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Dementia: The Disease of Our Time

*A Traveling Exhibit of Great Americans Lost to Dementia
by Deb Selsavage,
PAC Certified Independent Consultant*

My company, **Coping with Dementia LLC**, offers training for both professional and family caregivers. I was trained and certified by Teepa in 2015, and all of our curricula are based on Teepa Snow's Positive Approach® to Care. We are also great believers in Teepa's slogan, "Until there is a cure, there's care."

I spend a lot of my time at free speaking engagements to improve public awareness of Alzheimers and dementia. During 2017 alone, I spoke to more than 60 churches, businesses, and civic organizations with a combined audience of just under 1,600 people. This earned my company a "Health Care Hero" award for community outreach in Citrus County, Florida.

Last year my partner, Ed Youngblood, hatched an idea to build an easy-to-assemble traveling photo exhibit with images and information about great Americans who have succumbed to dementia. He went to our local Walgreens photo department and persuaded them to become the exhibit sponsor by providing large shadow-box portraits of 24 famous authors, actors, athletes, musicians, and politicians who have succumbed to dementia.

The exhibit is configured in three segments that can be arranged to fit a variety of available spaces, and it can be assembled and disassembled in less than an hour without tools. On each segment are educational statements about Alzheimers, and each portrait includes a brief biography of the person pictured.



The Great Americans Alzheimers Awareness Photo Exhibit was first assembled in front of the Alzheimer's Family Organization headquarters in Spring Hill, Florida in early October, 2017. To the left are exhibit designer Ed Youngblood and AFO President Debbie Selsavage.



Each segment of the exhibit displays eight large portraits of great Americans lost to dementia; four on each side.

Ed, who serves as Marketing and Communications Director for our company, explains, "The purpose of this exhibit is to create and promote a public conversation about Alzheimers and dementia. It is intended to overcome the stigma that causes many to avoid a discussion about how really devastating this disease is to our society."

Youngblood believes that while we are raising money and awareness in support of a cure, we should also be demanding that standards of care for individuals living with dementia be greatly improved throughout our state and national healthcare systems.

He says, “If we look at how our society and government have successfully confronted other diseases, we will notice a pattern. First, there is denial when people don’t want to talk about it. Next, it is realized that so many people are affected that there is an awakening. The private sector – usually through non-profit charitable organizations – begins to talk about it and raise money to tackle the problem. This growing public voice eventually creates the political will for our government to do something about it, primarily through the allocation of funding for research and care.”



Combined, there are 24 portraits in all, 12 on each side. Each frame is imprinted with educational information about Alzheimers and dementia.

To underscore his argument, Youngblood points out that many people living today remember a time when we just didn’t talk about cancer, and especially breast cancer. “Today,” he says, “There are pink ribbons everywhere and cancer has become one of the most heavily funded and vigorously fought diseases of our time.”



The debut of the exhibit at the Floral City, Florida public library in October, 2017. Left are Chief Librarian TerriAnne Caraluzzo and Coping with Dementia President Debbie Selsavage

This is the process he wants to see take place for dementia. He says, “This kind of awakening is what will be required to face a disease that will overwhelm our national health care system unless we prepare ourselves to deal with it.”

Youngblood admits that the photo exhibit appeals to America’s love of celebrity. He explains, “We are not trying to say that the less famous are less important. We are showing that this is a disease that respects no boundaries. The talented, the privileged, the rich, the famous, the super-intelligent are afflicted to the same degree as anyone else. No one is immune to Alzheimers and other diseases that cause dementia.”

He adds, “To show that this exhibit is about ‘everyman,’ we have included a cork board where people can post photos of friends and family they have lost to dementia.”

The exhibit had its debut last October at the public library in Floral City, Florida, where it stayed a month before it began a tour of five libraries in Citrus County.

Youngblood is convinced that the exhibit has the potential to contribute significantly to greater public awareness. “Collectively, the Citrus County libraries have almost 1,500 visits a day; there were more than 440,000 visits during 2016. This is a significant audience of individuals of all ages.”



The exhibit fixtures and photos fit into three traveling crates in a mini-van with room to spare. It can be totally disassembled and reassembled in less than two hours without the use of tools.

Coping with Dementia, LLC has donated the exhibit to the [Alzheimer's Family Organization](#), which will take over its public appearance schedule once it has completed its Citrus County Tour. The AFO is a regional non-profit that serves eight west-central Florida counties. It does not raise money for research; rather, all of its resources are devoted to service and support for caregivers of individuals living with dementia.

The eight counties served by the AFO include very large population centers such as Tampa and St. Pete; and all told, there are 50 libraries. In this context, potential exposure for the exhibit can reach a half-million people. Our plan is to keep the exhibit on the road until it is no longer serviceable. We think it would not be a bad thing to see it simply wear itself out and fall to pieces telling people about the growing threat of Alzheimers and dementia.

I am happy to report that four months into its tour, Citrus County librarians tell us they have not received a single negative comment. They say that people are fascinated with the exhibit and that the most common response is, "I had no idea that some of these people died from Alzheimers!" They tell us that reactions are sometimes very emotional, and that people are moved by the exhibit. They quickly grasp its message.

This exhibit seems to be getting the point across that dementia affects our society broadly and deeply. This is exactly what we wanted. We want people to realize how invasive and devastating this currently incurable disease is within our whole society. Then we want them to demand action for better care from our governments and health care providers.

Debbie Selsavage was introduced to dementia when she became a caregiver for her husband. Like many in her situation, she found it almost impossible to find information, support, and the resources to deal with her difficult and exhausting task.

She believed there had to be a better way.

Debbie entered the field of memory care when she took a job as an administrative assistant at an assisted living facility. She loved the work and within 18 months became a certified administrator, leading her own community to a Deficiency-Free rating.

She became a Certified Trainer in Teepa Snow's highly respected Positive Approach to Care and in 2015 launched her own company, Coping with Dementia LLC.

Its mission is to make life better for individuals and families living with dementia.

Debbie pursues this mission through knowledge, training, education, and an unwavering belief in the effectiveness of Person-Centered Compassionate Care. As a Certified Dementia Practitioner with an extensive knowledge of dementia, she focuses more on the person than on the disease.

In addition to fee-based counseling and training services, Coping with Dementia LLC sponsors free workshops, conferences, and family caregiver support meetings.