

Bob Savage: Thoughts on Resilience

For the Empowering Partnerships Workshop

October 9, 2019

My name is Bob Savage, and I was diagnosed with dementia 3 years ago. I want to spend a few moments this morning talking to you about resilience. Resilience is generally defined as the ability to adapt to change in a positive way, cope with stress, or to thrive after trauma or illness. I'd like to share my personal story as to how I discovered my own resilience and transitioned from a state of depression and despair to a life I would describe now as living well with dementia.

Shortly after receiving my Alzheimer's diagnosis, people started to look at me differently, speak more slowly and ask questions to my wife rather than to me. Some started to avoid me, and I wasn't invited to social events as frequently as I had been before my diagnosis. Immediately, I started to experience depression, started to avoid leaving my home, turned down invitations from my friends, and remained silent when family members visited. After six months, I began to feel more confident, and a crucible moment for me was meeting Geri Taylor, with whom I have the privilege of presenting today, and attending a two-week workshop for persons living with dementia. During the first week, we identified issues we were facing and explored how to compensate for our struggles. The next week, we further explored all of the issues that had surfaced. Through this process, Geri convinced me that I had to have a sense of purpose! My purpose is to do all that I can to reduce the stigma related to dementia.

Shortly after the two-week workshop, I stopped hiding behind my diagnosis and I began telling people up front that I had Alzheimer's. I started to speak out publicly and take more risks.

I have learned that it is so important to make connections with others. Being with other persons helps me to feel less alone and helps others in the community to see how much I still have to offer. I have dementia and despite this diagnosis, my life is full of contributions to others. I look forward to the next two days where we will have the opportunity to

showcase our strengths, while also being vulnerable and transparent about our challenges. I acknowledge the value we can bring to the table as subjects in research; however, I'm excited about the possibilities that exist in partnering with researchers in the room in other roles. I look forward to meeting and interacting with all of you and to learning about how I can serve in more robust roles such as co-investigator, advisor, consultant, and co-author in research.

Today, I am involved in so many new initiatives. I am a pioneer. We are all pioneers, doing something that has never been done before! It is both exciting and anxiety provoking. It comes with an element of risk. The risks I have taken have contributed to my sense of purpose, and I am a more resilient person because I have taken these risks and opened myself up to new opportunities. During these next two days, I encourage you to do the same. Take risks and be open to new possibilities!

Just last week, I along with 4 other persons with dementia gave a To Whom I May Concern Performance for over 100 persons, during which time we shared personal stories about what it is like to live well with dementia. We were proud to share our experiences and to have people listen. Experiences like this are confirmation of what we are capable of doing. To be a part of changing other's perceptions about dementia is a transformative experience. Audience members identified 3 words prior to and then after the performance. The initial words were negative while those at the end of the performance were all positive.

I'm hoping that these next two days help us all to explore our own biases. To researchers and care partners, I ask that you examine your biases towards persons living with dementia. For persons living with dementia, I will commit to exploring my own biases related to researchers, and urge you to do the same!

I have just spent a few moments talking to you about resilience. I want to introduce you to two paintings I created to artistically represent the journey I have just described. I didn't connect with art until after my diagnosis and this is yet another outlet through which I am building resilience. During our breaks, I'd love to talk to you more about my art and share the meaning behind these paintings.