care Leadership Summit in 2015, I had five requests. These have not changed.

First See me and interact with me as a person

Second See my care partner as of vital member of my care team. She is critical to the quality of my life and enables me to follow treatment recommendations.

Third Appreciate that I know and accept that I have this disease.

Fourth Support my needs as my disease progresses and please recognize that a significant portion of that care and support is outside of clinic walls.

Fifth Work within your organizations and across your collective organizations for shared standards and implementation of optimal dementia care.

THANK YOU