

MY JOURNEY THUS FAR

By Karen Kelly

THE PROFOUND EFFECT OF EARLY STAGE
DEMENTIA UPON AN UNSUSPECTING
AND
EVER-GROWING DEMOGRAPHIC:
PEOPLE AGED 40 TO 65



My name is Karen Kelly. I am a summa cum laude graduate from Bridgewater State College in Massachusetts and hold a Master's Degree in Education from the University of Massachusetts. In the early nineties, I became a Career Counselor, certified to administer the Myers-Briggs Type Indicator. For 13 years I owned and operated a Career Counseling Business called TimePeace Career Services out of my home office. In 2007, I closed my business for reasons described in this document.

My purpose here today is to promote awareness of an ever-growing demographic of young and vital people who are challenged with early stage dementia. I am referring to school teachers, CEO's, lawyers, professionals, contractors, small business owners, full time workers of every kind, stay at home Moms and Dads – people in the prime of life who find themselves dealing with diminished memory capacity, decreased organizational skills, the inability to get their words out, increasingly repeating their statements or asking the same questions over and over again -in general, a steady onset of cognitive challenges that result in job loss, disorientation, forgetting where they are going, easily disrupted concentration, and, most importantly, loss of confidence.

My central statement is that funding is needed for these people so unfairly stricken with a mental disability that robs them at an early age of their self-esteem, independence, and ability to support themselves. Funding is essential for the following:

1. **Awareness** of the existence and symptoms of early stage dementia – the word must get out to those people who know something is not right with their memory or organizational skills, but would never consider dementia as a possibility.
2. **Early Diagnosis of the disease in order to start care as soon as possible**
3. **Treatment through various means such as medication and education**
4. **Coping strategies for dealing with the world around them**
5. **Support from fellow diagnosed people and their own support people.**
6. **Continued research into the cause and cures for dementia.**

Though I was totally unaware at the time, my journey began over five years ago when I realized that I was unable to get myself organized for the next week's career counseling sessions. I was sitting in my home office with notes and session plans strewn about with the intention of organizing the following week's agenda as I had done so many times in the past. No matter how hard I tried to concentrate, I was unable to sort, file, copy, skim over, proofread, arrange, recycle, or in any way prepare for my upcoming clients that week.

In the weeks and months that followed the fear and frustration grew as I just could not get organized for my counseling sessions without the aid of countless written notes and a detailed syllabus that would hopefully prevent me from wandering off track as I guided my clients towards their future careers. Although this painfully thorough preparation brought me through each day and each session successfully, I found this to be completely exhausting as I struggled to concentrate and stay on task.

To make matters even worse, I found that I often had difficulty remembering clearly whether or not I had covered certain material with my client moments earlier in a counseling session. I wondered if I was repeating my statements often – or at least to the extent that it was being noticed by my clients. I just did not know. It was an unnerving and scary period in my life.

I had lost my confidence.

My concerns about my ability to think clearly and remember details finally hit home when, less than a year later, I walked up to my husband Dan and handed him the checkbook with the words, "I don't think I can do this anymore." After 20 plus years of paying all the bills, prepping the income taxes, and handling the household financial affairs, I could no longer make sense of the numbers I had handled so easily all my life. There was something very wrong.

Dan and our adult daughter Julie had already noticed that I was repeating myself from time to time, that I seemed to struggle with getting organized, and was having difficulty getting ready to leave the house on time for any type of appointment – not able to gather my belongings and perform all my pre-trip duties within the given time frame. After a family meeting, we decided that the time had come for me to be evaluated by a memory specialist. The initial diagnosis was that I suffered from "pseudo-dementia" caused by depression. Though Dan, Julie, and I were all highly suspicious of this diagnosis, we agreed to pursue treatment through anti-depressants. This treatment simply did not work because I had been misdiagnosed.

In 2009 I went through a battery of tests at the Dartmouth-Hitchcock Medical Center during which the medical evidence clearly showed the presence of Lewy Bodies in my cranial fluid. After three years of searching for answers, I was finally diagnosed with early stage Lewy Body dementia. I had just turned 60. Less than a year before my diagnosis I had been working full time as a career counselor. I was used to being on my own, especially when my husband was on one of his frequent business-related road trips. I was young and physically healthy. On this one day in 2009, my diagnosis had changed the terms of my life forever.

Upon learning that I had been diagnosed with early stage Lewy Body Dementia, my first question for various people in the health care field was, "Where do I find other people like me to talk to? Where can I find a Support group that focuses on the newly diagnosed?" A blank stare was the most frequent response I received. For the longest time I felt isolated because I did not know one other person who had been diagnosed with early stage dementia - nor was there anyone who could put me in contact with such a person.

Today, I am relieved to say that Dan and I are part of a support group that offers comfort, information, and camaraderie to other people who, like me, have had to deal with the intrusive reality that mental illness has robbed them of some of their brain function resulting in significant impact upon their lives. This demographic of people who range from their 40's into their 60's and suffer from the debilitating effects of early stage dementia is growing in number as awareness increases.

I consider my own personal story a success story. Even though I was initially misdiagnosed, I was fortunate to be properly diagnosed in time to benefit from the awareness of the medical and support communities. Through proper medication, education, and the camaraderie of my fellow diagnosed friends, I have been able to stabilize my life with the essentials still in tact. I have accepted the reality of my diagnosis. For example, I no longer drive because I don't trust my decision making skills to operate at peak performance at all times – especially when split-second decisions are called for. However, I am able to walk to many destinations or take public transportation. I have a family who loves and supports me. I have developed and implemented coping strategies that help me stay independent throughout the day. I am able to stay home when Dan goes to work and manage things quite well without the need of a care giver. I take extended walks on a daily basis, weather permitting. I am living in the world with maximum independence while still being able to contribute to that world and the lives of my friends and loved ones.

My sincere hope today is that funding for those with dementia will not be cut at all; rather, I hope that it will be increased as much as possible. I know from personal experience that sufficient funding is vital and valuable.